Northern Ireland
Assembly

COMMITTEE FOR
HEALTH, SOCIAL SERVICES AND
PUBLIC SAFETY

OFFICIAL REPORT
(Hansard)

Infertility Network UK

12 November 2009

NORTHERN IRELAND ASSEMBLY

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COMMITTEE FOR HEALTH, SOCIAL SERVICES AND PUBLIC SAFETY

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Infertility Network UK

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Members present for all or part of the proceedings:
Mr Jim Wells (Chairperson)
Mr Alex Easton
Mr Sam Gardiner
Mrs Carmel Hanna
Mrs Dolores Kelly
Mr John McCallister
Mrs Claire McGill
Ms Sue Ramsey
Mrs Iris Robinson

Witnesses:

Ms Sharon Davidson	)	Infertility Network UK
Ms Clare Lewis-Jones	)	
Dr Anthony Traub	)	Regional Fertility Centre, Royal Jubilee Maternity Hospital

The Chairperson (Mr Wells):

I welcome the deputation from Infertility Network UK (INUK). Ms Clare Lewis-Jones is the chief executive of Infertility Network UK and chairperson of the National Infertility Awareness Campaign (NIAC), Ms Sharon Davidson is the regional organiser for Northern Ireland for Infertility Network UK, and Dr Anthony Traub is the senior consultant at the regional fertility centre.

I have had the benefit of receiving an interesting briefing from Sharon on this fascinating subject, and members will be equally interested in what we are about to hear. I will give the deputation an opportunity to say a few words, after which I will throw the meeting open to members, who are not behind the door when it comes to asking questions.

Mr Gardiner:

I have already spoken to Sharon, and I was most impressed by what she said. Therefore, I will not ask any questions. I will channel them through another source.

Ms Sharon Davidson (Infertility Network UK):

I thank the Chairperson for his introduction, and I thank the Committee for Health, Social Services and Public Safety for inviting us here this afternoon. I appreciate the opportunity to have a chat with the Committee. We have already submitted an evidence paper, which, I hope, you have had an opportunity to review.

Infertility Network UK is a national charity supporting the needs of patients going through the realm of infertility. The Committee has received some background information about Infertility Network UK. The regional fertility centre in Belfast was founded in 1987, and Dr Traub was one of the original founders. We were one of the last regions in the UK to receive NHS treatment. From 1987 onwards, there were no NHS treatment cycles. However, we moved to NHS treatments in 2001. At that time, we were pleased that we had two treatment cycles in Northern Ireland. There were limiting criteria, but patients were offered IVF or intracytoplasmic sperm injection (ICSI). If the Committee wants any further definitions, we can provide them. However, you will be familiar with IVF treatment, and I will refer you to my colleague Dr Traub for information on ICSI.

In 2006, we went out to public consultation, because the previous decision on two treatment cycles was implemented without public consultation. At that time, the age range for women was increased from 37 to 39 — just before a woman's fortieth birthday. Equality legislation and adherence to section 75 meant that couples with children were able to access fertility treatment for the first time. The downside of that was a reduction to only one treatment cycle per couple.

People in Northern Ireland do not receive one full cycle of treatment. Members will be

familiar with the National Institute for Clinical Excellence (NICE) 2004 fertility treatment guidance. It stipulates that fresh embryos resulting from the treatment, plus any frozen embryos, should be transferred. That constitutes a full treatment cycle according to NICE guidelines. Although we say that we have one treatment cycle in Northern Ireland, it is really only one part-treatment cycle. The fresh embryos are transferred, but couples have to pay about £1,000 for the transfer of any frozen embryos from that stimulated treatment cycle. After one IVF or ICSI treatment cycle, couples have no option but to be treated privately, which costs about £4,000. In 2006, the Minister made available an extra £50,000 to improve access to fertility counselling services. At present, frozen embryo transfer must be paid for by patients.

NICE fertility guidance does not automatically apply to Northern Ireland. The DHSSPS established a link with NICE in July 2006. However, because the NICE guidelines were issued in 2004, the Department aspires to meet those standards. A review of the guidance began in May 2009, and, in October 2011**,** the Department will consider the applicability of the NICE guidance to treatment in Northern Ireland.

The guidelines stipulate that couples should receive up to three cycles of fertility treatment to give them the best chance of success. Couples are aware of that, and, if the first treatment cycle is unsuccessful, they will, unfortunately, get into debt, potentially at a dangerous level, to pay for a second and third treatment cycle. If they remain unsuccessful, couples can be left owing £8,000. Fertility treatment is expensive.

In March 2009, we were pleased that the Minister invested a further £1·5 million in fertility treatment and £800,000 to try to reduce the time spent on waiting lists to a maximum of 12 months. The complicated system of 16 waiting lists in Northern Ireland has been reduced to one. We are pleased about that and about the additional moneys. The waiting time is now 12 months, which is what the Minister aspired to in March.

There are 560 patients on the waiting list. In March 2009, when the Minister announced the additional moneys, he planned for 840 treatment cycles. We envisage about 600 treatment cycles being carried out this year because of difficulties in recruiting embryologists at the regional fertility centre. Six hundred new patients are added to the waiting list each year.

We are pleased that the waiting time has been reduced to 12 months. At the time, the Minister

said that, if the waiting time were reduced to 12 months, funding should allow for an increase in the number of cycles of treatment — that is why we are before the Committee today. As the waiting time now stands at 12 months, we have reached that important point, and we want to hear the Committee's views on the future provision of fertility treatments.

In the short term, we want frozen embryo transfer to be introduced. We have calculated the cost implications of that based on 600 cycles and the estimate that 50% of couples would achieve a frozen embryo as a result of their treatment. In the short term, it would cost around £250,000 per annum to introduce frozen embryo transfer.

In the medium, as opposed to the long, term, we want a move towards full implementation of the NICE clinical guidance, which recommends up to three treatment cycles for couples who need them.

Before I pass you over to my colleague, I will summarise my remarks. We have reached the 12-month stabilisation of waiting times, which was the Minister's commitment. We want a move towards a full cycle of treatment that derives both fresh and frozen embryos. We want further investment in fertility treatment in Northern Ireland to allow for the move to full implementation of NICE guidance, which recommends up to three cycles.

We also want outreach support for fertility counselling to be provided beyond Belfast. I have discussed that issue with several of you. At present, fertility counselling is available only in Belfast, with a limited service in Cookstown. Patients who live in many areas in Northern Ireland, such as Londonderry and Omagh, do not have fertility counselling on their doorsteps. Patients have opted not to go to counselling if it means that they must travel long distances. It goes without saying that counselling is an extremely important part of the equation.

We also want a fertility advisory and working group to be introduced, and co-ordinated through the Department of Health, Social Services and Public Safety (DHSSPS), to consider cost savings in Northern Ireland. You will probably ask where all of that extra money will be found. We envisage that some money would come from cost savings at the level at which GPs refer couples to fertility treatment, or, indeed, do not refer them should they decide that IVF is not needed and that there are other more suitable treatments. We would like a working group to be set up to deal with that.

I will pass you to my colleague Clare Lewis-Jones, who will discuss benchmarks with other parts of the UK and the elective single embryo transfer.

Ms Clare Lewis-Jones (Infertility Network UK):

Thank you for inviting us to the Committee. I will explain the other part of my job, which is to chair the National Infertility Awareness Campaign (NIAC). NIAC was set up in 1993, specifically to address infertility throughout the UK and to try to obtain NHS funding for fertility treatment. I stress that we do not campaign only for IVF: we want patients to get access to the most appropriate treatment for them, whether it is simply ovulation induction or one of the high-tech treatments. Although we talk a lot about IVF, we want patients to get the most appropriate treatment, which is not necessarily IVF.

Since 1993, NIAC has worked to raise awareness among Government, Parliament, commissioning bodies and anyone who is interested in the field. It is an umbrella organisation for more than 30 groups that work either directly in the field of infertility, such as Infertility Network UK, the Royal College of Obstetricians and Gynaecologists and the British Fertility Society; and those who work, perhaps, more indirectly in the field, which includes organisations such as Relate. The strain that infertility can put on a couple's relationship is well documented. Many couples seek help from Relate, and it supports our campaign for treatment.

I was involved in the NICE guideline development group, which, as Sharon said, published its report in February 2004. Some three years elapsed between the announcement of the group's establishment and the publication of its report. When the report was passed to NICE, the then Secretary of State for Health, Alan Milburn, said that the aim was to get couples fairer and faster access to clinically appropriate and cost effective forms of treatment. The guideline provides a full pathway from pre-conceptual care to high-tech treatments, so it is important that couples follow it, but the guideline was also intended to address the problems of NHS funding.

As Sharon said, the guideline recommends three full cycles of stimulated IVF for couples in which the woman is aged between 23 and 39, and who have received either a diagnosed cause for their infertility or experienced unexplained infertility lasting for at least three years. The guideline is being reviewed; no meetings have taken place, but NICE has invited interest from stakeholders. We hope to publish the guideline as scheduled in October 2011.

I will turn to the differences that exist around the UK. In England, decision-making is left to each of the 151 primary care trusts (PCTs) — formerly health authorities — as to what level of funding they allocate to fertility treatments. It is hard to get 150 people to agree on anything, so one can imagine the huge variation in provision across the 151 PCTs. However, the situation is improving in England; for example, in 2006, only 4% of those 151 PCTs provided the recommended three full cycles of treatment. The most recent data, which was announced in June 2009, shows that that figure has gone up to 27% in just a couple of years. We are pleased that matters are moving in the right direction.

The number of PCTs that provide only two cycles went up in 2007 but has come back down, because some have since increased their provision. The number of trusts that provide one cycle has gone down, but 25% of those PCTs fund one fresh or one full cycle. In England, measures are being taken to help to gain momentum in continuing improvement. In 2008, the Department of Health set up an expert group on commissioning to sit for one year. I sat on that group; its interim report made some recommendations, one of which was consideration of the development of a clear clinical pathway and a national tariff for the purchasing of IVF. I am pleased that the Minister of State for Public Health has taken up that recommendation and a national tariff for IVF and ICSI is being developed. I am told that it will take two or three years, so it will not happen overnight, but at least every PCT will pay the same amount of money for the treatments that they purchase from the clinics.

As I said, the guideline is being reviewed, and the Minister of State for Public Health was asked to write to the NHS commissioning organisations, making clear the definition of a full cycle, i.e. fresh and frozen, which she did. The Department of Health has also funded a project that allows us to work with PCTs to identify and share good practice in the implementation of the guideline and also to identify bad practice or misinformation. Infertility is a complex illness, and the available treatments are similarly complex. We discovered huge variations in the understanding and knowledge of infertility and available treatments. Perhaps some PCTs perceive that infertility is not an illness or a genuine health need. We also found that PCTS would welcome central guidance, rather than such a complicated issue being left up to them.

There are massive problems with waiting lists, and a huge variation in access criteria for treatment. The reasons that the PCTs use for their decisions on what they will fund, and why,

vary. Many clinicians are involved in that decision-making process, but there is no patient representation.

The Chairperson:

We have allocated 15 minutes for your presentation, so will you bring your remarks to a close in the next few minutes?

Ms Lewis-Jones:

I will. The move to single embryo transfer happened because it is recognised that the number of multiple births from IVF is unacceptable; it is much higher than the natural multiple-birth rate. Before that, the clinics were allowed to store a maximum of two embryos, but now they have been tasked with reducing their multiple-birth rate to 10% by 2011 by using single embryo transfer. Single embryo transfer initially results in a drop in the success rate in the first fresh cycle, which is another reason why we also need the frozen-embryo transfer cycles to be provided. We also believe that reducing the number of multiple births is a possible cost saving, as they are enormously costly to the NHS.

In Scotland, all females who are less than 40 years of age and have no children living with them can access three full cycles of IVF. Work is ongoing in Scotland on a project to tackle the problem of waiting lists.

In Wales, a guideline was produced, and a working group similar to the one that Sharon mentioned is being re-formed in light of the review of the NICE guideline. However, the funding situation is similar; funding is available for one fresh embryo treatment and one frozen embryo treatment. The Minister is considering a move from one to two cycles — especially with the single embryo transfer initiative — and subsequently, I hope, from two to three cycles.

The situation varies. In Europe, there is much reimbursement, particularly in countries that have embraced single embryo transfer.

Dr Anthony Traub (Regional Fertility Centre, Royal Jubilee Maternity Hospital):

Through Sharon, we have heard the voice of the patients, and we, the staff, are grateful to her for her hard work. I am here to represent the staff and to support the aspirations outlined on the penultimate and final page of the evidence that was submitted.

Those of us who work at the coalface have always thought that funding one fresh treatment, without providing the patients with funding to use their frozen embryos, caused patients and the staff who provide the service to face a moral dilemma. Therefore, the least that we want is the support of the Committee for funding the fresh treatment and any treatments emanating from that, so that couples can use their frozen embryos.

If the funding were available for one treatment using the frozen embryos, the couples could decide to use all of their frozen embryos in one go to give them the best chance of success, without their being out of pocket should they not have the financial means. If couples have multiple frozen embryos, they would have the choice to make use of their NHS funding for some of them and pay for further treatment with the remainder should they so wish.

Some 50% of the people whose treatment is funded generate frozen embryos. As I said, that creates a moral dilemma for them. Even if they cannot afford to make use of those embryos, few people would be happy to dispose of them.

The Chairperson:

That is an extremely difficult moral dilemma. Thank you, ladies and gentlemen, for your presentation. Sharon, you mentioned that, because of section 75, families who already have children are entitled to IVF treatment. I may be missing something, but why would someone who already has a family want IVF treatment?

Ms Davidson:

It may be because of a new partner.

The Chairperson:

So a change in relationship generates that situation?

Dr Traub:

Also, fertility issues sometimes arise after a couple's first child.

The Chairperson:

Do you mean a family that is not complete? Is it a more complex issue than a family with three

children wanting a fourth? I did not understand; I thought that people with no children would have priority. However, you said that that has been ruled illegal under section 75.

Ms Davidson:

An equality issue was raised during the public consultation, and agreement was reached in 2006 to fund treatment for couples who already had a child living with them. We are the only region in the UK that does that. However, other regions are trying to move to that system because they recognise that that is how it should be done. Therefore, we fund treatment for couples who already have a child living with them, whether that child is from a previous or current relationship.

The Chairperson:

You said that treatment can cost £4,000. Is that for a full three-cycle treatment?

Ms Davidson:

No, that is for one treatment cycle.

The Chairperson:

Does it cost £12,000 for three cycles?

Ms Davidson:

Someone who is not eligible for NHS treatment and pays for three treatment cycles, such as a female who has passed her fortieth birthday, could pay £12,000.

The Chairperson:

Someone who qualifies for National Health Service treatment could pay £9,000; that is, £1,000 and two sessions of £4,000? Is that how it works?

Ms Davidson:

If a person qualifies for NHS treatment, the NHS pays for the first part of the treatment cycle. However, if that treatment is unsuccessful, the person automatically becomes a private patient, and the second treatment will cost £4,000. If that is unsuccessful, the third treatment will cost a further £4,000. Does that explain it?

The Chairperson:

It does. You are in direct contact with many people who are in that position. How many simply cannot afford to take the treatment any further? How many people are denied that opportunity simply because they have run out of money?

Ms Davidson:

We do not have that specific figure. One in six couples in Northern Ireland suffers the effects of infertility.

Dr Traub:

The only figure that we have is that of the number of people who are no longer eligible but who are happy or able to fund their own treatment. People do not tell us that they cannot afford it. They do not want to be stigmatised and, therefore, are not forthcoming with that information.

The Chairperson:

If the money were available for the full three-cycle treatment, would there be enough staff available to administer it?

Dr Traub:

Infrastructure is an issue; we need to increase the size of our facility. We would need more staff, mostly nursing and administrative staff. Medical time and laboratory staffing was sorted out in the past year.

The Chairperson:

The hospital in Downpatrick, which is in my constituency of South Down, has the money for midwives but cannot appoint enough because they are not available. Are a sufficient amount of trained people available in Northern Ireland to crank up treatment levels to a level that is acceptable to the infertility network? Would there be a time lag before the staff are in place?

Dr Traub:

There would be a clear time lag, because fertility nurses require training. However, we can appoint nurses to do more mundane jobs while fertility nurses learn the necessary skills. Therefore, we could increase our capacity fairly quickly.

The Chairperson:

Do you need nursing staff rather than consultants?

Dr Traub:

Our medical time and embryologist staffing level are about right. The problem is nursing, administration and physical space; our facility needs to expand.

Ms Lewis-Jones:

We must not simply multiply the 600 cycles by three or four thousand. The issue is not whether a couple has a child or not; there are various reasons why people drop out of treatment during their cycle. It is stressful, and they might try treatment once and leave it. However, at least they can look back and say that they gave it their best shot. Some couples are successful and, therefore, do not need further treatment because their family is complete. Sadly, other couples are unsuccessful. My point is that, when we consider the cost, it is important to bear in mind that it is not a straightforward case of 600 patients multiplied by three cycles multiplied by £4,000.

Ms S Ramsey:

I apologise for missing the first part of the witnesses' presentation. I took part in the Assembly debate on infertility. I must be honest; some MLAs have had families as a result of IVF, and the debate was, therefore, highly emotional and emotive. I know people who are currently undergoing IVF treatment and I know some for whom it has not been successful. The treatment of infertility is about more than money. It can be soul-destroying and stressful for the people involved and their wider families.

Members of the UUP will jump up and down about what I am about to say, but money is sometimes used as an excuse. I was glad that you outlined the difficulties affecting England, Scotland and Wales. However, they also have CSR periods and face efficiency savings, yet they seem to be moving in the right direction.

On one hand, the Health Service states that it cannot introduce new drugs to treat arthritis until they have been tested and conform to the clinical standards of NICE. That is fair enough because testing is necessary. On the other hand, when NICE makes a recommendation, the Department refuses to implement it. That defies a moral, statutory, and probably legal, duty. In fairness, your group has made recommendations on the way forward. The Committee probably needs an update

from the Department on that point, because human, societal and family issues are connected to infertility treatment.

To be fair to the Minister, I remember that, during the Assembly debate, he pledged additional money, but we must move beyond always blaming money. Departments have a legal duty to implement the way ahead as recommended by NICE. I wish the Infertility Network all the best in its campaign, and I hope that the Minister steps up to the plate. Do not accept money as an excuse for inaction.

Ms Davidson:

I understand and appreciate that. The issue affects not only the couples involved but their family and friends. Infertility has the potential to break up couples, which is why many such couples attend Relate. I also mentioned that we must extend infertility counselling in Northern Ireland so that patients receive the advice and support that they need.

It is difficult to quantify the scale of the emotional and societal problem. I take the point that people may be hiding behind the financial issues, but few infertility patients will stand up and shout, because, in many situations, even their immediate families do not know what they are going through. Infertility is a personal and private issue. Those affected need us to fight their case because they are so stressed that they cannot do it for themselves.

Ms S Ramsey:

I am interested in the counselling services that exist outside Belfast. The Department does not have a joined-up approach to that. The community and voluntary sector has different structures and mechanisms in place for counselling, and the Department must look beyond its own nose. It does not necessarily always have to provide counselling services because those can be localised by the Department entering partnerships with people in the community. I recognise that some services are specialised, but they can be provided by community and voluntary organisations.

Mrs Hanna:

Infertility is a personal and sensitive issue, and I appreciate that not many couples come out and shout about it. I also participated in the Assembly debate, which was instigated by my colleague Alex Attwood. Another debate on the issue of fertility treatment in the Assembly is forthcoming.

The Minister has secured more resources for fertility treatment, and we all welcome that. However, for some couples not to receive one full cycle of treatment does not make economic sense**.** During the next Assembly debate, we hope to receive an update from the Minister on that issue and obtain his views on the NICE guidelines.

I support the provision of infertility treatment to couples, because it is a difficult issue for the couples concerned. Some of the debate centres on resources. It is not purely about resources; they are required for the treatment, and there is no way around that fact.

The Chairperson:
As the Deputy Chairperson of the Committee and Member for Mid Ulster Mrs O'Neill is not present, I can safely ask this question. *[Laughter.]*

The infertility counselling networks are important, and, with all due respect to Cookstown, I am intrigued as to why the counselling centres are situated there and in Belfast rather than in other locations.

Ms Davidson:
The counselling service in Northern Ireland is facilitated through the Fertility Counselling Service. That group is a voluntary organisation that happens to have offices in Cookstown that it could readily use. Therefore, it was primarily an accommodation issue, but the service also regards Cookstown as somewhere that is accessible from other parts of Northern Ireland.

Infertility Network UK has support groups in Londonderry, Omagh, Craigavon and Belfast, and patients in Londonderry and Omagh have called for the provision of counselling services on their doorsteps. They do not want to travel to Belfast for those services because they already have to travel there for their treatment. That commute means time off work and, for some, days unpaid, and, when they are trying to get the money together for their next treatment cycle, it becomes financially difficult. The Fertility Counselling Service has chosen Cookstown, but the provision should extend beyond that.

The Chairperson:
Are you thinking of six or seven counselling centres?

Ms Davidson:

Together with the provision that is already in place, one centre in Londonderry and one in Omagh might be enough to meet the demand. Those centres could be run as a part-time outreach service from the Belfast Fertility Counselling Service and could make use of local resources. The service would not need to hire offices and could, therefore, be run economically.

The Fertility Counselling Service has the expertise, and it takes a long time to build up that expertise in fertility counselling. We want to use the service that is already available because the patients are happy with it. When patients in Londonderry and Omagh learn of the service, they also want to use it, but it is inaccessible to them.

The Chairperson:

Some of the success rates for treatment seem quite impressive, and technology and science have moved on considerably in that field. Is there any indication that the treatment is becoming more successful? Are new techniques being developed?

It must be tremendously distressing for a couple to go through two cycles of fertility treatment and not conceive. Is any progress being made in attaining a 50% guaranteed success rate in the field?

Dr Traub:

One cannot lump everyone together because success rates are highly age-specific.

In answer to the first part of your question, success rates have risen steadily, and a major advance in the past 18 months in the laboratory saw success rates go up again. However, the move to allowing only one embryo to be used has decreased the overall success rates slightly. That is why we have to factor in the use of the frozen embryos. I am not sure whether that answers your question.

However, in these difficult economic times, the Committee should be aware of recent research papers — one from the United States last year and one from four different centres in Europe — that examined the long-term economic benefits of 4% of the population being conceived through fertility treatment. The American paper concluded that each person conceived through fertility treatment represented a 700% return on the investment, while the European paper suggested that

it was as high as tenfold. Therefore, it is not all one-way traffic with respect to finance.

The Chairperson:

Thank you very much. You raised a series of specific points at the end of your paper. The Committee will write to the Department and ask it to provide answers on those important issues. We will then send the full response back to you, Sharon, to keep you informed of the Department's thinking.

Mrs Hanna:

I agree with that. The SDLP put forward a motion in my name and that of Alex Attwood to the Business Committee, and it would be helpful to receive support to bring it to the Floor fairly soon. Those things can take a while.

Ms S Ramsey:

That is all worked out according to party strength now, and the SDLP may have the next option. Ensure that your party tables that motion because no other party can control the SDLP's motions.

Mrs Hanna:

No, but the support of other parties can get them to the House more quickly.

Ms S Ramsay:

The way forward on many partnership issues is through the community and voluntary sector. It would be interesting to have some more information. I sit on a number of groups that provide counselling services, albeit on different issues. I accept that infertility involves specialised counselling. Nevertheless, I am sure that a way can be found to create a link, either through the community and voluntary sector or through higher and further education.

Ms Lewis-Jones:

It is such an emotive issue. The law states that IVF clinics must have counsellors; indeed, the fact that they cannot practice without them is a reflection of the huge emotional impact involved, which is often likened to bereavement.

Ms S Ramsey:

I read a report this morning from one of the groups that I attend, which stated that 16 women have

registered to study for a diploma. We must tap into such resources.

Ms Davidson:

The final paragraph of our submission refers to what we want to happen, and I want to highlight one specific point that I mentioned earlier. We would like to see the establishment of an expert advisory group on infertility led by the Department with representatives from INUK and some medical consultants, including embryologists. We are keen for an expert advisory group, such as those in Wales and Scotland, to be set up in Northern Ireland. Those groups have had a positive impact in other parts of the UK.

The Chairperson:

What is the situation in the Republic with regard to infertility treatment?

Ms Davidson:

I will come back to you in writing on that matter. It is better than in Northern Ireland, as the Republic provides more than one treatment cycle per couple. I will send the full review to the Committee.

Ms Lewis-Jones:

We could get in touch with the patient organisation in the Republic too and forward its response to the Committee.

The Chairperson:

Thank you very much.

Ms Lewis-Jones:

Thank you.