The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

HEALTH AND SPORT COMMITTEE

Tuesday 24 March 2015

Session 4

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HEALTH AND SPORT COMMITTEE
10th Meeting 2015, Session 4

CONVENER

Duncan McNeil (Greenock and Inverclyde) (Lab)

DEPUTY CONVENER

*Bob Doris (Glasgow) (SNP)

COMMITTEE MEMBERS

*Rhoda Grant (Highlands and Islands) (Lab)
*Colin Keir (Edinburgh Western) (SNP)
*Richard Lyle (Central Scotland) (SNP)
Mike MacKenzie (Highlands and Islands) (SNP)
*Nanette Milne (North East Scotland) (Con)
*Dennis Robertson (Aberdeenshire West) (SNP)
*Dr Richard Simpson (Mid Scotland and Fife) (Lab)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Graeme Dey (Angus South) (SNP) (Committee Substitute)
Susan Seenan (Infertility Network UK)
Sylvia Shearer (Infertility Network Scotland)

CLERK TO THE COMMITTEE

Eugene Windsor

LOCATION

The James Clerk Maxwell Room (CR4)

Scottish Parliament

Health and Sport Committee

Tuesday 24 March 2015

[The Deputy Convener opened the meeting at 09:45]

Decision on Taking Business in Private

The Deputy Convener (Bob Doris): Good morning and welcome to the 10th meeting in 2015 of the Health and Sport Committee. I have apologies from our convener, Duncan McNeil, and Mike MacKenzie. I welcome the Scottish National Party's substitute, Graeme Dey, who has become a familiar face at the committee.

I ask everyone in the room to switch off mobile phones as they can interfere with the sound system. You will see some of us using tablet devices instead of hard copies of our papers.

The first item on the agenda is a decision on taking business in private. Item 4 is to consider our approach to the Carers (Scotland) Bill. We normally discuss such matters in private. Does the committee agree to take that item in private?

Members *indicated agreement.*

Subordinate Legislation

Public Bodies (Joint Working) (Integration Joint Boards and Integration Joint Monitoring Committees) (Amendment) (Scotland) Order 2015 (SSI 2015/66)

09:45

The Deputy Convener: Item 2 is subordinate legislation. We have six negative instruments before us, the first of which is the Public Bodies (Joint Working) (Integration Joint Boards and Integration Joint Monitoring Committees) (Amendment) (Scotland) Order 2015.

No motion to annul the order has been lodged, and the Delegated Powers and Law Reform Committee has made no comments on it. There being no comments from members, does the committee agree to make no recommendations on the order?

Members *indicated agreement.*

Public Bodies (Joint Working) (Integration Joint Board Establishment) (Scotland) Order 2015 (SSI 2015/88)

The Deputy Convener: Again, no motion to annul the order has been lodged, and the Delegated Powers and Law Reform Committee has made no comments on it. There being no comments from members, does the committee agree to make no recommendations on the order?

Members *indicated agreement.*

Personal Injuries (NHS Charges) (Amounts) (Scotland) Amendment Regulations 2015 (SSI 2015/81)

The Deputy Convener: No motion to annul the regulations has been lodged, and the Delegated Powers and Law Reform Committee has not made any comments on them. There being no comments from members, does the committee agree to make no recommendations on the regulations?

Members *indicated agreement.*

National Health Service (Optical Charges and Payments) (Scotland) Amendment Regulations 2015 (SSI 2015/86)

The Deputy Convener: No motion to annul the regulations has been lodged, and the Delegated Powers and Law Reform Committee has made no comments on them. There being no comments from members, does the committee agree to make no recommendations on the regulations?

Members *indicated agreement.*

National Health Service (Cross-Border Health Care) (Scotland) Amendment Regulations 2015 (SSI 2015/91)

The Deputy Convener: We are nearly there. No motion to annul the regulations has been lodged, and the Delegated Powers and Law Reform Committee has made no comments on them. There being no comments from members, does the committee agree to make no recommendations on the regulations?

Members *indicated agreement.*

Professional Standards Authority for Health and Social Care (Fees) Regulations 2015 (SI 2015/400)

The Deputy Convener: The final instrument is the Professional Standards Authority for Health and Social Care (Fees) Regulations 2015. Again, no motion to annul the regulations has been lodged, and the Delegated Powers and Law Reform Committee has made no comments on them. I invite comments from members.

Dr Richard Simpson (Mid Scotland and Fife) (Lab): In effect, the regulations pass the cost of running the Professional Standards Authority for Health and Social Care, which used to be the Council for Healthcare Regulatory Excellence, on to the bodies that it supervises. In turn, they will, of course, pass the fee on to individual members who are registered. I inquired what that would be; apparently, it is in the region of £3 per member, which is not a lot. On the other hand, if a nurse or a midwife has just had a 50 per cent increase in the fee that they pay to the Nursing and Midwifery Council, that could be another straw on the camel's back—maybe that is not the right expression.

It should be recognised—and I want to put it on record—that nurses and midwives have already had to sustain a substantial increase in their fees after their wages were initially frozen and then increased by a sub-inflation percentage until this year, so it is a matter of regret that this further—albeit small—increase in fees is occurring at this time.

The Deputy Convener: With those comments on the record, do members agree not to make any recommendations?

Members *indicated agreement.*

Fertility Treatment

09:50

The Deputy Convener: Agenda item 3 is our main business of the day, which is an evidence-taking session on fertility treatment. We will hear this week from patient organisations and next week from a selection of national health service boards.

I thank our witnesses for waiting patiently and welcome to the meeting Susan Seenan, co-chair of Fertility Fairness and chief executive of Infertility Network UK, and Sylvia Shearer, chair of the board of trustees, Infertility Network Scotland. If you are content, we will move straight to questions. Dennis Robertson will start us off.

Dennis Robertson (Aberdeenshire West) (SNP): Good morning. I have to say that I did not find much mention of male infertility in the submissions. What percentage of problems is due to low sperm count?

Susan Seenan (Infertility Network UK): In general, we tend to work on the basis that around a third of fertility problems are male factor issues, a third female issues and the final third joint factor problems with an identified cause. That is the general clinical basis for assessing the number of patients with various issues.

Dennis Robertson: Initially, the patient will see her general practitioner and discuss her problems with getting pregnant, and the GP will look at factors such as body mass, and whether the person's diet is appropriate. Is male fertility considered as a factor at that point, or is the sperm count carried out during a second phase, after the patient has been recommended for fertility treatment? As part of the initial recommendation, the woman sees a gynaecologist, but at what stage is the male looked at?

Susan Seenan: The male should be looked at early because there is no point in putting the female partner through a range of tests without the male partner being checked out, too. That process is fairly well laid out in the pathway that was put forward by the national infertility group. I do not have that with me at the moment but we can certainly send members a copy. In any case, the male partner should be looked at early in the process to ensure that he has no sperm count or motility issues.

Dennis Robertson: Do you welcome the progress that has been made on reducing waiting times, which in some areas were very long, and the fact that health boards are now meeting the 12-month target?

Susan Seenan: Very much so. That target has been met—in fact, waiting times in all health boards in Scotland are now less than 12 months—thanks to the Scottish Government's support of and investment in fertility services. The situation was very inequitable, with some patients waiting three to six months and others waiting about four years. There were other inequities, but the waiting time was a huge issue for patients and the Government's support and investment have made a massive difference resulting in, as I have said, waiting times in every health board in Scotland of less than 12 months. That is really good news.

Dennis Robertson: That is good. I have a couple more questions, convener.

The Deputy Convener: My apologies, Dennis, but I think that Sylvia Shearer wants to comment.

Sylvia Shearer (Infertility Network Scotland): I am just listening to what Susan Seenan is saying. I endorse her comments about the work that is being done under the national infertility group and the Scottish Government. It has made a tremendous difference.

It is fairly obvious that if a woman has waited a long time to have a child without becoming pregnant, time is passing. The criteria include a cut-off point, so the time factor becomes more essential the longer a person is on a list and waiting to be seen or given treatment.

Susan Seenan: With older couples, the female partner in particular is more likely to have fertility problems. The success rates also go down. Therefore, it is important that people are seen, diagnosed and treated quickly, because then the treatment is much more effective.

Dennis Robertson: What are the waiting times between the first, second and third treatment cycles?

Susan Seenan: Patients should be allowed to undertake a second cycle when they are ready to do so. However, it is clinically accepted that there should be a few months to allow the woman's body to return to normal. I think that the group recommends is that it should be around six months before a second cycle is undertaken.

Dennis Robertson: The second cycle could take place six months later. I take it that, were the patient to move on to a third cycle, the same period would be needed.

Susan Seenan: It could be. Some couples might prefer to wait a bit longer—some might not feel emotionally ready; others might not feel quite physically ready to undergo another cycle after a few months.

Dennis Robertson: That brings me on nicely to my next question. In the submissions, I did not note any areas where counselling is available to couples, which may happen after the second cycle has failed. Does counselling happen? Would you recommend it?

Susan Seenan: Absolutely. All couples should have access to counselling throughout fertility treatment. However, access to counselling is an issue. Counsellors in the NHS are in short supply. Although we have some very good counsellors, there can be a long waiting list. If a couple have had a failed cycle and they need to speak to a counsellor, they will not want to wait six or eight weeks for an appointment. That issue has been recognised, although we would love to see more investment in counselling.

Dennis Robertson: I did not note any comments in the submissions on artificial insemination by donor—AID. In certain cases, a person may have a hereditary condition that they do not want to pass on to a child, and the couple may look at using a donor. How common is that?

Susan Seenan: That question is probably best addressed to a clinician but I will try to answer it as best I can. There are two options if someone does not want to pass on a genetic condition to a child. They can have pre-genetic diagnosis, where the embryos are screened to ensure that they are not carrying the genetic condition, or they can move on to donor treatment. The decision on which route is best for the couple and their individual circumstances is for the clinician and the couple concerned. If donor treatment was the right option for the couple, they would move towards that route.

Dennis Robertson: Do we know what the numbers are?

Susan Seenan: Are you asking about the numbers of people who are accessing donor treatments?

Dennis Robertson: Yes.

Susan Seenan: I do not have the figures in my head, but I can get them for you.

Dennis Robertson: It would be interesting to get them.

Susan Seenan: Are you looking for the number of people who accessed donor treatment rather than using their own eggs?

Dennis Robertson: Yes—and the reasons why.

Susan Seenan: Do you want figures for donor sperm or donor eggs or both? Is it just the NHS figures that you want?

Dennis Robertson: I want the figures for donor sperm, but it would be interesting to see the figures for donor eggs, too. I would have thought

that the main area is probably donor sperm but that is just my thinking.

Susan Seenan: In general, and this is a figure for the United Kingdom overall, the number of people who access donor treatment is around 14 per cent of those who access fertility treatment. The figure is for donor treatment of all kinds, including private and NHS.

Dennis Robertson: Yes, I appreciate that. Thank you.

10:00

The Deputy Convener: I will let Dr Simpson in shortly, but Nanette Milne has a supplementary question on the cycle.

Nanette Milne (North East Scotland) (Con): I just want to understand exactly what a cycle is. Is it the whole process from harvesting to implantation? Does the implantation of frozen embryos constitute a new cycle?

Susan Seenan: A full cycle of treatment should involve the stimulation of the ovaries to produce the eggs, the harvesting of the eggs, the hoped-for fertilisation of the eggs to produce embryos, the replacement of one of those embryos as a fresh transfer and the freezing and subsequent replacement of any viable frozen embryos thereafter. That would constitute a full cycle.

Nanette Milne: That is helpful—thank you.

Dr Simpson: Can I just clarify something? Would a second cycle start from the very beginning again?

Susan Seenan: Yes. A second cycle would start from the beginning once all the frozen embryos had been replaced.

Dr Simpson: So a woman could have repeated implantation as part of her first cycle.

Susan Seenan: Yes. Everyone's cycle is different. In general, a couple might yield eight to 10 eggs, six of which might fertilise, although the number could be higher or lower. If they were all viable, in a normal cycle one would be replaced, because a single embryo transfer is the norm. Any that were left would be frozen. They might not all thaw successfully, so a woman could end up having one or two frozen embryo transfers as part of her first full cycle.

After that, the process would start at the beginning again and the woman would be stimulated to produce more eggs. The whole cycle would start again—that would be the start of a second cycle.

Dr Simpson: That was an interesting and helpful clarification.

I sat on the infertility commission in the 1980s—I did so as the GP psychiatrist, not as an expert on fertility. I do not think that we had a patient representative, which shows how our thinking has progressed since then. In my role on that commission, I had two or three things to say. One of them was that every couple who went through the process needed a named individual to act as their support. As a GP and a psychiatrist, I had experience of treating people who got quite depressed by the whole process, because it was prolonged and there were all sorts of issues with it. Therefore, I am really disappointed to hear about the counselling situation. Do people have a named person when they start the process?

Susan Seenan: Overall, no. As the patient organisation, Infertility Network Scotland tries to provide as much support as possible. Thanks to the support of the Government, we have dedicated staff in Scotland, whom patients can access at any time. We set up support groups across Scotland—we have about 10 or 11 support groups running. We try to ensure that there is always a point of contact, whether that is provided by our staff or by our volunteers, so that people can talk to someone if they have questions.

As a national charity, we also offer a support line that is run by a trained former fertility nurse who has counselling experience, and we have a range of helpliners who have been trained in basic counselling and listening skills. To the best of our ability, we try to make sure that patients know that that service is there.

As far as a named person is concerned, I think that the clinics in Scotland are fairly good at supporting patients. The staff are very supportive and helpful. The stumbling block is perhaps access to a proper counselling session. Patients in Scotland know that there are people whom they can talk to; it is when they want to have access to a trained counsellor that they sometimes face a wait. I think that that is unacceptable.

Dr Simpson: That is interesting. Perhaps that is an issue that we can look at in the future.

On the issue of the cycles, which Dennis Robertson raised, I pay tribute to our late colleague Helen Eadie who campaigned strongly on the postcode lottery that previously existed. It is very welcome to hear that that has stopped. Is there still a problem in relation to age? As I understand it, there is a difference between England and Scotland as regards the age at which people's ability to access in vitro fertilisation changes.

Susan Seenan: The recommendations are the same, in that a woman aged under 40 can access a different number of cycles compared with a woman aged 40 to 42. The recommendation is for

women over the age of 40 to access one cycle. The recommendation that the national group made for women under the age of 40 was for the couple to access three cycles. However, in the interim, until there was equity and waiting times were reduced, the decision was made to offer two cycles and to consider reviewing the number of cycles, as well as the question of existing children, early in 2015. That is what the national group is doing now. The recommendation in Scotland is basically the same as it is in England.

Dr Simpson: So, hopefully, we will now go for three cycles.

Susan Seenan: I cannot see any reason why we would not want to move forward to three.

Dr Simpson: Would the number move up to two for those over 40, or would it stay at one?

Susan Seenan: It would stay at one cycle.

It is not for every woman aged 40 to 42. There are tighter criteria. It applies to women who have not accessed fertility treatment in the past and who do not have a low ovarian reserve. Some women who are over the age of 40 and who have a low ovarian reserve have a much lower chance of success, and whether it would be cost effective, as well as clinically effective, to offer them a cycle is carefully considered.

Dr Simpson: My last question is again on something that was dealt with by the fertility commission in the 1980s. We noted the rather bad habit of tests being repeated. Women often went to non-specialist units for their infertility diagnosis, but they went to a specialist clinic when they moved on to the IVF programme. I presume that the arrangements are the same, but have we eliminated the repeating of tests, which was stressful for the patient—indeed, for the couple—as well as being costly for the NHS? That was one thing that we recommended should be eliminated.

Susan Seenan: We have moved a lot further forward with that. When it made the recommendations, the national group produced a patient pathway, which should be followed from the GP all the way through. We hope that that has made a massive difference in eliminating duplicate tests.

The Deputy Convener: In a moment I will allow Graeme Dey to ask a supplementary, and Rhoda Grant is on my list, too, but first I have a supplementary question about the need to expand counselling. We have all listened carefully to what you have just said, and we will ask NHS witnesses about it next week.

You also spoke about the environment in the NHS that couples go into when they start infertility treatment. Is it, by and large, a welcoming and supportive environment for the individuals and couples who seek infertility treatment? Counselling is very important, but the culture, environment and ethos have to be right to support couples. Have we got that right?

Susan Seenan: There is always room for improvement, but I would say that, in general, most patients are fairly happy and feel reasonably well supported in the NHS clinics in Scotland.

Sylvia Shearer: One patient commented that, when she went for her treatment, there were big signs saying “infertility clinic”, although she did not feel that she was, as yet, infertile. Boards may wish to consider that point.

The Deputy Convener: Would I be right in saying that the terminology is supposed to be “assisted conception”, rather than “infertility”?

Susan Seenan: In general, clinics are moving towards names such as “assisted conception unit” or some more positive reference to fertility. The patient in question went to a clinic that was labelled the infertility clinic, and Sylvia Shearer has made a good point about that. We got that comment just over a week ago, and we would like to take that up with the clinic to see whether anything can be done.

Patients want to feel that they are moving forward in a positive way, rather than being labelled infertile. There has been a big culture shift over the past few years across the whole UK.

The Deputy Convener: That is helpful—thank you for putting that on the record.

Graeme Dey (Angus South) (SNP): I seek some information. The Infertility Network submission says:

“the situation at the end of December 2012 was that around 20% of eligible patients in Scotland could potentially access three cycles of treatment, with the remaining 80% able to access two.”

What is the up-to-date position?

Susan Seenan: Everybody accesses two cycles now.

Graeme Dey: There is nowhere where people can access three at the moment.

Susan Seenan: Not in the NHS. The national group made the recommendation for three cycles but, in the interests of equity and bringing the waiting times down, it was agreed to move to two in the initial stages, with a recommendation to review that now. To repeat: everybody accesses two cycles.

Graeme Dey: Thank you—I just wanted to be clear on that.

Rhoda Grant (Highlands and Islands) (Lab): Before the review, a number of clinics offered three cycles on the NHS, which dropped down to

two. Why did that happen, and has it had an impact on people?

Susan Seenan: Some health boards were offering three cycles. We did a survey at the time, and nine health boards were offering three cycles, although some of them were smaller health boards.

Rhoda Grant: Do you know which, off the top of your head?

Susan Seenan: I can tell you which were offering three cycles.

Rhoda Grant: I have just seen that the information is in your submission. Sorry—I missed it. The boards were NHS Ayrshire and Arran, NHS Grampian, NHS Highland, NHS Tayside—

Susan Seenan: Yes, and some of the smaller health boards as well. A lot of health boards—nine of them—were offering three cycles but by the time that the national group started its work, two or three of the boards that had been offering three cycles had already dropped to two cycles. That is why only about 20 per cent of patients in Scotland were able to access three cycles. However, the patients who were able to access three cycles have been slightly disadvantaged by the change. The reason behind the change was to try to get equity across Scotland. The hope was that, ultimately, we would move to everybody being able to access three.

Sylvia Shearer: I am not directly involved in this, but, from what I can gather from colleagues, there is an element of resistance to the move to three cycles, despite the fact that we have now achieved equity and everybody is getting treatment within the 12 months. We do not really understand why that should be. They should be saying, "Now that we've achieved that, we'll move to three." We do not know why they are not doing it.

Rhoda Grant: Do you know who is putting forward that resistance?

Susan Seenan: It is a general feeling from the members of the national infertility group. We are a patient organisation, and my colleagues, who represent patients on the group, are very strongly behind the need to move very quickly to three cycles. We just have a feeling that it is not happening as quickly as we expected. We cannot see why boards would not just automatically move to three, given that that was the group's recommendation.

The group said that once the waiting times were down to below 12 months—by early 2015 at the latest—it would consider moving to three cycles and reviewing the criteria around existing children. That is what is happening now but it does not seem to be happening as fast as we would like. We think that now is the time to do it. The waiting times are down, so it is a no-brainer that we should move straight to offering everybody who is eligible three cycles. That does not mean that everybody would get three cycles; it would only be those patients who are eligible and for whom the clinician felt that it would be clinically effective to offer the third cycle.

Sylvia Shearer: That is an important point. We are not saying that women should have an automatic right to a third cycle. It is a clinical decision. However, we feel that the option should be presented.

Rhoda Grant: Is there capacity in the system that would allow that to happen?

Susan Seenan: Yes. There is no capacity issue. There was a capacity issue in Glasgow for a short time but its new unit has been opened and it now has no capacity problem at all. As far as we are aware, there is no capacity problem.

The Deputy Convener: I have a supplementary on a similar line of questioning to that followed by Rhoda Grant. In the boards that offered three cycles, were there any capacity issues? For example, a couple might hope that they would not need three cycles, although it was likely that they would need three. Did giving them three cycles prevent a new person from coming in to get their first cycle? I make no judgment about whether reducing to two cycles in those health boards was the right thing or the wrong thing to do, but with the move to two cycles, did new couples get quicker access to IVF or assisted conception?

Susan Seenan: That is difficult to quantify because at the same time that the health boards reduced the number of cycles from three to two, the Government invested £12 million in bringing down the waiting times. The waiting times were brought down massively, but that investment happened at the same time as the reduction in the number of cycles.

If couples were offered an additional cycle, technically there would be some impact on new couples coming on to the list, but I could not say what that impact would be. It is hard to quantify because of the investment that was made at the same time.

10:15

The Deputy Convener: Okay. My second supplementary concerns whether there is flexibility in the two-cycle system. If a couple goes through the first cycle and, for whatever reason, cannot have a fresh transfer there and then so the embryos have to be frozen, would that trigger something because the chance of their frozen embryo making it through—the chance of their

having a child—is less than it would be with a fresh embryo transfer? Are there any flexibilities in the system as things stand in relation to two cycles?

Susan Seenan: No. Basically, you are allowed access to up to two cycles, if that is thought to be clinically effective. If there is no fresh transfer, the embryos would be frozen and transferred as part of a fresh cycle. There is a lot of evidence now that frozen embryo transfers are as good as fresh transfers. A new study that is starting this year will consider whether everyone should have frozen embryo transfers and not have any fresh transfers.

The Deputy Convener: That shows that in a lot of the data there is conflicting evidence about what is best.

I apologise to my fellow committee members but I have a final supplementary on whether there is a need for flexibility in relation to two cycles. Of course, one lady may get six or seven eggs and another may get 12 or 13, but that may be related to clinical decisions about the protocol that the couple is put under and the type of stimulation that is used to avoid hyperstimulation. The whole thing is not an exact science.

Susan Seenan: It is not.

The Deputy Convener: As things currently stand—without making that judgment call about whether to go to three cycles—do you feel that there is a need for flexibility around the two cycles?

Susan Seenan: I am not sure how we could be flexible around that, which possibly highlights again how important it is to have a third cycle. Quite often the first cycle is almost what the clinicians call a diagnostic cycle. They do not always get it right first time. They tweak and change the protocol for the second cycle, and sometimes it takes them until the third cycle to get it right. I am not sure how flexibility within the two cycles could actually make a difference to what the clinicians offer. If a couple is given a particular protocol to which the woman does not respond, the clinicians will change it during the cycle if they can. The protocol is a moving target for some couples, if the woman is not responding.

The Deputy Convener: It was very helpful to put on the record that the first cycle can be diagnostic in terms of how the woman responds.

Dennis Robertson and Richard Lyle have supplementaries.

Dennis Robertson: This may be just a language point, but I think that Susan Seenan said that she felt that nobody is offering the three cycles. Are you saying that it is a fact that no hospital or health board is currently doing that? Could some health boards be moving towards three cycles without your being aware of that?

Susan Seenan: I not aware of anybody who is not following the current guidance, which is to offer two cycles.

Dennis Robertson: But could a health board be moving from two to three cycles without your being aware of that?

Susan Seenan: That could happen, but I am certainly not aware of anyone who is offering three cycles at the moment. As far as we are aware, everyone is following the standard access criteria and the two cycles.

Dennis Robertson: That is useful. Thank you.

The Deputy Convener: Is there anything to prevent health boards from offering a third cycle if they choose to? Is it against the rules? The national guidance says that they should offer two cycles, but if a health board wants to move to three cycles, is there anything in statute to prevent it from doing that?

Susan Seenan: Given that the recommendation of two cycles has been adopted and funded by the Government in order to provide equity, there would be a rightly perceived unfairness if some health boards were offering something different. A lot of people would have something to say if some were being offered a third cycle, because the whole ethos behind the recommendation was to move to an equitable and fair system across Scotland, in which there is no postcode lottery and treatment does not depend on which health board someone comes under.

Dennis Robertson: But the decision to move from a second to a third cycle depends primarily on clinical reasons. It is a clinical decision.

Susan Seenan: At the moment, the recommendation on a third cycle has not been adopted. If and when the recommendation is adopted, it will, as always, be a clinical decision whether to give someone a first, second or third cycle. It would always be dependent on whether the clinician felt that it was in the best interests of the couple and the most cost and clinically effective way to move forward.

The Deputy Convener: Thank you.

Richard Lyle (Central Scotland) (SNP): I may not get the chance to say this later, so I say now that I welcome this debate—we should do anything that we can to ensure that couples can have a baby. Many of us know what a trauma it can be for people who are trying everything to have a baby.

On the point about the three cycles, in your submission you say that we are

"not to lose sight of the very invasive procedures required during fertility treatment".

You go on to say that

"couples would not undertake a third cycle lightly"

and that

"There is also a cogent argument, made by the clinicians, that not all women will benefit from a third cycle."

You also say that:

"Many patients will not require a third cycle, but we feel strongly that those who will benefit from three cycles should have that option."

How many people go for infertility treatment, and how many require a third cycle? Do we have that data?

Susan Seenan: I do not have the information, but the national infertility group is working with colleagues in ISD Scotland to look at that information.

Richard Lyle: Would I be right to suggest that perhaps 20 or 25 per cent of people go for a third cycle? Is that too low or too high?

Susan Seenan: I am not quite sure. There is a difference between couples who opt for a third cycle, who would be paying privately for one at the moment, and couples for whom a third cycle would be clinically effective but who are precluded from accessing it because only two cycles are available to them on the NHS. They may not be able to afford a third cycle themselves, even though it may be clinically appropriate and effective for them to have one.

Sylvia Shearer: We cannot give you an exact percentage. ISD Scotland will be able to give you that. Generally speaking, the number who progress to the third cycle is not massive.

As I tried to point out earlier, we are not saying that everybody must have a third cycle. The option should be there under the NHS, but not everybody will avail themselves of a third cycle, either for clinical reasons that will be explained to them by their clinician or because they themselves do not want to go any further.

Richard Lyle: I totally agree with you. It is a situation that I know very well. To my mind, it should be possible to have a third cycle on the NHS because the percentage of people who will want to go for it will not be high.

If the convener allows me, I will come back to the point about the stress and trauma that women undergoing IVF go through. I say with the greatest respect that it is not the same for a man; for a lady, it is a tremendous pressure. For a woman, it is a great mental stress even to walk down the street and see children with their mothers.

Given what people go through in order to have a child, I believe that the third cycle should be on offer so that they can fully benefit from the treatment. I say that because I do not believe that a high percentage of people will need the third cycle, as you have quite rightly suggested. Would you agree with that?

Susan Seenan: Yes.

Sylvia Shearer: Yes. As I say, I cannot give you the percentage, but the point that you make is another reason why we do not understand why health boards are not moving to the third cycle.

Richard Lyle: I wish you success. As I say, it is a subject that I have had experience of and I support your view.

Sylvia Shearer: Thank you.

Susan Seenan: When couples know that three cycles of treatment give them the optimum chance of success but they are denied access to that, it is difficult for them to come to terms with the fact that they have not given it their best shot. That can have massive emotional and psychological effects on them. We know that the treatment will not be successful for everybody. We cannot guarantee that everybody can have a baby, but we should guarantee that they will be given the best possible chance. If they are given the best chance and are not successful, it is easier for them to come to terms with the failure to conceive and move forward. It is much easier for people to do that if they have given it the best possible chance.

The Deputy Convener: That is quite powerful. Thank you for putting that on the record.

Graeme Dey: As we have heard, it seems that the intention was always to look to move to three cycles once we had reduced and standardised the waiting times. You have told us that you believe that the capacity is there to deliver on that, albeit that it is difficult to quantify the numbers involved. In your view, is finance behind the apparent resistance on the part of the boards to the move to three cycles?

Susan Seenan: I cannot see any other reason for them not wanting to move to three cycles, because that approach is clinically effective. When the National Institute for Health and Care Excellence made its recommendations in England, it looked at a huge range of studies—four or five—and stated that three cycles gave the best balance of cost and clinical effectiveness. The national group looked at the recommendations and did its own research. Everybody on the group agreed that three cycles was the best way to move forward for patients. I have no idea why anybody would not want to move forward in that way, unless their stance is finance related—unless the health boards do not want to give couples a third

cycle because it will cost them. I cannot see any other reason why they would not want to do it.

Colin Keir (Edinburgh Western) (SNP): My question is on people who self-fund within the NHS. I am sorry if you have answered some of my questions previously, but I want to get the situation clear in my mind. Does self-funding mean that people jump queues in terms of the waiting time for the services?

Susan Seenan: Do you mean would they do so if they were to self-fund?

Colin Keir: Yes.

Susan Seenan: If people were to self-fund, that would not impact on NHS waiting times. Self-funded treatment and private treatment are completely separate from NHS waiting times.

Colin Keir: Is that the case even if the treatment is done within the NHS?

Susan Seenan: Yes—the clinics have different capacity. The NHS clinics that offer self-funded treatment offer a small proportion of such treatment and they will have a waiting list for that, which I think is balanced by their NHS waiting list, so if a patient opts to self-fund, they can do that in an NHS clinic and it should have no impact on NHS waiting times, because the health boards should all be contracting to do a certain number of NHS cycles in their unit. I hope that self-funding would not impact on NHS waiting times. There is also the option of private treatment; many people opt to go to private clinics.

Colin Keir: I apologise for my coughing. I have a ropey throat.

Sylvia Shearer: Fertility treatment is a highly specialised medical field, so only a small number of clinicians are practising in Scotland.

Dennis Robertson: My question concerns the belief that the delay in moving to three cycles may be because of resources—it could be financial. Is it possible—to take up Sylvia Shearer's last point—that because of the specialised nature of the fertility clinics there is a capacity issue, as well as a financial one, that affects the move to the third cycle?

10:30

Susan Seenan: We are not aware of any such capacity issue in NHS centres: as far as we are aware they all have the capacity to move to the third cycle. That may be something to clarify with the health boards themselves, but we have been told that they have the capacity to move forward with additional cycles.

Dennis Robertson: My concern, again, is language—we are using terms like

"as far as we are aware",

and we are not certain. That is perhaps something that we could follow up, convener.

The Deputy Convener: Absolutely.

Susan Seenan: The work of the national group and the ISD on the figures is on-going. There will in due course be much more clarity about the figures—unfortunately we do not have that at the moment because the work is on-going.

As far as we know, the clinics have the capacity. As Sylvia Shearer said, fertility treatment is a very specialised area, and the clinicians who work in the NHS centres also work in the private centres. In terms of the capacity of the public sector, there is not an issue, as far as we know.

Dennis Robertson: That is very useful.

The Deputy Convener: Earlier, we touched upon whether it is better to have a fresh embryo transfer or to use a frozen embryo. It was put on the record that evidence is starting to show that there could be greater success using previously frozen embryos. So, there is emerging evidence.

On technology—on what is best in relation to IVF, intra-cytoplasmic sperm injection and the variety of methods that are out there—has the NHS embraced all the technology that it should? For example, I am aware of Eeva, which is a technology that maps the developing embryos in the first three to five days, to work out which embryo has the highest chance to make it when transferred back to mum—although I am aware that it is not an exact science. I am sure that there are many other technologies out there; they may be unproven, but they exist. Is the NHS embracing those technologies in order to increase success rates?

Susan Seenan: Yes. The technology that you are talking about is actually called time-lapse imaging technology. Eeva is the trade name for one particular method of time-lapse imaging. Another one is EmbryoScope—the Scottish NHS clinics all use EmbryoScope. That is thanks to the support of the Government, which funded them.

Every NHS clinic has at least one or two EmbryoScopes, and I think that Glasgow has four. They give the clinics the best chance of picking the best embryos to use—the ones that are most likely to turn into a successful pregnancy—and those that are suitable for freezing. The NHS is embracing the technology.

The Deputy Convener: This may be developing into a bit of a research and development theme of questioning. This is an opportunity for our witnesses to suggest other emerging technologies that they would like the NHS, if not to embrace, at least to explore.

Susan Seenan: A new study about frozen embryo transfers is of interest to me. There is a school of thought that frozen embryo transfer is now as good as, if not better than, fresh embryo transfer. There is a large trial starting this year on which we are working with researchers from the University of Aberdeen and other units across the whole UK. They will be recruiting patients for a study to ascertain whether frozen embryo transfers for everyone might be a better way forward.

The reason why frozen embryo transfer might be better is that someone who does not have a fresh embryo transfer is less likely to have ovarian hyperstimulation. If the ovaries are stimulated to produce lots of eggs, and an embryo is replaced while the body is in that state, there is a risk of ovarian hyperstimulation. If the clinicians wait and always transfer a frozen embryo, it may be better for mum, providing that the success rates are not compromised. That is what the study will be looking at, and that is probably the most interesting thing for us to look at next.

Dennis Robertson: A very last point—

The Deputy Convener: Not unless it is specifically on that issue, because Rhoda Grant has been very patiently waiting to get in.

Dennis Robertson: That is okay.

The Deputy Convener: I apologise; I should have let you know.

Rhoda Grant: My question is a supplementary to the previous questions about self-funding. Why would people self-fund other than for the third cycle? If they are not seen any faster and two cycles of treatment are available on the NHS, why would somebody self-fund in the NHS?

Susan Seenan: Some people opt for private treatment—they go to a private clinic—because they do not want to wait at all or because they do not fit the eligibility criteria.

Patients who self-fund in the NHS centres also tend to be those who do not fit the eligibility criteria. If someone does not fit the tight eligibility criteria, they have no option but to pay for their treatment. There will always be room for private or self-funded treatment, because not everybody will qualify for NHS treatment.

Rhoda Grant: If someone goes to a private clinic, they are seen straight away; if they self-fund in the NHS, they join the waiting list with everybody else.

Susan Seenan: They do, but it is much shorter than the general NHS waiting list would be, although there is not such a vast difference now that the waiting times have come down.

A couple of years ago, when there was a four-year waiting list for some patients to access treatment, a person could probably be seen in a few months as an NHS self-funded patient. Now that waiting lists are down to under 12 months, I suspect that fewer people will opt to self-fund or pay for private treatment, if they fit the eligibility criteria. Many people, however, do not fit the criteria; they will always have to pay for their treatment, one way or another.

Rhoda Grant: So, someone would be seen sooner on the NHS as a self-funder than as an NHS-funded patient.

Susan Seenan: Yes. The difference is that the person is not really being seen on the NHS; the person is being seen in an NHS unit but is paying for their treatment in the unit. For instance, if someone goes to Glasgow and opts to self-fund, the money that they spend as a self-funded patient in an NHS unit is invested in university research. The person is not really an NHS patient: they are just being seen and treated at an NHS centre. It is almost like being a private patient at an NHS hospital.

Rhoda Grant: Could that be a disincentive for the NHS to fund the third cycle, given that people are paying for the third cycle now and that the money pays for research?

Susan Seenan: It could be. Equally, it could be a disincentive for clinicians if they are looking for people who will pay for private treatment in the private sector, as well as for self-funders in the NHS.

The Deputy Convener: Rhoda Grant's line of questioning is really interesting. The one thing I will add is on what Sylvia Shearer mentioned about there being only so many specialists. Are there swings and roundabouts, such that having self-funded individuals using facilities in an NHS establishment is one way of retaining highly specialist staff who might otherwise be lost to the private sector? Has any mapping been done in the most senior echelons of this expertise within the NHS or in Scotland more generally? Do you have to head hunt globally?

Susan Seenan: Most of the clinicians in Scotland work in both the NHS and the private sector, and not necessarily just with self-funders within the NHS but in the private centres. Every NHS clinician also has a private practice. Is that what you were asking?

The Deputy Convener: I am just trying to work out whether there are full-time specialists in the NHS and self-funders are a way of retaining them within an NHS facility. If not, I have misunderstood the dynamic; I am just trying to understand it.

Sylvia Shearer: It is difficult to say because we do not have statistics on that, but it might be something to ask the clinicians or the health boards themselves.

The Deputy Convener: We will take the opportunity to do that. Obviously, you do not need to have that information—I was just curious to know whether you had a view on it.

We have a couple of additional questions from Richard Lyle and Dennis Robertson.

Richard Lyle: The problem is that we do not have really up-to-date information. I am reading in a meeting paper that the national infertility group report shows that in 2011-12 1,368 cycles were provided by the NHS, and 703 were self-funded but provided in NHS centres. Only 2,071 cycles were provided in that year, and we do not have more up-to-date information.

I will move on to the questions that I want to ask. Do you believe that NHS boards view infertility treatment as a low priority, compared with treatment of other conditions?

Susan Seenan: I suspect that some of them view it as lower priority than some conditions.

Richard Lyle: Okay.

Susan Seenan: I think that that is wrong.

Richard Lyle: That is okay—I just wondered.

Nowadays people get married, they have to pay a mortgage, both members of the couple are working, and ladies are having babies later in life. Do you agree that wider social factors—for example, the tendency for couples to delay starting a family—have meant that the demand for treatment has grown while the incidence of infertility has remained the same?

Susan Seenan: The very fact that people are leaving it for longer before starting to try for a family means that there is a higher incidence of fertility problems in the first place. There is no doubt that the older someone is, particularly for women, the harder it is to conceive. They are more likely to have problems. Male issues are also more likely; the longer men leave it, the more chance there is of their having issues with their sperm—either in terms of motility or the count.

Lifestyle factors are also relevant. We are working very hard on raising awareness and providing education about fertility issues, and about how some lifestyle choices that people make when they are younger can make a difference when they try to have a family.

Richard Lyle: I know—speaking as an admitted smoker—that smoking can reduce fertility and that, although I do not do it as often, drinking can reduce fertility, too.

Coming back to the cost of cycles, I understand from the papers in front of me that treatment costs on average about £3,600 per cycle. Is that for every cycle, or do costs get higher as patients get older? Do you agree that an average cycle costs under £4,000?

Susan Seenan: Those are the figures that we have been given by the health boards. An average cycle costs about £3,600; that would be for anybody going through treatment. The cost will vary slightly, depending on the number of drugs and which drugs are needed, but the overall average cost is about that figure.

Richard Lyle: Just to finish off, and to get it clear in my mind, the average cost per cycle is under £4,000. Not all couples will go for three cycles—a very low percentage would need three cycles. Do you agree with that statement?

Susan Seenan: I would agree with that. Many couples become pregnant on the first or second cycle. Some couples will go on to have a third cycle and be successful, but some will decide not to have a third cycle and some clinicians will recommend that a third cycle is not in the couple's best interests. I agree that a low number of patients would need a third cycle, but it is massively important for those patients to have it.

Richard Lyle: Lastly, as the convener said earlier, for a lady who is going through this treatment, the more she has to go back the more it may affect her mental health—no one would want to have three cycles if they did not need to.

Susan Seenan: Nobody would want to go through fertility treatment in the first place if they did not have to. It is not the way anyone would choose to conceive a baby—absolutely not. If it is the only way for someone to have a baby, they will do it because having the baby is massively important to them. It is not a lifestyle choice—it is not something that anyone would ever do if they did not have to.

10:45

The Deputy Convener: We are in the last 10 minutes.

Dennis Robertson: I will try to be brief, convener.

Is there an option for couples to consider a multiple birth in the first instance—a transfer of two or three embryos, for example? Do couples have that option, or, from a clinical perspective, is there more success from one embryo?

Susan Seenan: The Human Fertilisation and Embryology Authority, which is the regulatory body for all fertility treatment in the UK, has set all clinics a target multiple birth maximum of 10 per

cent. All clinics should be trying to get to 10 per cent or fewer multiple births in their IVF treatment.

The best possible outcome from fertility treatment is a single healthy baby. Everybody is pretty much on the same page in agreeing that. The more embryos are transferred, the higher the risk of someone having twins or triplets. Although twins sounds like a good idea if someone is trying to have a family—it is an instant family—there are higher risks to mum of pregnancy complications and massive risks to the babies of being born prematurely and needing special care, which is an additional cost to the NHS. Such babies then need support throughout their lives; that can sometimes be just through their early schooling but, if they have real health issues, it can follow them through many years of their lives.

Everybody is agreed that the best outcome is a single healthy baby, so, for most couples, a single embryo transfer would be the best way forward. It is not one size fits all: some people may have a double embryo transfer, but very few do so now, especially on the first cycle.

Dennis Robertson: But is it possible by choice as well?

Susan Seenan: Only if the clinician and the patient have discussed it and the clinician feels that putting back only one embryo would compromise the chance of success. If they feel that a single embryo will be successful, the clinician would be very reluctant to put more than one back.

Dennis Robertson: That is very interesting. As a father of twins, I can say that it is exciting but challenging.

Susan Seenan: Yes. When twins turn out well, it is great; sadly, that is not always the reality.

Dr Simpson: I have two quick questions. First, are you satisfied with the current monitoring arrangements of the success rates and are the rates published?

Susan Seenan: The success rates are published on the HFEA website. The HFEA has carried out a big exercise on how it might improve the publication of the information and later this year it will announce changes to the way in which it publishes the success rates.

Dr Simpson: Yes, I wanted that on the record. I was aware that there was going to be a change.

Secondly, are you satisfied with the current eligibility criteria? I was stimulated to ask by your point that self-funders often do not meet the eligibility criteria.

In two of the constituency cases that I have had in the last 13 years, one of the partners has already had a child. I am concerned that, in a new relationship, the man or woman who has not had any children is barred under the current system from having a child under IVF. That seems discriminatory against the individual who has not had a child themselves.

Do you have a comment on that specific point and on whether you are satisfied with the eligibility criteria threshold and the difference between self-funders and NHS patients?

Susan Seenan: Taking the eligibility criteria first, at the moment couples are not able to access treatment if they have a child living in the home. That very much discriminates against couples who are in a second relationship in which one person has kept custody of a child and is therefore not eligible for treatment. Their original partner, who has moved on to a different relationship, would be eligible for treatment.

That is very inequitable and is one of the criteria, along with the number of cycles, that are being reviewed at the moment. The recommendation from the group was to move towards a criterion that couples could access IVF treatment on the NHS where one partner had no genetic child. The group felt that that would be a fairer way of addressing that inequity. That issue should be under discussion at the moment, and we hope that the national group will make a recommendation to change that criterion.

Dr Simpson: I would welcome such a recommendation, because I regard the current situation as completely inequitable. The massive inequity with the postcode lottery had to be solved first, but individuals are being discriminated against badly and, in fact, punished for taking custody of the child. The really frightening aspect is that if someone gets custody of the child when there is a break-up, that precludes them from having IVF.

Susan Seenan: The situation is wrong. Couples have come to us who are very upset about the situation; it has been suggested to them along the way that, if they gave up custody of the child, they would be able to access treatment. Clearly, they would not do that. The situation is very inequitable and we hope that the issue will be addressed.

Dr Simpson: If it does not get sorted, I suggest that you raise a European human rights challenge. It is a matter of human rights that is not being addressed appropriately at present.

Susan Seenan: Thank you.

The Deputy Convener: I thank our witnesses very much for taking the time to give evidence. Children who have been born via infertility treatment are a topical issue in the news. I reassure you, on behalf of myself and colleagues, that this is a long-standing piece of work that the

committee was determined to do regarding shining a light and the opportunities and benefits—and the happiness and joy—for families who have children via infertility treatment. We are completely supportive of such treatment and disassociate ourselves from any negative comments regarding it. I think that it is reasonable to say that.

You have given us a lot of information that can be used to shine a light on how NHS boards are dealing with the matter when we take evidence next week. We have a couple of minutes left, so you have the opportunity to make any final comments.

Susan Seenan: Thank you for giving us the opportunity to come and give evidence to the committee. Obviously this is a really important topic for us, but it is so important for patients that they get the best possible chance to address their fertility problems and to move forward. We welcome and thank you for your support. I hope that, very soon, the national group will address the issues of the number of cycles and existing children in the home. We appreciate your support in looking at all the issues.

Sylvia Shearer: I echo Susan Seenan's comments. I return to the education project that we are undertaking, which has been funded by the Scottish Government. We are trying to work along the lines of preventative education by going into freshers' week and so on. Our organisation would like to encourage and enforce such an approach. We seek to advise people not to leave it as late as they are doing, for the social reasons that have been explained. Otherwise, the danger is that they will have to go through IVF treatment. If we can get that balance right, there should be a relatively static need for IVF treatment as opposed to an ever-increasing need. We should tackle the issue at both ends.

The Deputy Convener: Thank you. Informed choice for people who wish to have families is vital and I commend you for your work. I thank you once more for your time this morning.

10:54

Meeting continued in private until 12:20.

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