OFFICIAL REPORT
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Health, Social Care and Sport Committee

Tuesday 29 October 2024

Session 6

The Scottish Parliament
Pàrlamaid na h-Alba

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HEALTH, SOCIAL CARE AND SPORT COMMITTEE
28th 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)
*Brian Whittle (South Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Professor Graham Ellis (Scottish Government)
Gordon MacDonald (Edinburgh Pentlands) (SNP) (Committee Substitute)
Professor Sir Gregor Smith (Scottish Government)
Professor Alison Strath (Scottish Government)

CLERK TO THE COMMITTEE

Alex Bruce

LOCATION

The Sir Alexander Fleming Room (CR3)

Scottish Parliament

Health, Social Care and Sport Committee

Tuesday 29 October 2024

[The Convener opened the meeting at 09:15]

Interests

The Convener (Clare Haughey): Good morning, and welcome to the 28th meeting in 2024 of the Health, Social Care and Sport Committee. I have received apologies from David Torrance and Ruth Maguire, and Gordon MacDonald is attending as a substitute.

I welcome to the committee Brian Whittle, who is replacing Tess White. Agenda item 1 is to ask Brian to declare any relevant interests.

Brian Whittle (South Scotland) (Con): The only interest that I have to declare is that my daughter is a national health service healthcare professional.

The Convener: Thank you.

Decision on Taking Business in Private

09:15

The Convener: Agenda item 2 is a decision on taking business in private. Do members agree to take items 5, 6, 7, 8 and 9 in private?

Members *indicated agreement.*

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

09:15

The Convener: Agenda item 3 is an evidence session as part of our scrutiny of the independent review of gender identity services for children and young people in England and Wales, otherwise known as the Cass review, and the implications of the review for provision of those services in Scotland.

I welcome to the committee Professor Sir Gregor Smith, who is the chief medical officer, Professor Graham Ellis, who is the deputy chief medical officer, and Professor Alison Strath, who is the chief pharmaceutical officer, all from the Scottish Government.

We will move straight to questions, starting with Carol Mochan.

Carol Mochan (South Scotland) (Lab): Good morning, and thank you for coming to give evidence to the committee.

Dr Cass appeared before the committee and provided a full, professional and caring update to us about her review. The Government has accepted the Cass review in full.

In the statement that the Minister for Public Health and Women's Health made to Parliament, she talked about the work that we need to do to make sure that we are providing the best care for the young people who are affected by that work. She also talked about a task and finish group. Can you update us on what that means and what stage the work is at? Is it complete, or do we still have things that we need to do? What is the timeframe for those things?

Professor Sir Gregor Smith (Scottish Government): I will begin to answer your question, then I will bring in my colleagues.

I agree with your assessment that Hilary Cass is a very caring and compassionate individual, who has completed a review in quite challenging circumstances. Her review is really important with regard to how we take gender identity services forward not just in NHS England, but across the United Kingdom. That is why I asked my deputy, Professor Ellis, accompanied by a multidisciplinary team that included Professor Strath, who is sitting to my right, to look at the implications of the Cass review for NHS Scotland.

You asked about a task and finish group; I think that you are talking about a separate group from the multidisciplinary team that assessed the Cass report's recommendations and looked at their relevance for Scotland. Since then, the chief operating officer's directorate in the Scottish Government has taken on further work, which is beginning to look at service models for the future and to put them in place. That work is separate from the work that Professor Ellis and Professor Strath were involved in. Although I am not involved in that work at the moment, my understanding is that the work is progressing under the reform programme that John Burns and his directorate are leading.

Professor Ellis might want to say a little more about any involvement that he has had in that, but at the moment I cannot say any more.

Carol Mochan: It might be helpful if I mention some of the things that I have read. The key recommendations were on healthcare services for young people no longer being provided in adult settings, a move to a distributed network, and an end to self-referrals, with access being available only through clinician-led referrals. Is that part of the work that has been going on?

Professor Graham Ellis (Scottish Government): Those were certainly the recommendations that we made in the report. As Professor Smith said, the chief medical officer directorate, which is responsible for planning and delivering services, including some of the more vulnerable and fragile services that need to be provided on a network model across Scotland, is taking over the implementation phase. A chair has been appointed and has terms of reference for a short-life working group. The group will meet over a matter of months—I am not sure of the exact timescale—to make sure that it is able to implement and deliver the distributed model, which means that we can provide care more immediately and closer to home, where possible. There will be a lot of logistics to be worked through in that, which I expect the group to do over the next few months.

Joe FitzPatrick (Dundee City West) (SNP): I was not here when Dr Cass gave her evidence, so I did not hear it directly. There has been a fair degree of controversy around the methodology of the Cass review—not least and most recently from the British Medical Association. What is your position on the methodology that was employed by the Cass review? Will you comment on the work of the BMA review and how the Government will respond to that review once it is published?

Professor Smith: The first thing to say is that probably everyone in this room would recognise that there was a controversial moment when the BMA decided that it was going to begin its own critique of the Cass review. My understanding is that the reasoning behind that was based on two papers that had been identified as being critical of the methodology that had been employed by Cass

during her review. It is very striking to me that the BMA has moved back from that position, following quite marked representation from its members and from other clinicians and scientists who were critical of the approach that the BMA took.

The two papers in question that the BMA had identified as being critical of the methodology—the papers by McNamara and Noone—have since been critiqued by other very credible scientists. I have to mention the credibility of the two papers, which were published online and—which is important—were not peer reviewed. In fact, one was, in essence, a blog and an opinion, rather than a research paper. It was critiqued through normal scientific process, and its credibility was undermined quite significantly as a consequence, which contributed to the change in the BMA's position on the approach that it will take.

I could send you a link to a wonderful paper that critiques the two papers and looks at the flaws in the way that they approached things—for example, their misunderstanding of what the Cass review actually was. We have to remember that the Cass review was an independent review. We have for many years in the UK been used to appointing a respected individual to conduct an independent review that takes evidence from a number of different sources. It was not a clinical practice guideline. Certainly, in one of the papers, there was a real misunderstanding of what the Cass review had set out to do and what its terms of reference were—hence, some of the comments about the methodology.

Even with that said, from what I have seen there were quite marked flaws in the way that the two papers approached their critique of the Cass review. We can go into that in more detail, if you wish.

One of the important things at this point is understanding of the scientific process. Scientific process is really important: it is one of the elements of human society that has allowed us to make such progress in how we understand the society that we live in, and the way that we go about developing clinical practice. There needs to be rigour and we need to be very careful about how we use, interpret and report on research papers that do not use that rigour and due scientific process, because it undermines the progress that we make as humanity if we fail to do that.

Unfortunately, much of what has been written about gender identity services and the Cass review does not have the scientific rigour that we must be mindful of when we are thinking about complex subjects. That said, we need more scientific research and evidence in the area—the guys beside me can speak a bit more about what is being done to develop that. A proper scientific process needs to be followed, both in interpretation of any commentary and in how we approach the development of evidence, which needs to be truly useful to the people who are seeking the type of service that we are discussing and the clinicians who are providing it.

Professor Ellis or Professor Strath might want to expand on that.

Professor Ellis: I completely agree. At the heart of the debate is the fact that the studies that exist are observational studies. They are poor quality and prone to potential bias, which leaves them open to interpretation. There are not enough rigorous scientific experimental studies that rule out bias in a way that means that we can trust the results. That is what we need. We have agreed to take part in the UK research trial on puberty blockers as part of a UK-wide consortium. That will be important in understanding and informing the evidence base without that risk of bias in interpretation.

Professor Alison Strath (Scottish Government): I reiterate what my colleagues have suggested, which is that not all evidence is equal. Normally, we use four types of evidence. The best evidence that we can get is from a randomised controlled trial, which uses the rigour that was described earlier. After that, there are various levels, including systematic reviews, which consider peer-reviewed literature; case study approaches; and observational studies, which are much less rigorous. It is important to get the balance of evidence right. That is what really drives the decisions that we make. For example, a decision on whether to license a medicine is based very much on a strong evidence base from randomised controlled trials.

Joe FitzPatrick: It would be useful if Professor Ellis or Professor Strath could give us an indication of the timescales for the trial, because people are keen to hear how that is progressing.

Professor Ellis: The trial is set up and funded, and it will have five component parts, of which the randomised controlled trial is one. It is planned that recruiting will start at the beginning of next year. Scotland's involvement has been confirmed, but I do not know exactly when we will start involving patients.

Sandesh Gulhane (Glasgow) (Con): Good morning. I remind the committee of my entry in the register of members' interests, which states that I am a practising NHS general practitioner.

Professor Smith, you have said today that we need more evidence in this area. You have also said:

"The Cass Review highlighted that the evidence for prescribing gonadotrophin releasing hormone (GnRH)

analogue to suppress puberty is inadequate and the risk of short- or long-term harm remains uncertain."

My question to you, therefore, is this. Why were we allowed to get in a position in which such medication was given to children, even though, according to your own words, the knowledge about it is uncertain and inadequate?

Professor Smith: As you will know as a practising clinician, evidence develops all the time and, sometimes, uncertainty begins to develop around a particular approach. As you also know, use of medicines in any sphere is governed by strict processes and licensing—in particular, by the Medicines and Healthcare products Regulatory Agency. Professor Strath might want to say a little bit more about that process.

Until the National Institute for Health and Care Excellence initiated its literature review of the evidence on use of GnRH analogues, there was uncertainty about the evidence base around them. That literature review showed that there was not a strong evidence base either for or against their use, and following that the MHRA began to consider the situation. Up to that point, the MHRA had been content with use of GnRH analogues, but following the review of the evidence it made the decision that they should no longer be used in that scenario. As I said, Professor Strath can expand on that.

09:30

Professor Strath: Thank you. I wonder whether it would be helpful to start with licensing. Dr Gulhane, you will probably appreciate some of this, given your background.

The MHRA is responsible for licensing medicines. It does that based on evidence from randomised controlled trials, and it will think about the quality, safety and efficacy of medicines. That is important because we know that, before we had a licensing system, harm was done to people because we did not have processes to make those decisions appropriately and to keep them under review. That is why the pharmacovigilance work that the MHRA does, in which it looks at real-world evidence, is also important.

When it comes to prescribing, we expect clinicians to prescribe licensed products, but there are times when they will prescribe something that we would call off-label, which means that prescription is outside of its licence. That tends to happen particularly in paediatrics, because we do not often do clinical trials using young people: you can understand why. We tend to try to translate information from randomised controlled trials, then think about the age and weight of a child and make correlations. It is therefore not unusual to see off-label prescribing.

Having spoken to some of the young people who have been impacted by the decisions that were made about the availability of GnRH analogues for puberty suppression, we know that they used the argument that the products are licensed for things such as precocious puberty: the thing is, they have been tested in that particular situation, but we have not tested them for different doses and strengths in different age groups.

It is really important that we base decisions on the evidence that we have, which is why the clinical trial is so important in building the evidence base.

Sandesh Gulhane: Absolutely, and that is where we are right now, but my question goes back to when the services were set up, when things were beginning and money was being spent on creating a service. Explain to me what randomised controlled trial—for "quality" and "safety", in your own words—said that the prescribing of GnRH to children was acceptable and safe in this case.

Professor Strath: I suspect that the issue is that local decisions were made using local governance processes and they were based on the best available evidence. That is not unusual. The key thing is that we review those decisions, look at the evidence and ensure that we continue to reflect on whether they are appropriate or not. Some of the evidence that is emerging from the work that Dr Cass did has started to expose the situation, as did NICE's evidence review. That emerging evidence base made people reflect on decisions that were made through governance processes around off-label prescribing.

We had a specialist adviser to the CMO for a period of time, and I remember him saying to me that the worst thing that we do is accept poorer medicines into clinical practice. The point is that reviewing the decisions is important, so that we can learn as we use them in the real world and apply the developing evidence base to our decision making. That is exactly what has happened in this situation.

Sandesh Gulhane: It is not really, because it was England that decided to do the Cass review, not us. The emerging evidence did not push us into asking whether we should pause, or have a think about where we are and launch such work. England did that and we have followed on the back of it. I do not necessarily think that what you say is exactly the case.

Professor Smith: Could I come back on that point?

Sandesh Gulhane: Yes.

Professor Smith: It is important to say that, from the moment that there was evidence that

there was going to be a review, we engaged with NHS England in order to watch that review and to make sure that we engaged with Dr Cass herself in the process of the review. It probably slightly misrepresents the history of the situation to say that we were not involved in the discussions or that we were not watching to see what recommendations Dr Cass would make, at that time. It is important to say that clinicians in Scotland in gender identity services and the officials who were responsible for the services in policy terms were very much part of that process right from the beginning and were watching very closely what Dr Cass was doing in order to consider their relevance for Scotland.

Sandesh Gulhane: In the devolved health service, we are watching, but we did not do anything to start it off.

My final question is for Professor Strath. Will you please give us an update on where we are with current research and current indications on what is happening? I appreciate that it is always difficult to tell with trials, but roughly when will we get an update?

Professor Strath: Colleagues have already discussed the fact that we have engaged, and our chief scientist for health in the Scottish Government has actively engaged with her counterparts at the United Kingdom department. We are going to participate in the NIHR—National Institute for Health and Care Research—clinical trial, which will begin at the turn of the year.

As my colleague Professor Ellis said, we do not know the exact start date for active recruitment of patients, but that will be one of the key things in terms of the emerging evidence base. There will also be work happening elsewhere, and we are actively engaged with the University of Glasgow, which is doing quite a lot of work in on-going research around the services that we are providing in this space, but we are also looking globally at the developing evidence base. The key part of the NIHR trial is that we will see emerging evidence from a UK perspective, but we also need to think about evidence that is coming from elsewhere, which will play into the overall thinking.

Emma Harper (South Scotland) (SNP): I will pick up the point about international collaboration and working together. We are talking about a small number of persons who are seeking care in relation to gender. In my previous job as a registered nurse, I would look at what people were doing in England, Ireland and Wales, and when I worked in California, it was the same thing—you network with the people who are specialists. That would be part of the engagement of networking with people who provide specialist care, such as researchers, doctors and so on. I imagine that that is what Professor Sir Gregor Smith is talking about. We are not just waiting and watching in Scotland for somebody else to take action: there has been participation and collaboration from the start.

Professor Smith: It would be a real mistake to adopt an isolationist position in world clinical medicine. If we were to look inwardly, and only inwardly, rather than utilise the very strong professional networks that we have across the UK and internationally in order to learn from others' experience, to bring back good practice and to learn from other people's reviews and approaches to care—if we were to fail to do that—that would be incorrect for us. We need to make sure that we are engaging with experts from a variety of countries, both across the UK and internationally, to learn from their experience.

What I have seen happening across this—as you said—very specialised service, is that with Cass conducting her review of services in England, it was always anticipated that there would be learning from it that would be directly and highly relevant to the way that we approach services in Scotland. As you can see from the report that my colleagues here have produced, a number of recommendations from the Cass review have either full or at least partial relevance to the situation in Scotland. I think that only six of the recommendations do not have some relevance to how we provide care in Scotland.

Brian Whittle: Good morning. I should say that I am late to this investigation, so I apologise if my questions cut across things that have been dealt with before.

I was very interested in what Professor Smith said about the importance of using a rigorous scientific process. I completely agree. With regard to the Cass report, you have commented on social transitioning in schools not being a neutral act. That concerns me, because having spoken, as a member of another committee, to teachers, I know that they are often on the front line in recognising the potential need for medical assessment or intervention in relation to issues with youngsters seeking professional or medical advice. Should we be, or are we, looking at updating school guidance to give our teachers the tools to enable them to recognise issues and to signpost people towards potential help?

Professor Smith: I will pass in a second to my colleague Professor Ellis to say how some of the wider issues have been considered in relation to development of services.

However, there is a principle that I want to highlight and make committee members really aware of. One of the strongest considerations that came through in the Cass report and, subsequently, in the response to it by Professor

Ellis and the multidisciplinary team, was the striking need to ensure that, when it comes to care for this group of young people, it is delivered not by an individual—although it might have to be led and co-ordinated by an individual—but by a wide variety of professionals. That is often because of the sheer complexity of other neurodevelopmental disorders that the young person might be experiencing at the same time.

I think that, from here on in, it would be a mistake for us to think about any one clinician practising in isolation. We need to take a holistic approach to providing care and support to the young people. Indeed, that will extend beyond traditional healthcare services. With the multidisciplinary team, there is, for me, a need to ensure that we have many professionals working together, including specialists not only in neurodevelopmental disorders, but in mental health support, in gender identity and in issues relating to endocrine use. All those people need to work hand in hand, and the wider the group of people who are able to provide support and recognise the broad issues that can affect a young person, the better. As I said, Professor Ellis might want to expand on that and tell you about some of the group's considerations. I would certainly support a wider societal response.

I want to say one last thing. We all have a responsibility here, and we all need to be very careful about the way in which we enter dialogue in this space because, as Cass has said and as others have commented, this is an area of experience and clinical practice in which there are very polarised views. Sometimes the debate and discussion around it can be very difficult both for people who are experiencing issues with their gender identity and for clinicians who are providing care. A much more balanced approach to the way in which we discuss the services and issues is something that we have to move towards in the future. Professor Ellis might want to give a more specific answer to your question.

Professor Ellis: This is a difficult area, and there are no easy answers. Something that I found really striking, when I spoke to a psychologist who provides the service, was her drawing an analogy between enabling the public and teachers to talk about other issues such as suicide and making safe spaces for people to talk about difficult subjects. This is one of those areas in which we need to equip people to talk about the difficult things.

The important point is that there needs to be a supportive and multidimensional response to an individual child's needs, because the children often have multiple other needs. Waiting list data that we have from Glasgow shows that one in four has other medical needs, one in three has a diagnosis of a mental health condition and two out of three have a neurodevelopmental condition either diagnosed or waiting to be diagnosed. They have multiple needs, but we need to accept them and create an environment in which they can thrive, while allowing them to feel safe to talk about such questions in a safe environment.

The early multidisciplinary response to support children and families, to address questions and to address their wider range of needs, alongside their questions about gender, is really important.

09:45

Professor Strath: We have some good experience of that already from the work that we have been doing in areas such as fetal alcohol syndrome. We have some links with the education system, and there is a lot for us to build on regarding the holistic approach that colleagues have just described. Positive steps are being taken in that direction, and we will be able to build on those in what is a developing area around neurodiversity and the role of schools.

Gordon MacDonald (Edinburgh Pentlands) (SNP) (Committee Substitute): I wish to ask witnesses a number of questions about the ban on private prescribing. I am new to the committee and I should also mention, before I forget to do so, that my wife is an NHS nurse.

I am aware that the legislation on regulation of medicines is reserved to Westminster, and that the previous UK Government introduced emergency legislation to ban prescribing of puberty blockers. What is the panel's view on the UK Government's ban on private prescriptions for puberty blockers?

Professor Strath: You are absolutely right that the legislation is reserved. The concerns that the Government at the time had were around how we would ensure that there were appropriate safety checks and balances in the system. That was difficult to do—not so much in relation to private prescribing in the UK but for private prescribing from other parts. We know that that is an issue in other areas of healthcare, and not just in this one.

The Government's view was that there should be an emergency ban that would be time limited to allow the Government to reflect on and think about what would be the best thing to do for the future in ensuring that the right safety nets were in place for decision making. That emergency ban was extended for a period and, as you know, there has now been a consultation on a permanent ban.

We understand some of the risks, we understand the benefits of having a process in which decisions are made with a framework that has good governance around it and we know the healthcare professionals who are involved in

prescribing and making decisions about the medicines. My view, on reflection, is that the ban allowed processes and systems to be put in place, and it allowed for a period of consultation with appropriate bodies on the best next steps. My understanding is that that consultation is now closed, and that we are waiting for analysis of its conclusions. That will drive the next steps in what happens around the availability—or otherwise—of the medicines.

Gordon MacDonald: You mentioned private prescriptions coming from abroad that have been purchased over the internet. My understanding is that any medication that a person has started on prior to the ban coming in will be continued. Is there clear guidance on the extent of community pharmacists' responsibilities when they are asked to continue to dispense privately prescribed puberty blockers?

Professor Strath: You are absolutely right: there are rules around what prescriptions can and cannot be accepted, and guidance on that point has been issued to all healthcare professionals in primary care. We continually consider how to improve that, and we work closely with the pharmacy regulator and the pharmacy professional body, as well as with the body that represents community pharmacy owners, to ensure that we are exploring all the avenues so that people understand what the limitations are and what they can and cannot do under the legislative changes. We continue to keep that under review. As far as I am aware, however, we have not had any particular issues or problems.

We do not really have any knowledge about the extent of private prescribing from Europe, because that is not captured anywhere, as it is for NHS prescribing through our NHS systems. It is difficult to know what exactly the impact is, but judging from estimations of evidence from individuals who have made representations about access, we think that it is relatively small.

Gordon MacDonald: Just to be clear, so that I have this straight in my head, if somebody goes into a community pharmacy with a private prescription to be fulfilled, is there no record of where it originated from?

Professor Strath: The pharmacist will keep a record, but it is in their pharmacy, written down in a book, so it is not openly accessible.

Gordon MacDonald: That information is not gathered centrally.

Professor Strath: Absolutely—it is not gathered centrally.

Gordon MacDonald: Right. That was just so that I am clear about that.

You mentioned the time limit, and you rightly identified that it has been extended from 3 September to 26 November. Are there any plans to extend it further, beyond that date?

Professor Strath: As far as I am aware, the consultation on the permanent ban will drive the decision that is made. If the decision is to introduce a permanent ban, that will supersede the temporary ban. If the decision is not to introduce a permanent ban, I suspect that the ban will be lifted.

Gordon MacDonald: Okay. Before the original ban was enacted, what consultation took place between the Scottish and UK Governments about it?

Professor Strath: We were informed by the UK Government that it was considering the temporary ban, and because it is reserved legislation we were not really able to move that in any way.

Gordon MacDonald: So there was, in effect, no consultation.

Professor Strath: There was no consultation.

Gordon MacDonald: Okay. The new health secretary, Wes Streeting, has committed to taking forward plans for establishing a clinical study to gather the necessary evidence to inform future care and treatment. Has there been any consultation with the Scottish Government about that?

Professor Ellis: I can answer that one. That is the trial that we have referred to. Scottish colleagues have been observers in development of that trial, before the point at which the review and so on was published, and we will be participating in the trial. It is the same trial that has been discussed by previous Administrations.

Gordon MacDonald: Okay. Thanks very much.

Gillian Mackay (Central Scotland) (Green): The panel will be aware that there has been a petition in the Scottish Parliament to end the pause on prescribing puberty blockers to children. In relation to that specific request of the petition, to what extent do doctors have discretion, as part of the current pause on prescriptions, to issue new prescriptions outwith the planned clinical research?

Professor Smith: At this moment in time, I am afraid that doctors do not have discretion to issue prescriptions beyond the pause, which has been put in place by MHRA and which has also been agreed within Scotland.

Gillian Mackay: Professor Smith, among the allegations by the petitioner is that the decision to pause prescriptions is ideologically driven, given that it is not unusual, as we heard earlier, for paediatric treatments by doctors to include use of

off-label antipsychotics. How would you respond to those allegations? Do you believe that the service should be available for children and young people?

Professor Smith: Professor Strath might want to say a little about the MHRA process, which she referred to in response to previous questions in our evidence session, and about how the decision to make that pause was taken by MHRA on the basis of the evidence that is available just now.

Professor Strath: The key thing for me is that, although there is the opportunity generally to prescribe medicines off-label, the evidence that came through from the literature searches that supported Dr Cass's review, along with her report, pointed to the balance of harm and benefit. One of the key points that she made was that, if we are too polarised in our thinking, we might be doing more harm and might not be researching medicines that might be more beneficial for young people, or looking across a range of options that might be more beneficial.

Although there was previously the ability to prescribe medicines off-label, the evidence that has emerged from the work that has been happening makes us ask whether that is the right thing to continue to do. We do not want to cause more harm than we bring benefit. The clinical trial, the on-going review of the evidence and research and looking globally at what is happening around the world give us the opportunity to ensure that we make the right decisions, as we go forward.

We need to put the needs of young people at the centre of what we are doing, and to apply the evidence-based approach in respect of harms, risks and benefits.

Professor Smith: I have one further thing to say about an important aspect of your question. You asked whether ideology, rather than science, lay behind that particular approach. In no discussion that I have been part of have I ever seen evidence of an ideological drive, but I have seen evidence that there is a real desire to get to the bottom of the scientific process and to find where the evidence lies—either in support of or against use of the drugs. There is an attempt to fully determine both the beneficial and harmful impacts for the patient group. I have never heard anyone with whom I have had such a conversation using ideology as a driver for decisions.

Gillian Mackay: I will go back to a point that Professor Strath made earlier. I have spoken to trans young people who cannot understand why some young people can be prescribed puberty blockers for precocious puberty but trans young people cannot have them. They do not feel very different to their peers who can be prescribed the drugs. Can you give me some insight into why we are where we are and why the research is going ahead?

Professor Strath: The key thing is that, for the age groups that we are treating and the dosages that we are using, the drugs have not been tested in the way that the medicines that are licensed for use have been tested. It is really important to understand whether additional harm is caused and whether the doses that we use are efficient and effective. It is important to apply the same rigour to our thinking about a medicine that is not licensed as we would apply to a medicine that we license.

If we rely on using medicines off-label and do not think about how to incentivise further research in the area so that we can find better medicines that come with less risk of harm, we will probably end up not providing the best care. I am not necessarily saying that off-label prescribing is always wrong, but it is important to consider the circumstances and to look at the evidence of the Cass review, which said that there might be harms that we do not know about because we have not done a rigorous scientific review of the evidence and benefits.

Clinical trials go through various phases. We know that the medicines are relatively safe, but we will not know whether they are safe for that use until we have tested them in different ways, at different strengths and on people of different ages. We have an opportunity to take stock and to think about how to better target research in the area, so that the most appropriate treatments are available.

Gillian Mackay: If there is time, I will ask one final question, which builds on what Gordon MacDonald asked earlier. Some young people were close to being prescribed either puberty blockers or hormones, or both, when the pause came into effect, and others who are going through the system may come to that point while the pause is still in place. Is there any monitoring of the possibility that those young people might access black-market medication because they do not feel that they can wait for the pause to be resolved? How are we monitoring the resulting harm, both of the potential use of black-market medication and of the harm done to young people who were given a pathway that they anticipated would have one result but which has come to a conclusion that they were not necessarily prepared for?

Professor Smith: Professor Strath will want to comment on that, but whenever medicine is accessed in that way, no matter the purpose of that medicine, it is incredibly difficult to assess the impact of the black market on the people who use it. That is a hidden aspect of care. When people choose to access medicines in that way, they are far more likely use them covertly and not to reveal that they are using them, which means that

monitoring any impact becomes incredibly challenging.

Professor Strath may want to say a little more about medicines generally. People are more able these days to access them through newer, less traditional routes, and she may want to talk about some of the impacts of that across a broad range of care. The issue does not relate only to the particular condition that we are discussing; there is a much broader risk to, and impact on, society.

10:00

Professor Strath: There are two points to make. First, the UK Government put in place a banning order partly to try to restrict some of that potential black-market access, but that order will not restrict it all. One of the key—

Gillian Mackay: I will just interrupt here. Could prohibition—a complete pause and inaccessibility, even through private prescriptions—actually drive more young people to use non-traditional methods of access, rather than potentially having oversight and monitoring from clinicians in the first place?

Professor Strath: For people who were receiving treatment through the NHS or privately within the UK, we were able to track specific numbers. The issue was where medicines were already coming from other parts of Europe and beyond. The concerns were about how we could ensure—as I said earlier—that we had quality monitoring and controls in place. We could not do that for those medicines, as we do not have jurisdiction beyond the UK with regard to that process.

The key point is that that issue does not relate only to the use of GnRH analogues. We have recently seen it arising with some weight-loss medicines, and there are other areas in which people are approaching sellers and buying medicines on the internet through routes that are not regulated.

There is a risk of harm—we see that with fake medicines coming into the supply system. Every day now, stories come through in the news about people who have been harmed by medicines that they have taken because they have not gone through the legitimate prescribing, monitoring and control processes. We need to think about how we get out some of the messages about the potential harm in that regard.

It is also important that we get the clinical trial up and running as quickly as possible, so that we can route people into an area where we can start to collect the evidence around that.

Professor Smith: That issue emphasises once again the need for a broader holistic care package, in particular with regard to the support package that exists for young people who are seeking help from the service. That would ensure that not only the support but the education is there, so that people are aware of the risks and do not choose to use routes that may bring potential harm.

A broader piece of work has been done, led by NHS Greater Glasgow and Clyde—as, I think, the committee has heard in previous evidence—to understand fully the broader needs of the community that we are discussing. That is important in order that wraparound support is available to those people as quickly as possible.

Joe FitzPatrick: Gillian Mackay mentioned that she had spoken to young trans people, and that that was where some of her questions were coming from.

The Cass review was about children—that was the work that was done. There is, however, a concern from some young trans people that its reach goes further than just children, and that there have been policy decisions that affect those in the 17 to 24 age group. Have there been such policy decisions? It has been suggested that the Chalmers clinic has paused gender-affirming treatments for that age group. What is the decision-making process around that? Is there a policy change, and what can those young people expect for the future?

Professor Smith: I will start—again, colleagues will want to come in, because they have been closer to some of the engagement with the boards that are actually delivering services just now. There has been no policy change in relation to 17 to 24-year-olds at this point in time. I am aware of on-going internal governance reviews in some areas that are looking at how clinical oversight is provided to some of the services, but there has certainly been no national policy change in that respect.

Let me be very explicit: the Cass review had a purpose. It looked at the services being delivered to children and young people, and that is where we have concentrated our recommendations and the service development steps that we have referred to with regard to the task and finish group on the further development of services for children and young people. As I have said, Professor Ellis might want to say a little bit more about that.

Professor Ellis: I would just underline those comments. We have purely addressed children and young people's services for the under-18s; we have made no reference to adult services or to anything policy-wise for 17 to 25-year-olds, so there has been no extension or bleed across to other areas in what we have done.

Joe FitzPatrick: Young people have said to a number of members that they have been told by

the Chalmers clinic that there has been a pause on gender-affirming treatments. Is that not true, or is it something that you would want to go away and have a look at?

Professor Smith: I understand that, at the moment, NHS Lothian is reviewing internal governance procedures around that service, which might have led to a pause. I know that colleagues are engaging with NHS Lothian just now to understand exactly the nature of the pause and how long it is likely to be in place, but it is certainly not part of any national policy decision.

Joe FitzPatrick: Anything that can be done to get some transparency on the matter would be very helpful, because a number of people are really concerned about it. However, what you have said has been helpful for now.

Paul Sweeney (Glasgow) (Lab): I thank the panel for their comments so far.

Some groups such as the Good Law Project have argued that the restriction of puberty blockers is causing harm to young trans people, citing an increase in deaths by suicide among that group. The Secretary of State for Health and Social Care in England commissioned a review of suicides and gender dysphoria in England, which made five points in its conclusion. First, it said:

"The data do not support the claim that there has been a large rise in suicide in young gender dysphoria patients at the Tavistock"

gender identity clinic. The second conclusion was that

"The way that this issue has been discussed on social media has been insensitive, distressing and dangerous, and goes against guidance on safe reporting of suicide."

Thirdly, it said that

"The claims that have been placed in the public domain do not meet basic standards for statistical evidence."

Its fourth conclusion was that

"There is a need to move away from the perception that puberty-blocking drugs are the main marker of non-judgemental acceptance in this area of health care."

Finally, it concluded that

"We need to ensure high quality data in which everyone has confidence, as the basis of improved safety for this at risk group of young people."

Has a similar review been commissioned in Scotland, or are there plans to do so?

Professor Ellis: There was quite a lot in that question, if I may say so.

With regard to suicide, it is an important area for really vulnerable children and young people, so we will want to ensure that we are supportive of them at what is a really high-risk point in their lives. It is important to underline that there was no evidence of an increase in suicide, but all the same we will want to try to respond actively and proactively to people who are in need and in distress.

As for the ban on puberty blockers, a minority of children and young people are on the waiting list for that particular treatment, but that does not mean that their other needs and concerns do not need to be addressed and supported. It is worth underlining that the evidence is uncertain with regard to the benefits of medication for outcomes in relation to mental health and suicide, but it is a fundamentally important point that we must adequately address in our research and services.

Our intention is to be more proactive in our wraparound support for the people involved and to recognise the distress that is there, but we have to be very careful about some of the language that is used. If there is, in data on suicide, no evidence of a real increase, we have to be very careful, as I said.

Paul Sweeney: But would you support a discrete inquiry in Scotland on the relationship between gender services and increased suicide risk?

Professor Smith: One of the things that I would say in this space is that NHS Greater Glasgow and Clyde's clinical validation review of people on the waiting list was incredibly insightful, and it began to develop additional information on experiences of distress or on other diseases that children and young people had while awaiting assessment.

Professor Ellis mentioned that a number of children and young people are experiencing mental health problems or thoughts of suicide, whether passive or not. It is important for us to take notice of that, as well as of the experience of children and young people who turn to self-medication to alleviate distress in this space. All those things need to be fully understood.

The starting point for that is the NHS Greater Glasgow and Clyde study. However, I would hope that what is being done in some of the research projects—particularly on providing the wraparound, multidisciplinary support that is being brought forward in response to the recommendations that we spoke about with Ms Mackay—becomes seen as a critical part of the way that support is provided to these children and young people in the future.

Professor Strath: I am not sure that a review here would tell us anything very different from what came out of the review that has been done elsewhere in the UK. The important thing is that we put our energies and efforts into addressing the issues that that evidence is showing us. We also need to consider the work that we have done around the Cass review and how to respond in

Scotland. Our efforts are probably much better put into trying to have a multidisciplinary, focused approach and thinking about the links to education rather than undertaking a review that, in six months' time, might point to the same thing.

Professor Ellis: I have a brief additional point. Professor Smith alluded to the work that NHS Glasgow and Clyde is doing on clinically reviewing patients on the waiting list. That work has highlighted a lot of the anxiety, depression, self-harm and suicide thinking, but it is not a passive process, as patients are referred onward for services and support. The health board is actively doing that for those on the current waiting list.

An important reason why we stopped self-referral to the service is so that people, having seen their GP, can be identified as having issues that need to be addressed immediately and as a priority. We can address that going forward.

Paul Sweeney: That is certainly helpful.

I want to develop some of the points on the monitoring of harms, which we have discussed. Professor Smith, you mentioned that it is in the nature of self-medicating that it is done covertly or discreetly, without any open discussion. Constituents have approached me and have been quite open about seeking to purchase medications online and so on, citing long waiting times to access the Sandyford clinic. There seems to be a culture—certainly in my anecdotal experience—of people being quite open about their need to self-medicate in that situation.

Are there opportunities to develop greater surveillance of that type of behaviour and the associated risks, perhaps in the context of presentations to primary care practitioners on mental health issues or presentations to alcohol and drug partnerships on drug and alcohol dependency? If trans people are seeking to self-medicate in those scenarios, are there ways of developing greater monitoring to understand the scale of that behaviour?

Professor Smith: I am in no doubt that there is a range of data on the issue that we need to develop. In fact, that is one of the central recommendations that was accepted—or at least partially accepted—in Scotland. Again, Professor Ellis or Professor Strath might want to say more about the consideration that was given around data in that regard.

We need to make sure that we have adequate data sets for Scotland and that they are comparable with the data in other countries, so that we can begin to benchmark care across different elements, particularly given that this is a relatively small group of people in a very specialised area of care. Benchmarking across borders is sometimes necessary in such situations. Developing data sets that tell us much more about the care experience and some of the ancillary issues that people experience alongside their presenting complaint will be really important. As I said, development of data is one of the central recommendations of the multidisciplinary team.

10:15

Brian Whittle: I will follow up on Paul Sweeney's point about the dark side of potential suicides.

Professor Smith, you spoke about the need for a more wraparound and holistic approach to dealing with this vulnerable group. That is exactly what we need, but the reality is that it is extremely difficult to access mental health services at the moment. We hear from teachers that some people are waiting up to five years to access mental health services and that some waiting lists have closed. How do we square that circle? This is a significantly vulnerable group of young people who are looking for help, but that help is not there in reality.

Professor Smith: Providing that complex care requires a multidisciplinary approach. The recommendations contained in the report that I issued about the Cass review clearly say that we must develop those services and ensure that they are in place for young people. To do that, we need adequate workforce planning for the whole multidisciplinary team in gender identity services. I would like to see that urgently being taken forward. As we have already heard, the task and finish group that is developing the service model is looking at that as we speak.

I touched on an additional element that must be in place. Clinicians working in the area speak about the great difficulties that they experience in providing care, partly because of the external discussion about how those services are provided and the "toxicity" that the Cass report referred to. We must change that dialogue in society and there is a responsibility for Parliament to provide leadership on that. If we fail to change the toxicity of that discussion, it will be very difficult to attract clinicians to work in the area. We must collectively ensure that we take a far more constructive approach to how we discuss that care. If that toxic discussion does not change at societal level, it will still be difficult to attract clinicians, no matter how much work is put in place by the task and finish group or by others to develop a service that is fit and appropriate to meet people's needs in Scotland.

Professor Strath: I will add three things about the micro, rather than the macro, level.

First, when I spoke to clinicians involved in providing the service, I was really struck—as I am

sure my colleague, Professor Ellis, was—by the challenges that we have just heard described, which they face at work every day. We must seek to address those.

Secondly, we made a recommendation about moving into paediatric services, although "paediatric" is not the best word to use for children and young people. Moving into that environment would give the opportunity for a far better multidisciplinary team approach to care. That can only be beneficial, because the pressure would not be put on just one or two individuals. You would still need someone to take the lead, but that multidisciplinary approach is important.

Thirdly, we have been working with NHS Education for Scotland to think about the knowledge and skills framework for everyone working in healthcare who will come across children and young people who might have questions about their gender identity or their feelings. Someone might come in and have a conversation with a community pharmacist, a GP or someone in another part of the health and social care system. We have spoken about how important it is to replicate that in education, so that we have a joined-up approach. Scotland has an opportunity to address that and to move forward because of our size and because we have good integrated work in general.

Emma Harper: I go back to what you said about multidisciplinary teams. When the Minister for Public Health and Women's Health gave her statement on 3 September, she said that there would be a move to a more distributed network, with a more regional model and a multidisciplinary team approach, which you have already described. What might such a regional model look like, especially when we are already struggling to staff services?

Professor Ellis: Would you mind if I came in on that? An important point, which builds on what Professor Strath said, is that Dr Cass described much of the care in this area as being "exceptionalised"—as happening somewhere else or somewhere other. We want to normalise such care and bring it within the bounds of NHS approaches to evidence, governance, recruitment, training, support and so on. One challenge with having a single national service, such as that at the Sandyford clinic, in an exceptionalised setting is that it does not have capacity to meet everyone's needs. For example, it is too far away for people from the Highlands and Islands, so it still feels a little exceptionalised.

We want to mainstream such care from child health services, whether they be in the community or in hospitals, and so make it more normal, accessible and local. In that setting, it is much easier to attract someone for a session or to hold a clinic in an afternoon, if they are already on site. As Dr Cass said, many of the skills from paediatrics and child health are transferable. This is normal childcare; it is part of what needs to be normalised. We think that, by using such a model, such care will be more accessible and that it will be more possible to retain, recruit and train people and to build up the quality and accessibility of services.

As for the work of the short-life working group—on matters such as how many centres there would be and how local or regional they might be—much of the detail is still to be worked through. There are practicalities around where we would centre services, who could be recruited, how the centres would be staffed and so on. There is a lot to be worked through, but that is the intention.

Emma Harper: I forgot to make it clear earlier that I am a former NHS Scotland and NHS England employee and am still a registered nurse.

I come back to the point about having a multidisciplinary team approach. We know that the skills that are required are specialist ones. Who would be in such an MDT?

Professor Ellis: The recommendation is that there would be psychiatry expertise and that psychology and paediatrics would be represented in some form or other, depending on the needs of the individual patient. Other members of such a team have been suggested, including those from occupational therapy, physiotherapy and speech and language therapy. However, it would depend very much on the needs of the individual concerned.

We use the term "multimorbid", because some people have complex problems in more than one area of their lives—in their physical or mental health, in their social life or through experience of bullying or trauma. They have often had experience of the care system. Therefore, we need people who have the relevant expertise to deal with those facets of care at the same time. This is not a single-issue approach. We want individuals to be developed to enable them to thrive, be at their best and be most able to progress.

The individual make-up of the team is still to be worked through, but the recommendation is that it should be as broad and as normal as that. That is part of how we often provide multidisciplinary care in other areas of paediatrics and adult health.

Emma Harper: It is about having knowledge and skills in the right areas. For example, neurodiversity is linked to gender dysphoria.

Professor Ellis: Absolutely. That is key. There is a lot of unmet need that has to be recognised.

Professor Smith: That is one of the critical components that we must address.

The only point that I will add to what Professor Ellis has described so completely is that we should recognise that a multidisciplinary team will change over time, according to the needs of the individual. People will come into or get out of the team as is necessary for that individual. Personalising care in that way, for that person's needs, is an important aspect of such an approach. It should underpin the way in which we provide complex care to anyone in Scotland.

Emma Harper: This will be my final question. Has the decision to stop self-referrals had any impact on the length of the waiting list?

Professor Ellis: It might be too early for us to know that, given the data that we have. We know that the number of people on the waiting list has come down slightly, and NHS Greater Glasgow and Clyde is actively exploring clinical discussions with individuals on that list. The number of those who self-referred was just under half of those who are currently on the waiting list. The board's retrospective approach aims to ensure that it identifies any unmet needs and plugs patients into services. That should have happened from the start, but it is doing that now.

Sandesh Gulhane: I want to ask two questions, if I may.

Building on Emma Harper's questions, I note that Professor Ellis said that the MDT would include a psychiatrist. We know from comparative studies that transgender young people are about four times more likely to think about attempting suicide, and the latest stats show that, in 2023, more than 7,000 children and young people had their referrals rejected by CAMHS, which is an average of 26 children a day. How are you going to get psychiatry involved in this particular MDT if we cannot provide basic services to children around our country at the moment?

Professor Ellis: Psychiatry is already involved, and I do not necessarily think that it will be that challenging to extend its involvement and capacity. I cannot speak to your comments about the CAMHS figures, although I suspect that "rejected" means that the appointment was no longer needed, or there might have been other explanations for using that term. It is possible to increase our capacity on that front—indeed, it is essential that we do so—but, given that the numbers in this area are relatively small compared with the overall numbers needing the involvement of psychiatry, I do not think that that will be particularly challenging.

Sandesh Gulhane: Professor Smith, hospitals are pushing more and more things to GPs—and I say that as a GP. The standards, as written, make it clear that gender services are able to push prescribing to GPs, too. Having spoken to many GPs, I know that they are very concerned, and a lot of them are not comfortable with prescribing puberty blockers, because, for example, they feel that such activity is off licence, they are awaiting robust evidence or they see that there is no formal protocol. Moreover, the Royal College of General Practitioners supports GPs not taking on shared care, there is the potential for litigation if patients decide that puberty blockers are harming them, one in two patients have, as Professor Ellis has told us, underlying mental health issues, and the General Medical Council has told us that prescribing must be appropriate.

If those issues are not addressed, are we following GMC competence? Can you reassure me that the prescribing of puberty blockers will not be pushed to primary care without GPs having the credentials—and, indeed, wanting—to take that work on, and that all GPs will be able to opt out?

Professor Smith: No decision has been made about puberty blockers or GnRH analogues and how they will be used in the future. We are therefore talking very theoretically. The RCGP is fully involved, and will continue to be involved, in the discussions. That is all that I can say just now.

Professor Strath: I should add that we have recently introduced directions to put a safety net under the prescribing of GnRH analogues in primary care. As a result, they now sit on the selected list, which means that a GP would have to actively choose to prescribe them. We have therefore put in some safety measures.

However, as my colleagues have said, it is important that, as such decisions are made, there be options to allow people to think about what further needs to be done to ensure that prescribing is appropriate. On a UK basis, we have used directions to restrict prescribing in general practice right now.

Sandesh Gulhane: Thank you.

The Convener: I am aware of the Scottish Government's announcement that it is seeking a UK-wide approach on conversion therapy, which was touched on in the context of the Cass report. Is it possible for the witnesses to give the committee an update on progress towards a UK-wide approach to banning conversion therapies and practices?

Professor Smith: I am not able to give you an update. I wonder whether colleagues are able to speak about that.

Professor Ellis: A Scottish Government policy is being developed on that, but I am not so au fait with the UK-wide approach. Obviously, we support Dr Cass's comments on conversion therapy

concerns, but I am not aware of the timescales in that respect, so I apologise for that.

Professor Smith: I will say one thing in relation to conversion therapy. Many people will have been following some of the concerns that have been raised about the ban on conversion therapy and the impact on people being supported through that process. It is really important for me to say that I see professional support and discussions of people going through gender identity treatment as something very different, and I am keen to ensure that, through the discussions that are taking place just now, there are adequate protections for professionals so that they can have the appropriate discussions and provide support to people experiencing gender identity issues. I see that as very much separate from the discussions that we have all had previously in relation to conversion therapy. In my view, conversion therapy feels like something that is done to people, rather than a discussion that is had with them.

10:30

The Convener: Thank you for that, Professor Smith—you have gone on to answer my next question.

On my previous question, it would be helpful if you could write to the committee about what discussions have been going on regarding a UK approach.

Professor Smith: I commit to engaging with officials who are overseeing that, in order for them to give you an update, as we are not directly involved in that aspect.

The Convener: It is absolutely fine if the committee gets an update from you through officials or the minister.

You also touched on what was going to be my third question, on the toxicity regarding some areas of gender identity services. We heard from witnesses in previous sessions about the difficulties that have been experienced in recruiting staff, which have consequently had an impact on waiting lists and will no doubt have an impact on anyone who is on a waiting list, regardless of whether they are a child or young person or an adult.

You touched a little on what would assist in making a career or role in gender identity services more attractive to healthcare professionals. Could you add anything else on that with regard to workforce planning and support for staff to encourage them to consider working in gender identity services, particularly in the proposed new multidisciplinary teams?

Professor Smith: We should not be mistaken: there are an awful lot of really motivated clinicians who want to work in that area. I have come across them when I have had conversations with them. People are committed to providing care in that area.

It is difficult, however, and we must acknowledge that. In my view, as we develop a workforce for the future, we must ensure that we have the support in place to enable people to do what is a very challenging job.

Collectively, we in this room have a responsibility, too. If I were to ask anything of the committee, I would ask for your leadership in ensuring that we have a different dialogue about services and care in this area. We need a different dialogue for a society that is perhaps more tolerant of some of the differences that people experience in this regard. If we can do that, we can create a different environment for people who have the motivation to work in this area to provide that type of care.

The toxicity is a complex and widespread problem; it is experienced not just in Scotland but across the UK, and internationally. We have the ability to change the national dialogue around the issue, in a way. I ask for your leadership, collectively, in assisting us to do that, so that we can attract a workforce of people who can provide the care that they want to provide through such services.

The Convener: I should put on the record that I hold a bank nurse contract with NHS Greater Glasgow and Clyde, as I did not do so at the start of the meeting.

I thank the witnesses for their evidence. I am sure that the committee will find it very helpful in our deliberations on the Cass review. At our next meeting, on 5 November, we will commence taking oral evidence as part of the committee's stage 1 scrutiny of the Assisted Dying for Terminally Ill Adults (Scotland) Bill.

That concludes the public part of our meeting.

10:34

Meeting continued in private until 11:27.

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