# Citizen Participation and Public Petitions Committee

8th Meeting, 2021 (Session 6), Wednesday 1 December 2021

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

## Note by the Clerk

#### Petitioner Ann McNair

PetitionCalling on the Scottish Parliament to urge the Scottish Government to<br/>review the Human Tissue (Scotland) Act 2006 and relevant guidance<br/>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 <u>https://petitions.parliament.scot/petitions/PE1911</u>

#### Introduction

- 1. This is a new petition that was lodged on 11 October 2021.
- 2. A SPICe briefing has been prepared to inform the Committee's consideration of the petition and can be found at **Annexe A**.
- 3. While not a formal requirement, petitioners have the option to collect signatures on their petition. On this occasion, the petitioner elected not to collect this information.
- 4. The Committee seeks views from the Scottish Government on all new petitions before they are formally considered. A response has been received from the Scottish Government and is included at **Annexe B** of this paper.
- 5. A submission has been provided by the petitioner. This is included at Annexe C.

### **Background information**

- 6. The SPICe briefing provides a brief overview of the process when someone dies in Scotland.
- 7. The briefing states that within the Crown Office and Procurator Fiscal Service (COPFS), the Scottish Fatalities Investigation Unit (SFIU) is responsible for investigating sudden, suspicious, accidental and unexplained deaths.
- 8. The Procurator Fiscal may permit a less invasive post mortem called a 'view and grant' which consists of an external examination of a body alongside consideration of the person's medical records. It is ultimately a matter for the pathologist to decide the appropriate level of examination and this decision must be defensible to relatives, COPFS and relevant professional organisations.
- 9. Permission from the nearest relative is not needed to carry out a post mortem examination if the death has been reported to the Procurator Fiscal. However, permission is required for a hospital post-mortem.
- 10. When tissue samples are taken or organs are removed for an investigation into a death, the nearest relatives should be informed and advised of the reason why. Similarly, if an organ has been retained after a deceased's body has been returned to relatives, they should be informed of this and asked how they want the organ to be treated once tests are complete.

### Scottish Government submission

- 11. The Scottish Government's submission notes that there are three types of post mortem examinations in Scotland:
  - Procurator Fiscal post mortem examination, as outlined in the background information;
  - Hospital post mortem examination; and
  - Private post mortem examination.
- 12. The role of COPFS in this context is explained in the submission also. It adds that it is essential that COPFS are able to undertake independent investigations to determine the cause of death, without which the death cannot be registered. The submission notes that in most cases the relatives' attitude towards a post mortem will be sought, however, it can proceed irrespective of the wishes of the nearest relative.
- 13. The collection and storage of tissue samples is explained in the submission. It states that tissue samples are a very small part of an organ and chemically treated to produce a tissue block from which a very thin section (10 times thinner than human hair) can be cut by a biomedical scientist. The submission states that

tissue blocks are stored in special cabinets and are kept securely in laboratories that keep very good records and control access to the laboratory.

- 14. The Scottish Government states that any organs removed for investigation during a post mortem will be replaced unless required for further examination.
- 15. Addressing concerns raised by the petitioner about the use of tissue samples, the submission states that tissue blocks automatically become part of the deceased's medical record. They can be used without the need to obtain authorisation for the purposes of:
  - providing information about or confirming the cause of death;
  - investigating the effect and usefulness of any medical or surgical intervention carried out on the person;
  - obtaining information which may be relevant to the health of any other person (including a future person); and
  - audit.
- 16. The submission states that authorisation must be obtained from the nearest relative to use samples for training, education or research beyond what is needed to ascertain or review the cause of death.
- 17. If the nearest relative requests the return of tissue blocks, the Scottish Government notes that any reasonable request will be treated sympathetically by the Procurator Fiscal. If suspicious circumstances cannot be excluded, it is noted that it will be appropriate to retain tissue blocks for possible further investigation.
- 18. The Scottish Government concludes by stating that -

'It essential that COPFS are able to undertake independent investigations into a cause of death, without which, the death cannot be registered. As such, the Procurator Fiscal cannot seek authorisation from the family before doing so. It is for this reason the Scottish Government does not intend to alter the Human Tissue Act 2006 in order for families to give consent to Procurator Fiscal post mortems.'

#### Petitioner submission

- 19. In a written submission, the petitioner details her personal experience with Procurator Fiscal post mortems following the death of her child.
- 20. The petitioner thought the procedure would be a view and grant (as outlined at para 8) but then discovered that it was a full post mortem. She was advised that the tissue samples 'belonged to no particular person' and would be held as part of Medical Records. However, she discovered that Medical Records handle paperwork and the samples are stored in other locations.

21. On the issue of returning tissue samples, the submission highlights that the policy is different in England, Ireland and Wales where relatives are automatically offered the samples back. The petitioner emphasises the importance for families to be given a choice, stating that –

"People may choose to decline the samples, the point is they are being given a choice. I felt these tissue samples were still part of my child. The child I gave birth to and others were telling me what was happening. All of this was so unnecessary, to put a grieving Mother/Family and relatives through such heartache."

22. The petitioner notes that it took her ten months to try and locate where the tissue samples were being stored and that 'no-one seemed to know where these samples were being held'.

#### Scottish Council of Jewish Communities

- 23. The Scottish Council of Jewish Communities raises issues regarding authorisation of view and grant post mortems and consent to retain tissue samples as part of medical records.
- 24. The submission explains that Jewish Law regards the human body as sacrosanct and requires that it should always be treated with dignity, including all body parts, organs and tissue. Once death has occurred, tradition requires that there should be as little interference with the body as possible. It is also important that the burial should take place as early as possible.
- 25. It is stated that for these reasons, it is very uncommon for families to authorise hospital post mortem examinations but there is a recognition that there may be occasions when it may be necessary for a Procurator Fiscal examination. In these instances, the submission raises concerns about a 'reluctance of some pathologists to even consider undertaking a view and grant examination'.
- 26. The Scottish Council of Jewish Communities highlights that no authorisation is required for the retention of tissue samples in the medical records of the deceased. It is argued that it is good practice to obtain authorisation or alternatively, to return the tissue to the family or destroy it according to their wish. To support this point, the submission quotes NHS Greater Glasgow and Clyde which states that 'Small samples of tissue, for histological purposes only, will be retained in every post mortem to confirm macroscopic findings unless consent for this is withheld'.
- 27. A call for this guidance to be replicated throughout NHS Scotland is made in the submission and a statement that the Scottish Council of Jewish Communities would support a review of the Human Tissue (Scotland) Act 2006. It is

recommended that an amendment be brought forward to require authorisation for the retention of all body parts, organs and tissue with a requirement to provide evidence of compliance.

#### Action

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

#### **Clerk to the Committee**

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

### Petitioner

Ann McNair

### Date Lodged

11/10/21

### 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*.



Briefing for the Citizen Participation and Public Petitions Committee on petition PE1911: Review of Human Tissue (Scotland) Act 2006 as it relates to postmortems, lodged by Ann McNair

Brief overview of issues raised by the petition

The petition urges 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
- offer tissues and samples to next of kin as a matter of course.

When someone dies in Scotland, they cannot be buried or cremated until a medical certificate with the cause of death has been issued.

If a death is sudden or unexplained, a doctor cannot confirm the cause of death and it is reported to the Crown Office and Procurator Fiscal Service (COPFS).

Within COPFS, the Scottish Fatalities Investigation Unit (SFIU) is responsible for investigating all sudden, suspicious, accidental and unexplained deaths. As well as establishing the cause of death, SFIU also has a role in establishing whether any criminality has occurred. The permission of the nearest relative is not needed to carry out a post mortem examination if the death has been reported to the Procurator Fiscal. This is different to a hospital post-mortem which does require the permission of the nearest relative.

The Procurator Fiscal may permit what is called a 'view and grant' post mortem examination. This is a less invasive post mortem which consists of an external examination of the deceased person's body alongside consideration of their medical records.

However, it is ultimately a matter for the pathologist to decide the level of examination which is appropriate. If the cause of death cannot be determined from a view and grant examination, then a more invasive examination may be required. The pathologist's decision must be defensible to relatives, COPFS and relevant professional organisations such as the General Medical Council.

Tissue samples may be taken or organs removed if the pathologist feels it is necessary for the investigation into the death. In such instances, the nearest relatives should be informed and advised of the reason why.

Tissue samples are retained and become part of the deceased's medical records.

If an organ has been retained after a deceased's body has been returned to relatives, the relatives should be informed of this and asked how they want the organ to be treated once tests are complete.

The statutory basis for these measures is contained in the Human Tissue Authorisation (Scotland) Act 2006.

Kathleen Robson Senior Researcher 16/11/2021

The purpose of this briefing is to provide a brief overview of issues raised by the petition. SPICe research specialists are not able to discuss the content of petition briefings with petitioners or other members of the public. However, if you have any comments on any petition briefing you can email us at <a href="mailto:spice@parliament.scot">spice@parliament.scot</a>

Every effort is made to ensure that the information contained in petition briefings is correct at the time of publication. Readers should be aware

however that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.

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# Scottish Government submission of 15 November 2021

## PE1911/B – Review of Human Tissue (Scotland) Act 2006 as it relates to post-mortems

I am responding as Interim Deputy Director for the Health Protection Division, with responsibility for the legislation and overarching policy governing the Human Tissue (Scotland) Act 2006.

The death of a loved one is stressful at any time and the death of a child is the most difficult thing any family can go through. That is why when someone dies it is crucial that services work together in a coordinated and appropriate way to reduce the burden on bereaved people.

A post-mortem examination is a thorough medical examination of a deceased person's body to establish the cause of death. It is carried out by a pathologist. The post-mortem examination should be carried out as soon after death as possible, although in very exceptional circumstances the examination can take place after some time has passed. Post-mortem examinations are not necessary if a doctor can certify the cause of death but in some cases they must be carried out to help establish the cause of a sudden, unexplained or suspicious death. There are three types of post-mortem examination in Scotland, a Procurator Fiscal post-mortem examination, a hospital post-mortem examination and a private post-mortem examination that the family arrange. Post-mortem examinations are more likely in certain circumstances, such as the sudden or unexplained death of a child.

A 'View and Grant' is a non-invasive procedure which involves an experienced pathologist externally examining the body of the deceased whilst considering the deceased's history and the events surrounding the death. The pathologist will confirm to the Procurator Fiscal that a full post-mortem examination is required if they are not in the position to certify the cause of death on the basis of a 'View and Grant' examination.

The Crown Office and Procurator Fiscal Service (COPFS) is responsible for the investigation of all sudden, suspicious, accidental, unexpected

and unexplained deaths in Scotland. It is for the Procurator Fiscal to decide which deaths it investigates and in how much detail, when a death is reported under the specified categories. For a post-mortem examination instructed by the Procurator Fiscal, authorisation from the nearest relatives is not required as it essential that COPFS are able to undertake independent investigations to determine the cause of death, without which the death cannot be registered. In most cases the relatives' attitude to a post-mortem will be sought. If a post-mortem is necessary it can proceed irrespective of the wishes of the next of kin.

If the post-mortem reveals the cause of death and no further investigation is required, the pathologist completes the medical certificate of death and the Procurator Fiscal informs the Registrar of the cause of death. The death can be registered and the body released for burial or cremation, with the Procurator Fiscal's permission.

The deceased's face, hands and feet are not normally affected by the post-mortem examination and relatives should be able to see the body again after the post-mortem examination. Any organs removed for investigation will be replaced unless required for further examination, as described in the paragraph below. In most cases a pathologist will carry out as thorough an examination as possible, to ascertain the cause of death.

Tissue samples are a very small part of an organ. These tissue samples are placed in formalin and are often placed directly into plastic cassettes. The tissue is then chemically treated to remove water, which is replaced by wax. This produces a tissue block, which is a hard block attached to the cassette and from which a very thin section can be cut by a biomedical scientist. This thin section (10 times thinner than a human hair) is mounted on a glass slide before being stained. A very large number of sections can be cut from one tissue block, and a number of different stains can be used to show different features. Tissue blocks and glass slides are stored in special cabinets and are kept securely in laboratories that keep very good records and control access to the laboratory. These techniques are the same as those used to examine tissue from living patients.

From 1<sup>st</sup> September 2006, tissue blocks and slides from the postmortem examination automatically become part of the deceased's medical record and can be used without the need to obtain authorisation for the purposes of: providing information about or confirming the cause of death; investigating the effect and usefulness of any medical or

surgical intervention carried out on the person; obtaining information which may be relevant to the health of any other person (including a future person); and audit. Exceptionally, the nearest relative may seek the return of such material and if this occurs any reasonable request will be treated sympathetically by the Procurator Fiscal. However, in certain cases, for example where suspicious circumstances cannot be excluded, it will be appropriate to retain tissue blocks and slides for possible further investigation. In cases of Sudden Unexpected Death in Infancy (SUDI) or Sudden Infant Death Syndrome (SIDS), there is no determinate cause of death and advances in medical knowledge may eventually provide a definite answer. Slides or blocks will therefore be retained with the post mortem records notwithstanding any request for their return. This arrangement also preserves the option of their future use for research purposes provided that the necessary consent or authority is obtained. In all cases, authorisation must be obtained from the nearest relative to use samples for training, education or research beyond what is needed to ascertain or review the cause of death.

In the case of hospital post-mortem examinations, authorisation of a family or nominated representative is required for hospital post mortems for all children aged under 12, and for all people aged over 12 who did not give their own authorisation when they were alive.

In summary, in cases of a sudden, unexplained or suspicious death, post-mortem examinations instructed by the Procurator Fiscal have a vital role in establishing the medical cause of death and play an important role in understanding if criminality was involved in a death. It essential that COPFS are able to undertake independent investigations into a cause of death, without which, the death cannot be registered. As such, the Procurator Fiscal cannot seek authorisation from the family before doing so. It is for this reason the Scottish Government does not intend to alter the Human Tissue Act 2006 in order for families to give consent to Procurator Fiscal post mortems.

# Petitioner submission of 11 October 2021

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

My child died suddenly at home in 2019. As a result, there was a postmortem carried out – which I thought was a Grant & View, I then discovered not only was it a full post-mortem, but the brain, throat and tongue had been removed too, I was horrified.

I was advised that the tissue samples taken from my **CHILD** belonged to no particular person and would be held as part of Medical Records. Yet when I contacted Medical Records, they advised they only keep paperwork and had nothing to do with samples.

I discovered that samples are stored in other locations.

The policy is different in Scotland from **England/Ireland & Wales**, where loved ones are given a **<u>choice</u>**, and automatically offered these samples back (perhaps to add to caskets or bury). I am sure many Scottish people are unaware of this policy at present, and those who have now discovered it are shocked. We are all part of the UK.

My friend lost her sister in Ireland months before I lost my child, and they were offered the samples back without asking for them. Yet I felt when I lost my child, I had no say at all in what happened, even right down to tissue samples that were taken and stored without consent.

People may choose to decline the samples, the point is they are being given a **choice**. I felt these tissue samples were still part of my child. The child I gave birth to and others were telling me what was happening. All of this was so unnecessary, to put a grieving Mother/Family and relatives through such heartache.

I discovered that in the event of a sudden or unexplained death the Procurator Fiscal provides this authorisation not the next of kin. This has to be changed, loved ones have no say in what happens to their loved one or their loved ones, tissue samples – this was my child's samples and what an ordeal I had to go through on top of grieving to retrieve them.

We are given the **<u>choice to vote</u>**, yet not given the choice regarding our loved ones. I believe this policy should be changed now. Relatives cannot go through this ordeal.

I was sent on a wild goose chase for around ten months, trying to locate where these samples were being stored all whilst grieving. No-one seemed to know where these samples were being held, which I find hard to believe. It was also discovered that, because of the Human Tissue Act 2006, these samples can be used for <u>education, research etc</u> without the consent of Next of Kin. I believe that all relatives should be given the **choice!** To accept these samples or decline them - This is their loved one! And as friend's have said this is robbery using samples that do not belong to them, the deceased didn't given consent to this.

Regarding Post-Mortems and the removal of brains, I was horrified to discover that my child's brain, throat and tongue were removed without consent. I accept that were a sudden death occurs post-mortems may have to be done, on a torso but removal of the brain, throat & tongue is **not acceptable.** Consent from next of kin should be asked for, then they have the choice, whether this is performed or not.

Where are the rights for the deceased or their loved ones? I have nightmares thinking about what happened to my child, and I cannot have another mother/family going through this. I had no idea this was happening to my child – consent should be asked for in all of the above then at least loved ones would have a say.

<u>No-one is being blamed for anything in the Petition</u> but all of the above has to be looked at. I personally felt this was cruel putting a family through all, of this heartache. Wasn't the shock of finding my child dead enough? And after all of the above this child has a death certificate of "Unascertained" meaning nothing yet on PM report there is a 1<sup>st</sup> & 2<sup>nd</sup> cause, testing for 2<sup>nd</sup> cause came back with no evidence and we have evidence of first cause, this is killing this family and, I believe, makes a farce of death certificates altogether. All of the above has destroyed this family, what a horrible world we live in. When others are making the decisions for YOUR loved one.

# The Scottish Council of Jewish Communities submission of 16 November 2021 PE1911/C - Review of Human Tissue (Scotland) Act 2006 as it relates to post-mortems

The Scottish Council of Jewish Communities (SCoJeC) is the representative body of all the Jewish communities in Scotland. SCoJeC advances public understanding about the Jewish religion, culture and community, by providing information and assistance to educational, health, and welfare organisations, representing the Jewish community in Scotland to Government and other statutory and official bodies, and liaising with Ministers, MSPs, Churches, Trades Unions, and others on matters affecting the Jewish community. SCoJeC also provides a support network for the smaller communities and for individuals and families who live outwith any Jewish community or are not connected with any Jewish communities, and assists organisations within the Scottish Jewish community to comply with various regulatory requirements. SCoJeC also promotes dialogue and understanding between the Jewish community and other communities in Scotland, and works in partnership with other organisations and stakeholders to promote equality, good relations, and understanding among community groups.

In preparing this evidence we have consulted as widely as possible given the short timescale among members of the Scottish Jewish community.

Jewish Law regards the human body as sacrosanct, and requires that it should always be treated with dignity. This respect extends not only to the body itself, but to all body parts, organs, and tissue. Once death has occurred, tradition requires there should be as little interference with the body as possible. Ideally, it should not be left unattended, and burial should take place as early as possible, preferably before sunset on the day death occurred. Although funerals may sometimes be delayed to enable distant family to attend or because immediate access to the cemetery is not possible, in most cases, delay or procedures such as a post-mortem examination are likely to be particularly distressing to the family of the deceased. In addition, the *shiva* (initial period of mourning) cannot begin until after the burial has taken place, and consequently any postponement delays the grieving process which inevitably causes great psychological distress to the bereaved.

For these reasons, it is very uncommon for families to authorise the

hospital post-mortem examinations that are sometimes requested by medical staff. We recognise, however, that there may be occasions when it may be necessary for a post-mortem examination to take place, for example if the death is unexpected and the cause unclear, in order to ascertain whether there is any risk to public health, or to determine whether the death may have resulted from a criminal act. We are grateful to the Crown Office and Procurator Fiscal Service for their frequent assistance in expediting such examinations, and for their willingness to accept the findings of non-invasive "view and grant" examinations whenever possible. We are also grateful to the various mortuary services for their assistance in minimising delays so that burial can take place as soon as possible after a death. We are, however, concerned at the reluctance of some pathologists even to consider undertaking a view and grant examination, so that an invasive surgical procedure may be carried out as a first line of investigation even when the non-invasive procedure might have afforded sufficient information to determine the cause of death.

<u>Under Section 40 of the Human Tissue (Scotland) Act 2006</u> organs removed during the course of a procurator fiscal post-mortem examination that are no longer required for the purposes of that examination may only be retained if retention is properly authorised under sections <u>42</u> to 46 of the Act.

However, under <u>Section 38</u> of the Act, a tissue sample taken during the course of a procurator fiscal post-mortem examination that is no longer required for the purposes of that examination "falls to be retained as part of the medical records of the deceased person". Unless properly authorised under sections 42 to 46 of the Act, no tissue should be used for any other purpose than that for which it was removed, but no authorisation is required for its retention.

Although no authorisation for retention of tissue is required by the Act, it is clearly good practice to obtain authorisation – or alternatively, to return the tissue to the family or else destroy it according to their wish – and <u>guidance</u> from NHS Greater Glasgow and Clyde states that "Small samples of tissue, for histological purposes only, will be retained in every post mortem to confirm macroscopic findings **unless consent for this is withheld**." (our emphasis). Although not explicitly stated, this, of course, implies that consent for the retention of tissue samples may be either given or witheld, and so must actively be sought – as indeed ought to be the case.

This guidance should be replicated throughout NHS Scotland, as the wishes of the deceased and his or her family should be paramount, and should be respected in relation to all aspects of a post-mortem examination, including the disposal of any organs and tissue that may have been removed from the body during that examination.

We would therefore support a review of the Human Tissue (Scotland) Act 2006, and in particular, an amendment to bring disposal of tissue samples taken in the course of a procurator fiscal post-mortem in line with the disposal of organs similarly removed, i.e. to require authorisation for the retention of all body parts, organs and tissue. Furthermore, in order to evidence compliance, there should be a requirement to document disposal in the medical record, including, if any organs or tissue are retained, a copy of the written authorisation.