OFFICIAL REPORT
AITHISG OIFIGEIL

Health, Social Care and Sport Committee

Tuesday 17 September 2024

Session 6

The Scottish Parliament
Pàrlamaid na h-Alba

Tuesday 17 September 2024

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HEALTH, SOCIAL CARE AND SPORT COMMITTEE
24th Meeting 2024, Session 6

CONVENER

*Clare Haughey (Rutherglen) (SNP)

DEPUTY CONVENER

*Paul Sweeney (Glasgow) (Lab)

COMMITTEE MEMBERS

*Joe FitzPatrick (Dundee City West) (SNP)
*Sandesh Gulhane (Glasgow) (Con)
*Emma Harper (South Scotland) (SNP)
*Gillian Mackay (Central Scotland) (Green)
*Ruth Maguire (Cunninghame South) (SNP)
*Carol Mochan (South Scotland) (Lab)
*David Torrance (Kirkcaldy) (SNP)
*Tess White (North East Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Dr Emilia Crighton (NHS Greater Glasgow and Clyde)
Tracey Gillies (NHS Lothian)
Rhoda MacLeod (NHS Greater Glasgow and Clyde)

CLERK TO THE COMMITTEE

Alex Bruce

LOCATION

The Sir Alexander Fleming Room (CR3)

Scottish Parliament

Health, Social Care and Sport Committee

Tuesday 17 September 2024

[The Convener opened the meeting at 09:00]

Decision on Taking Business in Private

The Convener (Clare Haughey): Good morning, and welcome to the 24th meeting in 2024 of the Health, Social Care and Sport Committee. I have received no apologies. We are joined online by Paul Sweeney.

The first item on our agenda is a decision on whether to take in private items 4 and 5, and whether to take equivalent items in private at future meetings. Do members agree to take those items in private?

Members *indicated agreement.*

Gender Identity Services for Children and Young People (Independent Review)

09:01

The Convener: Our next item is an evidence session on the independent review of gender identity services for children and young people, which was commissioned by NHS England, and the implications for the future provision of gender identity services in Scotland. I welcome Rhoda MacLeod, who is the head of adult services—sexual health, police custody and prison health care—including Sandyford sexual health service, at NHS Greater Glasgow and Clyde; and Tracey Gillies, who is the medical director at NHS Lothian. We also expect Dr Emilia Crighton, who is the director of public health at NHS Greater Glasgow and Clyde.

We move straight to questions.

David Torrance (Kirkcaldy) (SNP): Good morning. Will the witnesses detail the differences and similarities between Scotland and England in the approach to the care and treatment of young people with gender dysphoria/incongruence?

The Convener: Who would like to start?

Tracey Gillies (NHS Lothian): That is a bit of a PhD-level question, is it not?

A lot of the differences in how healthcare is organised between Scotland and England are also present across multiple services within England. I have not worked in England for 30 years, so I am less familiar with the exact mechanisms for commissioning services there.

In Scotland, we try to take a collaborative approach between the different areas that deliver healthcare services. Glasgow and Lothian try to work together, wherever possible, to avoid duplication where expertise is scarce. For the youngest people, therefore, Greater Glasgow and Clyde has been the service provider of the assessment of gender incongruence; then, between Glasgow and Edinburgh—NHS Lothian—any puberty-suppressing hormone treatment has been provided between the east and the west coast.

Perhaps I should stop there, as you might have further questions. It was a very broad question to start with.

Rhoda MacLeod (NHS Greater Glasgow and Clyde): I will add to that. It is fair to say that, internationally, all gender identity services for young people have evolved fairly similarly, and I do not think that Scotland is exceptionally different. We have evolved in a similar way—the service has grown organically, rather than being designed then developed from that specific design. In that respect, it is the same as England.

We have one assessment site in Scotland, which is similar to England having the Tavistock clinic. I cannot comment on the Tavistock's clinical interventions, but our assessment process in Greater Glasgow and Clyde is pretty robust. We spend a considerable amount of time with young people throughout that process. The kind of model that exists in Scotland currently is not that dissimilar, in that there is an assessment process and then there are links to paediatric endocrinology—or there have been, and there still are for those who are currently on medication. As time progresses and the service develops, those links will continue.

David Torrance: What are the main challenges in meeting the recommendations of the Cass report in Scotland?

Rhoda MacLeod: A lot of Cass report recommendations have implications for Scotland. It will be a challenge to develop the right service model that is inclusive, engages with young people and offers—at a more local level—a service and an opportunity for young people to talk about their gender-questioning issues. It must encompass a holistic assessment approach and expertise around neurodevelopmental conditions, rather than that being one area of the assessment process or there being one service that does that.

Other challenges are staffing and recruitment. The recruitment of staff into the young people service has been an on-going problem and will remain challenging. The introduction of a Scottish approach to the Cass report recommendations would be beneficial in offering that foundation for us to build a service properly and it would be a positive way to encourage staff to join the service.

It is about staffing and identifying what the multidisciplinary team and regional structure should consist of, as well as what else should be around, other than the services that are part of the national health service. I know that this discussion is about the NHS response to gender-questioning young people, but it is a broad issue. Other services have responsibilities in that area, and, in her report, Dr Cass mentioned the wider system. It is not just about what one specialist service can offer that group of young people.

Tracey Gillies: Taking a Scotland-wide approach is a sensible place to start. There are lots of things that we must do in a similar way, because we do not want a piecemeal approach to how and when healthcare records are changed and how that feeds forward into the rest of the system.

The point about the multidisciplinary team is really important. Who should be in the team? How do we make it truly person centred, so that it brings together different elements around an individual but does not hold up progression for the individual? That is difficult in all areas where multidisciplinary teams work, and I do not know that this situation will be any different. That is always a challenge.

Sandesh Gulhane (Glasgow) (Con): I declare an interest as a practising NHS general practitioner.

Good morning. Given the recommendations to move to a regional model to provide gender services, do GPs, who will input to the service design, sit on your panel? I ask specifically about a GP who is on the panel and in the room at every meeting and not just consulted or asked for input.

Tracey Gillies: It is too early for me to comment on that. We absolutely want to ensure that we are thoughtful about the place for primary care—specifically, general practice—in the on-going care of individuals.

For many GP colleagues, there have been challenges in the past about prescribing. In particular, people have wanted to ensure that they, as prescribers, feel comfortable about the prescribing. There will be a place for many professional groups within the multidisciplinary team.

Sandesh Gulhane: Forgive me, but we are straying away from my question.

You might not have a panel yet, but, when it comes to service design, will you guarantee that a GP will sit on such a panel in every meeting?

Tracey Gillies: I would want to understand what you expect the panel to do. A panel implies yes or no decisions, and I do not think that good holistic and multidisciplinary care will look like that.

Do I think that there will be a place for somebody to bring a general practice perspective into discussions about individuals in the right context? Yes, I do. Do I think that there will also be a place for wider primary care members within that discussion? Yes, I do.

Carol Mochan (South Scotland) (Lab): A quick question comes to mind. Will NHS Scotland be taking part in the review of adult gender services, as recommended by the Cass review across NHS England? Will there be some connection between NHS England and NHS Scotland on that?

Tracey Gillies: I am not aware of that. It will be important for people with responsibility for clinical governance and how services develop to keep their eyes on how services change in other areas—for example, on what happens as a result of the review in England, what changes are proposed and how are they implemented—and then to consider whether they are relevant in the context of NHS Scotland provision and wider provision. A little bit of that has been done to date through the chief medical officer for Scotland's review of the implications of the Cass review, what it means and which of those recommendations are relevant for Scotland and which ones are less relevant because of differences in the models.

Rhoda MacLeod: I do not think that there are plans for that at this point in time. I agree entirely with what Tracey Gillies has just said. If we are redesigning services for young people across Scotland, it begs the question what adult services should look like. They are separate to an extent, but in some ways they are not. It is no different to any other clinical service that has a children and young people's aspect to it as well as an adult service. You need to look at the transitions and at the service models and make sure that the flow between the two services works, so it would be a natural progression for Scotland to look at the adult service on the back of what is designed for young people. Both things need to happen—that is my recommendation.

The Convener: Thank you. Before I start my questions, I refer members to my entry in the register of members' interests. I hold a bank nurse contract with NHS Greater Glasgow and Clyde.

We had Dr Cass at committee on 7 May this year and we asked her about some of the criticisms that there have been of the methodology that she used. I am sure that the witnesses are aware that, since she gave her evidence to the committee, the British Medical Association has voted in favour of a motion which asks the BMA to publicly critique the Cass review, and subsequently the BMA created a task and finish group. To what extent do the witnesses accept that the Cass report is based on scientific methodology, or do you have any concerns?

Tracey Gillies: My understanding is that the University of York provided the critical appraisal of the evidence. It has a strong track record in relation to looking at evidence, understanding how that evidence has been gathered, and then bringing a perspective to that which has the sort of scientific basis that we would expect to see in any other area of clinical practice. As the University of York has a strong reputation in relation to this area, my perspective would be that the review has asked people with academic expertise in appraising the evidence, in totality, to provide that appraisal. Therefore, I would place a level of reliance on that methodology.

Rhoda MacLeod: I agree entirely with what has just been said. The only additional comment that I would make in reference to the recent discussions that have been happening within the BMA is that the BMA is not a clinical organisation—it is a staff-side organisation. The BMA is entitled to have its views and perspectives about the review, but we would adhere to the clinical perspective, and that is what we are doing.

The Convener: With regard to that, how do you anticipate that the provision of services might respond to the findings of the BMA's evaluation in the event that its findings are at odds with those of the Cass review?

Rhoda MacLeod: I think that we would need to find out what the BMA has to say first, and then we would have to look at the evidence and take it from there.

Tracey Gillies: I have to agree. Although we would want to consider a trade union's perspective, we would consider that alongside the methodology by which that perspective had been reached. Sound clinical practice considers all views but understands the evidence base that it has been drawn from and how that view has been developed. We need to place differential weights on different strengths of evidence.

09:15

The Convener: Do witnesses agree with the BMA's call for the implementation of the Cass review recommendations to be paused, pending the conclusion of the BMA task and finish group, which is expected to be towards the end of this year?

Tracey Gillies: I do not agree with that, no.

Rhoda MacLeod: No, I do not agree with it.

Joe FitzPatrick (Dundee City West) (SNP): On the BMA's view about the process of a critical review, the ultimate test of the robustness of scientific research is normally a peer review process. Apart from the University of York, which I think was a partner rather than a peer reviewer, are you aware of that having happened before the publication of the Cass review? Normally, there would be a peer review before someone published a paper in, for example, *Nature*.

Tracey Gillies: Peer review would be a normal process for an individual publication of a scientific finding, as opposed to a synthesis of evidence. There is a lot of methodology around how evidence is appraised, and my understanding is that the University of York followed the methodology. It did not publish a specific new finding as a scientific paper; it looked at papers that other people had published. We apply exactly that methodology in other areas of Scotland, within the guidelines of the Scottish intercollegiate guidelines network and in Healthcare

Improvement Scotland, which has that responsibility for looking at the evidence. Within SIGN guidelines, there is an approach that looks at the way that evidence has been brought forward.

There is also quite a lot of science behind how you look for evidence, to ensure that you gather as much evidence as possible. The committee will probably be aware from evidence that it has received on other topics that an important source of concern is the fact that, sometimes, trials related to new therapies in completely different areas of medicine are not published and that, therefore, the evidence is not there. Therefore, I would follow the expected scientific discipline in this area.

Joe FitzPatrick: Do you have any thoughts on why there appears to be a difference in this case? As you have said, this evidence exists—it was produced by other people—and it has, in the Cass review, been distilled in a particular way and used in coming to the review's conclusions. I have no medical training so I will not question that at all. However, it appears that people with similar qualifications and medical experience in other countries have come to very different conclusions. Do you have any thoughts on that? It is never black and white, is it?

Tracey Gillies: I think that that is what I mean. This is an important signal, but we need to apply the same standards that we would in other areas of practice. If there are mixed views about what good practice looks like—I am very definitely trying not to say "treatment"; I am trying to say what good practice looks like in a holistic way—it is important that we consider those. Therefore, we want to add in the fact that the process might bring in additional views, but, at the end of the day, when we move to a treatment phase with individuals, we need to be sure that that is safe and based on sound evidence.

Joe FitzPatrick: That is really helpful.

You mentioned treatment, so I will home in on one area of treatment about which there is concern, namely, hormone treatments. Prior to the assessment of the Cass review, of the significant numbers of people who came for support, a relatively small number were receiving hormone treatment. That has been suspended.

What are your thoughts on what that means for those young people? I am aware of constituents who, even under the previous system, were accessing hormone treatment by legal private means, with all the risks that go with being unable to get support with on-going assessment of their hormone levels. What will be the implications of the current restriction for young people?

Tracey Gillies: For clarification, can I ask what type of hormone treatment you mean?

Joe FitzPatrick: Just the ones that have been restricted—puberty blockers, but that might be quite coarse language for them.

Tracey Gillies: No, it is not.

Joe FitzPatrick: Those are the ones that I mean.

Tracey Gillies: It is important to make sure that we are talking about the same thing. We are talking about the suppression of puberty using drugs that are not licensed for that purpose. An important part of the beginning of the process is that for a prescriber to use a drug outside the terms of its licence brings additional responsibilities. That is set out clearly and helpfully in the CMO's report.

The issue with the suppression of puberty is that there is very little evidence on it, and this is where we get into the appraisal of evidence again. Puberty is a physiological process, so the suppression of it is likely to have physiological consequences. Some of those are known and some are postulated but not yet evidenced. The assessment process leading to such an intervention needs to have significant rigour. The shift that has followed the Cass report is that it has become very difficult for any prescriber to articulate why they might want to undertake that step. That is how I see it.

Prescribing outside a specialist service raises a number of significant concerns. I understand that many people have sought care because they do not feel that the NHS has been meeting their needs. It is really important for us to acknowledge that and then to think more carefully about how we provide support for individuals in a way that considers all their needs.

Joe FitzPatrick: That is really helpful in distinguishing between puberty blockers and other hormonal treatments. Have other hormonal treatments been restricted as well?

Rhoda MacLeod: Yes. For 16 and 17-year-olds, gender-affirming hormones have been paused as well, unless a person is already in clinical care receiving puberty suppressants—they will go on to gender-affirming hormones if that is the decision.

To answer your first question about the implications for people, we should not underestimate the fact that, for a small number of people, the decision is not insignificant. We have to acknowledge that it has been distressing for them and to try our best as a service to support people who are in that position. The decision was made quite suddenly, and we have a small number of people who were ready to progress treatment and that has been paused. I think that it is right to acknowledge that that is very distressing for those individuals and their families.

We have to weigh the situation against what Tracey Gillies has just said about the clinical risks and what we do not know. We do not know what the benefits of the treatments truly are. People tell us what they are—we have reports of people saying that they are beneficial—but, in a systematic sense, we do not know what the benefits and the risks truly are. Working in that uncertainty is not good, so we have to have some controls.

Just a couple of weeks ago, the minister announced the plan for us to engage with the English research that is being done through clinical trials. Tracey knows much more about how clinical trials work than I do, but it is within those trials that most new medication is managed and administered to children and young people.

The impact for a small number of people is quite great. We need to remember—I think that you have got the information there—that there are over a thousand young people on the waiting list and we cannot assume that all those young people are sitting waiting to get puberty blockers.

One of the problems is that the waiting list is so great that, by the time people get seen by a clinician, they are way past the stage where they could be prescribed these drugs anyway, because they are actually in puberty or they are too old to receive the drugs. We need to do something about that aspect of care in terms of how we support young people at an early stage and how we design the services. The medical pathway is very much the top end of this.

I want the committee to know that our numbers in Scotland are low, but that is partly to do with the fact that we do not have a big service and we do not have a lot of staff working in it. Therefore, we cannot draw conclusions about numbers from that because of the complexities and the challenges that the service has faced over the years.

Tracey Gillies: The assessment for those aged 16 and under takes place in the Sandyford clinic—Rhoda MacLeod has more information on that than I do. However, the emerging picture of a number of individuals with other health conditions such as neurodevelopmental diagnoses—or, for some of them, mental health conditions—puts a greater onus on us to treat the individual in a way that is truly person-centred care. It should be about bringing together those different aspects and making sure that enough support has been provided for the other aspects, rather than jumping in to deal with just one element of the care for the individual.

We need to do more work on that locally. Any local MSPs will know that we have longer waits than we would want to have in relation to our neurodevelopmental pathways. Separating out the different elements in relation to caring for an individual is likely to be disadvantageous to the individual, so we need to work on integrating the services more than they are currently integrated.

Joe FitzPatrick: Some of my colleagues might want to probe you a little more on that holistic aspect, which is important.

That has been helpful in laying out some of those points. However, some young people will feel that this is the treatment for them, and that they are being denied even being clinically assessed for the treatment. For them, the trial will be a ray of hope in terms of getting that support. Obviously, it is a UK-wide trial, which is normal for medicines—that is the way that such trials are done. However, is there a route for young Scottish folk to access the trial, and do you know the timetables? Also, do you have any thoughts on what the trial will look like?

Rhoda MacLeod: I hope that Dr Crighton can join us shortly, because she has been involved in engagement around that. However, my understanding is that the plan is for young Scottish people to be involved in the clinical trials.

Joe FitzPatrick: Do you have any thoughts on possible timescales?

Rhoda MacLeod: I do not, at this point. The trials are being led by NHS England through the National Institute for Health and Care Research, so they will govern the timescales in respect of that.

Joe FitzPatrick: That makes sense, but do you have any idea about when it might be?

Rhoda MacLeod: My understanding is that it will be into next year, probably.

Gillian Mackay (Central Scotland) (Green): Rhoda MacLeod mentioned earlier the distress for young people who were very close to accessing that treatment. How is that being monitored with those young people and their families? What support is in place for them? I know that many of them are very distressed and that the mental health impact on some of those young people will be great.

Rhoda MacLeod: The people we are prioritising in the service just now are those who are currently in our care and are being seen by our psychology team. They continue to be monitored by our staff at Sandyford and are being supported appropriately. If we feel that they require additional support, we will obviously connect them to other services, but they are being monitored, worked with and supported as best we can under the circumstances.

Gillian Mackay: That is great. What work is being done to reduce some of the wait times? As well as young people who have now had their treatment pathways changed because of a decision that is outwith their control, many other young people are waiting a very long time to access services.

09:30

Rhoda MacLeod: It is really challenging: we struggle to recruit staff to the service. We struggle to recruit staff to the adult service, but the nature of the young people's service and the publicity around it gives us an extra layer of challenge that does not happen as much in the adult service. Our problems with recruiting to the service mean that we struggle to take people off the top of the waiting list.

We have been focusing on doing a clinical validation exercise, in which we are speaking to all the young people who are currently waiting to find out how they are. We are checking with them why they are on the list, whether they still want to be on the list, how they are functioning, how they are doing and whether they need additional supports while they are waiting. That has been a successful piece of work. Young people have valued it—they have valued getting the phone call and an opportunity to be spoken to rather than hanging in the ether somewhere.

Also, some of the statistics that we are getting back from that work are really informative and interesting. People have had questions about the nature of the population, and we are getting back some good data about the mental health of individuals as well as neurodevelopmental conditions and their natal sex. It is about finding out who is on the list—who is waiting.

This relates to one of our challenges. Sandyford clinic is a sexual health service and it has a full range of services—the gender service just comprises one part of what Sandyford does. Sandyford has an open-door service, so historically the adult and young people's gender services evolved in the same way, through self-referral. We would get referrals to the young people's service from professionals, but a lot would be self-referrals and we did not know anything about them. They would just give us their name and say that they wanted to be on the list.

Therefore, one of the biggest challenges for us and one of the most important things to get to grips with is who is on our list. We need to get the right information about them and know who is on that list and how best they can be supported. That will also help to inform proper service development nationally.

I am afraid that my answer to your question is not perhaps what you would hope for. We are not in a position to reduce the waiting list quickly. The situation calls for a creative solution at the national level in relation to what the service should look like and what the first entry level should be for a young person who is gender questioning.

If all roads lead to Sandyford, it will not matter whether it is in Glasgow, Edinburgh or Inverness. If the service is in one centre, we will have the same problems. There needs to be a more dispersed model that uses a tiered approach, provides a range of services that young people can access, and gives them time to explore options. If the model is focused on one place, we will just recreate the same problems.

Gillian Mackay: Many young people would also prefer to have their treatment much closer to home and to not have to travel. I know a few young people who very much endorse that work, and that will bring its own challenges in terms of waiting times, as well.

I come back to the young people who have had their treatment pathways changed because of the pause in prescriptions. Are you getting a sense from those young people of the impact on them? I am keen that we keep those young people's views and experiences at the front of what is going on during the service redesign to more regional level, as well as hearing about any on-going impact and harm to them.

Rhoda MacLeod: There has been a double whammy for those individuals. There is the fact that the health boards have made a decision to pause treatment, or referrals to treatment, at this point in time, but there is the wider UK decision about private prescribing. A lot of people will go, "Well, we'll source it privately" but that—also for very good reasons—has been stopped as well. People might then take additional risks and try to start sourcing things overseas.

There are therefore risks associated with the change, in that people will try, in desperation, to find the drugs that they feel they need. We have to manage that by supporting people and advising them accordingly of the dangers.

Carol Mochan: With regard to hormone treatments, in the example of a female who is placed on testosterone, how do we ensure that people understand the potential risks of, for example, osteoporosis? Obviously, you will have much better in-depth clinical knowledge of such things, but the issue has been raised with me. Can people access bone density scans and so on, as they go through their life journey?

Tracey Gillies: It is puberty suppression that has an evidenced impact on bone density. If we are thinking about individuals, remaining sighted on the need to provide access to scans would be an important aspect of someone's transition into adult services. That would be a good example of where we need to ensure that we involve primary care in how we develop the lifelong journey around an individual's care.

There are always opportunities to improve the information that we give to people at the start of medical treatment, and to ensure that that is kept up to date with current knowledge. The information that is provided to a person about possible treatment options and the risks and consequences of those options is usually a lot to take in at a consultation.

We know from other areas of practice that, when people have waited a long time for something, they are understandably invested in the treatment option that they think they are coming towards. That sometimes means that, when they take part in a discussion about possible risks and benefits, what they hear is somebody trying to put them off or to act almost as a barrier.

In that type of decision about treatment, where the evidence base of the very long term is still lacking, it is important that we are careful about how we provide the information and that we give people multiple opportunities to think about the questions that they have and the need for them to explore the answers. That is right and proper; it just becomes very hard to do that in a service that is under pressure with waiting times. Those two things come into conflict, and we will need to think about how we address that.

My points about how information is provided—how people are given an opportunity to go away and think about the information that they have and to test it out in their own minds—are not unique to this area of clinical practice. The situation is the same in many areas of clinical practice.

Rhoda MacLeod: I have nothing to add to that.

Carol Mochan: Thank you.

Tess White (North East Scotland) (Con): Tracey Gillies, are you saying that much more work needs to be done on exploring the impact on someone who takes suppressant hormones? For example, it could impact on childbearing, and there have been cases of incontinence and detransitioning. Are you saying that more work needs to be done on the impact?

Tracey Gillies: The purpose of a research study would be to do something in a structured way to get longer-term follow-up of the consequences for individuals. Those might be very positive consequences in terms of someone's wellbeing, as well as, potentially, more negative consequences.

Tess White: Therefore, more work needs to be done on the risks.

Tracey Gillies: The purpose of a research approach is to provide a long-term follow-up, so that we know what has happened in five or 10 years' time, rather than having poor or very short-term follow-up of individuals. That takes us back to the evidence point: we do not know what the longer-term consequences are.

Sandesh Gulhane: The average age of puberty is 11 for girls and around 12 for boys. HIS standard 8 talks about understanding the risks and benefits of treatments and interventions. We are asking children of 10 to understand the risks and benefits of medications that have lifelong implications, that we do not fully understand yet as medical professionals and that we do not have a pathway set up for. How can we bridge that?

Tracey Gillies: You have articulated the reasons why, two years ago, we wanted to be much clearer about the indications for this type of treatment and why we wanted to move towards pausing and stopping it.

What you are articulating is correct. The drugs that are used for puberty suppression are licensed for the treatment of precocious puberty—I will be careful that I do not become too clinical in this space. Where individuals are showing signs of entering puberty at a much younger age than would be expected, the licensing around those drugs supports prescribing.

What we are not sure about is the longer-term consequence of use in another setting, particularly over what would probably be a longer period of time. In essence, what are the consequences of delaying puberty and then going through a less-than-usual physiological puberty by adding gender-affirming hormones into the mix? That is precisely why there has been real concern raised about the use of puberty-suppressing hormones and why there has been their cessation.

Ruth Maguire (Cunninghame South) (SNP): Thank you for your evidence so far; it has been really helpful. I will ask questions about the referral process, then move on to holistic care, which you mentioned in your responses to Gillian Mackay.

Figures in the press at the weekend showed that 352 under-18s were referred to the Sandyford clinic and that 130 of those were self-referrals. I am interested in exploring that. The article referred to the youngest individual being seven years old. It would be helpful for the committee to understand how children and young people might be self-referring. You spoke about the open-door policy of the clinic. What does that look like?

Rhoda MacLeod: The numbers in that age group have always been very low. They would probably be referred by their parents. They obviously would not be referring themselves; they would not know how to. Our approach at Sandyford has always been that we might talk briefly to the person and give them some general advice, but we would not take them into the clinical service.

Ruth Maguire: Are teenagers and younger adults self-referring?

Rhoda MacLeod: As you are aware, we stopped accepting self-referrals in August, but, yes, they were self-referring prior to that.

Ruth Maguire: What did that process look like? After referral, would they be placed on a waiting list?

Rhoda MacLeod: Yes, they were put on a waiting list and, once they got to the top of the list, we would contact them and engage with them. We would not simply engage with them as individuals; their family would be part of that, too.

Ruth Maguire: That is helpful to know. In your response to David Torrance's first question, you spoke about the need for robust assessment and getting a holistic picture of the child or young person. What will be different for children and young people? I was struck by Tracey Gillies' remark that people who have been waiting for a long time become very focused on medicine or an operation rather than on the whole picture. We understand that gender distress in young people is exacerbated for many different reasons, and you mentioned that you are becoming more aware about neurodivergent children and young people.

I am sorry—there is a lot in that. I am kind of blurting it all out at you, but I am keen to hear more about those issues.

09:45

Rhoda MacLeod: One of the CMO's recommendations to the Scottish Government is about where the service is located, with the suggestion that it be moved out of the sexual health service and into a children and young people's environment. That is absolutely the right thing to do, because clinicians there have knowledge and experience of working with children and young people.

We have been carrying out a clinical validation exercise. By 8 August, we had contacted 422 people who are on our waiting list. Those are young people from across NHS Greater Glasgow and Clyde and NHS Lothian, and we have also started speaking to patients from Lanarkshire. We know that 70 per cent of those young people co-operated with our calls and that more than 70 per cent of them are natal females. So, 70 per cent of young people on the waiting list are natal females and 50 per cent of them are reporting that they have completed an assessment for some form of neurodevelopmental issue. Just shy of a third report a diagnosis of a mental health condition.

That is a group of complex young people who need a really good, robust multidisciplinary team approach. Psychologists are sitting in Sandyford, with support from others, and trying to manage that. The Cass report and the CMO report both talk about diagnostic overshadowing. We have a specialist service. No one else wants to touch the issue of gender because they think that it is too difficult. It goes in the "Too hard to deal with" pile.

Ruth Maguire: Will you explain what diagnostic overshadowing is? I was nodding along, but I do not understand what that is.

Rhoda MacLeod: I beg your pardon. There is a feeling, which the Cass report also spoke about, that as soon as a child or young person mentions that they are questioning their gender, everyone goes, "I can't deal with this. They need to go to the gender service." They then end up on a waiting list at the gender service.

We know that some of the people on our waiting list are also receiving support from child and adolescent mental health services, that there might have been an intervention from social work and there is no doubt that their GP will be involved in supporting the family, but they are sitting on a waiting list for the gender service. The problem is that everything is seen through that lens, instead of looking at the entire child or young person.

Shifting the service into a holistic child-centred service with the right professionals who have good experience of working with children and young people would absolutely be the right thing to do. It would at least tackle the issue of diagnostic overshadowing and might prevent it from happening.

Ruth Maguire: This is quite a challenging thing for me to say, because I understand from listening to you both that you are delivering a service with care and expertise. However, it is quite shocking for me to hear that children have not been getting the best care and that there has been no curiosity about neurodivergent young women. I am not talking about individuals; I am talking about the system. It is difficult.

Rhoda MacLeod: The Cass report talks about that. My comments about the Scottish picture chime completely with the UK picture, which is no different. There has been a significant shift, over a very short time, in the population demographic of those attending gender services. That might not alleviate your concerns, but it helps to explain why we are on the back foot here with everyone asking where all this has come from and how we found ourselves in this position. Quite a significant change in healthcare has happened over a short period. Tracey Gillies knows more about that than I do, but it is a significant reason why we find ourselves where we are.

Tracey Gillies: As Rhoda MacLeod says, there has been significant change in a short time, but we know that our healthcare systems do not always do well at keeping up with that level of change. People in individual clinics are absolutely trying to do their best, but it is sometimes difficult to get a slightly more distant perspective and to see what that looks like overall.

We also know that waiting lists have been too long, so there has been a focus on trying to reduce them, which is difficult to reconcile with offering a holistic service that allows exploration at the individual's own pace of what they want or that allows trust to build up so that there can be good discussion of the things that trouble that individual. It is difficult to deliver services that need a high level of trust in an efficient way, because people inevitably need holidays or are absent from work, and you are relying on relationships that allow genuine exploration of questions and that require support for whatever decision is made. Good information has to be provided that will allow the individual to make their own decisions, but it is very hard to do that while trying to move people through a waiting list, within time constraints.

As Rhoda MacLeod said, it is difficult to recruit staff to that area and to build up the required level of clinical expertise, so there are real tensions. There is an onus on those who deliver services to ensure that the standards of clinical governance in those areas are the same as they would be in all other areas. The service does not have to be more developed than others; it just has to be as good as the others.

We are articulating the fact that there has been a very rapid shift in the population and that we must ensure that we keep up with what is needed.

Ruth Maguire: I really appreciate the candour of your answers. You are articulating something about the wider system, but I want to be really clear that we must never again get to a situation in which we are giving children and young people drugs that can have life-changing impacts without knowing the risks and benefits of doing so.

Tess White: My question is for Rhoda MacLeod. To what extent do you believe the criticism that truly holistic care is lacking in Scotland?

Rhoda MacLeod: By whom?

Tess White: You said that organic growth had happened in a very short time. Am I right in assuming that holistic and person-centred care have been lacking because the waiting list has grown so quickly?

Rhoda MacLeod: It has grown quickly, and we have tried to manage a response to that. If we were to sit down today with a blank sheet of paper to design a young people's gender service, I do not think that we would have it all at Sandyford in NHS Greater Glasgow and Clyde.

I say this without any disrespect for colleagues in other health boards, but because of the way in which the service has grown, it has sat within Glasgow, as part of NHS GGC. I spoke about the "Too hard to deal with" pile. Health boards deal with adult gender services, but no other health board has decided to develop a young people's gender service. We might ask why, but the answer is obvious. That takes us back to my earlier answer. We need a far more creative, and national, solution, with health boards working together.

Tess White: How many of the people who are currently at Sandyford are receiving holistic person-centred care? Is that a small percentage, or does everyone get that?

Rhoda MacLeod: It is only the small amount of people on our case load who can be seen by clinicians at this time.

Tess White: It is small.

Rhoda MacLeod: I cannot give you a figure—I would be making it up.

Tess White: That is fine.

I will move on to my second question. My colleague Ruth Maguire mentioned that children as young as seven have accessed gender services at Sandyford. That is from a total of 352 children. How are the parents and families of children and young people involved in the holistic person-centred care approach that you described? What role will they have as the delivery of gender services changes?

Rhoda MacLeod: As we develop into the new model?

Tess White: I would like to know about the current model and the new model.

Rhoda MacLeod: We engage with clinicians. To be clear to the committee, I am not a clinician; I manage the service. I cannot tell the committee about that in detail, because I have never taken a patient through care, but I know that our clinicians work closely with families and all the other professionals who are involved in a young person's life. We do not work in isolation. We ensure that our assessments are as robust and holistic as they can be with the resources that we have at Sandyford.

Going forward, we would want to inform and support the development of a good, robust process, wherever the service might end up being located.

Tess White: My third question is for Tracey Gillies. We have heard from you about the massive pressures that CAMHS providers are under, and the fact that patients sometimes have to wait for years to be seen. A number of GPs have told us that, under the 2018 general medical services contract, they do not have the resource to treat patients with gender dysphoria. They say that they just do not have the skill set, which is why they are referring patients. In your view, is Scotland equipped to move towards a more holistic approach to treating young people who access gender services? If not, what needs to change?

Tracey Gillies: We are trying to remain engaged with an area that is changing quite quickly. It also involves a wide range of clinical expertise and skills that are distributed across multiple clinical communities, such as general practice and the wider primary care community who are part of delivering the 2018 contract.

Our overall approach to many services is to pick them up and deliver them in a tiered way. We provide education and support, and we increase competency for services that can be delivered in a much more distributed way in the community. As a service moves up the tiers and becomes more specialised, patients are more likely to have to travel to access them. We would describe a similar approach for gender services, while recognising that there is a level of complexity there.

I come back to my point about the pressures within CAMHS, which Tess White picked up on. Expertise needs to be developed if we are to provide good therapeutic interventions. We already know that we do not have enough people to enable us to do that, so trying to do so in a more multidimensional way, and in gender care in addition, will be quite challenging.

I can tell from your face that I have not been clear enough.

Tess White: No, that was very clear. Thank you for your candour. It is a huge issue for Scotland to recognise that a service that has grown organically is under significant pressure and that it is a complex exercise to move CAMHS provision that is under such massive pressure to already stretched NHS boards.

10:00

Tracey Gillies: Yes, but we need to address that so that we give the best care to the individuals who experience gender incongruence or dysphoria. The separation of different elements—that is, thinking about gender in one place and about neurodevelopmental or CAMHS issues in another—does not make for good clinical care. We need to address how we will do that. We are really just at the start of working that through.

Emma Harper (South Scotland) (SNP): A lot of my questions have been answered.

I was just thinking about the gender identity healthcare services standards that were published by Health Improvement Scotland this month. I recognise that healthcare providers will be doing their best to provide the very best care. I am interested to hear your thoughts on those standards. What needs to be done with them? Which of them will be the most difficult to achieve? How we are doing at the moment? I am a nurse, so I know that we have been talking about how to deliver individual person-centred care for years, and that is obviously the goal of the standards. What needs to happen to ensure that they are achieved?

Tracey Gillies: We need to think about the evidence, underneath each standard, that different stakeholders would expect to see in order to know whether a health board or a service that is delivering that care is meeting that standard. One thing that will be hardest to do well is the transition of care from children and young people's services to adult services, because it is very hard to deliver good transitions around numerical age. There is a risk that we will end up maintaining a number of children and young people within a more children-orientated service, because that is where they have been looked after and where their family will have had good support; it then becomes a lot harder to move into the slightly less person-centred adult world. Doing that well will be difficult to achieve.

Rhoda MacLeod: Designing the service model for Scotland is a challenge, but we can do it. The issue is then about how to take that from one centre and look at how what boards are required to do with the standards manifests at regional level and in relation to what. It is unrealistic to ask every health board in Scotland to run a young people's gender service. That will never happen. It is not required. Although the issue is complex, the numbers involved are still pretty small, nationally. We need to be creative in thinking about how the service could be delivered a bit closer to people's homes. We have a regional structure. It is not for me to say, but my thoughts are that we could be working for delivery in a more regional way.

Tracey Gillies commented about the other challenges in CAMHS to do with neurodiversity and neurodevelopmental issues. We could do something quite clever around that, because there are increasing demands on those services for such assessments. We may be able to do something jointly with CAMHS in relation to the holistic assessment process.

It is great to have the standards. They set a framework for us. However, that does not tell us what a service looks like, which is what people want to know. They want to know where they should go to get help if they are beginning to question their gender, what the first stage of the process is, what the levels of service are, what the tiered approach to intervention is and when an intervention is right. Not everybody who is gender questioning needs an NHS service. I feel very strongly about that. There are lots of people questioning their gender, but they are just gender questioning; they do not necessarily need an NHS service. It depends on what else is going on with them, what their level of distress is, how they are managing to cope and function, and how they should be best supported.

What is the role of the NHS? The HIS standards set that out, but what does that look like for people in the real world? Where are they placed, and who is responsible for them? Again, the CMO's report made some clear recommendations about where that should shift.

Emma Harper: On the back of that, I understand that the process for monitoring how the standards are being implemented and delivered using a dispersed model and a tiered approach will involve self-assessment. Is that an acceptable approach?

Rhoda MacLeod: We are designing something pretty new, so we will want to have quite robust reporting processes to look at how that is developing and succeeding. In the health service, we do a lot of self-reporting. In other aspects of my work, there are formal inspections by Healthcare Improvement Scotland, after which a public report goes out. There are action plans, and we are accountable for ensuring that we deliver on the actions in those plans. In this area, I would imagine that the approach would be not dissimilar from what happens in sexual health, for example. We have a set of standards—we do not get inspections on those standards, but as a board, we have to ensure that we are attempting to do our best to meet them. I would think that we would easily put in place some kind of reporting mechanism that would require boards to report on meeting those standards.

Emma Harper: Is that response based on work that is already being done in NHS reporting systems?

Rhoda MacLeod: Yes.

Tracey Gillies: If self-assessment is at one end and a formal inspection through a scrutiny assurance process is at the other, there is something in the middle around systems providing a level of peer learning and support. Critical friends can be really helpful as we implement a new service. People can come in and look at the evidence that we have for how we meet the standard, but we also get shared learning. They may say, “Well, we do it slightly differently—have you thought about doing this?” There is a middle ground that could be helpful in this space.

Emma Harper: I have a final wee question. Ahead of today, in preparation, I was reading about how the system for people to access their GP works in Australia, Germany and other countries. There are opportunities for us to learn from approaches worldwide, looking at what works in other areas.

Tracey Gillies: That is absolutely right. We need to do our bit of design for changing our services and then we can look first within Scotland, then in a UK setting—we have already referred to how we can ensure that we do that—and then more widely.

Sandesh Gulhane: I will focus my questions mainly on the role of GPs in designing a service model, because I am deeply concerned about how this is going to play out. Designing a service model never really seems to involve GPs—HIS, for example, only took written evidence from them.

First, is the provision of shared care for gender identity healthcare contractual in the GMS contract?

Tracey Gillies: That would vary from board to board, depending on their shared care agreements.

Shared care agreements usually refer to the provision of medicines between a specialist and primary care, such as a GP service. Is that what you mean?

Sandesh Gulhane: Yes—according to the BMA, the GMS contract is clear that this is not part of shared care, and that it is outside the contract for core work that GPs would provide.

Tracey Gillies: Which element do you mean?

Sandesh Gulhane: Providing monitoring and prescription of medication.

Tracey Gillies: Which medication do you mean? Because that is where—

Sandesh Gulhane: All gender-related medication.

Tracey Gillies: The use of medicines outside the terms of their licence places additional responsibilities on the prescriber. I think that there will be quite a wide range in the feelings of GP colleagues about their ability to participate in that. Shared care agreements are usually developed at board level. We have a small number of them, but what is important is that there is good engagement across the interface about what would be involved in that shared care agreement, which is usually drug specific.

Sandesh Gulhane: Does a GP sit on your board to make that agreement?

Tracey Gillies: On which board?

Sandesh Gulhane: Where that decision is being made—you said that it was made at board level.

Tracey Gillies: What I mean by that is that the shared care agreements in NHS Lothian will be different from the shared care agreements in NHS GGC, NHS Fife or NHS Borders. They are locally specific, and they are usually agreed through the formulary committee.

Sandesh Gulhane: Under HIS criteria 6.1, it is suggested that there are

“local pathways”

to

“support shared care across services and settings”,

with flow charts showing discharge of patients into primary care, but with no set gender clinic follow-up. How can we expect GPs to be able to provide that care that you spoke about earlier when you said that GPs would organise the dual-energy X-ray absorptiometry—DEXA—scans under such stressed circumstances?

Tracey Gillies: I do not think that I said that GPs would organise the DEXA scans; I said that we needed to ensure that we had good longitudinal care for individuals who might need that, and we would then need to be clear about whether that was coming from primary care or not. That is a curtailed version; I did not say exactly that, but that was my intention.

This is a really difficult area for everybody participating, and we need to be cognisant of people’s expertise and skills. There is probably some model where related care might not come from every GP. Does that make sense? It is very difficult to develop the skills across this area. Essentially, it would be similar to what happens within many practices, where some individual GPs specialise in women’s health services and the distribution of patients seeking contraceptive advice or menopause advice, say, is not shared equally between GPs working within the setting.

We might see some level of developing expertise among some colleagues but, where there is a shared care agreement around prescribing, we need to be explicit about who is doing the prescribing, what skills and competencies they have, what the monitoring arrangements are, and what support there is for the answers that come out of those arrangements—or escalation. That needs a lot of in-depth discussion, which does not just come from one GP and one practitioner; it needs multiple views for people to come to a plan that is safe and effective.

Sandesh Gulhane: Can we opt out and say, “No—we don’t want to do this”? I say “we” meaning GPs.

Tracey Gillies: I realise that that is what you meant.

I could not give a yes or no answer to that. It very much depends on where an individual is. We know that, in more remote and rural areas, people will have a different, often longer-term, relationship, which involves a lot more continuity of care with a GP than in an urban setting. It is very context specific.

Sandesh Gulhane: Changing sex in medical records can potentially be quite dangerous. I will give you an example. The normal range of haemoglobin is different for men and women, so not knowing that somebody has changed gender could perhaps lead to quite significant harm occurring. How can we ensure that that is addressed in a standardised way across the NHS in Scotland?

Tracey Gillies: You are right: it is important to ensure that we do things in a standardised and consistent way and that, where we need to pick up the differences, if we make a change to a record, there is a way to link that to new lab reference ranges and ensure that we are clear about what they should be.

This is quite a complex area, which is why dealing with it in a standard, consistent way is really important. We need to be supported by other public bodies in doing that, not just health boards. It will not just be a matter for Public Health Scotland; there will important implications for NHS National Services Scotland around who gets called for what screening. There are a multiplicity of different questions here.

Sandesh Gulhane: I come to my final question. There is a big difference between the case of a patient who accesses NHS care, who is prescribed medication and then—normally—has a period of follow-up discussion, and that of one who goes into a private setting, who receives an initial diagnosis and then their GP is asked to prescribe medication. How can we ensure that there is a standardised approach across the NHS, not only to patient safety but to the safety of the clinicians who are involved?

10:15

Tracey Gillies: My understanding is that that is why the private route to prescriptions in this setting has been closed off.

Sandesh Gulhane: Going forward?

Tracey Gillies: I am not quite sure what your actual question is.

Sandesh Gulhane: There will be a point when that route will open up again. How can we ensure that safety is maintained?

Tracey Gillies: That is down to supporting individual prescribers to ensure that they are comfortable with prescribing a particular treatment. If they are not comfortable, we need to ensure that they are able to provide the right support for the patient, by saying, “What does this look like for you? How do we support you through that?” Nobody should be prescribing a medicine that they believe they are not safe or competent to prescribe.

Emma Harper: If GPs were to opt out from gender care, would that mean that we would miss young people who have neurodivergence or mental health issues? It is not just a black-and-white issue; this is about person-centred, total patient care and assessing individuals in a holistic way. We have been talking about a holistic approach. I am concerned that, if there were to be an opt-out, we would miss people who really need support with other conditions.

Tracey Gillies: That point might have got slightly lost in my earlier exchange with Dr Gulhane. I was trying to say that if an individual GP is not comfortable about doing something, there is an onus on us to ensure that the patient at the centre of the picture can still access care in the right way. That absolutely needs to happen.

Joe FitzPatrick: I will go back to the questions that we had earlier, when we were talking about hormone treatment. Other panel members gave us some answers, but we thought that Dr Crighton, who has just arrived, would be more able to give us answers on how young people in Scotland might access clinical trials and what such trials might look like. Thank you, Dr Crighton, for making it along, in spite of the challenges.

Dr Emilia Crighton (NHS Greater Glasgow and Clyde): I apologise for the mix-up and arriving late to the committee’s meeting.

To recap, I know that the committee heard from Hilary Cass at a previous meeting, and I saw the evidence that she gave. In her review, she stressed the importance of generating evidence of long-term safety. We looked at the data in Scotland on the numbers of young people who have access to puberty blockers or hormones. Those numbers are so small that, following discussion with the chief scientist, Professor Dame Anna Dominiczak, we agreed that we need to join forces with NHS England to ensure that we have the power to identify real effects, whether they be positive or negative.

Therefore, together with the CMO and the chief scientist, we have written to NHS England and the National Institute for Health and Care Research, expressing our desire to set up research and to participate in NHS England’s research. I have convened a sub-group with representatives of the University of Glasgow and service colleagues, with research and development support, to see how we can implement things on the ground. Again, the intention is to participate in and be part of the wider NHS England research.

As I understand it, we are at the stage where the protocol is to be peer reviewed, to ensure that there is scrutiny. Although there is what might be called a competitive tendering process, the process for a sound scientific basis needs to be followed. Therefore, once we have carried out the peer review, we will consider how we implement that approach Scotland-wide as well. We are poised to consider the additional resources that we will need to put in place to enable us to do that.

Joe FitzPatrick: I totally understand that you will conduct a clinical trial to examine the effects of treatment. However, most of us will have come across trans people who did not manage to receive support. I can remember one man who knew that he was a man when he was at the pre-teenager stage, but went through his whole life until he retired before being able to take affirmative action on that. That is someone whose life has not been as full as it might have been, had he had affirmative treatment sooner. Will you also be looking at the issue of not treating people?

Dr Crighton: Part of the assessment is about ensuring a patient-centred approach and finding what works best for them. There are psychological interventions, social transition and medical treatment. We envisage getting together with a patient to identify what would be best for them and would actually deliver what they truly require.

We know that a number of individuals will benefit from medical and surgical treatment, but we have to identify those for whom that will truly bring long-term benefits.

The Convener: I thank the witnesses for their very helpful evidence. The committee intends to take further evidence on the review of gender identity services for children and young people from the chief medical officer at a future meeting.

Subordinate Legislation

Personal Injuries (NHS Charges) (Amounts) (Scotland) Amendment (No 2) Regulations 2024 (SSI 2024/225)

10:20

The Convener: The third item on our agenda is consideration of one negative instrument, the Personal Injuries (NHS Charges) (Amounts) (Scotland) Amendment (No 2) Regulations 2024.

The purpose of the instrument is to amend the Personal Injuries (NHS Charges) (Amounts) (Scotland) Regulations 2006, in order to increase the charges recovered from persons who pay compensation in cases where an injured person receives national health service hospital treatment or ambulance services. The increase in charges relates to an uplift for cost inflation in hospital and community health services.

The Delegated Powers and Law Reform Committee considered the instrument at its meeting on 10 September 2024 and made no recommendations in relation to the instrument. No motion to annul the instrument has been lodged.

As members have no comments, I propose that the committee should not make any recommendations in relation to this negative instrument. I note that no member disagrees.

At our next meeting, we will take evidence as part of the committee’s further scrutiny of the National Care Service (Scotland) Bill at stage 2.

That concludes the public part of our meeting.

10:22

Meeting continued in private until 11:16.

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