HEALTH COMMITTEE

Tuesday 27 September 2005

Session 2

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HEALTH COMMITTEE
23rd Meeting 2005, Session 2

CONVENER

*Roseanna Cunningham (Perth) (SNP)

DEPUTY CONVENER

*Janis Hughes (Glasgow Rutherglen) (Lab)

COMMITTEE MEMBERS

Helen Eadie (Dunfermline East) (Lab)
*Kate Maclean (Dundee West) (Lab)
Mr Duncan McNeil (Greenock and Inverclyde) (Lab)
*Mrs Nanette Milne (North East Scotland) (Con)
Shona Robison (Dundee East) (SNP)
*Mike Rumbles (West Aberdeenshire and Kincardine) (LD)
*Dr Jean Turner (Strathkelvin and Bearsden) (Ind)

COMMITTEE SUBSTITUTES

Paul Martin (Glasgow Springburn) (Lab)
*Mr Kenneth Macintosh (Eastwood) (Lab)
Mary Scanlon (Highlands and Islands) (Con)

*attended

THE FOLLOWING GAVE EVIDENCE:

Nicola Barnes (Justice for the Innocents)
Professor Jeanne Bell (University of Edinburgh)
Professor Sue Black (University of Dundee)
Professor Stewart Fleming (Royal College of Pathologists)
Dr Brian Junor (Royal College of Physicians of Edinburgh)
Dr Adrian Margerison (Royal College of Paediatrics and Child Health)
Professor Graeme Murray (University of Aberdeen)
Dr Tony Peatfield (Medical Research Council)
Lydia Reid (Justice for the Innocents)
David Sinclair (Royal College of Surgeons of Edinburgh)

CLERK TO THE COMMITTEE

Simon Watkins

SENIOR ASSISTANT CLERK

Tracey White

ASSISTANT CLERK

Roz Wheeler

LOCATION

Committee Room 2

Scottish Parliament

Health Committee

Tuesday 27 September 2005

[THE CONVENER *opened the meeting at 14:00*]

Item in Private

The Convener (Roseanna Cunningham): I welcome everyone to this afternoon's meeting of the Health Committee. I have received three apologies. Helen Eadie is unable to attend because of a timing clash with the Edinburgh Tram (Line One) Bill Committee; there is a statutory obligation on her to attend that committee. Duncan McNeil and Shona Robison have also sent their apologies. We will be joined at some point by Kenneth Macintosh, who is the Labour substitute on the Health Committee.

Under item 1 on our agenda, the committee is asked to consider whether to take item 7 in private, to allow consideration of alternative options for the remit and methodology of the care inquiry. Is the committee content that that item be taken in private?

Members *indicated agreement*.

Subordinate Legislation

Mental Health (Period for Appeal) (Scotland) (No 2) Regulations 2005 (SSI 2005/441)

Mental Welfare Commission for Scotland (Procedure and Delegation of Functions) (No 2) Regulations 2005 (SSI 2005/442)

Mental Health (Form of Documents) (Scotland) Regulations 2005 (SSI 2005/444)

Mental Health (Care and Treatment) (Scotland) Act 2003 (Modification of Subordinate Legislation) Order 2005 (SSI 2005/445)

Mental Health (Class of Nurse) (Scotland) Regulations 2005 (SSI 2005/446)

The Convener: Item 2 on our agenda is subordinate legislation. Five negative instruments are listed on the agenda for our consideration. The Subordinate Legislation Committee has already considered these Scottish statutory instruments and had no comments to make on them. No comments have been received from anybody around the table and no motions to annul have been lodged.

Are we agreed that the committee does not wish to make any recommendation in relation to the instruments?

Members *indicated agreement*.

Human Tissue (Scotland) Bill: Stage 1

14:01

The Convener: Item 3 on our agenda is continued consideration of the Human Tissue (Scotland) Bill at stage 1. On Friday 23 September, the Executive issued a supplementary consultation on the bill, seeking views on the provisions relating to adults with incapacity. A number of options for action by the committee in response to this development are set out in a paper that has been circulated to members. I ask the committee to consider those issues when questioning the remaining witness panels—today's witnesses have been made aware that they may be asked questions on them. I ask the committee to agree to invite an additional witness to the evidence session on 3 October to cover the issue of adults with incapacity, and to request a summary of the responses to the Executive consultation when they come in. I also ask the committee to agree to write to the Deputy Minister for Health and Community Care to point out that the informal timetable that we agreed with the Executive makes no allowance for additional evidence taking at stage 2; therefore, if further issues emerge at stage 1, it will not be possible to adhere to the original timetable.

Do members agree with all those recommendations?

Members *indicated agreement*.

The Convener: I welcome Kenneth Macintosh to the committee. Will you confirm that you are attending the meeting in place of Helen Eadie in your capacity as Labour substitute on the Health Committee?

Mr Kenneth Macintosh (Eastwood) (Lab): I am indeed.

The Convener: We move now to the evidence-taking session. This is our third session of oral evidence on the Human Tissue (Scotland) Bill, and we will take evidence from two panels. The first panel, broadly speaking, includes people with medical and medical research interests. From right to left, we have Professor Stewart Fleming from the Royal College of Pathologists; Dr Peatfield from the Medical Research Council; Dr Juror from the Royal College of Physicians of Edinburgh; David Sinclair from the Royal College of Surgeons of Edinburgh; Dr Adrian Margerison from the Royal College of Paediatrics and Child Health; Professor Graeme Murray from the department of pathology at the University of Aberdeen; Professor Sue Black from the department of anatomy and forensic anthropology at the University of Dundee; and Professor Jeanne Bell from the department of neuropathology at the University of Edinburgh.

I will ask each witness to describe their interest in the bill, to comment briefly on the bill, to indicate their support or otherwise for the bill's provisions, and to flag up any issues that they consider worthy of further consideration by the committee. Panel members will realise that, with this number of members on the panel, I am not looking for five-minute orations from each of you. I am just looking for a quick thumbnail sketch to give the committee some guidance so that we can focus our questions better. I will start with Professor Fleming and then move round the witnesses in order.

Professor Stewart Fleming (Royal College of Pathologists): I am here representing the Royal College of Pathologists, which is the professional body for pathologists in the United Kingdom and most of the Republic of Ireland. The college broadly welcomes the bill and congratulates the people who have been involved in writing it because it focuses on what we regard as the main issues without drawing in many additional matters.

In our written submission, we have highlighted two or three areas that may need attention in the bill or in the practice guidelines that are produced once the bill has been passed. One such area is the occasional need for diagnostic testing of transplant donors. Another issue that needs careful consideration is the guidelines on the mechanism for transfer of tissue blocks and slides and post-mortem reports from the forensic medicine service so that they become part of the health record. Attention must be paid to the relationship between forensic medicine practice and the other parts of the forensic medicine service, such as those to do with justice, which include the Crown Office.

Dr Tony Peatfield (Medical Research Council): I am from the Medical Research Council, which, as members may know, covers the whole of the UK, not just England. Our submission was made jointly with the Wellcome Trust, which has a worldwide remit. We are interested in how the bill relates to what happens in the rest of the UK. In that regard, we are keen that, whenever possible, there should be similarities and convergences between the English and the Scottish legislation. We acknowledge that that may not be possible in all cases and that there may be good reason for that. However, if the legislation in the two countries were similar, that would make life much easier for everyone. It would make things simpler both for professionals who cross the border to take up new jobs and for cross-border transfers of material, and would reduce bureaucracy and therefore be cost-effective. Those are our general comments.

I will pull out two or three of the many specific comments that we included in our written submission. The issue of broad and enduring consent was dealt with in the Human Tissue Act 2004, which applies to England, Wales and Northern Ireland. We support the concept but, given how others—especially ethics committees—may view it, there may be difficulties in putting the provisions into practice in a workable way. People on ethics committees have told me that broad and enduring consent is an oxymoron and that such consent is not possible because a person would not know what they were consenting to. The MRC's view is that it should be possible for people to give consent to whatever may happen to their tissue in the future, regardless of whether they are alive or dead.

My second point is that the formalities for obtaining authorisation vary a great deal in different parts of the bill. I know that that issue has been mentioned by other witnesses and in other submissions. It is not clear to us why there are such differences. If nothing else, there should be some explanation and, if possible, some simplification of the apparent complexities.

Thirdly, at one point the bill talks about "Conditions attached to authorisation". That idea does not appear in the Human Tissue Act 2004. Although it is difficult to argue against it, it would be helpful to have some guidance on what sort of conditions would be acceptable. If someone said that they did not want their tissue to be used for such-and-such a purpose after their death, what sort of conditions would they be allowed to attach to their authorisation? Could they specify that their tissue could not be used for a Catholic, for a Protestant or for someone from overseas? It would be useful to have guidance on that.

Those are our main points; our written submission contains many more.

The Convener: I am told that our next witness is Dr Junor, not Dr Juror. There is a misprint in our agenda and on your nameplate.

Dr Brian Junor (Royal College of Physicians of Edinburgh): I am a renal physician in Glasgow, but I am representing the Royal College of Physicians of Edinburgh. The college broadly welcomes the bill for its definition and clarification of the issues related to organ transplantation and post mortem.

Our written submission included four relatively minor points, only one of which I want to mention—our plea for consistency in relation to authorisation. The bill may not be entirely consistent, in that different parts of it appear to contain different criteria for authorisation.

One point that is not in our written submission is the question mark over written authorisation for organ donation. Because the UK transplant register is electronic, someone can sign up to it and there is no written document giving authorisation.

The post-mortem issues could be dealt with more comprehensively by my pathological colleagues, so I will not go into those.

David Sinclair (Royal College of Surgeons of Edinburgh): The Royal College of Surgeons of Edinburgh welcomes the opportunity to be represented here today. The part of the bill to which the college is primarily linked is part 5, which relates to the amendments to the Anatomy Act 1984, especially those provisions that allow operative procedures to be performed on donated bodies.

As the committee knows, the college played a part in suggesting that such a change to the 1984 act should be effected, and it gives its very strong support to that significant and practical improvement. The change will, undoubtedly, permit a helpful widening of opportunities for surgical training in a realistic environment, as well as allowing such training the capacity to respond to the development of new surgical techniques. The college believes that that can only add to the public good, as well as being very much in keeping with the general intent of those who make the special and much appreciated donation of their bodies to allow others to benefit after their death.

I understand that another meeting is to be held with college representatives, relating to the parts of the bill that concern display and museums; that said, I have no concerns about that to raise on behalf of the college.

Dr Adrian Margerison (Royal College of Paediatrics and Child Health): The Royal College of Paediatrics and Child Health welcomes the chance to comment on the bill. The events around Bristol royal infirmary and Alder Hey children's hospital were obviously the driver for the legislation.

The bill is an excellent piece of work. The proposals are clear, succinct and unambiguous, and they deal very effectively with the appropriate use of tissue samples that are taken both at hospital post mortems and at post mortems that are ordered by the procurator fiscal. It is on the latter that we have our only minor concern, which is covered in the written evidence that I have submitted.

The bill was read by Professor Neil McIntosh of the University of Edinburgh, who is the vice-president for science and research at the college and sits on the ethics committee, and by Professor Peter Fleming of Bristol University, who is a leading light in sudden and unexpected infant death. Professor Fleming was the author of the

minor concern over the wording of the provision that permits the retention of samples when they are no longer needed by the procurator fiscal's investigation but does not require that the samples are retained. That is of some concern because the huge majority of procurator fiscal cases around sudden infant death are to do with child protection. We need to be careful that we do not throw away tissue that might later be helpful in leading to conclusions about child protection issues. In relation to genetic advances, it may also be beneficial for parents to have that tissue saved, as we may be able to tell them whether, for example, a death was a cot death.

Professor Graeme Murray (University of Aberdeen): The University of Aberdeen welcomes the bill. It provides a clear framework in which to deal with human tissue and surrounding issues.

Our written submission raises some minor concerns regarding hospital and procurator fiscal post-mortem examinations; however, there are no major concerns that we want to raise. We do not have any specific comments to make about the sections that deal with organ transplantation and donation.

14:15

Professor Sue Black (University of Dundee): I am from the department of anatomy and forensic anthropology at the University of Dundee. My written submission was made at our dean's request, so I speak on behalf of the university. However, I also speak as a licensed teacher of anatomy, but my opinions are primarily personal ones. I will be delighted to discuss them, if we reach that point. It is a bit unfortunate that licensed teachers of anatomy in Scotland did not respond as a group, but David Sinclair and I would be delighted to speak on their behalf.

I have no comment on the first part of the bill; my response is solely on the matters associated with the proposed amendments to the Anatomy Act 1984. My department and I fully support the amendments. We feel that what they propose is long overdue and very welcome. We believe firmly that the proposals offer an exciting opportunity for education and development in Scotland that is not available to many of our colleagues south of the border. This an exciting time for us in education and the proposed measures would allow us to take a significant step forward.

I raised three relatively minor issues in my submission, which are personal opinions more than anything. I am happy to discuss them, but I do not think that they need to be raised specifically at this time.

Professor Jeanne Bell (University of Edinburgh): I am professor of neuropathology at the University of Edinburgh. I am here because I have a strong interest in research and I represent the neuropathology community in Scotland. I want to speak to the parts of the bill that deal primarily with post-mortem examination. I support the bill, which will provide a framework within which we can communicate with individuals, their families and the public about the important issues that are raised in transplantation, anatomical examination and, particularly, post-mortem examinations. We must remember that the legislative process started with the issue of post-mortem examinations and retention of organs. I endorse whole-heartedly the basis of authorisation for the vast majority of activities that the bill details, with the exception of forensic post-mortem examinations. I also endorse the comments that my colleagues around the table have made.

I raised minor points in my submission. However, as a pathologist, I want to concentrate briefly on two matters. First, I want to pick up on the matter of retaining blocks and slides, which was alluded to a moment ago. I endorse what the bill proposes because I think that blocks should be retained for a number of important reasons, including general audit, audit of pathology practice and reassuring parents that the correct diagnosis was reached in a case. Indeed, retaining blocks may be helpful in the future for current cases in which we cannot reach a diagnosis.

That raises the important issue of research. The committee will be aware of the ruling in the appeals court on the review of baby deaths in England and Wales, which highlighted the need for research into the specific instance of sudden infant death syndrome. I envisage a difficulty with such cases and I would welcome further guidelines on how to proceed with them. The appeals court has underlined the need for research in cases where it is not known how a baby died, yet we, as potential researchers, are unsure who to ask for the necessary authorisation. In some cases, it may not be appropriate to ask a family for authorisation. What are we to do in such cases? Are we just to desist from research? We need clear instruction on that, because research is paramount.

My experience from running a research project in the forensic pathology service is that relatives are comfortable with our retaining blocks and slides. I have had no refusals when asking for research permission in that context. If people are told, there seems to be no problem. We now have a framework for not repeating past mistakes and we have had willing consent from everybody we have approached. We think that that is important and we wish to continue working with families in a context that is entirely open, but we need some guidance on the matter.

I am also concerned about training. Post-mortem examination is the main forum in which pathologists gain training. If we are required to obtain authorisation to use that forum for training and education that will perhaps represent a danger for the future training of pathologists.

The Convener: Can I get an indication of which of the eight witnesses are primarily interested in the post-mortem side of things? Will you put your hands up so that the committee members are clear about that? Four witnesses are primarily interested in post mortem, so can I take it that the remainder are primarily interested in transplantation?

Professor Fleming: I am a transplant pathologist.

Professor Black: We are interested in the Anatomy Act 1984 as licensed teachers of anatomy.

Dr Margerison: I am a practising clinician with interests in all those things but no specialist expertise in post-mortem examination or transplantation.

The Convener: Some of you are primarily interested in the post-mortem side and the rest of you are covering all bases. That is helpful to the committee. Before I invite questions from members, I want to say one or two things. First, because there are a lot of witnesses it will be no use if every single one of you wants to answer every single question. If that were to happen, we would be here for a long time, so I ask folk to come in only if they think that something has been missed or if their particular angle is rather different.

Secondly, I encourage you to ask one another questions, if appropriate, especially if we do not ask the questions that you want to ask. I know that that is quite difficult—it is probably not what you are used to—but the committee encourages you to talk to one another as well as to us. Sometimes we can get a lot of information out of listening to an exchange between witnesses. If issues arise on which there is a difference and about which a discussion—or an argument—ought to take place, please feel free to have one.

Dr Jean Turner (Strathkelvin and Bearsden) (Ind): I will kick off with some questions around post mortem. I do not know whether Professor Bell wants to elaborate, but there is a problem with clarity in the definitions of organ, tissue, ante-mortem samples, tissue banks and similar things. Because doctors have more idea what those things mean, I wonder whether you think that there should be more clarity in the definitions in the bill.

I will throw in another question so that people can think about it. The Royal College of Pathologists argues that there should be provision for hospital post mortem to be authorised even if there is no relative or friend—for example, in the case of rare infectious diseases where there is a need to safeguard public health.

The Convener: Can we hold the question of authorisation until we have dealt with the definitions. Two or three members want to ask about authorisation, so I want to keep that as a separate block. I know that you have concerns about the definitions and about the public display of bodies. I do not know whether you want to ask—

Dr Turner: I could ask those questions now.

The Convener: Yes.

Dr Turner: There are fears that licensing will be required for public display. Professor Bell, you mentioned having to get permission for the training of young doctors at post-mortem examinations. Would you like to say something about the timescale in the bill in relation to, for example, large historical exhibitions? One would assume that such exhibitions would be acceptable—you might want to display other exhibits, not only for student education but for public education. Are you happy with the bill as it stands? I got the impression from some of the submissions that people were a little bit unsure about clarity.

The Convener: I am not sure who is best to answer that question. I think, Professor Black, that you are the one.

Professor Black: For the second part of the question, perhaps, but certainly not the first.

The Convener: Which was the first bit?

Dr Turner: It was about the definition of organs and tissues.

The Convener: Professor Black, will you say something first before we turn to Professor Bell?

Professor Black: We need greater clarity on what is considered acceptable in terms of public display. As a discipline, we have suffered at the hands of the von Hagens situation. The public will watch those spectacles—because that is what they are—which are not in any way a reflection of what happens in an anatomy department. When anatomists and pathologists line themselves up in something that is a media spectacle, the professions suffer from it, unfortunately, because people say, "If that is what happens to my remains, I don't want to bequeath them." That results in a shortage of cadavers for educational purposes. Our inspector of anatomy seems to be fairly clear on what he perceives to be acceptable—or not acceptable—but I think that it would be helpful to have much stricter and clearer guidelines in the bill on what is considered acceptable and what is not.

The Convener: Dr Peatfield, do you want to say anything about that? I believe that some of those issues were highlighted in the Medical Research Council's evidence.

Dr Peatfield: Not really. The Medical Research Council does not have a specific interest in that area, but the Wellcome Trust was particularly interested in the public display aspect. It was mentioned in our submission, but it was put forward as an issue by the Wellcome Trust rather than by the MRC. It is not something that is particularly relevant to us, but I can refer you to what the Wellcome Trust said in our submission about that.

The Convener: We have that written evidence, so we shall take it on board.

Is there anything else that witnesses want to say about public display? I think that the issue arose out of the controversy 12 or 18 months ago with the touring exhibition, and public display in that form is obviously different from public display in other forms.

Dr Turner: Dissection is also videoed, and that can be used for tutoring students. As I understand the paperwork, it seems as if that is going to be licensed.

The Convener: I ask members of the panel to raise their hands if they feel that public display needs to be better defined in the bill. I see that the majority appears to be of the view that it could be rather better defined.

Professor Black: We are comfortable with the display of remains for student and educational purposes. We have done that for a long time and guard the practice closely, but the subject is now discussed on television programmes and in exhibitions, and that means that the public needs a little bit of guidance as to why we are not prepared to open the doors of our dissecting rooms. There must be guidelines for us, but there must also be an educational process for the public.

Dr Turner: The Hunterian museum in Glasgow has the older exhibits.

The Convener: I think that Professor Bell can answer the first question, on definitions.

Professor Bell: If I may, I would like to add a comment on the question of training. The training that I referred to was one-to-one education. The committee may come back to that later.

As regards blocks and slides, it is my view that they are quite well defined—or as well defined as they can be. I am familiar with the concepts: I know what we mean by organs and blocks and slides. Therefore, it may be a good idea to take views from other people who are less familiar with the area. With the publicity and information leaflets that are now available, it has been my experience that the public understand well the difference between whole organs and blocks and slides. Turning to the sensitive subject of babies, whose organs might be very small indeed, I think that people still have an understanding of what the difference is. That is perhaps something to be explored on a one-to-one basis with families.

14:30

The Convener: You had a specific issue, Professor Black, concerning the use of the word "macroscopic". Could you comment on that?

Professor Black: I suggested that it might be appropriate to remove the word "macroscopic" because in medical education we have a much more student-directed learning system. We have self-selected components, or student-selected components. For example, if a student who is dissecting a cadaver comes across a condition, they have the potential to expand their education. If, for instance, they found a tumour in the head of the pancreas, they could take that tumour for their self-selected component, section it and look at it under a microscope. In educational terms, they could follow it from the patient—the cadaver—through to the specimen.

The use of the word "macroscopic" would prevent that. My fear is that it would narrow the potential of the whole educational experience. The removal of "macroscopic" from the amendments to the Anatomy Act 1984 would allow us to expand the horizons or opportunities for learning that we can give to students.

The Convener: Would you like there to be no terminology there, with no attempt to make such a definition?

Professor Black: If you were to include a definition, you should include macroscopic and microscopic.

The Convener: So you would like both or neither to appear.

Professor Black: If the terminology is left out, that leaves open a route for radiographic imaging. If there was a particularly interesting bone condition, we could do some radiographs of the cadaver. Specifying "macroscopic" limits what we are able to teach the student.

Mike Rumbles (West Aberdeenshire and Kincardine) (LD): I am a bit concerned about this. The bill is clear on the control of public displays. Proposed new section 6A of the 1984 act, as introduced by the bill, says:

> "Subject to subsection (2), no person shall publicly display … an anatomical specimen … a body or part of a body which has been used for anatomical examination"

and so on. Proposed section 6A goes on to say:

"If the Scottish Ministers think it desirable to do so in the interests of teaching or studying, or training in or researching … they may grant a licence".

I am not quite sure what the issue is. The bill's intention is to ban public display and to protect people who do not want their body to be used in such a way. The bill will also give ministers authority to grant a licence for the various legitimate purposes listed. What is wrong with the legislation as drafted?

Professor Black: As a licensed teacher, I am easy and comfortable with legislation that states "no public display". I could not possibly speak for anybody else on that, however. There might be situations where somebody might legitimately want to educate the public on a certain condition—perhaps using anatomical material to explain that condition to a patient.

Mike Rumbles: But someone wanting to do that could apply to the Scottish ministers for a licence.

Professor Black: Yes.

Mike Rumbles: I cannot see what the issue is in that case.

The Convener: It is a matter to be explored. If we explore it to the extent that we feel that it is not in fact so big an issue, that is for us.

I wish to raise the issue of adults with incapacity. We have been told that there is to be an extra consultation because the Scottish Executive decided that it was not confident that it had explored the issue sufficiently in the context of the bill. I invite the views of those members of the panel who feel that they have a direct concern with the subject. Do you agree with the suggestion of the Royal College of Pathologists that the provisions of the Adults with Incapacity (Scotland) Act 2000 should be extended to the bill? I ask Professor Fleming to speak briefly to this first.

Professor Fleming: I do not have anything to add. Our view was simply that consistency should be ensured between the different areas of legislation.

The Convener: That is covered in paragraph 5 of the evidence from the Royal College of Pathologists. Does anyone have anything more to say on this matter?

Witnesses *indicated disagreement.*

The Convener: Am I to assume that all the witnesses agree that adults with incapacity requirements should be extended to the bill?

Witnesses *indicated agreement*.

The Convener: It is worth getting on record the fact that no one on the panel disagrees with the Royal College of Pathologists. I am sure that it is relieved about that.

As there are no further questions on this subject, I move on to the general and somewhat vexed question of authorisation, which has caused some controversy, partly because the bill sets out two different kinds of authorisation. I invite Nanette Milne to begin the line of questioning and I believe that Janis Hughes will also ask some questions.

Mrs Nanette Milne (North East Scotland) (Con): The written evidence highlights the fact that the bill sets out different procedures for authorisation and suggests that we need to keep things simple to ensure that confusion does not arise with different practitioners. Previous panels of witnesses have voiced the same concerns. I wonder whether the witnesses, particularly Professor Fleming, will elaborate on how to frame the legislation to make things simpler.

Professor Fleming: As a transplant pathologist, I know that diagnostic tests sometimes have to be carried out during the process of organ donation to ensure that the organ transplant is safe. Perhaps half a dozen times a year, the retrieval team that collects a liver or kidney for transplantation finds an abnormality that was unsuspected prior to the donor's death. Legally, because the donor is dead, any investigation of that abnormality is technically a post mortem. However, the authorisation process in that respect has been different, and we feel that it would be helpful to make the authorisation process consistent for the different parts of the bill.

Dr Junor: Authorisation is an issue in transplantation because, depending on the donor's circumstances, we will take a routine biopsy of the kidney before it is transplanted into the potential recipient. We are not sure where the authorisation for doing that comes in, because although the kidney has left the donor it has not been transplanted into the recipient.

Mrs Milne: Clearly the issue needs to be examined in more detail.

Section 6 allows an adult to give verbal authorisation for organ donation in the event of their death; however, withdrawal of verbal authorisation must be provided in writing. I believe that Dr Junor argued that the bill should allow verbal authorisation to be withdrawn verbally.

Dr Junor: It seems only fair to allow people to withdraw authorisation verbally and in writing. The provision is also inconsistent with the withdrawal of consent for post mortem, which can be given verbally as long as two witnesses are present. I find that difference strange.

Mrs Milne: That does appear inconsistent.

The bill also allows a relative's authorisation to be withdrawn. We discussed with a previous panel of witnesses the suggestion that the bill should set out how long before transplantation such

authorisation can be withdrawn. What is your view on the withdrawal of authorisation before donation and transplantation take place?

Dr Junor: I am not sure that I follow your question.

The Convener: There must be a point of no return in the preparations for transplantation, including the preparation of the donee. Would it help matters if the bill indicated the point beyond which authorisation could not be withdrawn? Surely if the bill contains a simple statement that authorisation can be withdrawn, it should also set out the point beyond which such a withdrawal will have pretty serious consequences for the donee.

Janis Hughes (Glasgow Rutherglen) (Lab): The recipient.

The Convener: The recipient—whatever.

Dr Junor: I am trying hard to think of circumstances in which it would be very difficult. I guess that cardiac transplantation might well be such a circumstance, as the recipient has to be prepared. However, in all other circumstances relating to permission for donation from the cadaver, I do not see that there would be an issue about time and consent or authorisation being withdrawn.

Mrs Milne: Concerns were expressed by the transplant co-ordinators.

Janis Hughes: The transplant co-ordinators' representative said that they use the point of going to theatre as a guide. As soon as the potential donor goes to theatre, that is the point of no return, so to speak. We were trying to ascertain whether it would be appropriate to specify in the bill a point after which there is no potential for withdrawal of authorisation.

Dr Junor: I am not sure that, from a practical point of view, that would be important. In my experience, a family has never withdrawn consent once they have granted it. It seems unnecessary to go into the level of detail at which you start to consider the timing of the donor going to theatre as opposed to starting to remove the organs.

The Convener: The point is that this was raised directly with us by transplant co-ordinators as being a potential problem. We have to clarify whether you believe this to be a problem. If you do not believe it to be a problem, you should simply tell us.

Dr Junor: As a physician who is involved in transplants, I do not think that it is a problem.

The Convener: Do any of our other witnesses understand the transplant co-ordinators' concerns?

Professor Fleming: I can see what their concerns are, but I agree with Dr Junor that the issue is not a practical problem. In my 20-odd years of practice, I have never heard of the situation arising.

Kate Maclean (Dundee West) (Lab): The transplant co-ordinators left us with the impression that a situation might arise in which the family of the donor said—at the very last minute—that they did not want the donation to go ahead even though a recipient whose organ had been removed was lying in the theatre, waiting for the organ. At that point, the recipient might be beyond the point of no return so, if the family or the nearest relative said no at that stage, that would be a huge problem. I accept, however, that you say that that has never happened.

Dr Junor: As I said, the issue might arise in relation to cardiac transplantation. However, the timing of the removal of the recipient's heart in relation to the removal of the donor's heart is beyond my area of expertise. I am not competent to answer that question.

Kate Maclean: Would it be reasonable not to allow a relative to withdraw permission at that stage?

Professor Fleming: The preparation of the recipient for heart, lung and liver transplants is performed in such a way that, if the transplant did not go ahead, that would have fatal consequences.

The Convener: That was clearly what was in the minds of the transplant co-ordinators when they raised the issue last week. Without asking questions of people such as yourselves, it is impossible for us to assess whether it would make any difference if the bill included something that would deal with that issue.

I appreciate that you are telling us that the situation has never arisen but we are locking into place a set of formal authorisations, consents and means of withdrawing consents and I am not sure about the extent to which the situation that we are discussing might become an issue.

Professor Fleming: One possibility is to have a fixed time that becomes a compulsory waiting time, but that creates other difficulties.

14:45

Mr Macintosh: There are two arguments: the philosophical one about at what point one can withdraw consent and the practical one. I am not clear. For some transplants, there might be a practical point at which withdrawing consent would be a problem. We have established that that is the case.

The Convener: That is what was in the transplant co-ordinators' minds.

Professor Fleming: That is the case.

Mike Rumbles: The situation where an adult authorises transplant in the event of their death is one thing, but I want to focus on the withdrawal of consent by the adult's nearest relative. Should there be a process for the withdrawal of authorisation once it has been given?

Professor Fleming: The alternative view that once authorisation for transplantation has been given it cannot be withdrawn would certainly solve the dilemma that we appear to have.

The Convener: The bill, however, allows for withdrawal of consent; the question is whether it should allow for that.

Mike Rumbles: Should that provision be taken out of the bill?

The Convener: The witnesses have no comment.

Dr Junor: It would make life simpler.

Professor Fleming: It would make life simpler; but we have no experience of the situation.

Dr Margerison: Do you usually legislate for hypothetical situations?

The Convener: We have done, yes.

Dr Margerison: I have nothing to do with transplantation, but if a patient has had their heart and lungs removed and someone suddenly runs into theatre saying, "I withdraw my consent for this to happen", the patient will clearly die. I do not know what legal responsibility the person who withdrew the consent has. It is not murder, but it is not far off.

The Convener: That is precisely why we need to clarify the situation.

Dr Margerison: Such a situation has not arisen. We can certainly apply a time limit, if we can think of a legal way around the problem. We could argue about it for ages. We could say that once the surgeons have started to operate, that is it—the consent has been given. If an adult with incapacity or a child is being operated on under someone else's consent, it would be difficult to suddenly stop. I am not aware that that happens often.

The Convener: The problem is that the issue was raised by the transplant co-ordinators, who are of course the people at the chalk face—they are the ones dealing with the families.

Mike Rumbles: The fact that it has not happened does not mean that it could not happen. The purpose of the bill, from the Executive's point of view, is to increase the number of donations, which have been decreasing in recent years. The bill would reverse that trend. Having more bodies become available for transplant increases the likelihood of such a rare event happening. That is the issue. Given that we are responsible for passing the bill, we have to consider every possible alternative; it would be a dereliction of our duty for us not to do so. We do not want to get into that sort of situation; that is why we are asking you.

Dr Junor: We cannot get into a position where once authorisation for transplant has been given it cannot be reversed. Someone might have given authorisation and gone on the organ donor register 20 years ago but wants to come off it now, because of an adverse circumstance. Would you not allow them to withdraw authorisation?

Mike Rumbles: No. I am not talking about people withdrawing their own consent, but the family of a dead person withdrawing authorisation.

The Convener: Notwithstanding the transplant co-ordinators' concerns, there is puzzlement among the panel about the issue. We will have to consider that and speak to others about it. We may have to go back to the transplant co-ordinators to ascertain why they felt that it was so important to raise the matter with us. We would not be asking you these questions if they had not been raised directly with us.

Professor Fleming: Is there a mechanism for us to consult a little bit further and submit more in writing?

The Convener: Of course.

Professor Fleming: Can I undertake to do that?

The Convener: Absolutely.

Mrs Milne: My impression was that the bill does not stipulate that authorisation can be done either by carrying a donor card or by electronic registration. A previous panel expressed concern about where authorisation is actually held. There would be concern if it was to be found in someone's general practitioner notes, for instance. In such cases, getting approval might be too late.

Should the bill stipulate how authorisation for organ donation should be registered?

Dr Junor: It would be sensible to get round the point of written consent when specifying the organ donor register; otherwise, people who have signed up electronically will not be deemed as having given authorisation.

Janis Hughes: A health board told us that it thinks that the bill appears to allow a person to give specific permission for one organ to be donated, but not another: take my heart but not my kidneys. Should that be clarified in the bill? Should

it be made more specific when a person has authorised the removal of one organ only, for example, or is that, by omission, excluding certain organs?

Dr Junor: I am not sure that that needs to be clarified in the bill. People can sign up to donating an organ or can refuse authorisation to remove certain organs on the written consent forms or donor cards. People have ideas about what they want to be buried with, and we should not interfere with that at all. If they felt that they wanted a particular body part to be buried with them, but are content to donate their kidneys, they should be able to do that.

I am not sure that that needs to be defined in the bill.

Janis Hughes: The bill emphasises the need to respect the wishes of the deceased. However, section 7 appears to allow a person to give specific permission for the donation of one organ, but then allows the nearest relative to authorise the donation of another organ not specified by the deceased. That could lead to conflict.

The Convener: If an individual gives advance notice of their intention to donate and specifies which organs, should we infer that they specifically do not want the other organs to be donated?

Dr Junor: If they specify the organs that they do not want to donate, that should be respected.

The Convener: But what if they do not mention them? If a person says that they are prepared to donate their heart but makes no mention of other organs, would you take it that by specifying that one organ they are telling us that they do not want their other organs to be used?

Dr Junor: I do not think that I would take it that way, no.

Professor Fleming: I think that I probably would.

The Convener: I probably would as well. If people go to the extent of specifying what organ they want to donate, by implication they are saying that the organs that they do not specify are not to be removed. That should be taken as non-authorisation.

Kate Maclean: Taken to its logical conclusion, not specifying authorisation for any donation could be taken as a tacit refusal to donate.

The Convener: I do not think that that logic follows.

Kate Maclean: We have different views then.

The Convener: We might have to discuss that. Does anyone else have a view?

Janis Hughes: The point is that the matter is subjective. We are asking whether we need to put something in the bill to firm up organ donation. Different people in the field will also disagree.

Dr Junor: How would you specify such a provision in the bill?

Janis Hughes: It is for the people who draft the bill to come up with that.

The Convener: We are looking at the principles of the bill and our job is to flag up where one or two issues need to be considered again or clarified. In which case, Janis Hughes is right—it then goes back to those who draft the bill to suggest the wording.

Dr Junor: Given the disagreement today, it would be sensible to clarify the matter.

Janis Hughes: We discussed with other panels the hierarchical structure of who is able to authorise organ donation. The situation is slightly different in England and Wales, but there is an accepted structure in Scotland.

One of the issues that arose was a potential dispute between parents over donation of their child's organs, particularly where one parent is an absent parent. How would that be resolved? We have tried to ascertain witnesses' views on that.

Dr Junor: As I understand it, the law is dictated by age at the moment—the older parent decides.

Janis Hughes: That is a new one.

The Convener: I do not think that that is the case.

Dr Junor: I might have misread the interpretation, but if siblings are involved, the hierarchy goes by age.

The Convener: Perhaps in the case of siblings, but I do not think that that applies to parents.

Dr Junor: Is that specified?

Janis Hughes: I was asking specifically about an acceptance that parents were responsible for making a decision about their child, but what happens when the parents disagree about what to do?

Dr Junor: I realise that that would be an awful situation.

Dr Margerison: I understood that the point of view in the bill was that it was the parent who was most responsible for the child's care who should make the decision. Correct me if I read that wrongly, but that seems to be what should happen.

Janis Hughes: That is a view. The view that we have heard so far is that if there were a disagreement, donation would not happen.

Dr Margerison: I give my view as a clinician who deals with parents who are frequently

separated these days; that does not mean that the other parent does not have rights or points of view. However, one needs a legal framework for the situations that we deal with—

The Convener: Do you think that the custodial parent should be the one who is regarded as the primary permission giver?

Dr Margerison: Yes, the parent who provides the care.

Kate Maclean: If the child lived with grandparents, would they be the primary carers?

Dr Margerison: Yes, if the grandparents are responsible for the child's care.

Janis Hughes: So if the grandparents were defined in law as the primary carers, they could give permission.

Professor Bell: That applies to transplantation and post-mortem examination.

Janis Hughes: Yes.

Dr Turner: Where there is no one to give authorisation and it might be in medical interests that a post mortem should go ahead, how would that be dealt with and to whom should one apply? Say that something like variant CJD were involved, there were public health issues and one needed to know about the cause of death, how would one deal with that situation if there were nobody to give any authorisation? I was in a situation where that almost happened, but a post mortem was granted in the end.

15:00

Professor Bell: It is unusual that nobody can be contacted, but it happens. At present, the clinician at the hospital can in the end give authorisation. Clearly, the pathologist who will do the post-mortem examination cannot just assume that authority; it must be given by somebody else. In the forensic situation, the procurator fiscal does that, but in the hospital situation, the hospital authority, through the clinician, can authorise the post mortem if they feel that it is of overwhelming importance.

The Convener: The problem is that the bill at present will allow a hospital to go through the hierarchy, but when the bottom has been reached and there is nobody left to ask, that will be the end of the story. The Royal College of Pathologists feels that there ought to be a provision to deal with that scenario, rare as it might be. We are talking about potential or hypothetical situations again.

Professor Fleming: The view of the Royal College of Pathologists is that the bill must make provision for such cases. The situation will be much more common than that of somebody withdrawing consent for a transplant. Our experience is that the situation probably occurs most years in Scotland, so a mechanism must be in place to deal with it. Ministers must authorise someone, perhaps the chairman of the health board or a comparable person.

Dr Peatfield: The situation may be different in England, where, under the Human Tissue Act 2004, once the hierarchical list has been gone through, there is no legal route of getting consent.

Professor Fleming: That is correct. The Human Tissue Act 2004 does not make provision for that.

The Convener: So if we amend the bill in that regard, you might advise England to follow our example—there is a thought. I see Dr Peatfield is nodding.

Dr Peatfield: I nodded; I did not say anything.

The Convener: We have had many questions about authorisation, for the obvious reason that it is the area in which most issues will arise. The bill has two different authorisation processes, depending on whether a transplant or a post mortem is involved. Do the panel members think that there should be a single authorisation process and, if so, which one should it be? Alternatively, do the panel members accept the Executive's arguments for proposing two processes?

Professor Fleming: Our preference is for a single process.

The Convener: Which one would you prefer?

Professor Fleming: The one that is outlined for hospital post mortems.

Dr Peatfield: Convener, could you repeat the alternatives?

The Convener: The bill will introduce two different authorisation processes, depending on the procedure that is involved. Do you accept the Executive's argument that the authorisation process ought to be different in different circumstances, or should there be a single process and, if so, what should it be?

Dr Peatfield: There should be one process and it should be that which is used for post mortems.

Dr Junor: I agree.

David Sinclair: I have no comment on that.

Dr Margerison: I suspect that, as children are always different, we need two processes. For example, mature children are different from younger ones. If we are to have a single document, it must be user friendly for all the people who will use it, which may be a difficulty.

The Convener: So you can see the argument for having two different authorisation procedures.

Dr Margerison: Yes.

Professor Murray: There should be one authorisation procedure, based on that for hospital post mortems.

Professor Black: It is not appropriate for me to comment, as the matter is out of my field.

Professor Bell: There should be one process. The difficulties of implementing the two processes down the line in hospitals and other situations will be considerable and will make it easier for people to make a mistake.

The Convener: Which process should be used, then?

Professor Bell: The one for hospital post mortems. Having one process would open up the possibility that if a person consents to or authorises an anatomical examination that proves to be unsuitable, consideration can be given to post mortem examination or research, as it will be known that that was in the person's mind.

The Convener: Do any panel members want to raise issues separate from those we have discussed?

Mike Rumbles: I am a little concerned about the choice of the age of 12 for authorisation. The bill says:

"A child who is 12 ... may authorise the removal and use of a part of the child's body".

Sue Black referred to that in her submission. If she has anything to add, I will be happy to hear it. I would also like to hear whether other panellists think that 12 is an appropriate age.

Professor Black: I considered the issue from the anatomical perspective. As I have children of that age, I know that if—God forbid—my child knew that she was dying of something, she would have the presence of mind to say that she could give something to keep other children alive. My child could understand that. My child could not understand donating her body for the purposes of anatomical examination, education and research. In my department, I could not ask any medical student to dissect a 12-year-old child, because we would have psychological problems with our medical students, who come out of school at 17 or 18.

What would I do with the cadaver of a 12-year-old? I could not ask my technicians to embalm that, because they would spend half their time in the embalming room in floods of tears. I find the age of 12 unacceptable. I could not deal with it from an anatomical perspective. Transplantation is an entirely different issue, but I have great fears about the anatomical aspect and support what you say.

The Convener: Do any other witnesses have views?

Dr Margerison: We should jealously guard the principle that a 12-year-old can make their own decisions if competent to do so. However, I agree that all the emotional overlay makes the situation extremely unlikely. The committee presents a what-if situation. Nobody in Scotland would accept that medical students or postgraduates would dissect 12-year-old children, but there is no reason for that—the reaction is emotional. That is the problem with the issue, which defines it well. It is being said that somehow, if a person is 18—perhaps the same age as medical students—that is acceptable.

The Convener: The issue is of capacity.

Dr Margerison: I do not disagree, because I do not think that, in practice, anybody will perform such a procedure. However, it is important to enshrine the ability of 12, 13 and 14-year-olds to give their organs for transplantation and so on. We should not necessarily write them out of that, but such procedures will not happen.

Kate Maclean: I agree. We are considering authorisation, not whether an institution would want to take up an offer. Authorisation is separate from what an institution finds acceptable. I still agree that 12-year-olds should be able to give that authorisation.

Professor Bell: I will return briefly to training for pathology. Under part 3, after the procurator fiscal post-mortem examination, we require to have authorisation for education, training or research. In the present time of contracting hospital post-mortem services, the forensic pathology service is a major context in which we train our future pathologists. If we do not have that authorisation—there will be subsets of the procurator fiscal practice from which it is difficult to obtain authorisation—we will be unable to train pathologists. Careful definition is needed to retain training if authorisation must be obtained for that.

Professor Fleming: I support that view. The Justice Department is dealing with training in forensic pathology. We have explored with NHS Education for Scotland the funding of training in forensic pathology. The Justice Department and the Crown Office see that as an important part of the future provision of forensic pathology. It is critical that the bill does not conflict with what the Crown Office and the Justice Department regard as needs.

Dr Margerison: In the past couple of years, my college has flagged up the shortage of paediatric pathologists, who practise a specific discipline in pathology. If we do not have them, we will be unable to do post mortems on children with exact scientific and proper competence. Sometimes, that

is not available if a paediatric pathologist does not undertake the post mortem. Such training is important.

The Convener: I thank all the panel members for attending. You are free to go or to stay and listen to the remainder of the public part of the meeting. We will be happy to receive in writing anything that you want to add to what you have said.

I suspend the meeting for the witness changeover.

15:11

Meeting suspended.

15:15

On resuming—

The Convener: I bring the meeting back to order and welcome the second panel that will give evidence on the Human Tissue (Scotland) Bill. Lydia Reid and Nicola Barnes are from Justice for the Innocents. Annmarie McDonald was to be the third member of the panel, but, unfortunately, there has been a bereavement, so she cannot come to the meeting.

I invite the witnesses to say something before members ask questions; I ask each witness to speak for no more than a minute or two, as I asked the previous panel to do.

Lydia Reid (Justice for the Innocents): I will make a short opening statement. When we first came to Parliament to talk about what happens to children and relatives during and after post mortems, we were told that things would be different in the future and that there would be the human right of choice for everybody and protection for children's bodies and their relatives as a result of a new human tissue bill. We cannot argue that research is unnecessary or say that we do not believe in it because every family in the organisation supports research. We would help in any way to promote positive publicity, but we disagree that people—children and adults—should be coerced or bullied into giving authorisation, or that the chance to refuse authorisation should be taken away from them. We ask that people's bodies be protected by the use of cameras in all areas of pathology buildings—that is made plain in our written submission.

Think back to what parents have told Parliament about health workers in general and their taking children's bodies and using them in any way possible to satisfy their desire for research. Think about the untruths and lies that have been told and the facts that were hidden from parents until they had spent months—sometimes years—fighting for the truth and getting it grain by grain. Members should think back to the discovery of more brains in hospitals, which were found only after we showed to members proof in writing of those brains' existence. We were then told that although they existed, it was not known to whom they belonged. It does not take a great deal of intelligence to work out that without histories—in particular, family histories and past medical histories—many of those brains would be useless for researchers, but they did not want to give them back to families.

Think back to the documents—which included pathology day books—that proved in writing that organs had not been returned to bodies, even though a pathologist told the independent review group that organs were always returned to bodies after post mortems. Members should think back to the families that were bullied into giving written authorisation while the bodies of their children were still being held. In severe cases, up to 12 members of staff—including ministers and priests—were used to gain signatures. In some cases, signatures were put there by members of the health staff. Those are the same health workers—nurses, doctors and pathologists—who hid the truth from us and Parliament and who thought, and said publicly, that we were making a fuss about nothing. They said, "Let's face it. These children are dead and can't feel anything, and we need the research." They are the same people who told us that parts of children were cremated with respect, although they had just been put into yellow plastic bags and thrown into an incinerator with the hospital rubbish. They did that despite knowing that families had professed a wish to bury their child or relative. They are the people who have stolen our children's and relatives' organs. We are being asked to have confidence and trust in them when they say that, although they have no proof, they have verbal authorisation for post mortems from children of 12 or older, old people, vulnerable people, patients who were alone or patients who had language difficulties.

We were told by the organ retention review group that parents should be treated with openness, respect, honesty and courtesy when they make inquiries about organ retention. Instead, parents have been treated as if they have mental health problems and as if they have no right to the information. Can you imagine how parents have felt when that has happened to them? It is probably more important that that shows that the change that we all hoped for has never materialised.

If the bill is passed in its current form—or anything near its current form—many human rights will be removed, particularly from parents of children who have died tragically from cot death. We desperately need research into cot death and

many other conditions, but is it fair to force parents into things and to cause more parents to have real mental health problems when they later discover that parts of their baby have been stored for research? People must try to think about how they would feel in such a situation if the child was their child.

Members may be unaware that that has already happened to parents who have asked the Crown Office to return parts of their children that are stored in Scottish hospitals. Magically, a new policy appeared that stated that the Crown Office has the right to keep parts of a child. That took as long as it took for the media furore to die down. Our hope today is that you will listen with honest hearts to what we have to say and that you will see the dangers of passing a bill that will allow health staff to say without proof that a child or adult has given verbal authorisation for a post mortem or for organ donation. You need honestly to consider a bill that states that a doctor or pathologist could go to prison for a year but which also says that, to avoid that, he only has to say that he had good reason to believe that he had authorisation. That makes no sense. If they had no intention of breaking the law, why would they fear a bill that says, "Do this, and you will go to prison"? Would such a provision be included in any other bill that deals with theft? If someone is caught stealing from a shop and they say, "Someone told me that I could steal that coat because I'm cold" or, "The security guard said it was okay because I'm cold", would they get away with it under other legislation?

Written authorisation is what a doctor or pathologist should work on, and with today's modern technology, they should be able to have that written authorisation in front of them before they do a post mortem. We should look at the progress that has been made by organ donation for transplant and the difference that has been made by positive publicity during the past few months. The work that has been done in that area has been amazing. The saying "the gift of life" is still used today. That could happen for research. You could persuade the public that giving authorisation would have a positive effect and that authorising that an organ be kept for research or teaching would improve medicine.

We have made many suggestions. For example, if discussion packs were introduced into high schools for people aged 15, as they are for donation for transplant, a young person could on reaching 16, when he or she is issued with a national insurance number card, say in writing whether they wish to donate for transplant or for research. Their decision would be made with all the facts. We believe that that could have a ripple effect for the families that are involved in the discussion.

We are asking you to honour the promise that we would own our own bodies and those of our children, and not to give doctors and pathologists the right to do what they have done in the past. The bill should include the recommendation that we have the same co-ordinators for post mortems and donation of organs for research as we do for transplant, and it should take all authorisation out of the hands of health staff. We do not want to come here in five years to lodge petitions and chain ourselves to railings for publicity—we have other things to do with our lives and some normality would be nice. Our future depends on what the committee and other MSPs decide to do with the bill.

The Convener: Thank you. Nicola, do you want to add anything?

Nicola Barnes (Justice for the Innocents): I agree with Lydia.

Dr Turner: All through your submission it is mentioned how important it is to you that medical staff be excluded from being witnesses. I can understand where you are coming from. Towards the end of your statement you also mentioned how you think that that problem could be solved. Who do you think should witness authorisation?

Lydia Reid: When a doctor or pathologist would like permission to do a post mortem, they could use either a bereavement counsellor or, by expanding co-ordinators' departments, they could use the same co-ordinators that are used for transplants. Those people are very experienced; they have all the experience that we need. They can go to relatives or patients and explain a post mortem to them and give them details. Relatives are not frightened of detail; they are frightened of being shut out and of not being given knowledge. Those people could give information that might even persuade relatives to give permission for post mortems and for organ retention for research and teaching.

Dr Turner: Obviously there are some illnesses that allow doctors more time to gather information and educate. However, it is sometimes difficult if things happen very quickly towards the end and relatives are stunned by grief. How would you deal with such situations? Would the co-ordinators speak to the relatives?

Lydia Reid: That is the most common situation. People in that dreadful stage are totally astounded and cannot believe that their relative is dead, particularly if that relative is a child. However, even though they are stunned and grieving, they respond far better to honesty and openness than to anything else. People should respect their intelligence and explain the situation. Nobody in Scotland is stupid; we are all reasonable people.

I believe that a lot could be done with regard to education before that situation even arises. What

has been done lately in education in relation to transplants has been wonderful. Exactly the same could be done in relation to post mortems. Instead of grabbing and taking, which is what the bill would, do, we should ensure that people can be persuaded to give permission for a post mortem in order to help people in general.

Dr Turner: Sometimes, persuasion could be considered to be bullying. How would you prevent—

Lydia Reid: What we suggest has happened in relation to transplants. Television programmes that have been on lately about transplants have been wonderful; they have shown the public that transplantation truly is the gift of life. The same could be done in relation to post mortems. People should be involved in the work that is being done. Why should research projects be a big secret? What is the problem with opening up the research to the public? People do not want to die of cancer, brain problems or heart problems. They need to be told that research projects are being undertaken in that regard and that they have to be brave enough, when their relative dies, to give the permission that is needed for a post mortem to be conducted so that people can find out what happened to the person's organs. That could be done.

Dr Turner: You might have heard the earlier discussion about the possibility that the issue could be dealt with on one form or in a register—

Lydia Reid: There has to be a register and an extremely explicit form. Some departments believe that less information should be given but I do not believe that. As much information as possible should be given. If post mortems were spoken about in the same way as transplants are, that information would no longer be as upsetting to a relative as it can be at the moment.

We should all accept that we will die at some point and that we might have the opportunity to donate organs for transplant or for research and teaching.

Dr Turner: I am happy to hear you say that.

The Convener: Do you agree that we should have a single authorisation process that is the same for transplants and post mortems and that there should be no difference between the two processes?

Lydia Reid: There should be no difference. At one point, I was worried that our objection to post mortems without permission might put the public off transplants. However, that has not happened, as is demonstrated in the submission that was made by UK Transplant. If there were one standard form, everyone would understand the situation better.

A few parts of the bill concerned me. I have a great deal to do with the Grandparents Apart self-help group and I deal with grandparents and parents who do not have contact with their grandchildren and children. Therefore, the portions of the bill that relate to parental authorisation concerned me a great deal. Which parent has greater parental rights? Is it the resident parent? Is it the other parent? I can see that issue causing problems in families.

For example, if the parents are separated and only the resident parent is in the hospital at the time and the other parent has been shut out of the child's life and has been fighting tooth and nail for contact with them, how will that parent feel if they discover years later that their child had a post mortem or had an organ removed for transplant? That is a frightening situation and it would be preferable to have everyone in agreement. One would prefer that people said yes to transplant, yes to post mortem and yes to organ donation for research, but when it gets to the stage that someone might develop a mental health problem because of what is happening to the dead body, we have to say no.

15:30

The Convener: We heard evidence at a previous meeting that when there was significant disagreement, it would be highly unlikely that a transplant would go ahead, notwithstanding that some members of the family were very much in favour of it. Would you take that view?

Lydia Reid: I would disagree with that position in only one situation. I will use myself as an example. I would prefer anything in my body to be used for transplant if it was useful and if it was not useful for transplant I would want it to be used for research. I would not like one of my family to be able to over-rule that, because I believe passionately in transplant and in research. I would not like a member of my family to be able to say, "That will not happen."

The Convener: We have heard evidence that once somebody has died that situation might arise if carrying out their wishes would cause enormous distress. I turn on its head your comment about the situation causing a mental health problem for a surviving relative. What if that situation resulted in a surviving relative having a mental health problem?

Lydia Reid: Okay. The problem is that transplant and in particular research and post mortem are not openly discussed in families. We need education.

The Convener: That is a fair comment, which is probably true of all families.

You have heard that the Scottish Executive is extending the consultation on the bill in respect of children or adults who do not have proper capacity to agree. We do not yet know the outcome of the consultation. That is why we asked the previous panel about the Adults with Incapacity (Scotland) Act 2000 and whether it felt that provisions that relate to adults with incapacity ought to be included in the bill. In your written evidence you mentioned your concerns about the situation when a person does not have the mental capacity to make an informed decision. What provisions should be made in those circumstances?

Lydia Reid: The important point is that when a person does not have the capacity to decide, we do not know their decision; we do not know what they would decide because they cannot decide for themselves. How can you do a post mortem on someone who cannot decide for themselves? How can you take their authorisation for granted? There was a discussion earlier about the fact that mental health legislation states that a social worker can eventually make a decision. Am I right?

The Convener: We are not dealing with mental health legislation.

Lydia Reid: Sorry. I meant to say the Adults with Incapacity (Scotland) Act 2000. Am I right to say that a social worker can make decisions for someone who is incapacitated?

The Convener: We do not have the 2000 act in front of us. We will have to consider the matter because of the extension of the consultation; we do not want to prejudge its outcome.

Lydia Reid: I am very concerned about the situation when someone who is incapacitated is living in care. Consider the situation when a child is in care and the parents have had their parental rights and responsibilities removed: that child is now in the care of a solicitor, a care worker or a social worker who has the right to make decisions in respect of that child's life or death. Some other provision must be made when it comes to people who cannot give permission because they are incapacitated, in a coma or something like that and have no relatives. If they have not given the right to make that decision to a close relative or friend, the procedure—whether it be a transplant, research, a post mortem or whatever—cannot go ahead. You must have a clear idea either that the person made that decision or that there is someone there, such as a close relative or friend, who can make that decision.

The Convener: Do other members of the committee have questions?

There is obviously the situation where the fiscal might be involved. I think that you were concerned about the fiscal having powers beyond the bill. Now, there will be times when that is obviously essential.

Lydia Reid: Of course. There is no way we would argue with that.

The Convener: Do you feel that the provisions for getting the fiscal's consent before organ donation are okay?

Lydia Reid: No. We have spoken to fiscal offices on several occasions when different families have been involved with the fiscal and we know from experience that when a doctor or pathologist wants a post mortem they do the post mortem and then get permission from the procurator fiscal. They will deny it, but that is what happens. That cannot be allowed to happen. If the request is put in writing—for all the time that that is going to take—it can be sent, faxed or e-mailed over. We have all those modern technologies, so why not use them? The fiscal should be allowed to read the reasons for the post mortem and then the permission—or authorisation or whatever you are going to call it—can be faxed or e-mailed back again. It should be in writing. Pathologists should have before them in writing authorisation for a post mortem, whether it be from a fiscal or from a hospital. There should be no excuses—none at all.

The Convener: Janis Hughes, do you feel that your question about disagreeing parents has been covered?

Janis Hughes: Yes.

Mrs Milne: I have a question about the incapacity issue. Suppose that, many years before they became incapacitated, somebody had given an indication that they might be happy for their organs to be transplanted if they died.

Lydia Reid: For instance, my name is on the organ donation register.

Mrs Milne: Do you regard that as standing even if you become incapacitated?

Lydia Reid: Yes, definitely, as long as it is done in writing. I think that everything has to be done in writing. I am deeply concerned about electronic authorisation. I know enough about Nicola Barnes to register her using electronic authorisation and she knows enough about me to register me. That is a very scary situation.

The Convener: You have sent us some very detailed written evidence, so we know your views. There are no further questions from committee members, but is there anything else that you want to raise briefly?

Lydia Reid: Yes. I would like to ask about Professor Bell's point on authorisation. Would not there be a point at which a co-ordinator could be useful? Professor Bell pointed out that things get to a stage where people are unsure where to go for authorisation. Surely trained co-ordinators would have all that information at their fingertips.

The Convener: Whether training would also be backed up by resources is a question of practicalities and a matter that we have to explore.

Lydia Reid: It seems to me that everybody is a wee bit lost. Do you know what I mean? All those parts that are lost could so easily be sorted out by co-ordinators or a bereavement counsellor dealing with post mortem and organ donation for research. If people want to make that a separate department, that is fine, but I truly believe that transplant co-ordinators now have so much experience that with just a little more training, and with more staff, they could do the job.

I am unsure about the idea of removing the word "microscopic".

The Convener: It is "macroscopic", not "microscopic".

Lydia Reid: I was wrong. I apologise.

The Convener: It is not easy when you just see it written. Macroscopic just means big, as opposed to microscopic, which is tiny. The concern was that if one says only "macroscopic" one precludes all other levels of investigation.

Lydia Reid: I will go home and have a wee look at that.

I had intended to speak about adults with incapacity and their primary carers as well as those with no relatives, but I would like to say a word about training. Yes, we need training, but do we really believe that it is okay, even for a procurator fiscal post mortem, to say that training can go ahead on a body without the permission of the deceased's relatives or parents? We are talking about somebody's baby or relative. We are talking about our bodies.

The Convener: I take the point that we should make sure that the consent forms are expanded to include training and research.

Lydia Reid: I would have no problem with that.

The Convener: To be fair to the professor, it was her concern that if there was not an explicit statement about training it could fall off the end of the table. That would be unfortunate because, as you said, most people would probably not object if they understood what was being proposed.

Lydia Reid: There are some changes that we would like to see introduced into training. For instance, it would be very useful if post mortems were videotaped more often. It is not as though the face or the head would be videotaped, just the post mortem itself, but the bill precludes that happening without some kind of authorisation.

The Convener: That is the issue of public display. It is a question of whether people are aware, when they give consent, of what precisely it is that they are consenting to. Some people may object to the videotaping of post mortems.

Lydia Reid: That is true. However, if it were ever included on the consent form and there was discussion—

The Convener: So you would like to see an authorisation form that covered all the possible uses and made it explicit what they might be.

Lydia Reid: If a consent form does not list all the possible uses, someone will say later, "Hold on a second, I did not give authorisation for that."

The Convener: Okay. That is fair enough.

Dr Turner: Can I be clear about something: you accept that there is a need for paediatric pathologists?

Lydia Reid: Of course there is. I accept that 100 per cent.

Dr Turner: That is okay. I am just clarifying.

Lydia Reid: We will give any amount of positive publicity to pathology or research, because it is desperately needed. We have no problem with research of any kind. All we are saying is—

The Convener: What we get from you is that what you would like is for a great big light to be shone on all of this—

Lydia Reid: Yes. Without a doubt.

The Convener:—and that the pathologist, the parents and every person involved should understand clearly what is happening, what has been agreed to and what has not been agreed to.

Lydia Reid: Our huge concern is the taking of verbal authorisation. That is frightening.

The Convener: Authorisation is clearly a big issue that we need to be very clear about. The committee will have to discuss what recommendations it might make on authorisation. Your organisation is not the only one to express concerns.

Lydia Reid: I noticed that.

Mrs Milne: You said that you do not like the idea of electronic registration. I am interested to hear that, because in this day and age everyone, particularly the young, is using electronic means of communication more and more and electronic authorisation will have a role in registration. Are you worried about the security of the electronic system?

Lydia Reid: Yes, of course I am.

Mrs Milne: If you could be assured of its safety, would you be happy to use it?

Lydia Reid: We have to be realistic. We have dealt with thousands of families from whom the

right to authorise was taken away. They have spent a great deal of time trying to find out what happened to the body of their child or relative, only to discover later that a post mortem was carried out without their knowledge or consent.

We are saying that there are some doctors, nurses and pathologists—we cannot lump everybody into one huge pot and say that they would all do it; that is not what we are saying to you—who would be prepared to go as far as to register a person on an electronic website, or whatever it is, if they want that body.

15:45

Mrs Milne: Is the issue for you who does it? I was registered electronically as an organ donor, but I was there when it was done. I filled in a form.

Lydia Reid: Fine. So, you have got the form.

The Convener: Are you saying that you do not preclude electronic registration but that you think it should always be backed up by written authorisation?

Lydia Reid: Definitely. It must be written—it must be an actual signature from the person or some other form of security. I do not know enough about the internet and how a site such as that could be secured. I do not know enough about the ways in which someone could say, "Well, it was definitely Lydia Reid who gave that authorisation, because there is the evidence." I do not know enough about how to do that. Could it be done? I do not know.

The Convener: I think that we understand. Thank you very much for coming along this afternoon. I hope that it was not too stressful for you.

Lydia Reid: I have one other little comment, which you probably will not like. I think that it is shocking that eight pathologists were invited to the committee but we were offered only three places. I think that is absolutely shocking.

The Convener: Well, first, there were not eight pathologists; I think that only four of the witnesses were pathologists. Secondly, although you were offered only three places, we will be hearing from another parents group, and it has been offered three places as well. I do not think that, in the circumstances, that is out of kilter.

Lydia Reid: I suppose that, if you put it like that, it is okay.

The Convener: Thanks very much for coming.

Lydia Reid: Thank you.

The Convener: You are welcome to stay for the remainder of the public session, which is not going to be very long.

Regulatory Framework Inquiry

15:47

The Convener: We move on to our subordinate legislation inquiry. As members are aware, the Subordinate Legislation Committee is undertaking an inquiry into how subordinate legislation is currently handled by the Parliament. We have been specifically invited to comment and I have been invited to give oral evidence to that committee. I have provisionally accepted that invitation, but I do not want to do that off my own bat; I would like to do it on the basis of some kind of discussion with the committee about the way in which subordinate legislation is dealt with at the moment.

Do members have any views on the handling of subordinate legislation? You might want to think about the timing of consideration, the roles of the different committees and whether instruments should be amendable. Members may prefer to make their comments by written submission rather than orally today. I do not want to go to the Subordinate Legislation Committee without some feel for what the committee's views are. I would prefer to represent the committee rather than just myself. Obviously, I have personal views, but it would be useful to know what members of the committee feel.

Are there any issues that members would like to raise today, or would you prefer to send us written comments?

Mike Rumbles: The fact that subordinate legislation cannot be amended by the committee hits a full whack below the waterline on the process. If we cannot amend it and there is no likelihood of throwing the whole thing out, the procedure is ridiculous.

The Convener: Do other members feel that it would be useful for the committee to be able to amend subordinate legislation?

Dr Turner: Yes.

The Convener: Okay. What about the timing? I have a big problem with the timing of a lot of subordinate legislation. We are frequently landed with statutory instruments when we have only one day on which to discuss them. That makes the whole procedure slightly farcical. Members who have been on other committees will know that that is pretty standard procedure. Does anyone want to make a comment about timing?

Dr Turner: How could it be improved?

The Convener: The Subordinate Legislation Committee is conducting an inquiry and wants to hear what we consider the problems are. I

presume that solutions will emerge from that inquiry.

Mike Rumbles: Statutory instruments cannot be amended, there are far too many of them and we do not get enough notice of them. It is as simple as that.

The Convener: Those are fairly standard criticisms.

Janis Hughes: We have dealt with more than 100 pieces of subordinate legislation in the past year. We already have a heavy workload, but sometimes we must discuss and pass a piece of subordinate legislation during a single meeting. That is impractical. Most subordinate legislation does not appear to be urgent, so why are there such tight time constraints for dealing with it?

Mr Macintosh: As a member of the Subordinate Legislation Committee, I can say that it will be useful for the committee not only to hear the comments that have just been made, but to receive examples of subordinate legislation for which the Health Committee believes it should have had more time.

For example, the Mental Health (Care and Treatment) (Scotland) Act 2003 involves a huge amount of subordinate legislation on mental health tribunals, which is going through right now. That could be an example of subordinate legislation that would have benefited from more time being spent on it.

Several issues are important, particularly how to build in more time to the process of amending legislation without clogging up agendas and how to differentiate between subordinate legislation that requires time to be spent on it, such as that for mental health tribunals, and others of the 100 or so pieces of subordinate legislation that the committee has considered in the past year that perhaps did not require much time.

The Convener: That is a good point. Ken Macintosh has given an example of the kind of subordinate legislation with which we have dealt previously. Statutory instruments arriving post implementation put us in a ridiculous situation. I have come across that previously and not just on this committee. The Executive must understand that if it dumps late or last-minute Scottish statutory instruments on us, it cannot expect us to adhere to other timetables that it may have imposed on us for other aspects of its business. Ultimately, the Executive directs all this work, because the SSIs come from it. Therefore, I believe that the Executive ought to consult us on whether we will be able to handle certain pieces of SSI work. It would be better if the Executive gave us more time in some circumstances.

Mr Macintosh: You might wish to state which SSIs you want consulted on, because you probably do not want to be consulted on—not the trivial—the less important.

The Convener: Amnesic shellfish number 153, for example.

Mr Macintosh: Exactly.

The Convener: That is a good example of a less important SSI, but there is a formal process to allow such SSIs to go through without discussion. Clearly, however, some SSIs are much more important and must be addressed more carefully. A number of the mental health tribunal SSIs probably come into that category. The danger is that by proceeding as we must in the timescales that we are given, important aspects of the implementation of legislation do not get much scrutiny. The potential for scrutinising SSIs is limited, which is worrying.

Dr Turner: On European legislation, when I first joined the committee we dealt with an affirmative resolution about vitamins. We had to pass it because there would have been penalties if we had not. I wondered why we were trying to scrutinise and discuss that instrument when we had to vote to pass it anyway.

The Convener: Occasionally, committees have refused to pass SSIs. I recall that happening in the Justice 2 Committee. It said no to an SSI and the Executive had to go away and do something different and bring it back a year later, as I recall. It is possible for a committee to do that, but we cannot exercise that power often. It would be far more sensible if we had the time front-ended.

Members are welcome to e-mail further suggestions for our response to the Subordinate Legislation Committee. I cannot remember the date when I will attend the Subordinate Legislation Committee meeting, but it is in November, which gives members time to make further suggestions.

That ends the public part of the meeting. I ask members of the public to leave the room.

15:54

Meeting continued in private until 16:05.

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