HOUSE OF COMMONS

Northern Ireland Affairs Committee

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

Monday 22 October 2018, Belfast

Ordered by the House of Commons to be published on 22 October 2018.

Watch the meeting

Members present: Dr Andrew Murrison (Chair); Mr Robert Goodwill; John Grogan; Mr Stephen Hepburn; Lady Hermon; Kate Hoey; Nigel Mills; Jim Shannon; Bob Stewart.

Questions 121- 168

Witnesses

I: Melanie Kennedy, Catherine O'Reilly and Reverend Dr Scott Peddie.

Examination of witnesses

Witnesses: Melanie Kennedy, Catherine O'Reilly and Reverend Dr Scott Peddie.

Q121 **Chair:** Can I formally welcome you to our deliberations today? What I would like to do very briefly is to ask you to introduce yourselves and say, broadly speaking, where you are coming from. Then we will proceed to some questions. So, a little bit about you and how you come to be here today. Shall we start with you, Scott?

Rev Dr Peddie: Yes. My name is Scott Peddie. I live with a diagnosis of bipolar affective disorder and I have done for quite some time now, around 10 years. Before that I had a diagnosis of major depressive disorder, so I have quite a bit of experience in the system here particularly, but also years back in Scotland.

I also work as a patient advocate in the Northern Trust, a mental health advocate, and I am a psychotherapist in private practice as well, but as I understand it, I am here to talk about my personal experiences. Thank you very much for inviting me to come along. It is much appreciated.

Melanie Kennedy: Hello, I am Melanie Kennedy. I would also like to thank you for letting me come along to speak today. I am a metastatic breast cancer patient. I have been living with breast cancer now for almost six years, very successfully. I also am the founder and currently the chair of an organisation called NICAM, which is a Northern Ireland charity. Our initial focus was to access treatments in line with the rest of the UK, because previously that was not the case. We also offer therapeutic services to people in long-term treatment for incurable cancers.

Catherine O'Reilly: Hello, my name is Catherine O'Reilly. I am here as a client of Action Mental Health. I have been using mental health services here for 16 years. Thank you for inviting me.

Q122 **Chair:** Thank you for being here. I am going to come on to mental health shortly, because I think we can all agree that in Northern Ireland we are not where we ought to be. I think all the figures bear that out.

I want to start on a more positive note, and that means cancer services and in particular provision for drugs that have been routine now for some time in England, and indeed in the rest of the United Kingdom, one way or the other. We have had some good news recently in relation to the Cancer Drugs Fund—or something approximating the Cancer Drugs Fund—in Northern Ireland, which will have the effect of providing the same sorts of provision as prevails in the rest of the UK.

Melanie, could you start by giving us a sense of your experience obtaining what you need, in particular, given obviously the very detailed appraisal you have made of what might be available elsewhere in healthcare in this

country and the sense that perhaps people in Northern Ireland are not getting the standard, up to this point at any rate, that approximates to that?

Melanie Kennedy: Yes. As I said, I was diagnosed six years ago and went through various chemotherapy options. When they came to a close, I started to investigate what else was out there, because obviously some chemotherapy agents can be quite toxic and have side effects.

I then became part of a support group that was UK-wide and a worldwide support group and realised that there were treatments—not just drugs, there were surgical options as well that maybe we are not availing of either—available elsewhere that I was not being offered here. When I asked my oncology team, I was told about the individual funding request process and the exceptionality clause, which it did seem to me was prohibitive. How can you prove that somebody—to apply for one of the drugs I needed, which I did three times, my oncologist would have to prove that I would respond better to that treatment than 95% of the other patients with exactly the same medical presentation as me. I do not know how anybody proves that. It seemed to me to be pretty much a gatekeeping exercise to stop paying for these drugs that were available through the Cancer Drugs Fund.

I had to go to some extreme lengths to be on the drug that I am currently on. It is a drug that has now been working for over 18 months. I am about to have my 23rd dose of it whenever I next go back up to hospital. I have gone from having a prognosis of five years, which I have already outlived, to now having a clear scan, which I think demonstrates the difference it makes being able to avail of these more modern, cutting-edge drugs. I realise they are high priced but the fact remains that I have not had an inpatient stay in the whole six years I have had treatment.

This is the way cancer treatment can go. I do not know the cost of inpatient treatment but I know a lot of people here are in and out of hospital. Their quality of life is reduced. Yet I know conversely, in other parts of the UK, people who are on similar drugs that I am on and who can avail of everything are still at work, still functioning members of society and they certainly are not having inpatient care as well. I think Northern Ireland needs to catch up a little bit.

I also think this is a result of very much a lack of strategy, and a sticking-plaster approach and very short-term vision thinking whenever it comes to the policy-making here. It seems to be a hot potato. It is passed from one Health Minister to the next and I think it is time that there was focus put on it and we had a long-term plan for the increasing amount of people who are going to be diagnosed.

Q123 **Chair:** I am bound to ask this because it comes up practically in any inquiry that we make. To what extent do you believe that the absence of a functioning Executive and Ministers to which you have referred has been responsible in part for lost time? We are now talking since January

last year, so we are approaching two years. That is a long time, within which, of course, civil servants do not feel able to take the kinds of decisions that really are the province of Ministers. I do not wish to lead you, but to what extent do you think that has been unhelpful in getting Northern Ireland up to where it needs to be?

Melanie Kennedy: It has had a massive impact. When we first started out we presented a petition here to the sitting Health Minister, who was Michelle O'Neill. Of the 20 or so supporters who came with me to hand that petition in, I would say 30% of them are no longer alive, so this has had a real impact on people who do not have time. Whenever I did meet Michelle O'Neill, in January 2017, it was literally the day before Stormont collapsed and we were made promises that there would be a reform of the IFR process. While the announcement has been made, I will say this, we have yet to get an implementation date and we have yet to get a realistic budget attached to it. Therefore, it has had a massive impact. There are people who are no longer here because of it.

Q124 **Bob Stewart:** Can I come in, Melanie? Thank you so much for that. You have had treatment here. Is there any possibility of someone like yourself, or indeed yourself, going to London to the top cancer hospital in the United Kingdom? Does anyone from here get the opportunity of going to see the top people in the country?

Melanie Kennedy: In regards to second opinions?

Bob Stewart: Yes, or in regard to treatment as well.

Melanie Kennedy: Very rarely. Very rarely.

Bob Stewart: But there is the occasional person who does?

Melanie Kennedy: Occasionally, yes, because with this IFR process 5% of people will get awarded funding. How they are awarded, we do not know. It is a very strange cloak and dagger exercise in creating those.

Q125 **Bob Stewart:** Does the IFR, which I have read, mean that you are allowed to travel to wherever your consultant thinks you should?

Melanie Kennedy: If the treatment you are asking for requires that, that would be the case. Certainly most people would approach my organisation to get travel costs and help with seeing somebody privately in other parts of the UK.

Q126 **Lady Hermon:** It is very, very good of you to agree to come along for this evidence live here this morning. Catherine, do you mind if I start with you? Is that all right? You have described that you are a client of Action Mental Health, a superb organisation, can I say, with whom I have had the pleasure of working on a number of occasions. You said that you had been supported by Action Mental Health for a number of years.

Catherine O'Reilly: Two years.

Lady Hermon: Two years. You are a very young person. Could you say

how you have experienced mental health provision as a young person in Northern Ireland and how bad or how good it was?

Catherine O'Reilly: I would not say it was the most positive. At times it was like a sticking plaster. It was okay enough to keep me alive and functioning, but I am 34. I got my first diagnosis when I was 18, which said I had a personality disorder, an inability to cope with stress and a lack of coping skills.

Q127 **Lady Hermon:** Did you receive any support at that stage, beyond your GP, who I hope was good?

Catherine O'Reilly: I think because of my age and because I was referred to a psychiatrist and I was given a diagnosis by a psychiatrist, it was then that I started to take antidepressants. I do not know if anyone knows, but antidepressants are hit and miss. What agrees with one person will not agree with another. Unfortunately, I have been on quite a few. At the minute the one I am on is working, but when I go back to my appointments it is pointed out that I have been on quite a few drugs, so if this one stops working there are not many other options to go to.

Q128 **Lady Hermon:** When you were told that, presumably that is quite worrying, if this one stops working, but perhaps it will carry on working effectively for you for quite a while.

Catherine O'Reilly: Some people can have a dropout on a drug and I had that reaction to one of the drugs—one of the more common ones. It just stopped working for me. I found that within the services—and I have seen changes in the situation here with each Government that comes in. With some of the initiatives, you are given a course and it lasts maybe six weeks, and then after that there is nothing. It does not go anywhere.

There are people who suffer from mental health problems and it might be a one-off. It might be because of a certain situation and then when that disappears—I have a mental health problem that I have had to learn to cope with. This is long term. I have found that the most help I have got for dealing with it long term has been Action Mental Health and the most help I have got for emergency situations have been with charities such as the Samaritans. If you are in a situation where you do not feel safe, you are told that you can avail of ringing up the out-of-hours doctor, but if it takes six hours for an out-of-hours doctor to contact you—

Lady Hermon: Is that an average that you have experienced?

Catherine O'Reilly: Yes.

Lady Hermon: It is not good enough.

Catherine O'Reilly: If you are not safe, it is not helpful. If I had to say something to somebody who is in that situation, I would tell them to ring the Samaritans or Lifeline. That is the best thing to do.

Q129 **Lady Hermon:** Has your experience of both of those organisations been

a positive one, a good one?

Catherine O'Reilly: Yes. It seems to be that, as Melanie said in her situation, there are not a lot of long-term outlooks. The first thing you get offered is medication, when really the most beneficial things I found were learning coping skills, getting tools to deal with the situation.

Q130 **Lady Hermon:** Yes. Did those come through Action Mental Health rather than through the NHS?

Catherine O'Reilly: Through Action Mental Health you can avail of courses. With the courses you get a certificate at the end of it, whereas the other services you do not get a certificate. Sometimes if your confidence is bad or your self-esteem is low and you are not feeling worth anything, you do one of those courses and you have—I know it seems silly but if you have a certificate—

Lady Hermon: No, it is not silly.

Catherine O'Reilly: If you have a certificate at the end of it, you know that—

Lady Hermon: It is meaningful.

Catherine O'Reilly: It is meaningful. Not only are they meaningful, but once you accumulate them you can work with them to get yourself a placement. I have found that the services in the NHS don't leave you with a lot of hope, whereas having worked with Action Mental Health, I have now started to make plans and can see something that was different than before.

Lady Hermon: It has enhanced your feeling of self-confidence. The more certificates you have and you see them on the wall, you think you have achieved something.

Catherine O'Reilly: I think a lot of people forget how important human interaction is if you have a mental health problem. A lot of the time human interaction might be the last thing you need, but at Action Mental Health there is a community whereby you can go in some day and you might be having a bad day and not want to talk. That is okay for everyone and you do not need to explain yourself. But some days you could go in and you could be having a bad day and you do want to talk to somebody and there is somebody there to avail of. So even that sense of community that you get within Action Mental Health is very beneficial for your wellbeing.

Q131 **Lady Hermon:** If we had the Assembly up and running again—fingers crossed that one day we will have the Assembly and we can use this lovely building, which is far too empty most of the time—what would be your number one ask when we have a new Health Minister? What do you think would benefit most people who found themselves in a mental health crisis, or several things?

Catherine O'Reilly: Personally, I think it should start as young as possible, within school years, that coping skills should be taught, because not everybody—nature and nurture. Not everybody is in a situation where they learn to cope with stress. Exams have changed. If you were to start from a young age—

Q132 **Lady Hermon:** Do you mean primary school age?

Catherine O'Reilly: Yes, because that is when mine started. I was always referred to as a nervous or sensitive child, and it builds up. Coping skills give you some independence so—it seems strange—you can be your own hero. Sometimes when you go into services and you are unwell, you are waiting for somebody to save you, you are waiting for a pill or a tablet or medicine to cure or to do something, but with the coping skills that you are given you can help yourself.

Services for older—sometimes going to the GP, just to make that first step, can be an incredibly daunting situation. Even though I am well aware of my condition, I still find it hard to go to the GP. It is not a pleasant experience. Even getting an appointment for the GP is incredibly hard.

Q133 **Lady Hermon:** We will not ask you to identify the GP.

Funnily enough, when we heard evidence last Wednesday in the House of Commons, the lady who represented Barnardo's was talking about developing schemes and projects where, through Barnardo's, they could deliver building resilience skills in schools. She was of the view that it should be primary schools, so that is very interesting.

Scott, could you reflect upon what Catherine has said of her experience? You have had the experience of being in Scotland. Would you draw comparisons and would they be favourable comparisons between Northern Ireland and Scotland?

Rev Dr Peddie: Unfortunately they would not be. I was a service user in Scotland about 16 years ago and I remember there, when I went along for my appointments, we would go into a shiny new hospital where you would see the psychiatrist very quickly, you would be referred to other psychological therapists. That worked really well, in hindsight.

Here it is very different. You will go along to a dilapidated building, primarily with paint falling off the walls sometimes, and it promotes this stigma almost of mental health being different to physical health. I do not think people would put up with that if they were going to, say, a dialysis unit or whatever it was, so there is that issue.

There is also the issue of the range of psychological therapies that are available. For example, I have paid for therapies privately because there are not the available therapies in the NHS.

Lady Hermon: Here in Northern Ireland?

Rev Dr Peddie: Here in Northern Ireland, yes. It is very much focused on medication, which in my case with bipolar disorder, medication is really important that you get that right. But in order to help people to live a meaningful and productive life, you need to have psychological therapy as well, or certainly I did, and it just was not there. I would have been offered cognitive behavioural therapy, which was good the first time I had it. The second and third time it was not the right therapy for me. Very much that is the issue that I would come across in the system here.

It is very difficult because when you find that there are no therapies there that work for you, it has a huge impact on the trajectory of your illness. For example, if that therapy was there and if it was delivered on a timely basis, I can look back and say that I would probably have been much more productive. I would have been in work for longer, I would have been able to achieve more meaningful goals in life.

I think that stretches out across the board. That is my experience but people I talk to would say pretty much the same thing. There is a lack of frontline staff. I have to say the staff that I see at the moment out in the community mental health setting are fantastic, the psychiatrists are fantastic. They all work really well and they work really hard but you get this impression all the time that they are working almost with their hands tied behind their back, in that they cannot offer you the services that would be best for your condition.

Q134 **Lady Hermon:** Because they do not have the funding?

Rev Dr Peddie: Because they do not have it, they just do not have it. For example, if they identify you as being someone who could avail of, for example, a trauma therapy, EMDR, it is not there in the numbers that are required, so you have people who are waiting for months and months and months. There is a disease burden, if you like, that they do not need to have because there are effective treatments out there.

Q135 **Lady Hermon:** They simply cannot access them?

Rev Dr Peddie: Yes, they cannot access them. From my perspective, as I said, I had to go private to get the treatment that I really required.

Q136 **Lady Hermon:** Yes, mental health services in Northern Ireland are still very much the Cinderella services compared to elsewhere.

Rev Dr Peddie: Very much so and it is very obvious. I think I mentioned in the piece that I submitted about my experience of being an inpatient that that was not a good experience by and large, although again the staff were fantastic. I felt very much as if it was a warehousing exercise, if you like. You go into the ward and you are given your drug treatment. You may, if you are lucky, get some input from a psychologist but that is quite difficult to get. Then you find when you are discharged you have to go on a waiting list to see another psychologist, so there is not that continuity of care there, which is detrimental, at least from my perspective. That is how I experienced it.

Q137 **Lady Hermon:** I have to say the expression "warehousing" is very striking and it is very painful hearing you express and describe your experiences as something like a warehouse.

Rev Dr Peddie: Yes, absolutely.

Lady Hermon: That is how you felt.

Rev Dr Peddie: That is how I felt. In one ward that I was in there was great occupational therapy input, which made a big difference, but it is very patchy. I mentioned that I have been admitted to wards in the Northern Trust, the South Eastern Trust and the Western Trust. It is a very patchy service; it can be completely different.

Q138 **Lady Hermon:** It is a postcode lottery, the treatment that you receive?

Rev Dr Peddie: Yes, in a sense. If you get a good facility, it is definitely worthwhile. If you do not, then again there is that sense of warehousing, because they look to get you stable on your medications and then you are out again. In fact, if we are trying to help people, it needs a much more holistic approach than what we have at the moment.

Q139 **Lady Hermon:** Could you identify which trust had the best experience?

Rev Dr Peddie: The Northern Trust. I work in the Northern Trust. It is quite difficult for me to go into a facility with people who I may know, but they were very professional and they were very good. It is always very traumatic going into hospital, but I think the services that they offer—particularly in terms of occupational therapy. I saw a psychologist, which was very helpful. There are elements of good practice there but again it comes down to the fact that they do not have the number of people that they need to provide that input.

I think also there are opportunities that are being missed. For example, in interfacing with nursing staff there is no real therapeutic relationship there. There is an opportunity for them to input into your care therapeutically if they had more time or if they had more resources.

Q140 **Lady Hermon:** What about the training? Is it the training of the nurses?

Rev Dr Peddie: I think it is partly training but it is also because they are rushed off their feet constantly. They are doing what they need to do. They are writing up notes, they are dispensing medication and they are doing the physical side of things but they do not have time to do the therapeutic input. Training is part of that because, as I understand it, it is not part of their compulsory training at the moment. Some of them may have additional training post-qualification, but it is something that could be looked at very easily and I think it would make quite a difference to outcomes.

Lady Hermon: Thank you. I will come back to Melanie later because Melanie is a constituent of mine and I will save some questions for her at the end.

Chair: Bob?

Bob Stewart: I have asked my question by intervening at the time.

Q141 **Jim Shannon:** Thank you very much for coming along with your comments. Could I start with Melanie? I said to you earlier on that I read your story—quite a poignant story and very personal to you. I am glad to see you are doing so well, first of all, in what you have done.

Melanie Kennedy: Thank you.

Jim Shannon: You have outlined here the differential that there is between Northern Ireland and perhaps on the United Kingdom mainland. Last week we had a debate in Westminster Hall on breast cancer. I spoke on it. I am my party's health spokesperson and it is something of particular interest to me. It is also a particular interest because at this moment of time my wife has a good friend, and my son as well, who is undergoing some of that very, very intense treatment. At the beginning she probably came through it not too badly but the next stage is starting and it is much harder and she has lost all her hair. It is very particular to her.

There seems to be, to use terminology that is much used at this moment, a backstop. There is a backstop down the Irish Sea when it comes to cancer care between the UK mainland and Northern Ireland. There is a backstop down the Irish Sea for access to drugs at the same level that there is in the UK mainland and not here. You mentioned that a few times in your contribution, by the way, as well. What would you like to see in Northern Ireland?

Melanie Kennedy: I would like to see a cancer strategy, a long-term cancer strategy. I hate the term "Cancer Czar" but we could do with somebody who is dedicated to cancer services in Northern Ireland. While there has been nobody at Stormont, we have had nobody to lobby, we have been—who do you turn to?

Also, in Northern Ireland itself, despite the difficulties with us keeping up with the rest of the UK, there are massive disparities between the trusts and between care and between different types of cancer. Breast cancer is probably one of the best known cancers and if you get it in time it is very, very treatable, but there are cancers out there—like ovarian and pancreatic—that are very late stage by the time they are usually found, and in Northern Ireland the prognoses for people suffering from those cancers are terrible. That is something that needs to be addressed. We need a long-term strategy. There has not been one in place, as far as I can see, for about 15 years.

We all know the statistics. It has gone from one in three to now half of us will have a cancer diagnosis. We would all sleep a lot better in our beds at night if we knew that somebody out there was actually thinking long-term and thinking, "Well, there is going to be X amount of people who are going to be diagnosed with cancer. How are we going to treat them? What services do we need?"

Q142 **Jim Shannon:** The drugs fund, which the Committee was made aware of three or four weeks ago, is a small amount of money, to be fair, that has been set aside. Would it be your opinion as well that you would like to see access to the drugs that are available in the mainland here in Northern Ireland? I know the answer will be yes, but I just want to give you a chance to say that on the record.

Melanie Kennedy: Yes, I would and now the drugs that are approved in the rest of the UK go through quite rigorous processes, so we only adopt drugs that are actually proven to be useful. We are not asking people to spend money on treatments that are not going to extend lives or improve quality of life. This is the thing: in previous times you looked at the price of a drug and thought, "Well, it is going to extend somebody's life by three months and that is someone lying in a hospital bed who was not really functioning," and that is not the case. I am living proof. I am sitting here today to show you that it makes a massive difference to people's lives and the quality of their lives.

Q143 **Jim Shannon:** In your presentation you refer to the cancer centre of excellence at Queen's University, and you describe some frustration that neither you nor any other patient was able to participate in any of the research. Could you give us a bit more detail of that, please?

Melanie Kennedy: Yes. Whenever you have incurable cancer, shall we say, one of the options that will be available to you is to partake in trials, and I cannot do that because I come from Northern Ireland and I have not gone through the protocol of drugs they like you to have taken before you can apply to be on a trial, and I cannot do that.

We have some of the best cancer researchers in the world at Queen's University and the cancer centre of excellence, which is 15 miles from my door, yet I cannot actually partake in any of their trials and nor will I, when they finally come up with something, be able to get that treatment the way things are at the minute, and that is very hard to take; very hard to take.

Q144 **Lady Hermon:** Who has set those criteria?

Melanie Kennedy: The people who set up trials will set those criteria because this will be the standard of care in the rest of the world and other parts of the UK. Usually a trial will be funded by a larger body that is UK-wide or worldwide. They will set those parameters, so while it can run in Belfast they cannot attract local cancer patients if they have not gone through a certain protocol of drugs.

Jim Shannon: The other thing to say is about how cancer drugs and cancer have moved forward. My father, who died three and a half years ago, but not due to cancer, was a cancer survivor on three occasions. On the first occasion the doctor told my mother, "Go away and get your affairs in order," and he lived for 34 years after that. That happened two more times. I am just saying that cancer drugs and the treatment have come on in leaps and bounds.

I have a quick question on mental health. Northern Ireland has some of the worst statistics in mental health in the whole of the United Kingdom, and not only in the United Kingdom; some of the figures are even worse than in Israel and Lebanon. You would expect the problem to be worse in those two places. Unfortunately, again I have been aware of families who have lost loved ones. The rate of suicides as well is at a level that is almost unheard of.

I am just wondering, either Scott or Catherine, what your opinion would be and how we can change that. I am ever mindful—and the stats say it—that more people have died from suicide since the signing of the Belfast agreement than died in Ireland's 30 years of the troubles. The stats are horrific. They indicate a worsening trend and also—I brought this up at a different organisation last week—the mental health issues for children and the problems we have there as well. I see a real intensity. You referred, Scott, to the occupational therapy provision. You also referred to inpatient facilities being generally very poor. Again, I will ask both of you how we can improve that.

Rev Dr Peddie: From my perspective anyway, there is lots of help out there for people who are suicidal, from the voluntary sector as well as the statutory sector, but unfortunately, as I have said before, the resources are not there to fully resource those particular services. Therefore, you may present as being suicidal and you will go perhaps to a crisis response team, and they will make a decision as to whether you are admitted to hospital, which these days is increasingly unlikely.

If you are admitted to hospital it is really a lottery. You could be sent anywhere in Northern Ireland. A lot of the time you are sitting waiting for a bed to come up, so that is a big issue and that impacts on people in terms of the trauma that they suffer as well.

The resources are not there when people go forward. I explained the issues of living with a chronic condition, like bipolar disorder. Most of the time everything is fine, but when you go through a crisis it is incredibly tough and you really need to have the resources there in order to help you through that. Those resources, as far as I can see and as far as I have experienced, are not there to make that impact. I have no doubt that that impacts on suicide figures.

We talked about trauma as well. I don't think that the health service here is particularly good at treating trauma. We need to put a lot of investment into that as well because, as I said, we have a lot of people who are living with the burden of disease—mental illness—that is not properly treated, and I think that feeds through into those suicide figures unfortunately.

Catherine O'Reilly: We talk about suicide. I know that recently one of the charities in Belfast closed down. I think that a grassroots approach within the community is needed. I think that once suicide starts happening in certain communities it seems to have a knock-on effect on

other people. People don't know how to cope with it. The world is not a very nice place at the minute. It has changed a great deal, even from when I was younger, but we as people, as humans, have not changed, so it is okay to hold your hands up and say you cannot cope with what is going on.

I would not know where to begin. I just know that any help is an improvement.

Jim Shannon: At least steps in the right direction are what you want to see and, to be fair, what Scott would want to see as well.

Rev Dr Peddie: Absolutely. In fairness, the voluntary sector does a huge amount of very positive work. In my opinion, the statutory sector isn't doing what it should be doing. That is where there is that tension between the services that are out there that you can avail of in that sector. When you come into the statutory sector I don't think it is as good as it should be.

Q145 **Chair:** Jim mentioned the term "backstop", slightly controversially, but of course it is a political term that can be translated into what we are discussing today. Another one will be parity of esteem. If you mention parity of esteem in GB it is usually in the context of mental health versus physical health, so it means different things to different people. In terms of Northern Ireland—setting aside politics for one moment—what you seem to be describing to me is a lack of that parity of esteem in relation to the mental health position here, which I think is actually quite alarming, since that concept is fairly well advanced now in the rest of the United Kingdom.

We talk about it a lot but that does not seem to be where we are at the moment in Northern Ireland. The peeling plaster on the walls is perhaps symptomatic of a wider problem. Would you agree, Catherine, that there is a disconnect between physical and mental health?

Catherine O'Reilly: Mental health is such a big issue but a lot of times, when you tease it out—for instance, you have certain companies, and so on, that will tweet that it is World Mental Health Day, but how do they treat the people who have mental health problems within their company? It is okay saying, but it is about actually doing.

Mental health is something that impacts upon everything. If you have another illness, if your mental health is good and you are positive, I believe you are more likely to recover. It is something that should be basic and it is not. We talk about the stigma. I still would not tell people that I have problems. I am very much ashamed of it a lot of the time because I do not feel like a functioning member of society in my situation, and you do feel like there is a weakness, that you are inadequate. We have a huge thing where we compare ourselves with each other all the time.

If mental health provisions were basic and were everywhere and it was just taken as a foundation—you might actually have to start in places like schools, because younger people generally catch on to things a lot quicker than older people—it would really help.

Q146 **Mr Goodwill:** Incidentally, in cricketing terms, backstop is the guy who is there in case the wicketkeeper isn't doing their job properly, and if we have a good wicketkeeper we would not need a backstop.

Turning to cancer survival rates, there are a number of factors affecting that. We talked about the use of new and innovative drugs, which a small proportion of patients will need to access in England, which is a problem here, but one of the other factors is access to the very best clinicians. Could I ask Melanie in particular: is there a problem here in Northern Ireland in recruiting people at the top of their job because maybe they are not able to use these cutting edge technologies, or is it about pay rates, or whatever? Do we have an issue in Northern Ireland too?

Melanie Kennedy: I would argue, yes, it must be very frustrating to be an oncologist in Northern Ireland because you cannot offer the same range of services as you could elsewhere, and that is not just job options. That is really your logical options as well and surgical options. There are things that are just not available here or just are not offered because the system is under pressure.

There is also a massive issue with imaging at the minute. People are having scans very, very late. They are not timely enough and they are not being read, and people are waiting a long time for results, which again impacts mental health for cancer patients. I believe, and I am sure these guys do too, that physical and mental health are intrinsically linked, so this cannot be good for anybody—sitting and waiting around for something that could be a life-changing scan result, and you are living in limbo waiting on it.

There is definitely an issue with attracting people to our services and it is not going to get any better unless people can offer what is standard elsewhere.

Q147 **Mr Goodwill:** Is that the case with mental health clinicians as well?

Rev Dr Peddie: Absolutely. There is a sense of frustration. I am not sure what the situation is at the moment in Scotland, England and Wales, but certainly if you go to see a consultant psychiatrist, all of that is really on the agenda. There is medication, so prescribing medication and tweaking medication.

I am sure that they have many more skills that are not being used because of time constraints, so there is no therapy there as such. There is no psychological intervention, so I think that that is something that is frustrating because you can wait a long time and then you see a psychiatrist and it is only looking at the one thing, and you are on a

waiting list to see a psychologist or whatever it might be, so very much so.

That parity of esteem issue is very closely felt in mental health because you do feel as if you are right at the bottom of the pile in terms of health provision. As Catherine was saying as well, that stigma, even coming forward here and talking about something that is deeply personal and quite painful is very difficult, and people judge that sometimes, unfortunately. There is that issue of stigma and, as I have said, it is about the health service working to break that stigma down in a meaningful way.

I also have to say that now within all trusts there are recovery colleges. There are peer-led places where people who have a mental health condition can go. You can do courses, like Catherine was saying, so that sort of thing is coming in that is helping with the stigma. Unfortunately, that does not get rid of the issue that people need those services—they need them when they need them in a timely manner. So there is good practice there, but there is stuff that needs to be worked upon.

Q148 **Mr Goodwill:** It is clear from what we have heard this morning that one of the major factors in rolling out better healthcare for people in Northern Ireland is the lack of agreement at a political level here. Obviously, there are reasons why people cannot agree. Certainly, talking to people here in Northern Ireland, do people generally form the view that it is more important to get an agreement for things like cancer treatment, health treatment in general, instead of worrying about some other fairly irrelevant—in many people's view—issues like the Irish language or whatever? Are people in Northern Ireland dying at the moment, not getting treatment at the moment, because of this political impasse? What message would you give to the political parties here in terms of getting together and working together?

Rev Dr Peddie: I think that is absolutely essential. I had a sense five or six years ago that there was a momentum building within the health service. Things seemed to be moving in the right direction and it was quite encouraging. Now it is just desperate. As Melanie was saying, who do we go to to talk about these issues? Who is listening? How can we get local services delivered on a local basis? It is unacceptable that we do not have a functioning Assembly because it impacts on every single one of us, it really does.

Melanie Kennedy: Yes, I think overall—as you probably saw from my story, I did stand in the last election because I was so annoyed at the way things were going and people were not being heard. I did get a lot of support. I think they need to realise that people are getting a little bit fatigued with what has gone on, that the things that they seem to have sticking points about should just become a side issue and be debated while they run the country, because people are suffering. These guys are suffering, cancer patients are suffering, school children are suffering, and

our country has not only ground to a halt; it is starting to go backwards because there is a lack of guidance and a lack of leadership.

Chair: I think that puts the case extremely eloquently, if I may say so.

Q149 **Mr Stephen Hepburn:** I will ask a question to all three of you, if you do not mind. You have mentioned the differences between Northern Ireland and the mainland, and the better quality services on the mainland. What happens in the Republic? Would you receive better treatment in the Republic? Would you know?

Melanie Kennedy: I would know that.

Mr Stephen Hepburn: I do not know if that is through support groups that you are involved with or whatever.

Melanie Kennedy: You probably have more drugs available to you in the Republic of Ireland if you are a cancer patient. I think it is co-funded, though, and I think there is a dual system with a national health service and medical insurance. Certainly, they would be ahead of us definitely in prognosis and survival rates. I am not 100% sure how or why.

Again, we do not really have parity with them either and we seem to be this little isolated block that doesn't seem to have any sort of parity with the UK or any sort of parity with the Republic of Ireland. Certainly I know, from support groups and things, that Irish ladies are able to get things that I previously wasn't able to get.

Rev Dr Peddie: In terms of the mental health system, I am not too familiar with the system down south. I do know that the basic healthcare is not particularly good either. Other than that, my own experiences would be, as you say, over the water.

Q150 **Kate Hoey:** Thank you very much all of you. Melanie in particular, you have been such a leader in all of this. You must feel very proud and we should all feel very proud of what you have done.

I was really struck by that whole thing about Queen's University. I hope we might be able to look into it. Are you saying nobody in Northern Ireland is one of their—

Melanie Kennedy: Some studies that are done or trial studies will have people who will qualify for certain things. If they are looking for somebody who is just newly diagnosed with a metastatic cancer, for example, who has not had any treatment that is fine, but certainly in my case or in the case of ladies with my subclass of breast cancer, which is a HER2-positive—and there are a lot of treatments out there now that we previously could not get—I could not get on to a trial even in England, Scotland or Wales because I did not meet the parameters. It is a worrying trend.

I have met with oncologists who are involved in trials in Northern Ireland. They are massively frustrated. Now, with the new immunotherapy and

things coming in, we are sitting on the cusp of cancer almost becoming a curable condition. That is what all the research is for and that is what everybody has wanted, but what is happening is because of the lack of being able to attract patients in Northern Ireland, because of the lack of access to drugs previously, trials just will not set up here. There is research being done at Queen's University but, inevitably, if they get brilliant results we are not seeing the results of them where we are, which is on their doorstep. It is going elsewhere.

Q151 **Kate Hoey:** That is very helpful. Now, tell me, I understood that in Londonderry there was a state-of-the-art newish cancer unit.

Melanie Kennedy: The cancer centre, yes.

Kate Hoey: Also, you have Belfast City Hospital cancer centre.

Melanie Kennedy: Yes.

Kate Hoey: They get great publicity as being the best of the best. What is your take on that?

Melanie Kennedy: Yes, they are good facilities but they really are 10 years behind because they are just catching up with the backlog. I will also say this: the continuity of care in these larger centres isn't happening and a lot of patients identify that as being very, very important. I am very lucky that my oncology team know me. I know my oncology team and I go up and they know my history. Whereas, people are going to these larger cancer centres at the minute and they could be seeing their registrar and somebody will not see their actual consultant for months and months.

If they present with an issue, somebody who knows them would say, "Well, actually, maybe we need to look at that". Things are getting missed and I think while investment in these is fantastic, again, they are oversubscribed. They are struggling to deal with the workload, so as I say they are about a decade too late and we need to start opening more of them, or expanding them certainly, to keep up with the fact that more and more of us are going to have a cancer diagnosis.

Q152 **Kate Hoey:** I have a friend who recently had breast cancer and everything went perfectly, in terms of timings and all that. One of the issues seems to be—and we don't talk very much about this—behind the scenes admin, in terms of people getting late notices of their appointments, and that kind of thing. Are we looking too much at the actual practitioners and forgetting that if they don't have the backup behind, things can go wrong with information not being passed back and forward between different—

Melanie Kennedy: That is a very valid point. We need a joined-up approach, which is why again we need a strategy and we need somebody who is looking at the experience of a cancer patient from first GP visit

and suspected cancer to post-treatment and their mental health going forward and carrying on with the rest of their life.

In the case of somebody like me where the situation isn't curable, we need to look at it from diagnosis to what is happening with them because, for the first time ever, the Belfast Trust is the first trust that is keeping stats now on people who are living with cancer. Up until recently we did not know—we still don't know—the full extent of how many people in Northern Ireland are actually living with cancer, and that is a bit shocking. How can we know what we need in the future if we don't know how people are living, how long people are living and what their life looks like and what ancillary services they need, so that is a very valid point, yes?

Q153 **Kate Hoey:** Can I also ask you about how many people in Northern Ireland when they are first diagnosed or they find something along the way are then going privately just to get quick access?

Melanie Kennedy: An alarming amount.

Q154 **Kate Hoey:** Does that mean those consultants that are doing that private practice are actually taking on appointments outside their NHS hours, or is it stopping people who are on waiting lists being treated?

Melanie Kennedy: I am not sure I can comment on that. I do not know enough about that, to be honest, but an alarming amount of people are relying on crowd funding and self-funding to get appointments quicker, to get treatments quicker. It is fast becoming a two-tier system. I am a believer in the NHS and it is something I am very, very reluctant to see and I would say it is happening a lot faster than it is in other parts of the UK because of our circumstances.

Q155 **Kate Hoey:** That is certainly what you pick up apocryphally.

Melanie Kennedy: Yes.

Q156 **Kate Hoey:** One final point. As you probably know, there is a Bill—which is probably going through Parliament this week—to change the way that decisions are made at the moment, to perhaps allow civil servants more say more quickly in making decisions. How would you feel if there was a direct ministerial appointment from the United Kingdom Parliament Minister to take responsibility for health generally in Northern Ireland, so that there was a genuine straightforward accountability to the Minister of Health in the meantime until we get the Assembly back, whenever?

Melanie Kennedy: It would be very, very welcome certainly from cancer services.

Q157 **John Grogan:** Hello, Melanie. Just to come back to the change in the individual funding request process that was announced, how significant a change or not do you think that is? As far as I understand it, there is now going to be a clinically-led regional scrutiny committee that is going to take the decisions. The changes are going to be implemented within this

financial year, I think. Is that your understanding as well? It seems to have taken from January 2017 when you met the Health Minister, the day before the Executive collapsed. It has taken nearly two years to get us to this stage. Do you think this will make a difference?

Melanie Kennedy: I really, really hope so. We wanted a clinician-led decision-making basis. Clinicians are not going to give you a drug that is not suitable for you. They are just not. If it is not clinically beneficial they are not going to do it. A scrutiny committee, I don't know. We are a bit wary of this term because we don't really know what it means. It has not been clarified what it means. If it is all clinicians making a collective decision or in individual cases that is fine. If there is input from other areas we don't know because, again, the budget attached to what they have announced is very small for what we consider is needed, so we feel there must still be something in place to gatekeep certain drugs from the patient.

We obviously welcome this. It is a massive step forward but it is still not putting us on a footing with the rest of the UK.

Q158 **John Grogan:** To follow up on my colleague Robert's question, when I was looking at some of the figures it is quite alarming. I think about one-quarter of radiologist posts aren't filled and there is a shortage of specialist nurses and so on. Is that something you recognise? Will you say why you think that is? Is it because people are going elsewhere or because they are not satisfied with the care they can provide here, or what can we try to do to attract more people to—

Melanie Kennedy: Hopefully, with regards to consultants and oncologists, maybe being able to avail of treatments that they know will be beneficial will help. In terms of specialist nurses, there is a massive lack. There is nobody in Northern Ireland at all, for example, that deals with secondary breast cancer. We only have straightforward primary breast cancer nurses. I know that is something that my own organisation is thinking about trying to address and co-funding maybe or funding ourselves through the voluntary sector.

I don't know to be honest with you. I know there is an awful lot of stress. I know that these wonderful people who already work in our health service are amazing, and they are under a lot of stress. For example, the clinic I go to on a Tuesday at the Ulster Hospital, in the six years that I have been going there has trebled in size but the staffing has not increased. There are days that those nurses are not getting out of there until 7 o'clock or 8 o'clock at night because they are obviously putting the patients first. They are not going to leave somebody untreated.

This again falls right back to a lack of strategy. We know there is going to be an increase in incidents of cancer. We cannot pretend that the same amount of staff and the same amount of funding is going to deal with it, so I think at the minute it is probably a very stressful job for all involved and that has got a lot to do with it.

Q159 **Lady Hermon:** I have to say, Melanie, I am very grateful to you for that very passionate defence of the staff who deliver in very, very difficult circumstances, and they do. We do not have a strategy and we do not have a Health Minister, so in the absence of all of that we do have a Permanent Secretary. We have a Permanent Secretary for Health, who is running the Department—who has had to run the Department—in the absence of a functioning Assembly and Health Minister. What access do any of you have to the Permanent Secretary? Are you invited to go and meet him at any stage?

Melanie Kennedy: No.

Q160 **Lady Hermon:** Let's hope he is watching this session of evidence by the Northern Ireland Affairs Select Committee. I suggest that would be a next step for all of you if you have not already done it.

The other issue that really concerns me is that we have heard a lot of speculation that in the event of a no deal Brexit, part of the preparation is the stockpiling of medicines. Have you thoughts about how that might impact on you personally? Have you made any enquiries as to whether in fact you might be impacted by that?

Rev Dr Peddie: I have not made any enquiries but it is very worrying. I live with a chronic condition. I am on quite a few different medications. If any of those medications were not available that would have a serious impact on my health. I have not thought of that specifically. In fact—

Q161 **Lady Hermon:** I am sorry. When we see the Brexit Secretary, the Brexit Secretary has indicated to the Committee Chairman that in fact he is very keen to come and see us at some stage, so we will reflect that to him. Melanie, have you given it thought?

Melanie Kennedy: There is a duality with this. There is, yes, the impact it will have immediately on people accessing drugs, but it might also give the UK a bit more power in dealing with pharmaceutical companies because cancer drugs is a two-edged sword. There is an issue with the pricing of drugs and there is an issue with being signed up to certain World Health Organisation treaties that mean the UK has to partake in certain price fixing that goes on, more or less, between pharmaceutical companies. Again, that would only be a positive if people at Westminster were looking on that as a positive and want to use that power to negotiate with pharmaceutical companies.

Q162 **Lady Hermon:** To reduce the price?

Melanie Kennedy: It is a double-edged sword. There are negatives and positives in that.

Q163 **Lady Hermon:** Okay. Catherine is there anything that you have—

Catherine O'Reilly: That is the type of thing I have been worrying about, also because of the European Union. A lot of the positive things I have been involved with have received money from the European Union,

so if there is a no deal, or something happens, who will fill that void? Where does that come from?

Q164 **Lady Hermon:** Yes. I think that is a very good point indeed and perhaps it is one that Action Mental Health might construct a letter about and send it to 10 Downing Street, for example.

Melanie, can I just come back to a phrase that was used earlier on? That is, you talked about 5% of those who are able to access exceptional drugs. You used the phrase "It is a sort of cloak and dagger process".

Melanie Kennedy: It is, yes.

Lady Hermon: You need to explain that to us.

Melanie Kennedy: Your oncologist applies via an individual funding request to—

Lady Hermon: Applies to?

Melanie Kennedy: A quango, which is—I don't know what they are called but each trust has one.

Q165 **Lady Hermon:** Right, so this is Northern Ireland. This is specific to Northern Ireland?

Melanie Kennedy: Yes, it is specific to Northern Ireland and they have to make the case for your medical exceptionality to avail of this drug or treatment. It goes to this quango where your name is removed, your age is removed, all you are is patient X with a statement from your oncologist and somebody somewhere decides who gets it and who doesn't and nobody really knows how that is done.

Q166 **Lady Hermon:** And the appeal process—

Melanie Kennedy: It is lengthy and laborious and not usually very successful.

Q167 **Lady Hermon:** Each of the trusts, each of our five health trusts, has a separate quango?

Melanie Kennedy: I think so. That is something I would need to fact check. I don't think it is made up even entirely of medics. I think there are other people involved, so again it is a very complex exercise. I have never been able to get to the bottom of who makes these decisions.

Q168 **Lady Hermon:** Even though you have been campaigning very, very stridently and very successfully in this particular area, you still do not know who comprises these quangos?

Melanie Kennedy: No, I don't. That is the sad fact, so yes.

Lady Hermon: That is certainly something we will have to ask the Permanent Secretary when he comes to give his evidence at some stage. Thank you. Thank you so much.

Chair: Thank you. We have come to the end of our session, our roundtable. I am sure my colleagues have last-minute questions. What I want to say is to thank you for taking the time. It is difficult I know to come and talk in this setting. What you have given us is extremely valuable and it has certainly given strength to our deliberations because, clearly, discussing these things in abstract with "experts"—in inverted commas—who create policy is all well and good, but what really matters is finding from people who use the service their experiences, which you have shared with us. I think what you have said has been extremely insightful.

I have to say I am shocked—I think I will say that on the record—by your account of the difference in the quality of service you have received and what would generally be available in the rest of the United Kingdom, although obviously in compiling this report I am going to have to discuss the wording that we choose with my colleagues and with great care.

I think it is true to say that, from what you have said today, there are real concerns about that disparity, notwithstanding the devolution settlement and the different directions perhaps health services might inevitably take as a result of that. Nevertheless, I think there is an expectation that standards will be broadly similar across the UK, and you have given us an account that suggests that that is not the case and that we have slipped back in Northern Ireland. Of course, the lack of an Executive has been part of that piece, which is a real cause for concern and, I think, a concern we are bound to reflect when we come to write up our report.

Thank you so much, once again, for coming here today. It has been great to see you. We are very grateful.