HOUSE OF COMMONS

Northern Ireland Affairs Committee

Oral evidence: Funding Priorities for the 2018-19 Budget: Health, HC 1447

Wednesday 12 September 2018

Ordered by the House of Commons to be published on 12 September 2018.

Watch the meeting

Members present: Dr Andrew Murrison (Chair); Mr Gregory Campbell; Mr Goodwill; Nigel Mills; Jim Shannon.

Questions 59 - 84

Witnesses

I: Margaret Carr, Northern Ireland Public Affairs Manager, Cancer Research UK, Roisin Foster, Chief Executive, Cancer Focus Northern Ireland, Samantha Nicklin, Assistant Director of Policy and Campaigns, Breast Cancer Now, and Martin Abrams, Change Delivery Manager, Prostate Cancer UK.

Written evidence from witnesses:

- Breast Cancer Now
- Cancer Focus Northern Ireland
- Cancer Research UK
- Prostate Cancer UK

Examination of witnesses

Witnesses: Margaret Carr, Roisin Foster, Samantha Nicklin, and Martin Abrams.

Q59 **Chair:** Good morning, everyone. Thank you ever so much for coming a considerable distance to talk to us this morning. We meet this morning in a good mood because we have had some good news, which we will discuss shortly. Before doing that, would you very briefly introduce yourselves and say a very little bit about the organisations you represent? Roisin, would you like to start?

Roisin Foster: Good morning, everyone, and thank you very much for inviting me along today. I am Roisin Foster. I am the Chief Executive of Cancer Focus Northern Ireland. We are a local cancer charity. We will be 50 next year, so we are looking good for our age, I hope. We have been working across all cancers and all age groups since then. We were started initially by a cancer patient who was very concerned that there was no cancer research happening locally. When he recovered from his cancer, he set up our organisation. Our main areas of work are funding local research in Northern Ireland, cancer prevention programmes, care and support for people who are living with cancer and affected by cancer, and then the lobbying and campaigning work that we are here to do today.

Margaret Carr: Good morning. I am Margaret Carr. I am the Public Affairs Manager for Northern Ireland for Cancer Research UK. We are the largest charity funder of cancer research in the world and we fund a good bit of research, including clinical trials, in Northern Ireland. Our other area of expertise is policy and information, and that is the area that I work in. We have been involved in Northern Ireland for quite some time and doing all the usual charity things, fundraising and events and so on, but we have a strong lobbying presence and work in that way in all areas of cancer care, from prevention all the way through to research.

Samantha Nicklin: Good morning. I am Samantha Nicklin, Assistant Director of Policy and Campaigns at Breast Cancer Now. Breast Cancer Now was formed by the merger of Breakthrough Breast Cancer and Breast Cancer Campaign in 2015, and we are primarily a funder of medical research into breast cancer. We fund about £25 million of research each year. We are currently funding three projects in Northern Ireland around BRCA mutations and triple negative breast cancer, which is a particularly aggressive form of breast cancer. Thank you very much for inviting us to speak to the Committee today.

Martin Abrams: Good morning, Committee. I am Martin Abrams, Change Delivery Manager for Prostate Cancer UK. We are the largest prostate cancer charity in the UK and we have one simple aim, which is to stop men from dying from prostate cancer. We do this by working across all four nations to radically improve diagnosis, treatment and support for men impacted by prostate cancer.

Q60 **Chair:** Thank you very much. The background to this is the fact that

people in Northern Ireland have a lower expectation than people throughout the rest of the United Kingdom, particularly England, in respect of survival from common forms of cancer. We know that access to cancer drugs has been relatively poor in Northern Ireland. We also know that waiting times in respect of cancer diagnosis and treatment are longer than one would expect in comparison with the rest of the UK.

I very much welcome the announcement made by Richard Pengelly today in respect of access to cancer drugs, which will have the effect, as I understand it, of allowing an equivalence between access elsewhere in the United Kingdom and Northern Ireland. It is very welcome, long overdue and will cost between £2 million and £2.5 million a year, as I understand it. One thing that I think is worthwhile saying just for the record is that while we very much welcome the announcement made by the Department of Health, of course, we do await some understanding of where that money will come from. Hopefully, it will not adversely impact upon services and treatments elsewhere within health and social care in Northern Ireland.

That is a question I am not going to put to you because that would be unfair, but the question I would like to put to you is why you feel it is that patient expectation in Northern Ireland in respect of management, treatment and, crucially, survival has lagged behind the rest of the UK, in particular England. Roisin, would you like to kick off with that?

Roisin Foster: Yes. I think that the cancer drug thing is part of that. It is a bit of a sweet day for us because we have been campaigning to get equality of access back to 2012. While we are delighted, we would have liked to have seen it before now. Some of the people who started that campaign with us are sadly no longer with us, and I am thinking about them very much today.

It really starts, I think, with pressure on our GP services where people may have a symptom they are concerned about, it might be something they feel uncomfortable about, they try to see their GP, and it is three weeks before they see their own GP. There is where your first delay starts.

There are problems with diagnostics. Routinely, if you go to a GP now in Northern Ireland, not a red flag referral necessarily but if there are symptoms that might be cancer, you will be asked, "Can you afford to go privately for an MRI or a CT scan?" If you can, it does relieve pressure on the health service but off you go and you get your scan within three or four days. If you do not have that money—and a lot of people do not—then you are into very long waits. In the Southern Trust where I live, an urgent gastroenterology referral is over a year. Some of those people will have symptoms that could be cancer. If it is red flagged, they will be seen quicker.

There are delays in diagnostics, then there are delays in treatment starting and ministerial targets not being met. Shall I go on? There is

then access to drugs. We run a helpline in Northern Ireland and the calls that we get very rarely complain about the quality of the treatment that they get from their nurses and their doctors. It is all about systems. It is about test results not being there. It is about call backs not happening on time. It is about long waits for scans. I always say our patients are called patient for a very good reason. They have to be patient. They have to be exceptionally patient. We know all the research points to the fact that the sooner you get diagnosis, the sooner you get treatment, the better the outcome is.

I cannot point to one thing; it is a whole system thing that needs addressing. We do need to look at the restructuring of our health service. I am long enough around to have seen four or five different reviews of the structure of our health service that were saying broadly the same things, with some differences around numbers. They are all sitting mothballed, and I think that it is a great shame that we do not have an Assembly and an Executive to drive all of this forward.

Q61 **Chair:** You have hit the nail on the head there. Certainly, since you have mentioned it, I am sure Committee members would have made that point had you not. The Bengoa report is great and to an extent it is being implemented by the Department of Health on the grounds that Ministers prior to the collapse were, broadly speaking, in agreement with the things that Bengoa was recommending. To what extent do you feel that the absence of proper governance in Northern Ireland is impeding? I think that what you have said is spot on in relation to structures and the problems that relate particularly to Northern Ireland, not necessarily in respect of financing but the way the health service is put together. To what extent do you feel that the absence of proper governance in Northern Ireland is materially impacting upon patients' expectations right now, in particular in relation to cancer?

Roisin Foster: What is really lacking is consistent leadership. Democracy is hard and changing a health service is hard. It is not easy and there are lots of different vested interests. We need absolute leadership and it does need to come from the people we have elected to give us that leadership. Hard decisions will have to be made about reconfiguring our health service. When we responded to Bengoa, we said we were very happy with a lot of what was in that but what we really do not want is yet another consultation and review that goes nowhere. Guess what? That is precisely what we have.

I know that there are some things happening, but we need that leadership and we need all of us to take responsibility for implementing that. It does not just lie with our elected representatives and the Department. It is the voluntary sector, ourselves and people working out in the field. It is patients giving their view right from the ground up. We do need to be moving forward on it and it is a source of the greatest frustrations that we cannot make those changes and cannot make them in an overarching way. There are excellent things happening out on the

ground, but that lack of strategy, the lack of a transition budget to get us from where we are to where we are going and a long-term look at the finances—this is a great Committee and it is fine, but we are looking at how to spend a budget six months into the year. We should be looking at how we are going to spend this in five years' time. I do a five-year budget for my organisation. Six months into the financial year is short-term thinking and there is money coming forward that are short-term fixes, but they are sticking plasters on a large wound. We need to take a much more grown-up, long-term approach to it.

Chair: Yes, I think that is probably right. I am sure the Department of Health in England would agree with that given its insistence now. I think that we have accepted we will have a 10-year funding settlement for England, and it would seem appropriate that that is a general model. I am going to hold my question that I put about trying to determine why there is a difference between the patient experience in Northern Ireland and the rest of the United Kingdom. I am going to come back to that, but before I do that I am going to turn to Jim Shannon, who has a particular interest in these matters.

Q62 **Jim Shannon:** Ladies and gentleman, nice to see you here. Thank you for coming the distance as well. I am my party's health spokesperson here at Westminster and health matters are something that I have a particular interest in. In my capacity as an elected representative, now as the MP but in a former life as an Assembly Member and also as a councillor, I am aware of the issues of access to the drugs. It was tremendous news this morning, Mr Chairman, of what we have all heard and we are a bit shocked and pleased that it has happened. It is tremendous news.

The particular types of cancers are some of the ones that concern me, and I just think of three very quickly. Ovarian cancer is one where getting the early diagnosis is very nearly impossible, but it can almost happen by accident, if that is the way to put it. Breast cancer as well, and I know that you have a special interest in that, Samantha, and you might want to give us some idea as to how we are addressing the issues of breast cancer and also ovarian cancer.

What I really want to ask is this: I was at a thing last week that was to do with blood cancers and the person who was there was a professor. She gave an example of someone who had something wrong but was not quite sure what it was. They got the biopsy done, sent the biopsy off; it came back clear. But what the biopsy needed was another more intense investigation of what it was, which then came back with the diagnosis.

I was at Queen's University a way back at the beginning of the year at the special cancer unit they have there. I never knew before but there are about maybe 40 or 50 different makeups of blood cancers for individual people. You could have 100 people and 50 different cancers or maybe more. The complexity is so important. Where are we in Northern Ireland when it comes to having the ability to respond and check those

cancers and give the early diagnosis and the right diagnosis for the complexity?

Margaret Carr: I can speak to that if you don't mind. Northern Ireland has a very strong personalised medicine programme. My office is in the cancer research building, so I am very familiar with what is happening. The molecular pathology lab in Northern Ireland is one of the strongest certainly in the country, if not in Europe and beyond. The Cancer Registry is very good. All those things have to gel and come together in order to be able to identify down to the molecular level. If you and I have a blood cancer that technically has the same name, it is not the same in you and me because we are different people. Being able to delve down into the microbiology to be able to understand the cancer is very important. We have a pretty good setup to be able to do that.

The access to cancer drugs will help. We have not been engaging in a number of molecular tests in Northern Ireland because we do not have the drugs and we did not have access to the medicines that would fight them. Now that we have those medicines, it will mean that there are more routine molecular tests being done in order to use the medicines that are now available.

In general, we have a very good programme in Northern Ireland of personalised medicine. It is the way of the future. It is the way things are going to go as we continue to understand more and more about the biology of cancer. It is down to the detail and we are pretty good at that in Northern Ireland.

Q63 **Jim Shannon:** Are we able to improve the rate of diagnosis of ovarian cancer, for instance? I know the advances we have in the mainland here, but it is still that killer disease, as indeed many are. Are we anywhere more advanced in Northern Ireland?

Margaret Carr: I would say probably not, no. Ovarian cancer is just by its nature difficult to diagnose because the symptoms can be mistaken for quite a number of other conditions and very often get missed by the women themselves and missed by GPs sometimes. Tests can be inconclusive, so it is just by its nature more difficult to diagnose.

One of the things that could help is a wider campaign on awareness of signs and symptoms. In Northern Ireland we have been very slow to run awareness campaigns. We have not run one in two years. Be Clear on Cancer is the one that runs here in England, and there is one in Scotland as well. Perhaps down the road that is something with specific reference to ovarian cancer that might help.

Q64 **Jim Shannon:** In relation to breast cancer, in all the cancer figures that we have and our stats that we have before us, we know that breast cancer survival rates are not that good in Northern Ireland when compared to the rest of the United Kingdom. Samantha, what do you think we could do? Why does that happen and what do you think we can

do to improve survival rates for breast cancer in Northern Ireland?

Samantha Nicklin: We know patients in NI are at a significant disadvantage, I would say primarily because of the lack of access to two kinds of cancer drug. First, we know that lots of the new, more expensive cancer drugs like Kadcyla and Perjeta, which were available to patients in England through the Cancer Drugs Fund, were not available apart from through the individual funding request system. The principle of exceptionality meant that many patients who applied with their clinician to the individual funding request system were rejected because their cases were not deemed to be exceptional enough. Patients with metastatic breast cancer, which is the disease that kills and is incurable, would not have had access to life-prolonging medicines. We welcome the announcement today. We think this will deliver significant change for patients in NI.

Speaking to your earlier question around ovarian and blood cancers, we know, in our role as co-chair of the Access to Cancer Medicines Coalition, that there are drugs on the CDF currently in England for ovarian and blood cancer. We imagine—we hope—that once the detail becomes apparent about how this new funding mechanism will operate, those drugs will become available to patients in NI and we will see increasing survival outcomes for those patients.

Potentially what we could learn is from activity that is being led by the Department of Health in England in having a cancer strategy that sets out opportunities to improve earlier diagnosis. One of the things that NHS England is looking at in the long-term plan is for signs and symptoms, whether non-specific or general, where there is opportunity to refer people in through one-stop shops. I know where there are challenges in access through GPs who are gatekeepers, potentially there are other systems or there is the possibility to route people into earlier, faster diagnosis through other routes. That is one of the things that we are influencing around in England and potentially could be of benefit to patients in NI.

One of the areas that I would also like to touch on is access to bisphosphonates. Bisphosphonates are cheaply available, widely available drugs that were initially used in the treatment of osteoporosis. In 2015 *The Lancet* published a study that found that bisphosphonates could also be used to prevent the spread of breast cancer. When given in the adjuvant setting, so alongside chemotherapy, they were found to prevent the spread and reduce the risk of spread where the disease metastasises by 28%. At an England level, that would save 1,000 lives a year, so a significant contribution.

The challenge with these drugs is that they are off patent and clinicians would have to prescribe them off label, so there are a number of challenges in delivering this at a system level. We have been campaigning for this for a number of years and recently secured a recommendation within the NICE guidance around early and locally

advanced breast cancer for this to be routinely offered to all patients who are postmenopausal and who are at a high risk of recurrence of breast cancer. We would like to see that guidance endorsed in NI, and that is something that could happen as soon as possible.

Q65 **Jim Shannon:** That will not happen through the Cancer Drugs Fund?

Samantha Nicklin: No, that is separate. These drugs are already in use within the NHS or within the health system. The issue is using it for this indication, so instead of using it with patients with osteoporosis, using it for patients with breast cancer. For example, one of the things that could be done very easily and rapidly would be to issue correspondence to health commissioners and clinicians around the new indication. This is something that we called for in England and have successfully achieved.

Q66 **Jim Shannon:** I would be very interested in following that up. One of the things in Northern Ireland that I was not aware of until I read through the notes that we have in front of us is that there seems to be a higher level of cancer in the deprived areas of Northern Ireland. Do you have any indication of why that is and how we address that?

Samantha Nicklin: On breast cancer specifically, it may surprise most people that it is more common as a disease in wealthier, more affluent areas, but we find that survival outcomes are much worse in areas that are more deprived because people are more likely to present later with the symptoms of the disease. Obviously, as Roisin said, the later breast cancer or cancers are detected, the poorer the survival outcomes.

We know there are a range of initiatives that can be put in place to encourage people to be aware of the signs and symptoms. For example, Breast Cancer Now run a campaign called TLC, which stands for touch, look, check, to encourage women to check their breasts on a regular basis to know what is normal for them, to spot the signs and symptoms and then to refer themselves into diagnostics. As Roisin says, where you are waiting three weeks to even see your GP and then there are further delays within the diagnostic system, it can be very hard to get a diagnosis and from then on, with limited treatment options, we know that patients in NI fare worse.

Roisin Foster: Something to mention in respect of that is smoking. Smoking rates are seven times higher in deprived areas, and that in turn raises the incidence of lung cancers, bladder cancers, stomach cancers, all the cancers that go along with smoking rates. It is something that we have been very hard on since we were set up, but it is something that needs funding. It needs a big public awareness campaign. It needs consistent investment in prevention, and that is one of the big issues. It is not the only issue, but if we were to ban smoking tomorrow in Northern Ireland we would see cancer rates tumble. It is a hard fact but it is a fact.

It is higher in deprived areas and the smoking rates of children in deprived areas is really deplorable. When we challenge smoking, which we do all the time, we get back, "It's a nanny state, you are controlling. People are adults; they make their own decisions". Most people start smoking as children. I do not know anyone who started after 18. It is the 12, 13, 14 age group. That is the holy grail for us. If we can reduce smoking rates among those children, then we will reduce cancer rates across the piece. It is a hard fact but it is a fact.

Q67 **Jim Shannon:** In relation to prostate cancer, Martin, you and I and the men around this table are very loath to go and see the doctor, so prostate cancer is unfortunately one of the developing cancers for males. I can well remember—I am not going into any detail now—having to go and get the check done and it can be quite off-putting. How do we address the issue of prostate cancer in men to make them, first, look out for the symptoms and, secondly, go and see their doctor and respond? I think there are stages 1, 2, 3 and 4. I had a very good friend whose diagnosis was stage 4. It is very late. What can we do?

Martin Abrams: The issue with prostate cancer is that in most men it is asymptomatic, so the best tool that we have in our box is to raise awareness of men's risk. To put it in a nutshell, if you are over 50 you have a higher risk of prostate cancer. If you have a family history or if you are a black male, you have a higher risk of cancer. A lot of our work is about awareness raising, similar to what Samantha illustrated at Breast Cancer Now. We are doing a lot of that in Northern Ireland.

Jim, you touched on the issues with diagnosis in Northern Ireland. That is something that we are really focusing on at Prostate Cancer UK. One of our main priorities is the rollout and adoption of a new scanning technique called multiparametric MRI that we want across all diagnostic pathways in the UK. At the moment, in Northern Ireland the situation is pretty bleak. Only 40% of the health boards, so two out of the five health boards, have this diagnostic technique available to men, and that is not operated to the standard that we would like to see. That is compared to England where 87% of areas have access to this diagnosis. In the first instance, getting an accurate diagnosis of prostate cancer in Northern Ireland, there are barriers already there for men over there.

In terms of patient expectations, which I would also like to touch on, our experience has shown that patients' expectations are lower. One of the key issues that we have flagged over the last few years in Northern Ireland is that access to prostate surgery is non-existent in Northern Ireland. If a man is diagnosed with prostate cancer and informed and given the option to have radical surgery or advised to have radical prostate surgery, he cannot have that surgery in Northern Ireland. All men have to travel to the English mainland to have that surgery currently. If that was the case in England, if all men had to travel over the Irish Sea to have surgery, it is likely that there might be more coverage of that and maybe more fuss made.

A lot of our volunteers over there are working and shouting about this tirelessly. Jim, you came to one of our events earlier in the summer that was organised by one of our volunteers whose husband had to travel over to England to have his prostate surgery and had to travel over four times before actually having his surgery and then had to go through obviously flying back very soon after his surgery and all the risks and the inconvenience and the problems that that may cause, flying so soon after having surgery. That event got quite a lot of attention and over 500 people turned up to raise awareness of this issue in Northern Ireland.

While patient expectations might be slightly lower, there are people working very hard over there to raise awareness of this issue. We now know that later this year surgery will commence again in Northern Ireland, which is good news because the Belfast health trust has just acquired a robot to commence robotic prostatectomies. That is progress.

Q68 **Chair:** Can I stop you there? I am pleased you mentioned robots because that is state of the art. The problem—and I would invite your comment on this—with blandly stating that the absence of a particular treatment in a particular location is self-evidently a bad thing needs to be challenged, does it not? Evidence suggests that treatment in a specialist centre is usually attended by better outcomes than treatment in a centre that deals with issues on an infrequent basis. I suppose the question is whether Northern Ireland has the critical mass to guarantee to patients in Northern Ireland those first-rate clinical outcomes, otherwise we have to challenge the easy assumption that ease of access is self-evidently a good thing.

Martin Abrams: I welcome that challenge. We at Prostate Cancer UK do not have a problem with people having to travel to specialist centres to access the best possible treatment. The issue arises in that men's experience of having to travel so far can be quite detrimental. As far as we are aware, all men had to travel to Addenbrooke's Hospital in Cambridge or Guy's Hospital in London to have their surgery. They also had to pay for their flights and book their hotels themselves and then reclaim that back. It might not be possible for people on low incomes to even have that initial outlay to pay for. Referral from the Northern Ireland health board, which made the decision to approve the referral to have the surgery, meant that men were facing fairly significant delays of up to six months or sometimes more to have their surgery, which is unacceptable.

Yes, if the treatment is available in a specialist centre, that is good. It then comes down to the men's experience of how far they have to travel and the impacts that can have on their lives as well.

Q69 **Jim Shannon:** I have one last question and it is in relation to child cancers. It has been quite topical in the press back home, which you probably all know. We do not have any stats or figures here in front of us, unfortunately, that indicate what the levels of child cancer in Northern Ireland are. I am not sure, Roisin—

Roisin Foster: Just under two children a week will be diagnosed with cancer in Northern Ireland.

Q70 **Jim Shannon:** What are the survival rates of those?

Roisin Foster: I do not have those to hand, I am sorry. For some cancers it is improving. For example, with leukaemia things are improving, but there are some other cancers, brain tumours, that are still fatal for most children. I cannot give you that but I do know it is about 100 children a year, and it is 100 too many.

Q71 **Jim Shannon:** We have come on in leaps and bounds in relation to how the health service is able to respond and deal with cancers. My father was a survivor of cancer on three occasions, as many others are. It probably gives an indication that the research that we do and the care that we do is substantial, but we still are far behind the rest of the mainland. As the Chairman said earlier, is that down to not having a Minister in place to administer and help the Health Department work better or are there other reasons?

Roisin Foster: A few years ago when I first came into post, which was 2010, around that time, we were not lagging behind other areas in the UK. We have failed to keep up and that has been exacerbated by the lack of a Health Minister and an Executive. It is that other people have become better rather than that we have become worse. As has been described by colleagues here, we have been very slow to get on board with new systems for diagnosis, new systems for treatment. Funding has been an issue, there is no doubt about that, but I do feel very passionately that if you live in Northern Ireland you should have the best chance of a good outcome.

You raised the issue of children's cancer and it is particularly heart-breaking when a child gets cancer. It sometimes is masked by the fact that cancer is primarily a disease of adults and a disease of older people. We can see the graphs go up quite substantially from middle age onwards. Colleagues have raised the lack of a cancer strategy. Our cancer strategy is 10 years old and the world has changed so much in 10 years. We know from our Cancer Registry that by 2035 incidences will go up 65%. We have nobody saying, "What are we going to do about that?" We barely can deal with the patients we have now; how will we cope with a 65% increase? We really need to get serious about our prevention because if we can stop that 65% figure, that would be the optimal outcome. How are we also going to treat the people that do come along? How are we going to get to them quick enough that the treatment is perhaps less invasive or surgery will sort it rather than getting it to the more expensive—well, it is not more expensive but the treatments like chemotherapy and radiotherapy, if we can avoid it, for example? Getting people diagnosed as soon as possible, the public information campaigns that Margaret has referred to. We do need a strategy that will take us from prevention right through the treatment process and out the other end. We have to stress that.

Q72 **Chair:** I am warming to my theme of treatment in specialist tertiary centres because the outcomes in those centres do tend to be rather better, but equally I am rather alarmed that people in Northern Ireland have to go all the way to Cambridge in East Anglia or to Guy's here in London in order to secure that treatment.

Given that a great deal of this has to do with critical mass and the number of patients with particular conditions being treated in centres that are sufficiently large—I know in Prostate Cancer UK's written evidence you cite a shortage of radiologists specifically in Northern Ireland—the island of Ireland overall has a critical mass of patients, which would allow the recruitment of specialists and subspecialists to an extent that is not the case taking Northern Ireland alone. What do you think the future might hold? This is all to do with politics, as so much is in Ireland, of course. If the politics were to allow greater co-operation between Dublin and Belfast in this respect—and there had been early moves particularly in relation to paediatric cardiology; it is very much at early stages—to what extent do you think a development of that might help us get around this issue of access for people both in Northern Ireland and Ireland to specialist tertiary services of the sort that deliver the very best clinical outcomes?

Martin Abrams: I think that will help. If men were given the choice of whether they had to get on an aeroplane and fly to Cambridge or here in London or get in a car or get on a train and go to Dublin, I think that most men would probably choose the latter option. Yes, that has to be looked at and that is happening with some conditions, as you have pointed out, Chair.

Workforce is something that we are very concerned about. One of the reasons that that diagnostic technique is not available in every health board to the standards that we would like to see in Northern Ireland is because there is a chronic shortage of radiologists in Northern Ireland. We illustrated in our written evidence that 25% of radiologist posts are currently sitting vacant over there. It is not always about having the equipment or paying an initial outlay to have this new scanning equipment. Often the equipment is there but does the hospital or the trust have the capacity to get those scans done? Is the workforce there? Can they cope with the workload with the current workforce they have? At the moment, it is clear to see that they can't. It has to be considered whether there is more opportunity to look at the island of Ireland as a whole and see what skills or expertise can be shared.

Q73 **Chair:** Radiology is a particular specialty and its uniqueness is, of course, that radiologists can be sited quite a long way away. They do not have to be there in front of the patient to interpret a scan, do they? I am wondering whether, in fact, coming back to the point made about structures earlier on, part of the solution might be to obtain reports from radiologists who are not necessarily located within Northern Ireland.

Martin Abrams: That is already happening. Remote monitoring and interpreting scans is already happening from radiologists who are sometimes based in other countries. That has to be fast tracked more than it is, and that will probably require slightly more investment than we are seeing at the moment.

This all comes down to—and I know that a number of us have mentioned it already—the fact that there is a lack of a cancer strategy in Northern Ireland. That means that there are not the ambitious targets or milestones being set that we need to see in order to have that direction of travel. We are not just talking about remote monitoring now. We are also looking at artificial intelligence to look at scans for diagnosing cancers. Without a cancer strategy and that top-down direction, things are moving at a much slower pace. That is why things are falling behind in Northern Ireland. Wales, Scotland and England have cancer strategies and, while they are not perfect, they do offer the strategic direction that is needed to focus on survival rates and much better outcomes for cancer survival. Without that in Northern Ireland I think that we are going to continue to see things fall behind.

Margaret Carr: It is an example. In part of the £100 million of confidence and supply money for this year allocated to the health service, one of the things that is being funded is the implementation of the imaging review. The imaging review has been completed for, I think, 18 months but there was no funding to implement it. That includes a lot of the things that Martin has talked about. It is an example.

There is an imaging review that is being funded by that money. There is a pathology modernisation project that is being funded by that money. There is a lot of work on general practice. There is a piece of work specific to cancer treatment on delivery of chemotherapy and radiotherapy, which I am lucky enough to sit on the board for, but it is an example that all those individual pieces are out there being thought about but there is no whole and there also is no long-term thinking.

Part of the problem is that we are just putting sticking plasters on things and it results in a system that is inefficient. As soon as one thing gets fixed, something else breaks and you have to fix that. It is indicative of a system that needs a cancer strategy more than anything else, something that analyses all the issues, as Roisin said, from research through treatment, including workforce, research and data. All those things for cancer need to be looked at, where we are now and how we go forward over a number of years. We just do not do that.

Q74 **Mr Campbell:** Welcome, all, a long overdue welcome this morning. I wanted to come back to the issue that my colleague Jim raised on prostate cancer. You are Prostate UK?

Martin Abrams: Prostate Cancer UK, yes.

Q75 **Mr Campbell:** I am interested if there is a distinction in this ongoing

issue of the lack of early presenting by principally adult males across the UK. It just seems to me that not every adult male but most adult males, as adult females are, are reasonably logical in every other aspect of life. If the lawnmower is broken, you take it to a lawnmower repair shop. If the television is broken, you call in the TV repairman. I do not quite fathom why we as men do not go to the doctor if there is something wrong. I just do not get that as an adult male. Obviously, this is applicable across the UK. Have there been targeted campaigns that have been more successful in some parts of the UK, less in Northern Ireland, or vice versa?

Martin Abrams: That is a really good question. If you are looking at awareness of the two cancer societies that are sitting next to each other today, breast and prostate cancer, I think breast cancer has been really successful over the last three to four decades as to raising awareness and smashing through certain glass ceilings and breaking down barriers in getting women to talk about their health. We as a cancer charity are really putting all our work into doing that as well. Like I mentioned earlier, the tricky thing with prostate cancer is that in a lot of men it is asymptomatic. Sometimes when symptoms are then presented, it can often be when the cancer is at a later stage to have curative treatment or to increase survival time.

We are doing a lot of work on awareness. One specific campaign that is currently happening in the mainland is focusing on black men in London and the West Midlands. That is called Stronger Knowing More. That is targeting those communities to increase awareness, and we are doing that through public health and public awareness campaigns, billboards and posters in a lot of shops, and TV adverts as well. That does work.

Q76 **Mr Campbell:** That sounds like a targeted campaign. Are there other campaigns in different parts of the UK not specifically targeted at higher risk groups, which you have outlined again and again now, that have proved more successful in getting men to present earlier?

Martin Abrams: None that are coming to mind. We operate in all four nations and we do a lot of work in Northern Ireland. I mentioned some of the awareness-raising events that we are doing. The one we did in the summer called the March for Men is really about raising that awareness of what is happening in Northern Ireland, the risks of prostate cancer but also about the current healthcare situation over there and why things must be improved for men with prostate cancer.

We are looking into why some groups of men are presenting at a later stage, and that is combining social deprivation data with data from Public Health England in terms of diagnosis at a certain age and geographical location. While I do not have that data on me now, I would be very happy to submit that to this Committee when it is at a more presentable stage, which is probably going to be later in the autumn. That is something that we are going to be much more targeted on, going to the areas where

men are presenting at a late stage and going about public health campaigns and raising that awareness in those areas.

Q77 **Mr Campbell:** It seems to me that like the analogy that I have used on a number of occasions in the past, if the washing machine is broken, by and large it will not fix itself. If the television has stopped working, by and large it will not just start again. You get it fixed. I think that we really need to target. It is the same with breast cancer and ovarian cancer and other cancers, but for some reason there is this continuing lack of awareness among adult males.

Roisin Foster: Could I just follow that up? We run a service called Keeping Well. It is a mobile service that goes out into communities in a van with a nurse on board and a health promotion person on board. It is our only service that is used by more men than women. Whether there is something about the van, I don't know, but it is the places we go to as well. We go to farmers' markets, Orange Order parades, Gaelic football matches. Wherever men go, we go. We talk about hard-to-reach groups, but if you go to them they are not as hard to reach as if you wait for them to come. We find it is a very successful way if we target it, if we go out.

It is also the attitude of the staff. Our staff are not shockable. We do have men come on and say quite openly, "I haven't seen my doctor for over 20 years". We have had people whose blood pressure has been so high we have had to say to them, "Can you get someone to come and drive you home, please, and drive you to a hospital because you are at risk of a stroke?" We are picking up stuff that is not just cancer related. It is a way of reaching those hard communities and reaching men and going to them.

We also raised earlier about the incidence in areas of social deprivation. Research shows that people in those areas are much more fatalistic about cancer. They think if they get cancer it is curtains, they are going to die, and that is not necessarily the case. It is bringing that information to try to build up courage. We can judge people and we say, "It is men". We have to start from where they are and we have to say, "This is an issue for men". We need to go to them and we need to go to them in a way that they feel comfortable with.

Q78 **Mr Campbell:** Is that outreach programme funded departmentally?

Roisin Foster: No, it isn't. I wish it were. We are funding it and we are funding it on a shoestring in many ways. I do feel that it is the way to go and that we can go out and reach people and target those areas of deprivation and those groups of people that we are finding hard. We are creating champions in those areas. We are doing work with older people. It was originally funded by the Big Lottery, and we are working with older people in local communities to give people the confidence, to say, "That is worrying. If when you go to the toilet there is blood in the toilet, that is worrying and you should go and see your doctor" and give people the

confidence to do that. People are nervous. They are embarrassed about some of the symptoms and it is just sometimes giving that little bit of a nudge or a wee bit of a push and support. It is not unsolvable. We just need to come at it from the basis of where people are.

Martin Abrams: What I would say is that things are getting much better. Men are talking about their health and I think that there is a lot of positives to look to as well. We are aiming to be much more targeted and we will continue to do that. You might have noticed my badge that I am wearing. Like Roisin said, we go to where men are to talk to them about their health. We work a lot with the football leagues and various other sports in what we call passion points for us to engage with men and to help raise awareness. Barriers are being broken down. We still have a lot of work to do, but we have a very ambitious 10-year strategy within our organisation in order to do that. Within that 10 years, we aim to stop men dying of prostate cancer.

Mr Campbell: I am sure your appearance today will help us with that.

Margaret Carr: It is statistically proven that people who live in Northern Ireland are, in fact, less likely to go to the doctor than even people over here. The Public Health Agency, when they were creating Be Cancer Aware, for example—unlike Be Clear on Cancer and whatever the one is in Scotland at the minute—ran a campaign at the very beginning called a primer campaign to not talk about signs and symptoms and not talk about disease in particular but just to say to people, "If there is something wrong, your GP does want to see you". It featured GPs. There were a couple of different iterations of it featuring GPs saying, "Don't put it off. Come and see me. That is my job. That is what I am here for".

If we were running those campaigns consistently, which we have not been, all of them should have a mention of, "Come and get checked". The breast cancer one that we ran, for example, had a female GP who said, "If you find something, just come and talk to me. It will not take very long. It is not invasive, but you have to come and tell me. I cannot read your mind".

The problem with those awareness campaigns—we are not running them and have not run them for over two years in Northern Ireland—is that it drives more people to get checked. There is no question about that. The breast cancer campaign drove lots of women to get themselves checked or to check themselves and then present, but the issue is once you get into the diagnostic system in Northern Ireland that is the problem. As Roisin said, her helpline does not have lots of people who say that they have a problem with the treatment and care that they have received, but lots of people, I suspect, will have the problem getting into the system. The diagnostic system in Northern Ireland needs a lot of work on cohesion, better screening programmes, better awareness, organising diagnostic testing, locations, workforce, and making sure we have enough kit, machines and what have you. It is not unreasonable to worry

about that, that people do not present, because that is true about those of us who live in Northern Ireland.

Q79 **Mr Goodwill:** When the Cancer Drugs Fund was introduced, it was largely a response to some new, very expensive drugs, which by and large seem to be life extending as opposed to life saving. With that in mind, if we did have £2.5 million to spend in Northern Ireland, could that be spent in a better way, maybe with speeding up diagnosis or smoking cessation or all those other things, or is it just the fact of life that I could get another three months of life, it is going to cost £20,000 but that is an immediate call rather than some other strategies that take longer to feed through? In the case of smoking cessation, that may take 20 years to save somebody's life.

Roisin Foster: I agree with that. However, if it is good enough for the rest of the UK, why shouldn't Northern Ireland patients be able to avail? You are in England; that is not an either/or, it is a both. I feel that our patients are just as valuable, so I do not think it should be an either/or for them. If you have six months to live and there is a new immunotherapy treatment that could give you several years, where you will as a result have fewer side effects, fewer admissions to hospital for crises, I think you would take that, Mr Goodwill. I know I would, so I do not think for our people it should be either/or.

Samantha Nicklin: I would also say that for us it is a huge injustice that breast cancer patients in NI have not been able to access these best new first-class medicines like Kadcyla and Perjeta routinely up until now. When we look at Perjeta, which is a combination treatment—pertuzumab is given in combination with Herceptin, which is a very common breast cancer drug—these are targeted therapies that provide 19 months' progression-free survival. In terms of life extending, we would see that, from the patient perspective, as excellent value for money. We are campaigning in Scotland now to ensure that Perjeta is routinely made available because it is still going through the SMC process.

We would want to see equality of access across the UK. We know that increasingly the NICE technology appraisal process has significant challenges around the cost-effectiveness of these combination treatments. Essentially, the cost of the treatments is just piled up, and we see mechanisms like the Cancer Drugs Fund as key to developing that evidence base to understand whether these treatments are effective. Then that assessment process can understand whether they are cost effective to the health service.

From the patient perspective, we know several of our supporters have got in touch to say where they have gone through the individual funding request process and they have not been deemed exceptional, they have then either crowd funded to have that treatment, remortgaged their homes or used up their life savings in order to pay for these treatments. I am sure you can imagine at a time when you are diagnosed with an incurable illness, that is the last thing that you want to have to do. We

believe that this news today is welcome news, but we want to see the detail of how sustainable that funding will be and how this will ensure that patients have access to these best new treatments, especially where they are particularly expensive.

One of the things that I want to flag to the Committee is the renegotiation of the Pharmaceutical Price Regulation Scheme, the PPRS, which is currently happening. That is the agreement between the UK Government and the pharmaceutical industry on the price of branded medicines. Currently, the system works to ensure that a rebate on the price of those medicines goes back into the Treasury coffers, essentially. We think this is a perfect opportunity to negotiate for that funding to go to Northern Ireland for access to these new treatments. We hope that that would make, for example, today's announcement more sustainable over the longer term as the negotiation that is struck will last for usually five years.

We would also want to see a commitment put in place to ensure that the NICE technology appraisal process is reviewed. We know that these very expensive treatments that are coming down the line, combination treatments and immunotherapies, which hold such potential for patients for both life extension and potentially curative potential, is where there is a real opportunity to influence the system at large over the longer term.

Q80 **Mr Goodwill:** In terms of public health, is there more that local authorities could be doing to try to improve some of these lifestyle issues, smoking and obesity? They are not constrained by the lack of political direction at the moment. Is that happening or is it a priority?

Roisin Foster: It is, but it could certainly be enhanced. Our Public Health Agency is excellent and it produces excellent research, and there is a very good public health strategy, but we do need the political direction in that and it does need to be funded. It needs to be planned and it needs to be part of a coherent strategy, as we have all been saying today. We need to make it as easy as possible for people to make healthy decisions and as hard as possible for them to make unhealthy decisions. We do need to be looking at the minimum pricing for alcohol. We need to be looking at controlling sugar, especially for youngsters, and continuing the fight on tobacco, which I have already mentioned, working very closely in communities, with communities and not this top-down approach. We need to embed and make it as easy as possible. Make unhealthy foods more expensive. It gladdens my heart now when I go into supermarkets and I hear youngsters saying, "I want apple. I want apple" because you go into a major supermarket now and they have free apples, oranges and bananas for youngsters and your children are clamouring for them. That is great as opposed to clamouring for sweets.

There is a move, and again it is an all-systems approach. We need to be working with our supermarkets and it needs to be as easy as possible for people to make the right decisions. I like the idea that is coming into Scottish schools about them getting run-a-mile during the school day.

That is fabulous. Increasingly you are seeing people of my generation with our Fitbits now, but we need to start that very early on, that an active lifestyle is embedded from the word go and part of our curriculum.

We work a lot with schools on tobacco. Our earliest health promotion starts in nursery school where we have a healthy living goat that visits nursery schools. We talk about healthy diet and then we move into our farmyard, and we talk about activity. We do smoking awareness from primary 6 and all the way into secondary school. You just need to be continually beating those messages home from every step.

There is a big change. When my children were small you could send chocolate in a lunchbox. That is definitely a no-no now. Lunchboxes in schools have to be healthy. That is a very positive step but again it is something that we all need to work together on.

Q81 **Mr Goodwill:** When I was at primary school I was sent to the village shop to get the teachers cigarettes; that is how things have changed. We are winning the battle on tobacco but obesity and diet is still one. Northern Ireland is one of the places where it seems to be a harder nut to crack.

Roisin Foster: It is. It is areas of social deprivation as well. Not solely but it is an issue that we do need to be consistently working on.

Q82 **Nigel Mills:** The title of our inquiry is funding priorities for health in Northern Ireland, so we could do with getting some recommendations you would like us to make that would meet those funding priorities. I think I am right that Northern Ireland has the highest funding per capita for health of the four UK nations. It is quite a lot higher than England but we do not seem to get the outcomes quite as high in some of these cancers as we do in England. If you could change one or two things that you would like us to try to make happen in the next year or so, what would they be?

Martin Abrams: For us, the number one priority is having that cancer strategy and working out if there is a way, in the absence of having an Executive over there, that to have that decision-making process to work out that strategy can happen. I do not think we can wait much longer to have that strategic direction and those ambitious targets that would form part of that strategy. For us, that is the number one at the moment in Northern Ireland. That would encapsulate anything from prevention to diagnosis to treatment and support for men with prostate cancer. Any recommendation that would come from this Committee would be to basically outline the decision-making process that is available to work towards a strategy.

There has been a decision made today on the cancer drugs fund, which is very welcome. Can a decision be made by the Permanent Secretary over there to kick off the work around a cancer strategy? We are all available to help with it. We are chomping at the bit and we have the expertise,

the knowledge, the intelligence to help work that out. We do not think it should be delayed any further. That is a priority for us.

Q83 **Nigel Mills:** Ms Nicklin, is that the same answer or do you have something else?

Samantha Nicklin: As I have mentioned, some of our challenges in improving outcomes for breast cancer patients are non-financial. Thinking about the availability of bisphosphonates, these aren't expensive drugs that are out of reach because of their cost. There are cheaply available, widely available medicines that are currently used within the health system. The issues there are around clarity of commissioning guidance, clinicians having the confidence to use these medicines in the way that NICE recommendations suggest. That is the quick win from our perspective.

We would agree, and in our written evidence we were clear, that a cancer strategy is critical. That is where we have seen advances in treatment and care in England, Scotland and Wales. We believe in a planned approach, looking at where there are gaps with geographical inequalities, or socioeconomic or age inequality. We know, for example, that older breast cancer patients fare worse because they are less likely to have the full range of treatments offered, particularly surgery.

Where we identify these problems across the patient pathway, a cancer strategy allows us to adopt different initiatives that will improve diagnosis and improve the speed of delivery. But what underpins that strategic approach is also investment in infrastructure and workforce.

In a similar way to the prostate cancer, we know that there is essentially a demographic timebomb, a challenge of high vacancy rates and, in the future, higher retirement rates of radiology staff and radiographers. We know that there is an ongoing problem with workforce and, without a strategy or clear plans for how those staff will be recruited and trained, we do not know what the prospect is for the workforce going forward.

One of the issues I will also mention on workforce is these areas for innovation. From the newest research coming through, we know about the use of AI, or machine learning, in supporting pathology, supporting radiography. Where an X-ray is taken of the breast, could a machine, in the same way as we have facial recognition software, be the first check in establishing whether a patient has breast cancer?

These are emerging technologies and without a longer-term plan it is not clear where the headroom would be for service innovation because we are not even getting the basics right now. But without that longer-term strategy or plan we are also not going to have an NHS that is fit for the future.

Q84 **Nigel Mills:** Ms Carr, did you have something different?

Margaret Carr: I do not. The cancer strategy is obviously our number one call and has been for an awfully long time in Northern Ireland. It does require a Minster's approval to start it, at least the way things currently sit in Northern Ireland. Barring that, Cancer Research UK's priority would be in increasing early diagnosis.

We know that the earlier a cancer is diagnosed the easier it is to treat. It is better for the patient and less expensive for the health service, so there are lots of benefits for that. Improving early diagnosis runs everything from—Northern Ireland is the only part of the UK that has not committed to changing two of the important cancer-screening tests for bowel cancer screening and cervical cancer screening. The tests themselves have been agreed to change in all three other nations and we are the only one that has not committed to that. That would be included, for me, in early diagnosis.

As Sam has said, the diagnostic workforce is important. We know that there are issues. Implementing the radiology or the imaging review will help but we know that there are other issues; in endoscopy, for example, and locations of where tests are offered and how many endoscopists there. Getting cancer diagnosed sooner would be within a cancer strategy, if that is not possible today, would be my wish list.

Roisin Foster: I would go with cancer strategy again, but looking straight at finance, going back to the question, it is a long-term budget and a long-term look and also a serious look at how we implement Bengoa when we get to that. It will need transition from then. There was no mention of funding in that at all, how much it would take, what some changes might save and what things would cost. But you do not go on any journey without it costing, so if there is a part to free up funding for me it would be a transition fund and a serious transition fund. That is not going to happen in the next six months but it is something we should be looking at and taking a real strategic look at.

Chair: Thank you very much for the evidence you have given us today. What you said is extremely insightful and I am already formulating my own conclusions on where this evidence takes us. You have given us some strong messages about structures and the lack of a strategy in Northern Ireland and we have also touched upon things like screening and the imaging review. All in, it has been extremely useful for us in informing our thinking and certainly will help very much when it comes to writing a report that we intend to report shortly on the important issue of health and social care, so thank you.