Citizen Participation and Public Petitions Committee

10th Meeting, 2023 (Session 6), Wednesday 14 June 2023

PE1911: Review of Human Tissue (Scotland) Act 2006 as it relates to post-mortems

Lodged on	11 October 2021
Petitioner	Ann Stark
Petition summary	Calling on the Scottish Parliament to urge the Scottish Government to review the Human Tissue (Scotland) Act 2006 and relevant guidance to ensure that all post-mortems— • can only be carried out with permission of the next of kin; • do not routinely remove brains; and • offer tissues and samples to next of kin as a matter of course.
Webpage	https://petitions.parliament.scot/petitions/PE1911

Introduction

1. The Committee last considered this petition at its meeting on 17 May 2023. At that meeting, the Committee heard evidence from Dr James Adeley, Senior Coroner (Lancashire); Dr Simon Beardmore, Consultant Radiologist (Lancashire); Ann Edwards, Coroner Services Manager (Lancashire and Blackburn with Darwen council); and Dr Mark Sissons, Consultant Pathologist (Blackpool Teaching Hospitals NHS Foundation Trust).

2. The petition summary is included in **Annexe A** and the Official Report of the Committee's last consideration of this petition is at **Annexe B**.

3. The Committee has received a new response from the Petitioner which is set out in **Annexe C**.

4. Written submissions received prior to the Committee's last consideration can be found on the petition's webpage.

5. Further background information about this petition can be found in the SPICe briefing for this petition.

6. The Scottish Government's initial position on this petition can be found on the petition's webpage.

7. Every petition collects signatures while it remains under consideration. At the time of writing, 804 signatures have been received on this petition.

8. At today's meeting, the Committee will take evidence from the Lord Advocate (whose role includes overall responsibility for the investigation of deaths in Scotland) and Andy Shanks, Head of the Scottish Fatalities Investigation Unit from the Crown Office and Procurator Fiscal Service.

Action

The Committee is invited to consider what action it wishes to take.

Clerk to the Committee

Annexe A

PE1911: Review of Human Tissue (Scotland) Act 2006 as it relates to post-mortems

Petitioner

Ann Stark

Date lodged

11/10/2021

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to review the Human Tissue (Scotland) Act 2006 and relevant guidance to ensure that all post-mortems—

- can only be carried out with permission of the next of kin;
- do not routinely remove brains; and
- offer tissues and samples to next of kin as a matter of course.

Previous action

I contacted my local MSP who is taking up my individual case but is also supporting my petition to achieve wider change.

Background information

My child died suddenly at home. As a result, there was a post-mortem. I thought it was a Grant & View but discovered not only was it a post-mortem but that, the brain, throat and tongue had been removed. I was horrified.

In the event of a sudden or unexplained death the Procurator Fiscal provides authorisation for a post-mortem, not the next of kin. I believe that this must change. *I also believe that brains should not be routinely removed.*

I was advised that the tissue samples taken belonged to no particular person and would be held as part of Medical Records. When I tried to retrieve them, I was sent on a wild goose chase for ten months, all whilst grieving.

This is different from *England/Ireland & Wales*, where loved ones are automatically offered the samples back (perhaps to add to caskets). People can decline the samples, but at least they are given a *choice*.

Annexe B

Extract from Official Report of last consideration of PE1911: Review of Human Tissue (Scotland) Act 2006 as it relates to post-mortems on 17 May 2023

The Convener: Agenda item 2 is consideration of continued petitions. PE1911, which is on a review of the Human Tissue (Scotland) Act 2006 as it relates to post mortems, was lodged by Ann Stark, who I believe is with us in the gallery this morning—you will have to forgive me, because my glasses are not that good, but I am aware of people at the other end of the room. Thank you for coming along this morning to observe our discussions.

The petition calls on the Scottish Parliament to urge the Scottish Government to review the Human Tissue (Scotland) Act 2006 and relevant guidance to ensure that all post mortems can be carried out only with the permission of the next of kin; do not routinely remove brains; and offer tissues and samples to next of kin as a matter of course. This morning, we will take evidence remotely from witnesses, because we will be exploring the relevant issues as they relate to practice in England, which the committee has been intrigued by in our previous considerations of the petition.

I am delighted to be joined this morning by Dr James Adeley, senior coroner; Dr Simon Beardmore, consultant radiologist; Ann Edwards, coroner services manager; and Dr Mark Sissons, consultant pathologist. Thank you all for giving us your time this morning and for joining us to discuss the petition, because the committee is genuinely intrigued to understand the different practice in England and why for the moment it is judged as being difficult to emulate in Scotland.

Having wished you all good morning, I will move to questions. I should say that our clerks will be keeping a careful eye on things, so please just indicate when you wish to contribute.

All of you provide a post-mortem scanning service in Lancashire and Blackburn with Darwen Council, and it is a collaboration between the county council, Lancashire Teaching Hospitals NHS Foundation Trust and a private scanning provider, Digital Autopsy UK. I understand that the whole arrangement has been in place since 2016 and was the first of its kind in the United Kingdom.

Can you, by way of introduction, provide a bit of background? What prompted the establishment of the service? Was it simply a good idea? Was there similar public concern about the arrangements that had been in place? Was it a matter of professionals coming together who believed that it was possible to do things differently and in a way that better served the public interest? I am very interested in understanding how all this came about in the first instance.

Who is going to kick off? I am looking for one of our witnesses to volunteer.

Dr James Adeley (Lancashire and Blackburn with Darwen): I was the coroner in place in 2016. About two or three years before that, we looked into the future and realised that, because the number of pathologists was decreasing rapidly, we would not have any form of post-mortem service. That was coupled with research being developed, particularly in the University of Leicester, that showed that quite a lot of post mortems could be done through post-mortem scanning. It is not a panacea, but it can deal with a large number of cases.

We started to look at how to set up a service to achieve that. It was difficult—it was certainly the most complex work that I have ever done—and it required all of us, including Simon Beardmore and the local authority, to act in concert.

I will explain one of the driving forces behind the service. For those of you who have never been to a post mortem, I note that it involves the person’s body cavities being opened and all their organs being removed. The organs are examined before being put in a plastic bag and put back in the abdomen. The body is then reconstructed. There have been advances in computed tomography scanning, but that procedure is still very invasive. Quite a lot of faith communities would not accept it, and families are upset by it. In my view, offering a different service is the way to go as technology develops.

Providing that service required everyone to act together. We wanted to provide a post-mortem scanning service based in a hospital next to the mortuary, with all the personnel undertaking the tasks being within the NHS. That was to be part of their job plan so that we did not have difficulties with ad hoc arrangements. The service was to run year in, year out.

When it comes to setting up such a service, the mechanics of it are not the problem. The issue is the past history of pathologists who have done post mortems and the fact that this is a new technique; it is an imaging technique, not an invasive technique.

I am not sure whether I am helping any more. Do you wish me to go in a different direction?

The Convener: What you have said is very helpful. At the start of your comments, you said that there was a rapid reduction in the number of pathologists. Can you elaborate on why that was the case? Has that reduction continued apace, or has anything been done to try to arrest that decline?

Dr Adeley: I will answer first and give my perspective, but Mark Sissons will also have a valid viewpoint, given that he is a practising pathologist.

About 15 or 20 years ago, the Royal College of Pathologists made a change. It used to be that a pathologist was required to undertake post mortems as part of their training. It was found that people were not going into the profession because they did not want to do post mortems, but pathologists were still needed to look at all the slides and biopsies from the living. Consequently, there is now a split training regime in which people are not required to undertake post mortems as part of their training—it is something that people volunteer for.

As a result, it tends to be older pathologists who have expertise of carrying out post mortems, and they are coming to the end of their working lives, so there was a fairly rapid reduction in the number of those pathologists. In Lancashire, the issue became incredibly acute over a short period of time, but the problem exists almost everywhere. Even now, we have only Dr Sissons and one NHS pathologist for a population of 1.4 million people. Given those numbers, we could not even mount an external body examination service, let alone a post-mortem service.

I will pass over to Dr Sissons so that he can give his view.

Dr Mark Sissons (Blackpool Teaching Hospitals NHS Foundation Trust): I agree with what Dr Adeley has said. The majority of trainee pathologists do not want to get involved with coronial work. There are many reasons for that, but the main one is that they are very busy with their laboratory-based work. There are lots of demands on the system. For example, there are a lot of cancer diagnoses to be done in laboratories, and there are timeframes associated with those. Therefore, most trainee pathologists do not want to get involved with coronial work, because it is almost like private work—people need to do it in their own time. The way in which things are organised means that any coronial work must be done in addition to the normal laboratory work that people are expected to do. For those reasons, the majority of trainees are just not interested in becoming coronial post-mortem workers.

The Convener: From what you have both said, it sounds as though there was a driving necessity to bring about a change in the arrangements that were in place. Every bit as much as clinicians and others thought that it was the right way forward, it sounds as though the previous arrangements were potentially dangerously unstable in terms of being able to provide a service.

On that basis, I am interested to know whether, to your knowledge, in the interim since 2016, the practice that you have evolved has been rolled out to other parts of the United Kingdom outside Scotland. In so far as you were able to establish a service, will you tell us what the main challenges were in trying to bring about what you have achieved, as a general introduction to the questions that will then follow? I do not know who will volunteer to speak.

Dr Adeley: If I start and Dr Beardmore comes in afterwards, would that suit?

The Convener: Yes. That is fine. When questions are asked, to avoid us operating in a vacuum, it will possibly be helpful if I come to you first and you direct us to the colleague who you think would be most appropriate to answer.

Dr Adeley: Okay.

The pathology service for coroners was about to cease to function around that time. The set-up that we have here is quite different from the set-up in a lot of other parts of the UK. When Dr Beardmore and I set this up together, we took the view that, when you CT scan somebody, it is an imaging process and you get a series of images on a screen. There has been a lot of work comparing images against causes of death established at post mortem so there is correlation between the two. We decided that, when someone has enough experience as a radiologist of seeing scans against dead people, they are able to say, from looking at a scan, that a person has died from a particular disease. That is in much the same way as, over the past 300 years, pathologists have gained experience of looking at diseased organs.

My view was that, in most cases, we did not need to involve a pathologist with the radiology images. Post-mortem scanning does not always give the answer, and you do need to have pathology there—it is still a very important part of coronial practice for those cases in which you cannot make a diagnosis and in certain other areas, which I will come back to.

However, we had the problem that, first, there really were no pathologists; secondly, I could not justify a pathologist being involved, because they are needed for treating the living; and, thirdly, if it is an imaging modality, it takes too long to train a pathologist to understand the images. Consequently, as there is a shortage of pathologists, we would have been making things worse.

The other problem that we run into is that, given the volume of scans—the population in my area is about 1.4 million and we do 1,650 scans a year—if you add on the very low fees for a pathologist to review the radiologist's report, which would be £100 each time that they do that, you would increase your costs and slow down the process. For that reason, I took the view that I would ask the radiologists to report on this. That is not what is done in a lot of areas, where radiologists work as they do in the NHS when they are assisting the living. They provide an opinion and that is sent to a pathologist, who looks at the opinion and says, "Yes, I think that's okay," or, "No, I don't think that's okay." I have a problem with that due to the fact that they are reviewing what someone else has written, without reviewing the scans themselves. I wonder why they are involved at that point.

However, pathologists are very important for those cases in which post-mortem scanning does not produce a result. When that occurs, it depends how you scan, and there are two types of scan. We took the view that we wanted the scan that would provide the greatest number of diagnoses because, otherwise, if we had to go on to a post mortem to find a cause of death, the limiting factor was our pathologists.

The two types of scan are a plain scan, in which a person is simply put through a CT scanner, as they would be if they were in casualty, and an enhanced scan, which is what we have. In an enhanced scan, we perfuse the coronary arteries with dye, and we will sometimes ventilate the lungs. Dr Beardmore is better at that than I am.

That gives us a diagnostic rate of around 94 per cent, interpreting on the basis of the radiologist. If the radiologist is uncertain, we can go back to the clinician who treated the deceased at the time to ask them whether that accords with their views on the living. If they can be provided with negative findings, they will quite often be able to give more input into the cause of death.

Has this approach been rolled about across the UK? There is not another service like this one that runs on just radiologists. The rest run on pathologists and radiologists. More centres are doing it, but I think that the number is still less than 10. Dr Beardmore may know better.

You asked about the challenges in setting this up. The biggest problem that we ran into was that the pathologists quite rightly have the view that establishing the cause of death has been their purview for the past 300 years, and there is the consideration of how they will remain involved in the coronial process and whether they will be part of the post-mortem scanning service. A debate about that probably needs to be had between the royal colleges to sort it out. However, given the fact that we are running out of pathologists, that seems to be going only one way.

The Convener: That is very helpful. Thank you.

Dr Simon Beardmore: Good morning. Dr Adeley has picked up on most of the things that I was going to say.

There are places around the country that do CT post-mortem services. Leicester does them—we did the training there—Oxford is doing things, and the private set-up is operating through Stoke, Stanwell and Birmingham way. Those are the ones that I know about.

Radiologists are quite adaptable. We can move from one sub-speciality to another, and most radiologists who have trained in CT scanning can quite easily report a scan of the dead as well as the living. From our point of view, there is not too much training needed to report on a scan of the dead.

We can turn scans around quite quickly. We can do probably one scan every half an hour and get a full report out to the coroner. We do one session a day Monday to Friday. Therefore, we do eight scans a day, which equates to around 1,500 scans a year. That is probably a quicker turnaround service than there would be with a traditional invasive post mortem.

The other thing that we can do as radiologists is remote report, so we do not have to be on site where the body is. Therefore, you could get a group of radiologists together in a different country if you wanted to, and they could report the scans remotely. As has been said, a non-invasive scan is better for religious beliefs and a lot of faiths that do not like invasive post mortems.

Are there any specific questions about radiology or the scan process that you would like to ask?

The Convener: Fear not. We will have a number of questions.

This is all incredibly technical. In some of your answers, you may well volunteer information that will come up again in questions that my colleagues will ask. It is quite a complicated subject, and we are keen to understand it as well as we lesser mortals can.

The conclusion that I am coming to is that there is variable practice, but the common feature no doubt is that the number of pathologists is reducing everywhere because of the way in which the service is structured and the voluntary nature of electing to participate in post mortems. That is an interesting consideration.

I will bring in my colleague David Torrance. We have been told by the Crown Office in Scotland that achieving the skill sets required to move to different technology would be incredibly difficult.

David Torrance (Kirkcaldy) (SNP): Dr Adeley, earlier you talked about training of pathologists and using radiologists.

As the convener has already said, the Crown Office and Procurator Fiscal Service has identified skills shortages within its workforce. Was there any need to upskill pathologists at Lancashire and Blackburn with Darwen?

Dr Adeley: Upskilling radiologists to read scans is a two-week course; it is just an adaptation of what they already do. They are looking at how bodies change after death, which is a special skill set, but it does not take a radiologist long to learn because they already have the basic skills. The course is therefore straightforward. It was taught to the 14 radiologists we use in Lancashire at the University of Leicester in two-week courses, in three tranches.

Upskilling the pathologists was not necessary. We give the pathologist the scan report and ask what they can see on a series of images. It gives them information about how to approach the post mortem and where they might wish to go. For example, if the scan report of somebody who has died suddenly says that it cannot see any bleeds within the brain, one might not need to go inside the head to examine it if one can find something else in the rest of the body that has caused the death.

The pathologists did not need to be retrained. They continued to do the job that they have always done.

David Torrance: So, no post-mortem imaging training was given to the pathologists at all.

Dr Adeley: We can do it one of two ways. We can train radiologists to look at the images, which is relatively quick because they are already skilled at doing that. If we want to run a service in which pathologists look at scans, that will require a considerable amount of training and effort. Pathologists are not skilled at looking at radiological images: it is not within their skill set. If we wish to approach it in that way, we can do so, but I do not know of anybody who is even considering that. Very few pathologists read scans. There is Dr Guy Rutty in Leicester and there is somebody in Oxford, but it is unusual to find a pathologist who does that. They have usually been in the process for a very long period of time, having started at the beginning where they would do the scan and then do the post mortem.

However, in the system that we run, and in most of the other operations in the UK—the six that Dr Beardmore mentioned—imaging is all reported by radiologists simply because of speed and ease of training. The scan can be given to the pathologist and they can read about what can be seen on it, and I do not think that they require any further training for that, although perhaps Dr Sissons could help you with that.

Dr Sissons: Training pathologists to interpret radiological images is a non-starter. I do not think that there would be any enthusiasm for that. It is not appropriate for pathologists to be involved in reporting X-rays. They are chalk and cheese—the post mortem that we do and the radiological images are two different things, and that reporting is not something that pathologists would want to get involved in. They would be quite happy to read the report of the radiologist and take all that on board.

Dr Beardmore: Training for a radiologist to report scans of the living takes five years in this country. Once you have the skill set to report on a CT scan, it does not take too much to adapt to reporting CT scans of the dead once you have already done the training in interpreting CT scans. We did a three-day course in Leicester to show us the changes that happen after death. After that, we were fine to report on post-mortem CT scans. If you were to train a pathologist to report on a CT scan, it would take more than five years for them to become good at it.

David Torrance: I want to pick up on that point. In Scotland, radiologists are like hen’s teeth and the NHS is under huge pressure. Is there any way that pathologists could be trained in post-mortem scanning in a shorter time? Could that form part of the training that pathologists do?

Dr Beardmore: I do not think that they have the willpower to do it. Most of the pathologists whom I have asked, “Would you be interested?”, have said, “No,” so I think that attempting to train pathologists to interpret scans is a non-starter.

David Torrance: Thank you for that.

I have a final question. Given the pressures on pathology post-mortem and forensic services, to what extent does use of post-mortem computed tomography scans reduce those pressures?

Dr Beardmore: The use of PMCT scans does not reduce the pressure on brain scanning of the living. Through training 14 of us, we have spread the workload between us, so that one radiologist does not take a big hit, so to speak. We do one session every two weeks, which is not too onerous.

You are quite right: there are pressures on scanning the living, just as there are on scanning the dead. That is the case across the board. There is a 10 per cent vacancy rate in radiologists in the UK. The only thing that I can think of is that, as radiologists, we can turn the scans around a lot more quickly than the pathologists would have been able to turn around invasive post mortems. Therefore, the process is slightly more efficient from that point of view.

The Convener: I want to go back over some of that territory. You have spoken about the fact that it is felt that it is a “non-starter” to consider retraining pathologists and that the desire for that does not exist among that community. You have alluded to the shortage of radiologists. To be perfectly candid, it is not a public secret that Scotland is acutely short of radiologists. For example, the 62-day cancer standard is not being met by any of Scotland’s health boards. The waiting time for all the key diagnostic tests, including radiology, is not being met anywhere in Scotland. The statistics from December 2022 show that just 45.8 per cent of patients waited less than six weeks for their diagnostic test.

This is not necessarily a question that you can answer, but I wonder whether similar pressures were advanced in the arguments that took place when your service was set up. The Government might say in response to the petition, or to any initiative that we might subsequently seek to promote, that faced with an acute shortage of radiologists, its first priority should be the living and that any such proposal would divert and potentially further undermine our ability to satisfy or meet currents needs, or even to close the gap, as regards current provision. Was a similar sentiment advanced when you set up your service?

Dr Beardmore: There was a concern. However, not all radiologists report on cancer scans. For example, I am a musculoskeletal radiologist, so I am not under pressure to report on cancer scans; I deal mainly with bones and joints. We have quite a few interventional radiologists who do some reporting for us, too.

It is true that such pressure exists, so it is necessary to decide where you want deploy your experience, or in what areas you want your radiologists to be reporting. However, not every radiologist is a cancer specialist. There are a couple of people who report on cancer scans who also do post-mortem CT scans, but as I said, because there are 14 of us who are trained, we can spread the load between us to provide a service.

The Convener: That is helpful. Scotland has a 62-day cancer treatment standard. For my understanding, is there similar pressure in your area in respect of that discipline?

Dr Beardmore: Yes, there is pressure to get scans turned around. I frequently see emails saying, “Patient is back in clinic; we need a report the next day”, so we have the same pressures on us as you have in Scotland.

The Convener: That is helpful to know, because it sets in context what we are discussing. It means that our situation in that regard is not unique, and yet the provision has been established elsewhere.

Fergus Ewing (Inverness and Nairn) (SNP): Good morning. I have questions first on quality assurance and the efficacy of CT scans as opposed to conventional post mortems and, secondly, on the cost aspects.

On quality assurance, the petitioner claims that scanners are 99 per cent accurate in establishing the cause of death. However, a submission to the committee from the chief coroner highlights guidance on the use of imaging in post mortems. It references a joint statement from the Royal College of Radiologists and the Royal College of Pathologists on post-mortem cross-sectional imaging. I am told that the most recent version of that details the strengths and weaknesses of imaging in establishing the cause of death. For example, it details its accuracy in establishing deaths from trauma, stroke and heart disease and its limitations in diagnosing deaths from conditions such as sepsis and poisoning. I guess that I have—[Interruption.] Excuse me. I am sorry—I will just turn my phone off. My apologies, convener.

With that introduction, which I thought might be helpful to set the background, I have three questions. I will come to Dr Adeley first. First, how do PMCTs compare with traditional post mortems in terms of accurately establishing a cause of death? Secondly, can the witnesses detail the main strengths and weaknesses of using imaging in post mortems? Thirdly, what proportion of deaths could have their cause accurately established by using imaging?

Dr Adeley: Those questions are interrelated. With regard to peer review and the different types of post mortem—[Interruption.] I am sorry; my clock is chiming in the background. The review is not done by one pathologist sitting with another pathologist going through the same post mortem at the same time—there is no peer review. Also, unless samples are taken there is no permanent record—these things are not photographed—whereas with a post-mortem CT scan, the scans remain as digital images for as long as they are kept. We are required to keep ours for 15 years.

On quality assurance—I will ask Dr Beardmore and Dr Sissons to come in after me on this—there are different types of scans. A plain scan, for example in the case of heart disease, relies on the amount of calcium that is deposited in the arteries that supply the heart. That gives a score and tells us how likely it is that the person died from coronary artery disease. The technique that we use—in younger patients where clots in the heart are more likely—involves putting in a catheter. Because we are using a relatively much more invasive approach—imaging things with dye and catheters within the coronary arteries—our diagnostic rates are considerably higher.

As I said at the beginning, it is accepted that CT scanning is not a panacea. There are certain things that it does not do well. Sepsis in particular is one of those things. Sepsis is a generalised infection that runs throughout the body, and we need to look at the organs for that. If someone has been poisoned, we will quite often be looking at a Home Office post mortem, which is of a completely different character, but we might wish to instruct a post mortem that is performed by a pathologist directly. We would not go to a CT scan to begin with. There are academic articles that say that, in some circumstances, CT is better for things such as trauma but is not as good for other soft-tissue injuries.

The issue that I was running with when I was setting things up was that it really does not matter which system is better if there are no pathologists. That dictates the choice that is made. The situation in Scotland might be different, but if there is one option and it will do the job nearly as well in most circumstances, that is the choice that will be made. There are academic papers on that, if you wish to be referred to them.

On producing causes of death, we scan 1,600 deceased people a year. We are probably the largest scanning outfit in England and Wales. About 6 per cent of our scans go on to pathology. It is very useful to have pathology for things such as suspected sepsis and for when someone has had an operation. It is absolutely essential if people might have a genetic component to heart disease. In such cases, biopsies are needed to send to specialist pathologists. We also need to be able to take biopsies for people who have suffered from industrial disease in order that claims can be pursued.

It is not really an either/or question. Both approaches are needed, even if a post-mortem CT scan is going to be run.

Dr Beardmore: We give causes of death in 90 to 95 per cent of cases, but that does not necessarily mean that we always get it right. We run on the rule of the balance of probability, which means that we have to be right in 51 per cent of cases. As long as we are correct 51 times out of 100, we are still within the law. That is why we can give causes of death at a greater rate than some papers on the accuracy of post-mortem CT say.

As Dr Adeley said, CT is very good for trauma and spotting fractures, and at coronary artery disease using a non-invasive approach in which we use calcium scoring, or a minimally invasive approach in which we pop in a catheter and put some dye down the coronary arteries. Both techniques are very useful.

The deaths of the majority of people who drop down dead without a cause of death relate to cardiac disease. We follow the rule of the balance of probability, which is why we can give the causes of death that we give.

A radiologist mindset that has to be got around is that, when radiologists report on the living, they have to be nearly 100 per cent accurate in what they say, whereas when they report on the dead, that level of certainty is not required. Therefore, a cause of death can be given even if the person is not 100 per cent certain that that is what caused the patient to die.

Dr Sissons: There is no doubt that computed tomography post mortems are very useful. They relieve the burden of a lot of invasive post mortems.

I get involved with industrial disease cases in which large samples of tissue need to be taken, maybe from the lungs. Those are the common cases that I deal with. It is important that young people who have died from heart disease have an autopsy or a limited autopsy to get samples of the tissues for expert analysis and genetic testing.

I come across cases in which the CTPM is incorrect. My main worry about CTPMs is pulmonary emboli, which are what happens when blood clots travel from the leg or pelvic veins and block the arteries in the lungs, causing sudden death. In my experience, there is no doubt that the CTPM misses some of those. From my point of view as a pathologist, in the cases that I work on, the one disappointing aspect is when I see pulmonary emboli that are not detected on a CTPM scan. However, I think that evolving techniques will improve that situation and, overall, the CTPM service is very useful. It solves the problem of invasive post mortems not being able to be done by pathologists, and it means that people are not waiting a long time for invasive autopsies to be completed.

Fergus Ewing: I will ask one supplementary question. I think that the witnesses will be aware that the petition that is before the Scottish Parliament was occasioned following the sudden death of the petitioner’s child. The petitioner’s child underwent a post mortem that was much more extensive in nature than the petitioner had originally thought it would be. Obviously, anyone’s death involves grief, sadness and bereavement for their family, and the post-mortem issue is very sensitive. That is otiose—I do not need to tell any of the witnesses that, because they deal with the matter in their professional work.

However, obviously, the death of a child is particularly hurtful and causative of long-lasting, perpetual, eternal emotional harm, and that is really why we are taking evidence today. With that backdrop, are there any particular strengths or weaknesses in relation to the use of a scan after the death of a child, most especially an infant or young child?

Dr Adeley: The issue of children is a particularly problematic area because, after death, children do not scan in the same way that adults do. Children need to be put through an MRI scanner rather than a CT scanner; MRI scanners work on magnetism, whereas CT scanners work on X-rays.

The problem is that the number of unexpected child deaths is extremely small. The reason for that is that most child deaths are either expected—because the child has a long-term illness and has been treated within mainstream healthcare—or the death is completely unexpected and there is a criminal suspicion with it, in which case it will go down the Home Office post-mortem route. That leaves very few cases in the middle, where the death is not suspicious but is unexpected. The problem is in maintaining the skill set of the radiologists in doing enough of those cases to know that they are getting the right answer. When it comes to numbers, that situation is very different from scanning adults.

With regard to children who are older, as in the case of Mrs Stark’s son, there is a particular concern around young adults who die suddenly, because there is something called sudden adult death syndrome, which is a collection of heart diseases, some of which might be genetic. Unless we take a biopsy for that, we will not be able to diagnose it, and the problem is that, because there is a genetic aspect, other family members might be at risk. In order to deal with that more effectively, we have just signed up to a pilot for limited post mortems, in cases in which samples need to be taken for genetic testing, which requires an invasive post mortem.

However, when we deal with such issues, we usually ask the family about their views about post mortems, because there is a range of views when it comes to how families approach the subject. Whereas some families are not bothered by it, some families are extremely distressed, particularly those in the faith communities.

In those cases, a conversation takes place between the coroner and the pathologist. The body will be scanned first and, if nothing can be seen from the scan of the head, the pathologist will be asked to look at the heart. If they find the cause of death or if the heart looks abnormal—for example, if it is markedly enlarged—they will be asked to limit the post mortem to the areas that are most likely to produce a cause of death.

The difficulty with limiting the pathologist’s investigation is that they might not see what they expected to see when looking at the slides using a microscope, so a cause of death might not be found. The process involves a series of unknowns when it is done in real time, and the investigations cannot be done quickly enough to avoid hanging on to a deceased person’s body for a long time while all the investigations are conducted. The answer is therefore not straightforward.

Would Dr Beardmore or Dr Sissons like to comment?

Dr Beardmore: In our country, it is only specialist children’s centres that do paediatric post-mortem scanning, and that is done only on a research basis. Therefore, as far as I know, such children still go on to have invasive post mortems. The reason for that is that, as Dr Adeley said, there are so few child deaths that places such as Preston will not get enough experience to be able to confidently report on such scans, because we do not see enough of them. That is the main issue relating to child deaths. By concentrating the expertise in children's hospitals, we might eventually be able to build up the experience to be able to report on CT and MRI scans in those circumstances.

Fergus Ewing: Thank you.

The Convener: My colleague Foysol Choudhury has a supplementary question.

Foysol Choudhury (Lothian) (Lab): As has been said, any death results in a sad time for the family. Do families have an opt-out option? For example, in some faith communities, people want the burial to take place as soon as possible. As the witnesses said in answer to the convener's questions, there is a shortage of professionals, so people might have to wait a very long time. What value is given to those families? How much information is given to them when organs are removed from the body?

Dr Adeley: We have very good relationships with faith communities. Our system applies to everyone, no matter their religion; if it applied only to the Muslim faith or the Jewish faith, that would be discriminatory. If there is a very good reason for an expedited post mortem—for example, for religious reasons, or because the family is travelling here from abroad—we will move the case through the system much more quickly.

We are well aware of the concerns of faith communities regarding post mortems and the body being a holy object. Faith communities are very much behind the post-mortem CT scanning. Mosques have raised money to pay for additional body storage.

In Lancashire, the average time between someone dying and their getting a post-mortem CT scan, if that is needed, is about three or four days. In most cases, a post mortem is not necessary. However, if it is necessary because there is no obvious cause of death, we have a conversation with the family and explain what we are doing. We have discovered that faith communities want two things. First, they want the burial to occur as soon as possible. Secondly, if that is not possible, they want us to provide information on how long the process will take, so that we do not cause social difficulties in relation to accommodating all the family members who come.

The tension usually arises when a young person—someone under the age of 60—dies suddenly and there is a concern that the death was caused by a genetic cardiac condition. If it is a single child and there is nobody else around, it is not going to affect anybody, so we would not do an invasive post mortem. However, quite often, families are quite large and there are brothers, sisters and cousins who might be at risk of inheriting that disease, which could be treated.

In those cases, I will have a conversation with one of the religious leaders and I will explain why we are doing that and why it is necessary—to stop the possibility of the next event occurring, which would be another family member dropping dead. It is not a decision that I ever take lightly, and each case is dealt with on its own merit. If you like, I can give you the contact details of the local Muslim burial societies, so that you can speak to them about how they find dealing with us, but they were very supportive of CT scanning because it is faster.

To give you an idea, we once put 18 bodies through the CT scanner in a single day. The radiology department asked me to never do that again, but it can be done. You would be lucky to get four post mortems done in a day. The reports come in that evening or the next morning. Dr Beardmore treats the living, and if he gets called away, we will wait. However, usually, the delay is 14 hours and no more. Usually, the report comes back on the same day. Does that answer your question?

Foysol Choudhury: It does, but the situation is never clear, because every case is different, as you have said. Most of the time, the family feel that they are not getting the information that they should be getting. There should also be an opt-out option. It is not clear whether the family is allowed to say that they do not want to go through all that difficulty.

The Convener: Thank you for that.

Before I bring in my colleague Alexander Stewart, I am conscious, Ann Edwards, that you have been sitting patiently with us this morning, so might I bring you in to make any general reflections on the comments and evidence that we have heard so far?

Ann Edwards (Lancashire and Blackburn with Darwen): Yes, thank you. Good morning. On our role as a local authority, we have a statutory duty to resource the coroner in order that he can carry out his judicial functions. My role is in relation to the finances. From a local authority point of view, the CT scanning service is cost neutral, so it does not cost us any more than the invasive post-mortem service did.

We have a number of key performance indicators that we use to monitor the service. I will give you some figures. Dr Adeley has already referred to these, as, I think, has Dr Beardmore. In 2022-23, 94 per cent of our scans showed a cause of death, which left 6 per cent that did not. Of our post mortems, 92 per cent were non-invasive; that is the highest non-invasive post-mortem rate in England. Do you have any questions around the finance side of it?

The Convener: We do, in fact. I was getting ahead of myself by saying that I would bring in my colleague Alexander Stewart, because my colleague Fergus Ewing, who spoke a moment ago, has some questions directly on the finance side.

Fergus Ewing: I will try not to be so long winded this time, but, as a lawyer, I always find that a bit difficult.

How do the costs of the post-mortem CT service compare with those of traditional post mortems? Secondly, are the post-mortem CT scans generally provided free of charge or is there typically an out-of-pocket payment? If so, what is that usually set at?

Ann Edwards: On your first question, our CT scanning service was set up so that it would be cost neutral against the invasive post-mortem service, so it costs us no more than it did when we were doing invasive post mortems. We use a private contractor that provides us with an end-to-end service. It provides us with the transport of the deceased from our satellite mortuaries to our scanning facility in

Preston. That is all included in the price, which is cost neutral relative to that of the invasive post-mortem service.

Fergus Ewing: What is the additional cost or is there a range of additional costs?

Ann Edwards: Additional costs in what sense?

Fergus Ewing: I am asking whether a payment is asked to be made from the family in the case of extra costs for the CT scan, as opposed to the traditional invasive post mortem.

Ann Edwards: No; there is no cost to the family. The service is free of charge and is provided by the local authority.

The Convener: That is very helpful. Thank you very much. I bring in my colleague Alexander Stewart, who will ask some questions about tissue samples.

Alexander Stewart (Mid Scotland and Fife) (Con): Dr Adeley, you touched on the samples and biopsies that are taken. We have already heard from the Royal College of Pathologists, which talked about the potential challenges that are associated with tissue samples and any returns of those samples. Do you recognise the challenges that the Royal College of Pathologists described when it comes to returning samples? Have you had issues in that area? What are your views on the process?

Dr Adeley: I am unfamiliar with the challenges. If I explain what we do, it might answer the question in a roundabout way. What happens with any sample that contains even a single cell is that the family are asked what they want to be done with the sample when it is finished with. The family are given a number of choices. The coroner’s officer will ask whether the sample could be retained by the hospital for medical research and teaching, or it can be returned to the family and their undertaker. Alternatively, they can elect for the sample to be disposed of by the hospital in a lawful and sensitive manner. Those are the three choices.

This applies with an invasive post mortem, not with CT scanning. After an invasive post mortem, the pathologist will fill out a document saying what they have taken in terms of organs, histology samples, blood and urine, then the coroner’s officer will ask the family what they would like to be done with that. That will be fed back to the hospital where the post mortem took place, which will then deal with the samples in that way.

We have no problems with that process—it is very straightforward and it works very well. The only time that it causes problems is when the family elect to have the samples put back in the body before it is returned, because then the body has to be retained. For certain pathologists, we have a backlog of a year before we can get a report. Quite often, that can be managed so that the funeral takes place and a second funeral is held, when the grave is excavated down to the coffin and another casket is put on top.

I do not know about the challenges that have been raised by the Royal College of Pathologists, but we have no problems with that system. It works almost faultlessly and with very little administration.

Alexander Stewart: That is very good to hear. The communication process was identified as an area of challenge, and you have explained what you do to inform the relatives, the next of kin or individuals who require information and how that is managed. The college found that there were sometimes barriers in communication and in making sure that individuals understood what was expected and what would happen to the samples. It identified that area in its evidence to us.

Dr Adeley: Ann Edwards used to be my senior coroner's officer, so she has first-hand experience of having conversations with families. If you would like to explain the difficulties that were raised, I am certain that she would be able to answer your questions.

Alexander Stewart: If I can, I will explain that to you, Ann. Reference was made to the complexity of the communication process as a potential barrier. The Royal College of Pathologists felt that offering relatives options for tissue sample handling—Dr Adeley explained how that process is managed—could present a barrier. Have you encountered any challenges around communications and the options for seeking informed consent?

Ann Edwards: No. In my experience, families sometimes need some time, which is absolutely fine. The coroner's officer will contact them, explain what samples have been taken, go through the options and then give them some time; you can go and explain it to them the following day. I understand that, especially when whole organs are taken, that is quite a big decision.

What families want to know will vary. For example, if the brain has been taken, we would explain to the family that it can take some time for the process to be gone through before the pathologist can look at the slides. Some families do not want to know that, whereas some families are really interested in the process. We are guided by the family when it comes to how much they want to know, but we will always inform them of exactly what has been taken and what their options are in relation to that once the pathologist has finished doing their tests. In my experience, I have not encountered any issues with that.

Alexander Stewart: Excellent. Thank you very much for that.

The Convener: Yes, thank you for that. In the written evidence that we received, the Royal College of Pathologists put up what the committee felt was almost a smokescreen—I do not think that that is too strong a word to use—in discussing the issue, by saying that a decision would have to be made that the tissues were no longer of use; that if the tissues were to be buried or cremated, that would delay the process; that if the tissues were not to be buried or cremated with the body, the options would need to be explained and understood; and that the process would be very complicated, which could lead to delays and to the family not properly understanding matters. You mentioned the Home Office; here, matters would be referred to the procurator fiscal. That would be a completely different type of event.

From what you have articulated, it seems as though an operational practice has been established where you are that has not led to a massive increase in cost and which has worked perfectly satisfactorily for all those concerned. That is quite an important piece of counter-evidence.

I am sorry—in summing things up, I hope that I have not editorialised anything that you said.

Ms Edwards mentioned brains. I want to come back to a couple of general issues that arose out of the petition that have not been covered in the commentary that we have had to date. In her petition, the petitioner asks that all post mortems

“can only be carried out with permission of the next of kin”

and that post mortems

“do not routinely remove brains”.

What is your view on those two propositions?

Dr Adeley: Families are always involved in the decision on what post mortem is taking place. That will be explained by the coroner’s officer. I appreciate that I might sound paternalistic here; I am not intending to be paternalistic. The problem comes when the family is fractured, which quite a lot of the families that we deal with are. Therefore, a coroner might be dealing with two or three different parts of a family, one of which will want a post mortem to be carried out.

In a situation in which one family member does not want a post mortem to be carried out and another one does and it is a question of genetic testing for heart disease, which somebody else might die from, giving the final choice to the family might cause all sorts of problems. The same issue arises when biopsies have to be taken for compensation for lung disease. We find that, with post-mortem scanning, there is nothing like the same level of concern. Now, if someone is under the age of 65—I think that that is the age—the most that will happen is that a very small incision will be made under their left collarbone for a catheter to be introduced. Other than that, there will be no marks on the body. What Mrs Stark has described happening to her son seems to be a standard post-mortem practice, which is extremely invasive.

I do not know what your rules are, but if you are going to make the procurator fiscal responsible for establishing the cause of death, you would have to have some provision so that, if the family refused to have a post mortem undertaken, they are not required to proceed.

The final area where I would raise concerns is that that should not apply to a Home Office post mortem. If it did, a parent who is accused of killing their child could veto the ability of a Home Office post mortem to take place.

I hand over to Dr Sissons or anybody else who wants to speak on this particular point.

The Convener: Does anybody else want to contribute on that point? Before anyone else comes in, there was also the issue about brains being routinely removed.

Dr Adeley: I will ask Dr Sissons to come in after me. The Royal College of Pathologists has guidelines as to how a post mortem should be undertaken. Those will set out what steps should be taken, and the examination of the brain is one of the standard investigations as part of that.

Here, if we have done a post-mortem CT scan and we can see nothing in the head—there are certain conditions that you cannot pick up, including types of stroke—we can assure the pathologists to some extent that there is nothing going on there and that they should restrict their investigation to the other parts of the body.

The question as to why that is a routine procedure in its guidance is one that the Royal College of Pathologists would need to answer rather than coroners. We actually have to specify not to do that rather than to specify that it is something else.

Dr Sissons: That is where CTPM scanning helps. In my experience, if we have got a normal brain on the CTPM, I feel quite confident that I could proceed with the invasive autopsy without examining the brain in most cases.

I think that you are right. The Royal College of Pathologists' best practice is that you should always look at the brain. However, I think that CTPMs can really help to minimise that so that it need not be done on some occasions.

The Convener: Thank you. Again, that is very helpful to our consideration.

That brings us to the end of the questions that we wanted to put to you. I am enormously grateful. You are all very busy professionals and clinicians, and the time that you have given us to hear your evidence this morning really will help the committee considerably as we consider the petition and how we might take forward some of the issues in it. Thank you all very much for your participation. I say on behalf of everybody here in the Scottish Parliament how very much it has been appreciated.

I will move now to Monica Lennon MSP, who is joining us this morning and has joined the committee on previous occasions when we have considered this petition. Before the committee reflects on what has been heard this morning, which I think that we can all say has been very interesting, is there anything you would like to reflect on and add, Monica?

Monica Lennon (Central Scotland) (Lab): It is lovely to be back at the committee. Thank you for all your work on the petition. That was an excellent panel. The evidence was very interesting and I have been taking copious notes. Ann Stark, the petitioner, and her husband, Gerry, are in the gallery today. I highlight Ann's work in building research in Scotland and making connections with colleagues elsewhere.

On my reflections, convener, I was struck by our need to modernise, to keep pace and to address some of the future challenges. It was really interesting to hear the work that colleagues have been pioneering in the Lancashire region in England. Obviously, there are other examples down south. However, there is some really good practice there, and for us in Scotland—both the Scottish Parliament and the Scottish Government—there is a lot that I hope we can learn from.

It was interesting to hear from Ann Edwards that the service—which, as came across strongly, is being delivered in partnership with a number of different partners but working closely with communities—is cost neutral. That is an important point for all of us. Also, there is no cost to family members from having the scans undertaken.

On the workforce challenges for pathology and radiology, it feels to me like there is a framework that we can consider. If colleagues in the Scottish Government wanted to consider it, they might want to have a different approach. Clearly, there is a big role for a private contractor and the Scottish Government might want to consider something different.

We should remember why we are here. Richard Stark passed away almost four years ago. He was 25. That is no age at all. He was very loved by his family and it was only when Richard died that they started to realise and understand what can happen to each of us or to our loved ones when we die. There are big issues around bodily autonomy and choice. I heard colleagues say that families are all different and there can be challenges within families. However, the issue is not only having information but informed consent, choice and dignity.

Before I came in, I was looking on my phone at the petition that Ann Stark lodged. I think that there are about 570 signatures on it now. The number has gone up quite a lot in the past couple of days because there has been some publicity about the work that the committee is doing. The more that we have such conversations, the more people want to get involved. The point was well made that some families might not be that bothered and do not want to know but, for others, the situation will be deeply distressing. Therefore, it is important that we bring the matter into the light.

As members know, there are different aspects to Ann Stark's petition. Today, the committee has rightly focused a lot on the experience of colleagues in England with the use of scanners. However, that reinforces to me the point that there are alternatives. Technology is advancing all the time. We have heard that not a lot of work is required to refine the skills of colleagues in radiology. We have a fantastic workforce across the UK, which gives me a lot of hope.

We could spend all day talking about the issues around human tissue and genetic testing that were brought out towards the end of the discussion. They are emotive issues and, if there are opportunities to inform other family members that they might be at heightened risk of a disease or condition, of course we want to get that information to them but, as the petitioner has always said, the approach needs to be proportionate. Routinely removing brains and doing fully invasive post mortems are not necessary.

As we have heard a number of times from colleagues, time is really important. It is the biggest resource that we have across the public sector. The teams that we have heard about today are dealing with the living and the deceased. They have incredibly important work to do and, if we can be more efficient and more people centred and can bring people's human rights into the matter, we should.

I am here because my constituents Ann and Gerry, who are sitting behind me, have had a horrific experience. It is bad enough to lose a loved one and to lose a child, but I would not want any family to go through the trauma that they endured after Richard died. That is why I am glad that the committee has been diligent in the work that it has been doing.

The evidence session brought out some of the challenges. Of course, no one expects what the petitioner is asking for to be perfect and a panacea but it strikes me that, in Scotland, we have fallen a bit behind. Really good practice is happening in Lancashire in particular. We need to learn from that. I hope that the Scottish Government will take that on board.

Because Ann is persistent, which I always encourage, she wrote again to every MSP in the past few days and had a tremendous response. The matter resonates with colleagues because we all have constituents and families. It is really about our humanity. We want to be able to learn lessons and apply them to future medical practice and so on. The topic has been neglected in Scotland and the research is underdeveloped, but we now have good evidence and engagement with colleagues across the UK. I thank the committee for its time.

The Convener: Thank you. Like you, I hope that our guests in the public gallery who are directly concerned with the issues have appreciated the evidence session that we have held this morning, which will certainly help to inform the committee. It seemed that, in a number of areas, there is clear opportunity for progress; in others, it might be more complicated.

In summation, colleagues, we will clearly want to further reflect on the evidence at a future meeting. We might anticipate that, following that consideration, we would then want to have the opportunity to put questions to the minister in relation to some of the issues that have been raised. Do members agree that we should seek to secure a session with the minister, and that, before then, we should have the opportunity to reflect further on the evidence that we have heard?

Members indicated agreement.

Annexe C

Petitioner submission of 5 June 2023

Richard Stark’s Law PE1911/MM: PE1911: Review of Human Tissue (Scotland) Act 2006 as it relates to post-mortems

Further to the recent committee meetings, I would like to express my heartfelt gratitude for the overwhelming support I have received from both the public and Members of the Scottish Parliament regarding my petition. The outpouring of compassion and understanding has been overwhelming, and it underscores the significance of the concerns I am raising.

In early 2020 when trying to retrieve the samples of my son the Procurator Fiscal suggested I may think about counselling! It is mainly due to their archaic practices that I have extremely horrific nightmares and anxiety. Of course, my son’s death has impacted me but it’s what happened following his death that really traumatised me. The people responsible for inflicting this trauma having the audacity to suggest that I seek counselling left me with a profound sense of betrayal and disbelief. The last evidence session was a breath of fresh air to learn that other regions have better practices. This feeling is shared by many families who have endured similar ordeals and highlights the urgent need for change.

I expected a view and grant post-mortem for Richard. I did not know the invasiveness of a full post-mortem with the removal of the brain, throat and tongue. The recent evidence session showed how the current Scottish system lacks empathy, accountability, and respect for the deceased. Richard Stark’s Law is about ensuring that future generations are spared the anguish and distress we have endured. The evidence session in May really affirmed the devastating impact of Scottish post-mortems being performed without due consideration of the deceased's medical history or the wishes of the family.

We heard compelling evidence that other parts of the UK and across the globe adopt practices, such as digital scanners, that prioritise the emotional well-being of families to limit & avoid invasive post-mortems. Scotland must follow suit for many reasons, but one which I will note again is to alleviate the burden on pathologists, allowing them to focus on the living and reducing the financial strain on our healthcare system. I believe that you should not go out of this world scarred and with pieces missing, not without consent. I cannot believe what my family have gone through. Pathologists are seemingly exempt from the legal consequences of causing bodily harm.

We are a very quiet living family, Richard was in the garden the night before he suddenly died. There was medical history where a seizure had been considered – this living medical evidence was ignored, my son had attended A&E and a seizure was considered. We heard at the May evidence session that England takes a different approach and does consider medical history. Richard's cause of death was pieced together by me and I had a subsequent fight to have his death certificate changed. It was only after a charity named SUDEP Action who are experts in seizures and gave their own professional opinion, that a pathologist then changed from "Unascertained" to Suspected Seizure/Cardiac Arrhythmia – cause uncertain". I was advised in a report from a neurologist received this morning that Richard died of a seizure, after looking at a recording. I expect the pathologist to change his DC to seizure only, the pathologist had refused to look at the recording. They told me that their decision was final and could not be changed under any circumstances. They swiftly changed their mind when challenged by other experts in this field. The pathologist advised me that they do not welcome external pressure but did make the change grudgingly. The certificate is still incorrect, as arrhythmia was not supported in tests, the pathologist refused to look at a recording of Richard having a seizure. Pathologists and officials must comprehend the lasting impact and trauma they inflict on families when there are alternate practices available to them.

We are advised to protect our identity, yet current laws are allowing tissue samples to be retained without consent, **DNA of a family**. In my opinion, this represents an abuse of rights and privacy of the grieving families.

I have read stories from across the world on tissue-sample retention and DNA. It is disheartening to witness the lack of protection, essentially equating to the theft of a family's DNA.

Part of Richard Stark's Law is to ensure it becomes a standard procedure to offer tissues samples to the next of kin. We heard in May's evidence session that this happens in England and I know it happens in

Ireland and Wales too. It is unacceptable that these samples are retained without consent in Scotland. Furthermore, I am deeply concerned about the storage and use of retained samples. Scotland's capacity to store these samples raises questions regarding their whereabouts and potential uses. It is crucial to ensure transparency in this regard and prevent any misuse or unauthorised access to deeply personal genetics.

I look forward to the outcome of the evidence session attended by the Lord Advocate and the subsequent steps taken to review and reform the existing laws and guidance.

Scotland is a beacon of human rights and individual choice. Introducing Richard Stark's Law with an opt-out system, akin to the organ donation system, would empower individuals and families to make decisions about post-mortem procedures, respecting personal autonomy and preserving the dignity of the deceased.

Scotland should be leading the way. We have a bill coming forward that will discuss assisted dying, all people want is **choice**. I don't have words strong enough to express my feelings as I write this. I will never forgive those who did this to my son, my son would have had less damage to his body if he had been attacked by a dog. I firmly believe you should go out of this world the way you came in.

The current law and procedures fail to **<u>prioritise human rights and the right to choose</u>**, leaving families like mine feeling abandoned and disempowered. Richard was such a gentle and sensitive boy, I am hoping he leaves a legacy behind.

Be part of that legacy. Future generations can be spared the suffering of my family. Please enact the necessary reforms to protect the human rights and choices of all individuals involved.