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Assembly

Committee for Health, Social Services and Public Safety

OFFICIAL REPORT
(Hansard)

Ovarian Cancer Awareness:
DHSSPS and Public Health Agency

19 February 2014

NORTHERN IRELAND ASSEMBLY

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Members present for all or part of the proceedings:
Ms Maeve McLaughlin (Chairperson)
Mr Jim Wells (Deputy Chairperson)
Mr Roy Beggs
Mr Mickey Brady
Mrs Pam Cameron
Mr Gordon Dunne
Mr Samuel Gardiner
Mr Kieran McCarthy
Mr David McIlveen
Mr Fearghal McKinney

Witnesses:

Mr Jackie Johnston	Department of Health, Social Services and Public Safety
Dr Heather Livingston	Department of Health, Social Services and Public Safety
Dr Miriam McCarthy	Public Health Agency
Mr Steven Wilson	Public Health Agency

The Chairperson: You are very welcome. You know the procedure here: a 10-minute presentation and then we open it up to members.

Mr Jackie Johnston (Department of Health, Social Services and Public Safety): We wish to thank the Committee for the opportunity given to the Department and the Public Health Agency (PHA) to brief you on the important women's health issue of raising awareness of the potential symptoms of ovarian cancer, which, annually, affects an average of 163 women in Northern Ireland and their families and friends. I am joined today by my colleagues Dr Heather Livingston, senior medical officer in the Department; Dr Miriam McCarthy, public health consultant with the PHA; and Steven Wilson, assistant director with responsibility for communications in the PHA. We have provided you with a short briefing paper, and I will add a few short points to that by way of opening.

Since the Assembly debate on ovarian cancer in March 2013, the PHA has been developing its detailed approach to a comprehensive awareness campaign, including ovarian cancer, to be delivered in 2014-15. This will be included in the agency's programme for health-related awareness campaigns in the year ahead, which is likely to include, for example, obesity and sexual health issues. The agency believes that the most effective way forward is to raise awareness among the public about the need to seek early diagnosis and treatment for cancer generally and then to focus on raising awareness about possible symptoms related to the most prevalent cancers.

In approaching the development of the campaign, the agency will build up its evidence base to determine the most effective awareness approach for the Northern Ireland public. This will involve studying and learning from similar campaigns running in Great Britain, including an ovarian awareness pilot campaign. From this evidence base, a targeted awareness campaign for ovarian cancer will be developed. It is likely to be most effective in a tailored approach targeted at the women's population groups most affected by this type of cancer and working with ovarian cancer charities to get across the message of early diagnosis in the most effective way possible. Since the debate last year, the agency has also been developing a patient pathway for ovarian cancer for GPs. This will be a further important element in a targeted awareness approach to the disease.

In conclusion, I want to reinforce that there is a firm commitment from the Minister, the Department and the agency to take forward this very necessary work. The detailed work is ongoing, and we hope that you will see the fruits of that in the year ahead with the delivery of an appropriate campaign. Again, thank you for inviting us, Chair, and we are happy to take questions from members.

The Chairperson: Thank you for that, Jackie. May I just confirm that you are talking about the inclusion of ovarian cancer in a wider cancer awareness campaign?

Mr Johnston: That is correct.

The Chairperson: So it is not a stand-alone campaign.

Mr Johnston: It is not a stand-alone campaign; it will be prioritised within an overall awareness campaign.

The Chairperson: Why is it not stand-alone?

Mr Johnston: The evidence that the agency has pulled together so far indicates that the best approach is to, first, raise general awareness among the public about cancer and, then, target specific populations groups affected by the most prevalent cancers. In that way, we believe that we will get the most effective use of resources. Of course, the resources for this are limited, and such campaigns can be very costly. We want to ensure that we get the most effective and most beneficial approach to these targeted campaigns. That will probably involve working with charities and GPs and making sure that we get the appropriate literature and messages out.

The Chairperson: A motion was passed in the Assembly for a stand-alone campaign, which the Minister also endorsed, so does this represent a change?

Mr Johnston: The Minister, I believe, gave a general commitment to taking it forward. The work since last year's debate has been focused on deciding how that can best be done. This advice will be given to the Minister, and he will have the ultimate sign-off. At the moment, the advice that will go to him is that we have a general campaign and specific targeted messages within that.

The Chairperson: A number of members have indicated that they want to come in. Before that, do you not accept that the low awareness and diagnosis of this cancer suggests that we require a stand-alone campaign, particularly given that the Assembly and the Minister endorsed that approach?

Mr Johnston: I do not want to quibble over definitions with you. This is in the context of what we mean by a targeted campaign. If it would be useful, as we go through this, we could give you more detail on what we have in mind specifically for ovarian cancer. That will, I hope, explain the approach that we propose.

The Chairperson: Before bringing in members, I want to make the point that, at the event that Cancer Research held here yesterday — the Deputy Chair was there, too — a specific ovarian cancer campaign in England was mentioned. Cancer Research went to great lengths to highlight its very positive impact on uptake and quicker diagnosis.

Mr Johnston: I understand that a regional pilot is being rolled out in the north-west of England of a general awareness campaign about ovarian cancer. Steven could maybe tell us a bit more about that, but that is one of the campaigns that we want to learn from. If the outcome from that demonstrates that a specific message is a better approach, we will certainly take that on board. We have not ruled that out totally; we are looking at the evidence being produced before coming to the best decision on getting the right message across to the Northern Ireland public. A specific campaign has not been totally ruled out; it is just that we are waiting to see what the impact of that pilot scheme in England will be.

The Chairperson: My point is that the learning seems to be already there. I will come back to that.

Mr Wells: I attended that Cancer Research UK event yesterday, and the message was absolutely clear. A very stark graph, which included ovarian cancer, showed that detection within two months led to a very high level of survivorship. Detection in the normal way of things in Northern Ireland led to a 3% survival rate at one and five years. That is down there with pancreatic cancer. Even more worrying is that there has been no significant change in that in 20 years. We have made rapid strides in, for example, breast cancer, leukaemia and stomach cancer, and the prognosis for many such conditions is extremely good, yet ovarian and pancreatic cancer remain tied to the floor.

There is a blood test called, I think, the CA125. Many of those who have, quite rightly, been lobbying us very strongly on ovarian cancer, including Una Crudden, argue that a woman in the right age group, which is 50-plus, presenting with irritable bowel syndrome should automatically have the CA125 blood test. It is not entirely diagnostic, but it can often show the onset of ovarian cancer. We also know that early detection leads to an 80% survival rate, so why is that not being considered as an automatic procedure for women aged over 50?

Dr Miriam McCarthy (Public Health Agency): I will provide a little background, some of which will reiterate what I am sure most of you already know. There are facts and figures for what we already know. Ovarian cancer is one that needs to be looked at for a variety of reasons. It is not a particularly common cancer: there are in the region of 160 or 170 cases a year, and, in 2012, there were about 175 cases.   However, as with many cancers, there is a clear association between the time of diagnosis and outcome.

Ovarian cancers tend to be staged, and there are stages 1, 2, 3 and 4. Women diagnosed at stage 1 tend to do very well at one year and very well at five years. Unfortunately, women diagnosed at stage 3 or 4 do very poorly because, no matter how good the treatment, surgery and chemotherapy, it is, for many patients, a bit too late to eradicate the disease. The average outcome at five years is that about 30 to 35 people survive. That average is, however, a mix of those who do well and those who, unfortunately, do very badly and are not alive after five years. We also know that that outcome is not as good as in other parts of Europe. It is not a cancer for which the picture looks very rosy elsewhere, but we know that northern European and Scandinavian countries have a five-year survival rate of above 40%. So there is clearly something that we can do to help to raise our survival rate.

The debate focused on awareness, and the Minister is, of course, committed to increasing that. However, we need to put that in the context of what is the best way to proceed. Shortly after the debate last March, we in the Public Health Agency began work to determine how best to roll this forward. We could have gone out directly with a public awareness campaign, either stand-alone or part of a wider campaign, but we were acutely conscious that doing that in the first instance might make women and their families more aware of the disease, but it would not necessarily increase awareness among doctors in primary care and elsewhere — they are the ones who see the patients first — about what they ought to do.

Over the past six to eight months, a key piece of work has been our engaging with primary care practitioners and hospital practitioners to ensure that we have a crystal clear pathway for what to do when someone presents with suspected signs and symptoms. Exactly as Mr Wells said, there is a test called the CA125. A pathway based on the best available evidence coming from the National Institute for Clinical Excellence was issued this week. It has probably been sent out today and will be with all GPs in the next day or two. That pathway is fairly straightforward. It says to GPs that, if any woman over the age of 50 presents with bloating, abdominal distension, change in bowel habits or symptoms that are abnormal for them, the very first step after examining and talking to the woman is a CA125. That is a very simple test requiring a small amount of blood and tends to come back from the laboratories in about two days, so it is a very quick turnaround. The test is done in all of our laboratories and is readily available to general practitioners. A cut-off level determines whether it is normal, marginal or high.   We are asking GPs to request an ultrasound scan if the blood test comes back at a certain level because that is the next recommended step. So GPs now have two very easy steps to take, and many already do so. That advice is not brand new; NICE issued it a few years ago, but we want to reinforce that message for new GPs, trainees in general practice and locums.

Also, we recognise that any one general practitioner may see a woman with ovarian cancer only every four to five years. Even in a practice covering 10,000 patients, it will not be a common presentation. So we want to increase GPs' awareness and their index of suspicion. We want them to think about ovarian cancer when women present with what can be very vague symptoms, which can be really hard to put a finger on, and know the next steps to take. We have done a lot of work on that, and we felt that having our healthcare practitioners ready and primed was the first step in taking this forward. The next step in the sequence is to ensure that the population likely to be affected is made aware of ovarian cancer as a disease that they should at least be thinking about, bearing in mind that women who present early will do much better. I know that we are here primarily to talk about that, how we plan to do it and what we are planning to do.

Mr Wells: That, following on from what the Chair said, indicates to me that ovarian cancer is a particularly difficult and different form of cancer. With lung cancer, a persistent three-week cough is almost certainly an indication that further investigation is required. I have met Una and her group, and they all reported with symptoms of what could have been irritable bowel syndrome. The test was not carried out, and, by the time that the formal diagnosis of ovarian cancer was made, it was too late. Indeed, of the four women with whom she joined to form her group, she is the only one still alive. Are we saying that, from 1 March 2014, every woman aged 50 or over who reports with these symptoms will get a CA125 test?

Dr M McCarthy: That is what we are recommending to general practitioners. Of course, there needs to be some clinical judgement. General practitioners will examine women, which is important. If, for example, a general practitioner examines a woman and feels a large lump, that means referral to hospital without waiting for further tests to be done. The advice is that, for women with symptoms of bloating, abdominal pain, putting on a bit of weight or whatever, a CA125 should be done if there is any suspicion at all. Included in that advice is a very clear direction that, if it sounds like irritable bowel syndrome but is presenting in a woman over the age of 50, think of something else because irritable bowel syndrome very rarely presents in that age group. People with irritable bowel syndrome tend to have developed it earlier in life. Therefore, we are telling GPs that, if a woman presents with new symptoms of abdominal swelling, feeling full after eating, crampy abdominal pain or a change in bowel habit, although those are not very specific on their own, they should think about the possibility of ovarian cancer and do the test. It is a simple test, the result comes back in two days and it is helpful, either in highlighting a potential problem or providing reassurance

Mr Wells: How reliable is the test? Are there situations in which stage 2 ovarian cancer is missed by the tests?

Dr M McCarthy: My understanding is that the test is pretty reliable. Remember, however, that we are talking about a test combined with symptoms and an examination. There always needs to be a little bit of clinical judgement. So, for example, if the test comes back completely normal, but a woman still has the symptoms and the GP has a suspicion that something might be going on, the test can be repeated. Thinking about repeating the test is included in the advice. It is reliable, but no test is 100% foolproof, so we rely on doctors also to draw on their information and knowledge of the patient.

Mr Wells: At the risk of repeating the Chair's comments, all of which I support, surely this is such an unusual form of cancer that it warrants a specific campaign rather than being grouped with lung, testicular, stomach and all the other cancers. This is a very unusual set of circumstances. You say that the numbers are small, but the survival rate means that it is the fourth biggest killer of women from cancer in Northern Ireland. So the numbers are small, but the survivorship is dreadful. Did you give any thought to running a specific campaign for this one condition?

Dr M McCarthy: We are considering what we need to do for ovarian cancer. The difficulty is that the terminology of stand-alone suggests that it is isolated from other things. We need to ensure that the messages go out in a way that is relevant to the population and not as an isolated strand. We are considering what messages we need to get out, how to deliver them and how we do that in a way that engages, but does not frighten, those who need to hear them. We know from other research that some people are reluctant to go to their doctor because they are afraid of cancer. Therefore, we must tailor that message in a measured way that will bring people to a healthcare professional.

We could put out a "Big Bang" kind of campaign on television, radio and other media. That has been explored in parts of England, and we need to see how that works. Alternatively, we could think about targeting the campaign because we are predominantly, although not exclusively, talking about women over 50. By and large, it would target women from the age of 50 to those in their 80s. We want to think about trying to tailor the message so that it is appropriate, not too complex and targeted at that audience. In doing that, we will work up an approach and make sure that we have got it right so that it is tailored to those who need to hear it.

We are mindful that some older women, in particular — the cancer can occur in women in their 80s — live alone. However, they tend to have families who take them to the doctor and check up on them to see how they are. We are conscious that it is about getting the message to individuals and to their carers or family members. We will look at the specifics of what is needed for ovarian cancer, particularly the specifics of what we need to do and how we will do it, and how we will measure its success. Although we are not talking about a stand-alone campaign, we will link that into other cancer awareness efforts as part of the programme, as appropriate, so that it will not be fragmented. However, we will also recognise that there are specific messages on ovarian cancer that need to be distilled. We have begun the work on that.

Mr Steven Wilson (Public Health Agency): I would just like to pick up on what was said earlier. I thought that yesterday's briefing session was very valuable, and some of the insights brought to the table by Cancer Research UK were highly significant. One that stood out for me was what Amanda Boughey recommended needed to be done. She had two recommendations. The first related to the need for the regional coordination of cancer awareness campaigns in Northern Ireland. I thought it very significant that she presented a slide on the piecemeal nature of campaigns prior to Be Clear on Cancer being introduced in England. That campaign was predominantly about awareness of specific tumours and cancers. Yet one of the main added values to come from the whole programme was how, under the cohesive brand of Be Clear on Cancer, the messaging had credibility, and its impact was significant. Each of the individual cancer awareness campaigns then fed off one other, and, in turn, produced an overall success rate for tackling individual tumours. It was interesting to see that ovarian cancer has come on to the campaign's planning programme. It is being taken through the cycle of being tested: first, at pilot level; then in a regional format; and, potentially, into a national format, depending on the success factors.

Mr Wells: In January, Karen McKevitt MLA asked the Health Minister a very useful question about the test. I was shocked to read that it was adopted by NICE in January 2009 as an applicable test for ovarian cancer. Here we are, over five years later, introducing it only now. I have to ask the obvious question: have women died needlessly as a result of it taking us that long to reach this situation?

Dr M McCarthy: The test has been around and is done in Northern Ireland many thousands of times a year, so it is being used. As part of the pathway that we are sending to GPs, we are reminding them and reinforcing the message to do the test if a woman presents with a set of circumstances and a set of signs and symptoms suggestive of ovarian cancer. The test is available and used to a significant extent by our primary care practitioners and hospital doctors. The test is not new, and our GPs are familiar with it. The message to do the test when a woman presents with certain signs and symptoms needs to be reinforced.

Mr Wells: There is also some hint of a genetic factor — the BRCA cancer gene. There are also such issues as multiple ovulations, late menopause, not breastfeeding etc. Surely there should be a target of giving the test to women in that group, particularly those with a family history of the condition. Should there not be an automatic call-in of all women aged over 50 who have a genetic predisposition to the condition?

Dr M McCarthy: That is a really important and, indeed, topical question. A research project on exactly that has been going on for about seven or eight years: whether there is benefit in screening women of a certain age for ovarian cancer. Belfast is part of that. It is always some time before we see the results of that type of population-based research project. However, there is research in the field that will, we hope, have an answer in the next year or two to whether there is any benefit in screening all women by doing this test. At this point, we do not know. If the result of the research trial is positive, we will expect the UK National Screening Committee to look at that. In the meantime, because the evidence is not clear, the best thing is not to screen all women but to test those whom it is appropriate to test in light of what they are complaining of.

Mr Gardiner: Thank you, Mr Johnston, for your presentation. To be honest with you, I was disappointed and not at all excited by it. I lost my mother and two sisters to cancer, and what you have produced today is not one step further forward from where we were. This should be out in the public domain, and you should be working with people. I am sorely disappointed.

Mr Johnston: I apologise for that, Mr Gardiner. Do you want to develop where you think our failings are? Hopefully, we can respond.

Mr Gardiner: What are you actually doing? This is hands-on. There is a paper before us, but I want to see action for the good of the people in this community and throughout the world, if that is necessary, which it is, because everybody carries cancer somewhere.

Mr Johnston: Steven, do you want to say something about the campaign that we have in mind?

Mr Steven Wilson: I will say something by way of context. The Public Health Agency is required to look at public information across a range of issues. For example, the campaign sits within the programme for 2013-14. To date, we have already completed and run campaigns on obesity and mental health.

Mr Gardiner: How long has it been sitting in that pigeonhole, as the saying goes?

Mr Steven Wilson: It has been at the planning stage from early 2013. However, we have to live within an envelope of approvals when it comes to how much money can be spent on public advertising. A series of priorities have to be met. As I said, this year, we have committed to running seven public information campaigns. We are looking at a programme of proposals for eight campaigns in 2014-15.

Mr Gardiner: You speak of a campaign, but which is more important? Is it the campaign or the drug to cure cancer? You put a lot of money into campaigns.

Dr M McCarthy: I suppose that that is a difficult one to be definitive on. In an ideal world, the best thing would be to prevent any cancer. We do our best. The first key prevention message is about smoking. If people did not smoke, there were would be fewer cancers. That has been tackled on many fronts by the Public Health Agency and through lots of community programmes, etc. Excess alcohol can be associated with cancer, as can diet, exercise and obesity. Therefore, we are tackling it through other health promotion and disease prevention messages. We are tackling all that in an effort to improve people's health and well-being generally and to reduce the risk of cancer associated with those aspects.

However, no matter what we do, we will not prevent all cancers. We have seen an increase in cancers, primarily because we have an ageing population. It is good that we are all living longer, but the longer that we live, the more likely that we are to develop a cancer. That being the case, we should prevent the cancers that we can prevent. The cancers that we can identify early through our screening programmes are a really important group. We do breast screening, cervical screening and now bowel cancer screening. That will have a big impact on the early identification and treatment of a cancer before it takes hold.

The next step for most, but not all, cancers is for patients to have access to good diagnosis and good surgery, and, following that, good chemotherapy or radiotherapy. We are taking each of those measures. There is not any one step for any particular patient or cancer. It depends on the circumstances and the stage of the disease. Radiotherapy is very helpful for a number of people. Cancer drugs are helpful as well. Many, many people —

The Chairperson: Sorry, may I interrupt you there? From your answer to Sam's question, I think that we are getting to the nub of the problem. We are talking about cost. That is what I seem to be picking up. We have statistics that state that only 3% of people in the North are aware of the signs and that, following diagnosis, 75% of women have only between three and five years to live. Now we are hearing that there is a cost implication. Are we effectively standing over the lack of an awareness campaign because of cost, which is costing lives?

Mr Gardiner: With all due respect, it is a bit like an old story that we have heard over and over again. We want a cure.

Mr Johnston: It is not so much a cost issue. It is more that we have a number of campaigns to run, and on a limited budget. It is really how we sequence the campaigns and roll them out.

The Chairperson: I do not accept that. There is public demand and public need, there is a health inequality, there is political will across the Assembly, there is a very brave woman heading a public campaign and there is ministerial endorsement, so adding a solo campaign on such an important issue should not break the bank. In fact, finances should not get in the way of the need that is there.

Mr Johnston: I wanted to reassure you that we are not talking about a one-off initiative in the year ahead but about the start of a process to raise awareness over many years. Therefore, this is not going to be a one-off campaign; rather, it is going to be a process that we take forward over several years. It is a crucial issue. I see the Minister's postbag, and he gets numerous pieces of correspondence from Members, the public and charities on it. Therefore, we are seized of its importance.

The Chairperson: Do you accept that, with ovarian cancer, there is a specific lack of knowledge or awareness of the signs that is not the case with other cancers?

Mr Johnston: Yes, indeed.

The Chairperson: Sorry, Sam, for interrupting you. Have you finished?

Mr Gardiner: Yes, we are not getting anywhere.

Mr K McCarthy: Most of what I wanted to say has been said and said very well by you, Chair, Sam and the Deputy Chair. I am an ardent supporter of the Public Health Agency. I always have been and hope that I will continue to be. However, I am disappointed to hear you mention cost, Jackie, as did you, Miriam. We have to consider cost, but we should also be considering the lives that are threatened. To me, performing a simple blood test does not seem to be awfully costly. Perhaps you can explain how much a blood test that would give the results that we are looking for would cost so that action can be taken.

Mr Johnston: There is no cost, bar on the availability of the test, and Miriam can explain that. When we were talking about the cost of raising awareness, we were talking about it in the context of making the most effective use of the available resources. We are not saying that it is not an expenditure priority, because it is. It is about how we best use the funding that will be allocated in the year ahead to make sure that we get out the most effective message. Therefore, we have to consider whether television advertising will be the most effective use of the resource, as opposed to a more tailored campaign. It is about an effective use of the resource rather than its availability.

Mr K McCarthy: I hear what you say, but how long will that take? People will lose their life. Una had four or five colleagues, and she is the only one left. That cannot be right, and you are using time to come to a decision. That is disappointing as far as I am concerned and as far as patients are concerned.

Mr Johnston: I apologise for that.

Dr M McCarthy: The Public Health Agency and the board have no doubt that something needs to be done. That is not refuted at all. We understood that after the debate last March, and, indeed, probably before the debate. We are absolutely committed to making a difference.

However, we planned specifically that the first thing to do was to make sure that primary care practitioners were absolutely familiar with what to do and how to do it when someone presented at their surgery. We saw that to do it in any other order was to do a disservice to people potentially affected. That was the key first step. We have been engaging with general practitioners and with our gynaecologists and gynae oncologists in the trusts. That leaves the greater opportunity to target the information at the women affected or likely to be affected. That is absolutely key and is the next step.

We need to work out how we do that, what message we put out there and how we put it out so that it is taken seriously and women know what to act on. It is really important that this does not be a one-off campaign. If we were to do it today and over the next couple of months, we would be targeting a population that then moves on to deal with other things in their life and, six months later, may or may not be aware of the cancer signs. Therefore, we need to think about how to run the campaign so that today's women in the over-50 risk group and women approaching that age group know what to do. It is about tailoring the campaign so that it is not just a here-and-now approach but one that will be a message that we can use over a number of years to keep reminding people. That is important, because we know that we sometimes need to repeat messages and reinforce them, and sometimes we need to tailor messages to different groups depending on their environment or circumstances. For example, and we have not given this great thought, a number of women in the age group who are developing ovarian cancer are not necessarily even living at home. They may be in a residential or nursing home. They may not be coming forward with symptoms. They may have memory loss or other health problems. Therefore, they may need a carer or a family member being aware on their behalf of the campaign.

We want to make sure that the campaign is done properly and in a way that makes a real difference. We are absolutely aware of that. Perhaps this has taken a bit longer than you expected, but it needs to be done with the improved outcome. Where we really want to see a difference is in having women diagnosed earlier and living longer. That will be the acid test.

Mr K McCarthy: Thank you very much for your contribution. The Assembly agreed last March's motion unanimously, and the Committee agrees with the Assembly. On leaving here, will you be influenced at all to move faster?

Mr Johnston: Yes, we will take on board fully what the Committee is saying to us. The central issue is what the campaign should entail. Are we talking about a need for a general, high-profile advertising campaign or what we are indicating, which is a more tailored campaign? We will take that question on board, review it and look at the evidence that is coming from the regional pilots on awareness campaigns in England, and then come to the best decision.

Mr K McCarthy: And waste no further time on reaching a decision.

Mr Johnston: Yes.

Mr Beggs: Thank you for the presentation. The ovarian cancer figures are truly shocking, with a third of women diagnosed at A&E when secondary symptoms show. I understand that 75% of diagnoses occur when the cancer has already spread. Therefore, the cancer is more difficult to treat, and the prognosis is not good. There is then the issue of one third of women initially being misdiagnosed with irritable bowel syndrome.

In 2013, we were advised by Una Crudden and Target Ovarian Cancer that only 58% of GPs in Northern Ireland were aware of the NICE guidance introduced in 2011. You have come here to tell us that you sent a letter to GPs today. Can you explain what you did in between? Why did it take almost a year to contact GPs?

Dr M McCarthy: First, it is not just a letter. There is a pathway developed that indicates clearly the steps that need to be taken and what is expected of general practitioners, such as how they access the tests and how quickly the tests are to come back. Although that sounds straightforward, we needed to have quite a bit of engagement with general practitioners and with the hospital and radiology side so that we knew exactly the logistical issues that potentially had to be met. That engagement itself will have raised awareness of the issue, the tests, in what labs they are done, etc. What has been done — namely, an increase in awareness — may not be visible, but it has been happening anyway.

GPs have access to the NICE guidance, and the NICE website is easy to use and very interactive. The steps that we are taking, which are entirely consistent with the NICE advice, will make sure that the 58% of GPs aware of it will increase to something hopefully approaching 100%. As I mentioned, we have locums coming in and out of general practice and trainee doctors, so we want to make sure that those who are new to general practice are familiar with the pathway.

Engagement takes a bit of time, but it is important that the right people are involved and engaged when we put out something such as the pathway, because it makes a big difference to its acceptance and utilisation.

Mr Beggs: I appreciate that it is important that good guidance goes out and that there is good process, but 120 people have died in that year. In what way did you contact the 42% of GPs who, according to the survey, were unaware of that NICE guidance prior to today?

Dr M McCarthy: We have not contacted individual GPs, and we do not know who the 42% are, but contacting all GPs is the way of getting the message across and reinforcing it with them.

Mr Beggs: I certainly wish that it had happened before today. It is good that we have brought you here or it may not even have happened today, so I am pleased that we invited you along.

Mr Gardiner: Hear, hear.

Mr Beggs: My final question concerns information given to us a year ago. At that stage, 42% of GPs had direct access to specialist ultrasound to assist them in early detection. What percentage of GPs currently have access to it?

Dr M McCarthy: The GPs can refer for an ultrasound directly to the local trust's radiology department. There are two different varieties of ultrasound —

Mr Beggs: My question was what percentage of GPs have access?

Dr M McCarthy: All GPs will be able to request an ultrasound from their trust.

Mr Beggs: How many of them have ultrasound in their own health centre?

Dr M McCarthy: I do not know, but the vast majority of GPs will access ultrasound through radiology departments, and ultrasound will be undertaken by radiographers. There may be a small proportion that have ultrasound in their practice, but the number will not be significant at all.

Mr Beggs: We were advised a year ago that 42% had direct access. Are you satisfied that there is appropriate access? Bearing in mind the delay in women recognising the symptoms of this particular cancer and going to their GP — for example, a quarter of women waited more than three months before doing so, and a third of women, after having visited their GP, waited a further six months or more before they were correctly diagnosed — is there sufficient access to enable its speedy detection? The cancer is aggressive and very difficult to treat in the latter stages.

Dr M McCarthy: There absolutely should be. The six months that you have quoted that some women wait between presentation and referral or diagnosis is a key one. If GPs follow the pathway, as advised by NICE, that six months will decrease, because, at the first sign of suspicion, a simple blood test helps indicate whether further action is needed. Asking GPs to do that test early will make the difference. Only if the test is abnormal are we recommending that women go for ultrasound. The test will be done, and many women will not have any problems with it, as the results will be normal. They then have a degree of reassurance, and finding out the cause of their symptoms will be the next step. For women in whom it is raised, they will be referred for ultrasound. We are asking that, when they are referred, the results of the CA125 blood test be included in the request, because that helps to alert the hospital that something is going on. We also ask that the test be requested urgently, because we would like to see women back in two weeks, as we do not want, and cannot have, women waiting months for the test. That is simply not going to happen.

We are going to be monitoring very carefully what is happening with the number of referrals and the time for testing. We will be keeping a very close watch on that. We will be looking at additional training for radiographers and others in the testing to make sure that that capacity is available and people are well trained.

I am confident that we are addressing each of the key issues. The next issue will be the awareness to help reduce the time that you have quoted — three months — before women even seek advice. If they are experiencing symptoms for a month or more, we want to encourage them to seek advice.

It is worth remembering that a lot of women may have symptoms of abdominal distention, pain or bowel changes, and that most symptoms will not mean ovarian cancer, but the advice will be that they seek the view of a general practitioner.

Mr Beggs: My question was not about whether women should have speedy access but whether they currently have suitably direct access in each trust area.

Dr M McCarthy: They do, and if they put in an urgent request and provide the CA125, the test result should come back quickly. However, we monitor that to ensure that it is the case.

Mrs Cameron: Thank you for your presentation. I feel myself getting increasingly frustrated by the minute by this evidence session. I feel frustrated, as I know the rest of the members do, because we had the debate, and everyone around this table — apart from you perhaps — expected to see, within a relatively short time, some form of awareness-raising, solo campaign for ovarian cancer.

As a woman, I know about the confusion that exists with cervical cancer and how difficult it is to encourage women to take their smear tests, and all the rest of it. However, there is just not the awareness of ovarian cancer that there should be. I have to concur with some of my colleagues and say that I am very disappointed that that has not come about to date. It is great that work is being done with the GPs and that all that needs to be done on the health side is being done, but we still need to empower women with the information that they need. At the end of the day, it will probably not be the GPs who will suspect that something is wrong but the women themselves. Women know their own bodies, and they need to be empowered with the information. They need to know that, if they have any of symptoms, they can go and demand the simple blood test — the CA125 — and have ovarian cancer ruled in or out at that stage.

I do not mean to knock the health service. It does a great job when it detects these things, and the treatment that it offers is fabulous. The point is that too many women are not aware. As you said yourself, they may present to a doctor only every four or five years anyway. In my opinion, that is where the campaign has to start. I do not see why we could not have had a campaign six, eight or 10 months ago, alongside whatever work has been done with GPs and health professionals. That is the source of my frustration. I feel that the Department has not done enough, and what has been done should have been done earlier. I have heard nothing to tell me why it should not have been done before now.

Mr Johnston: We take on board fully your disappointment that the campaign has not moved forward more quickly.

Mrs Cameron: Can we be assured that there is a solo campaign in the offing? Will every avenue be explored to ensure that that happens?

Mr Johnston: The detailed work is under way. You have our firm assurance that that is now happening. We will have firm plans in place a short time ahead.

Mrs Cameron: Can we be assured that we will not be sitting around the same table in 11 months' time again talking about the same issue in the same manner?

Mr Johnston: Yes.

The Chairperson: On Pam's point, why can there not be a two-pronged approach? Why can you not proceed with the work? We are reminding GPs, who are professionally trained individuals, what to do, and that is OK. Perhaps people apply processes differently, but why can that piece of work not sit alongside a solo awareness campaign?

Mr Steven Wilson: I will pick up on the focus of the campaign. We recognise the anticipation and expectation that there will be a single campaign on ovarian cancer.

The reason that we as an organisation follow a very robust methodology in planning public information campaigns is that we know that it is reliable. The campaigns work effectively when they are done well. The first part of the process is gathering the learning and the evidence from elsewhere. It is interesting and particularly significant to note the evidence coming from England and Scotland. Scotland, for example, has a Detect Cancer Early campaign. Scotland looked at the range of cancers and decided at the first stage to roll out a sustained programme. That is what we are talking about embarking on: a sustained, planned programme of campaign around cancer awareness. Scotland decided that the first stage in its strategy was to look at communication-priming in order to try to tackle many of the issues and beliefs that people had about cancer. Despite there being, for example, good levels of awareness of symptoms, those were obstacles to moving to early detection, etc. Communication-priming focused on trying to develop confidence and reassurance around the generic Detecting Cancer Early benefits. The campaign talked about building the belief that you can survive cancer. It also looked at raising awareness that outcomes significantly improve if cancer is detected early, and it tried to dispel any worries around people with concerns making an appointment with a GP. Those were found to be real obstacles in the way of moving from the symptom-awareness and symptom-identification phases to seeking treatment. That is some of the learning that we are looking to bring into the focus of the campaign as it rolls out over a planned programme.

Likewise, England has looked again at the issue. It is looking at how it can take further the individual cancer tumour campaigns and sustain awareness around them. As Miriam says, this is not just a single initiative or focus; rather, it has to be done within a programme of planned intervention over a sustained period. That is what we as an agency are looking to do over the next number of years.

I understand the frustrations, particularly around the ovarian cancer issue, but the learning that we have gathered and are now taking into the process is very much about trying to pull the different strands into a cohesive cancer-awareness approach that will pay many dividends in the long term.

Mr Dunne: I thank the panel for coming in this afternoon. Is it fair to say that the issue is very much about risk. If you look at risk assessments, the risk is that the probability of having the cancer is low but the impact is high. Bearing that in mind, can you tell us what the real disadvantages are of setting up a programme to review all women over the age of 50? Why are we not going down that road?

Dr M McCarthy: There are very strict criteria. Heather is probably closer to the detail, but there are strict criteria about what works for a screening programme. If you are going to screen a population, you need to know that the screening test is fairly straightforward and reliable and that people then have access to a treatment that is definitive. We do that, for example, with breast screening. We know that breast screening picks up disease at a very early stage that is amenable to treatment and cure. Those criteria all need to be met.

The jury is still out on whether screening women in any age group for ovarian cancer is an appropriate thing to do and whether it would meet the criteria. The research trial that is under way will help inform the debate, but we do not know the outcome yet. I think that it is due in the next year or two, but, when that information becomes available, it will at least help inform the position. It may show that it is a useful test to screen everybody, or it may show that it makes no difference. I do not know; I have not seen any information coming out of it.

If the research suggests that it may be a useful thing to do — we do not know that yet at all — my expectation is that national groups such as the National Screening Committee would look at it. However, we would embark on screening an entire population only where we know that the benefit of doing so is much greater than the risk, the inconvenience and the anxiety that it would cause. It is much too early to say whether that is the case for ovarian cancer screening. We just need to watch that over the next couple of years; there are always developments and good research.

You are absolutely right that although the numbers are small the impact is high. That is key . We are also aware that we can talk about numbers, but, as with so many things, these people are not numbers. For every woman who is affected, whether she does well or not, her family and friends are anxious and she has surgical treatment and/or chemotherapy to go through. None of that is a good experience; it provokes great anxiety and can be incredibly stressful for an entire family, with children, grandchildren and others affected. We are conscious that there is a big impact on a small number of people, as you very eloquently said.

Mr Dunne: We all recognise that a lot of good work has been done in the treatment of cancer in Northern Ireland. We are aware of that in our constituencies and, in general, we get positive feedback. There have been issues recently around people being called for tests and so on perhaps not as promptly as they would like. Outside of that, however, the treatment is generally good. Is there a possibility that ovarian cancer would be seen as a lower priority and might be lost in the round on the treatment side? Will the resources be there to address the issue?

Dr M McCarthy: It is absolutely not a lower priority. We have very good treatment services. Because the numbers are small, most people are looked after by a regionally based team in the cancer centre in Belfast City Hospital. We have gynaecologists whose expertise is in managing cancer and who do the surgery for ovarian cancer. They are expert and very experienced. They refer women as necessary for oncology and chemotherapy treatment, and people have access to good, specialist drugs and the right chemotherapy. The treatment is very good and is managed by a very good team. In that respect, it has every priority that it needs.

Mr Dunne: There is an issue with GPs. I spent about an hour and a half with a local GP in Bangor and had a very useful meeting. I came away convinced that GPs have a heavy workload having gone in thinking that they did not, to be honest. We need to do a lot more under Transforming Your Care, which is the driver. I feel that they will need additional resources in order to take on this task. As you said, they will need awareness training and so on. Is there a risk that people will go to their GPs wanting this test having seen the publicity? There is a lot of publicity in the media, which is good, but they are going to join the queue and they will get frustrated and complain to their local MLAs and so on. Is there a possibility that that will add to the problem? Does that need to be addressed? We have all been assured that it is being addressed under Transforming Your Care; perhaps we will find out later today because it is on the agenda. To me, that is still a concern.

Dr M McCarthy: Hopefully, we will not be adding workload. You are absolutely right: general practice is a very busy place, and it is the first port of call for most patients when they are not well. There may be some women who will go to their GP to ask for the test because of anxiety. Our advice to GPs is that they should do the test if there are symptoms or signs after examining the woman. It is for the GP to speak to a woman about her risk and her anxiety and her family history etc and to determine when the test is appropriate.

However, my sense is that women in the over-50 age group — remember that we are going up to people in their mid-80s — tend to visit their GP from time to time to get medication, a blood pressure check or whatever. Hopefully, therefore, it will not be additional work for GPs. We have to remember that women who have the signs and symptoms do end up being diagnosed. However, we know that they have been diagnosed too late. What we have heard today is that they attend their GPs with vague symptoms that are not clearly ovarian in nature. They are already there with their general practitioner and in the system, but we are trying to make sure that they are identified earlier in their pathway.

Mr Steven Wilson: England's programme has followed a methodology of testing at pilot stage. Part of that process has been testing the impact of public information on the services side. We would always maintain that we cannot go with public information in isolation because it will have an impact on services. We fully expect that, in the development of the campaign, we will work in conjunction with the general practice side of the house to look at the possible impact of public information coming into play.

The Chairperson: Surely, when awareness is a life-saving issue, we are not taking decisions based on the impact on services.

Mr Steven Wilson: No.

The Chairperson: That is what you are after saying.

Mr Steven Wilson: No, I am saying that it is so that we can anticipate and manage appropriately the likely impact that will arise.

The Chairperson: We have identified the learning that you keep referring to. The fact that 3% of women in the North are aware of the signs is all the learning that we should need. We should not be taking decisions about whether to run an awareness campaign based on the impact that it might have on services.

Mr Johnston: What we are saying is the opposite. It is about planning so that we are geared up with service delivery and have appropriate resources to respond to demand that may arise from the campaign. It is not about trying to deter people; it is about increasing resources to make sure that we can respond properly.

Mr Brady: I share the disappointment that has been expressed by other Committee members. We have all met Una Crudden and were impressed and heartened by her commitment to this cause. It seems to me sometimes that the "experts" think that they know better.

There are two sides to this. It is very encouraging to hear about the GPs and the primary-care teams being made aware, the blood tests and all of that. However, if the patient does not present, it does not matter how well prepared the doctor may be. That is a simple fact of life. There needs to be a stand-alone public awareness campaign that targets the women aged over 50 whom you talked about. They seem to be the majority, although presumably there are women under that age who are affected.

The patient needs to be aware of the symptoms. It has been described as a silent killer. Many women present too late when it may have reached the point where doctors think that it is something else. If the person is not aware, it does not matter how well prepared the system is. You need interconnection. We need a public awareness campaign targeted specifically at ovarian cancer. You can put out a general campaign about cancer awareness, but people tend to get confused. There are particular cancers that affect men and others that affect women; it is about trying to target those groups. That is what is important.

It is disappointing that decisions made in the Assembly have been ignored. Sometimes I wonder whether people are really listening. What is the point in us sitting here if the Assembly makes a decision that is ignored? I go back to the point that sometimes the "experts" think that they know better.

Mr McKinney: I, too, share the frustration that has been expressed around the table. Much of that frustration seems to be about acting or not acting. Are you, as a Department and a health agency, doing anything to interrogate your own processes on how to act quickly when something is brought to your attention? Do you say, "This is an issue; let's move." Have you systems and process available as opposed to taking a broad sweep and being unable to turn the tanker? Have you got small boats, if you like?

Mr Johnston: Yes. We have an escalation process in place in the HSC system, and issues can be escalated to the highest levels very quickly to respond quickly if there is a need.

Mr McKinney: Have you exercised it in this case?

Mr Johnston: With regard to this campaign, we have been working with the agency on its overall profile of campaigns for the past year and the year ahead, and a good number of them are priority and urgent. It is about working with the agency to work out how we roll that forward. An example is the organ donation campaign. The Minister announced his initiative on that last year; therefore, we had to work with the agency to take it forward. We are in constant dialogue, Mr McKinney, with the agency.

Mr McKinney: Have you exercised the escalation process in this case, given the debates and the significant mortality rates? Have you exercised your own processes around fast-tracking this?

Mr Johnston: Escalation is a live issue; therefore it is constantly under consideration and discussion. It is not, as it were, being siphoned off.

Mr McKinney: I am really not hearing a yes or a no.

Mr Johnston: Yes, in that it is a priority for us and, therefore, we are attaching a priority to it alongside all the other campaigns that we are working on with the agency at the moment.

Mr McKinney: Have you done enough, fast enough?

Mr Johnston: I do not think that we can ever do enough or be fast enough. It is a case of taking the whole range of priorities and trying to move them forward as quickly and as best we can in a way that uses our resources appropriately. Having listened to the debate and the questions today, we can review it to see whether more could have been done more quickly, and we will certainly do that. However, we now have a firm way forward, which you will see coming to fruition in the year ahead. Turning to Mrs Cameron's point, we will not be sitting here in 11 months' time having the same conversation.

Mr McKinney: I do not want to put words in your mouth, but I am hearing an admission from you that you have not done enough fast enough.

Mr Johnston: I am not talking about a specific issue. I am talking about the generality of working in the health service, where there is always more that we can do and more that we can strive to do. We have been very active in moving this campaign forward as quickly as we can.

Dr M McCarthy: There is always the dilemma of knowing how quickly to react to things and where the priorities are. It is fair to say that the public awareness campaigns that are done each year by the Public Health Agency have to be limited to a discrete number because there are only so many messages that we can get out to the public without their feeling that we are constantly bombarding them. Moreover, the campaigns are very time-consuming and need to be done properly.

There were other priorities — Steven is much more familiar with the list — for campaigns that were already in the system. Therefore, being able to prioritise immediately a public awareness ovarian campaign would have meant that something else was not done. In that regard, though, we can still be fairly nimble on our feet, and we need to be nimble on our feet to do things as quickly as they need to be done. We are committed to a cancer awareness programme in 2014-15, and we started to plan for that over the past number of months. We anticipated that ovarian awareness would be part of that. When we say campaigns, we need to understand the terminology. Not every campaign is a media campaign; nor does every campaign need to have television, radio or other public outlets. A programme might be targeted at a population where that population is, as that can be more fruitful for that particular target population. We need to think about that for ovarian.

In particular, we may want to think about targeting where women are over the age of 50, rather than targeting 1·8 million. We have yet to decide on the best way, as we need to rely on the evidence. However, you are right: we need to be prompt and nimble in doing in that. However, what is not always visible is that doing one thing affects many other parts of the system, and we need to take account of that. The programme of increasing awareness of ovarian cancer will be taken forward. However, we need to make sure that GPs are not snowed under as a consequence. That does not mean that an impact on GPs would prevent it from happening. However, we need to be aware that there are consequences for the system, for the number of referrals and perhaps for the number of lab tests. We need to monitor and be aware that doing one thing can influence other steps in the system. We do a disservice to everybody in the system and patients if we do not take account of that at the outset. That appears, sometimes, to slow things down, but it is our responsibility to plan things thoroughly so that the end product is the best possible product. Invariably, that takes time.

The Chairperson: Excuse me for being facetious, but some might say that we ran out the door on the organ donation awareness campaign. Any decisions on public awareness have to be based on need. In that regard, there is a clear need to be addressed. I do not think that we need to access any other learning. We have the statistics before us.

Mr Wells: On 14 January, Fearghal McKinney MLA asked a very useful question; I hope that he does not quote it and use it against me. I will be serious now, because it is a serious issue. He asked about the availability of the drug Avastin — I hope that I have pronounced that right — which gives prolonged life to ovarian cancer sufferers. In GB, it is part of the £200 million cancer drug funding and therefore can be given. Here, a special bid has to be made for it by the consultant or GP. The argument is that, at the minute, we cannot really hold out much hope of a cure for ovarian cancer, but we could at least enhance the remaining months and years that people have. Where do we stand on that drug at the moment?

Dr M McCarthy: My understanding is that Avastin is recommended by NICE for a variety of things; I cannot remember all the indications. However, it is not recommended for the treatment of ovarian cancer. NICE looked at it and did not recommend it. We are very keen that patients have immediate and good access to specialist cancer drugs where they are recommended by NICE or other bodies across the UK, and we commission the drugs that are recommended for patients across Northern Ireland. For drugs that are not recommended, we ask clinicians to put in what is called an individual funding request (IFR) if they wish to obtain it for a patient. That is something that we look at within a week. We look at those every week and they can be approved in certain circumstances. I am not familiar with whether we have received many, or any, requests for that particular drug for ovarian cancer. However, at this point, it is not routinely commissioned.

Mr Wells: On 28 January, in response to Mr McKinney, the Minister said that Target Ovarian Cancer had campaigned for the drug in GB and that it is being administered to quite a few sufferers of the condition in England and Wales. You are saying that it is not applicable here, but is there any difference between sufferers here and those in England and Wales?

Dr M McCarthy: My understanding is that it has probably been made available through the cancer drugs fund in England and Wales rather than commissioned by local commissioners.

Mr McKinney: If you are content that you have answered the first question from Jim on the treatment side, I have a question. Will you tell me your thoughts on the cancer drugs fund and the inequalities, if you like, that it is producing in the health system, not only because of Avastin but because of the 37 other drugs that are available in England through that system and not available here? As Jim quite rightly points out, people's suffering is the same. Would a cancer drugs fund model be helpful here?

Mr Johnston: Our view is that our individual funding request system — Scotland has a similar process — is working effectively. Ultimately, it is a clinical decision as to whether a particular drug is prescribed. If there is a clinical recommendation on it, there should be nothing inhibiting the system in Northern Ireland going forward on an IFR basis.

Mr McKinney: Do you recognise the inequality that I talk about, given that such a range of drugs is available through that system that is not available here?

Mr Johnston: The inequality is not caused by the system here. We have questioned some of the evidence that has been presented about the availability of drugs in England and Wales compared to Northern Ireland. We do not fully accept the premise that any particular drug is being denied here.

The Chairperson: I do not want to stray too far into that, but you are right, Fearghal; it is a critical issue.

Mr McKinney: We need a discussion on it.

The Chairperson: By way of conclusion, I do not find what we have been told today acceptable; I find it extremely frustrating and disappointing. Those are the words to use. There are two issues that we need to separate: treatment and a stand-alone campaign. All of us should be doing everything in our gift to ensure that NICE guidelines are in place, that GPs are informed and that the pooling of resources can take place. However, there was a very clear commitment, based on need and the fact that 3% of women recognise the signs of ovarian cancer, on the need for a targeted, solo awareness campaign. A year in, we are now being told that we are getting only a pathway, which is in and around treatment and not awareness. If women cannot recognise the signs, they will not present to their GP. The message is loud and clear from all members today: there needs to be a stand-alone campaign. I would hate to think that that is being prevented because of financial situations. Ultimately, as we move on for another year or 18 months, people are dying. That is the harsh reality. They are dying because they do not recognise the signs early enough. We do not need to look at learning from anywhere else; we know the statistics. The message going back to the Department and the Minister is that there needs to be a stand-alone campaign.

Thank you for your time today.