

CITIZEN PARTICIPATION AND PUBLIC PETITIONS COMMITTEE

Citizen Participation and Public
Petitions Committee
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CONSIDERATION OF PETITION <u>PE1911: Review of Human Tissue (Scotland) Act</u> 2006 as it relates to post-mortems

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 postmortems—

- 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.

This petition was lodged by Ann Stark on 11 October 2021 and has been considered by the Citizen Participation and Public Petitions Committee on seven occasions, most recently at its meeting on 29 May 2024. At that meeting, the Committee agreed to write to you on a number of issues raised during the lifetime of this petition.

The petitioner, Ann Stark, has campaigned for a number of years to bring about changes to post-mortem services following the sudden death of her 25 year-old son, Richard Stark.

The Committee has considered written evidence from a number of key organisations, the petitioner and concerned members of the public. In addition to written evidence, the Committee also heard oral evidence to inform its view on the issues raised in the petition. Ownership

Throughout the Committee's consideration of this petition, Members have been struck by the lack of clear ownership over policy, direction and decision-making across postmortem services in Scotland. The Committee put its evidence to relevant professional bodies but found that no organisation took responsibility for addressing concerns or leading on improvements to post-mortem services.

During oral evidence, the Lord Advocate emphasised that her role is to operate within existing law and established practice rather than drive forward changes to services. Beyond the Lord Advocate's unique role, post-mortem services appear to be absent from ministerial responsibilities. It is still unclear to the Committee where oversight of post-mortem services lie.

Andy Shanks, Head of the Scottish Fatalities Unit at Crown Office and Procurator Fiscal Service, explained during <u>oral evidence</u> that –

"The Crown Office and Procurator Fiscal Service is essentially a service recipient; we are not the service provider and we are not in charge of the pathologists. We rely on service providers from across the country, including the NHS, local authorities and universities that provide the service. We have a number of contracts and service level agreements in place with those organisations, so they are responsible for the level of service across the country (...) The matters under discussion are essentially matters for the service providers."

The fragmented nature of pathology services in Scotland and the difficulty we have found in finding anyone to take responsibility for tackling issues with these services is reflected in the HM Inspectorate's Annual Report 2022-23 which states that consideration of a delivery model for forensic pathology is required. The report states that rather than reform being driven by the Crown Office and Procurator Fiscal Service (COPFS), there is a need for a co-designed approach to securing a long-term vision for pathology services. It suggests that —

"Given the cross-sector nature of the work, that role would more appropriately fall to the Scottish Government."

Similarly, the COPFS has called for the appointment and establishment of a National Pathology and Mortuary Service under NHS leadership and management. The COPFS noted that it cannot unilaterally design and implement a national service model, and that "wider government direction and support" would be required.

The Committee recommends that the Scottish Government takes ownership of and leads the development of a delivery model for pathology services.

Based on its consideration of this petition, the Committee agrees with the Inspectorate's view that a co-designed approach is required to design a delivery model for pathology services and recommends that the Scottish Government brings together service providers, the Crown Office and Procurator Fiscal Service and stakeholders to achieve this.

Improvements to pathology services

Communication with the next of kin

The petitioner, Ann, raised concerns about the communication with families following the death of a loved one. When Ann's son, Richard, passed away she believed that a view and grant examination would take place but later found out that it had been a full post-mortem examination. She was then distressed to learn about the approach to tissue sample collection and retention which had not been made clear to her until much later.

Ann's experience raises concerns about inconsistent and unclear communication with the next of kin about investigations into unexpected and sudden deaths.

Scanners

This petition highlights the distress caused to families by full, invasive post-mortems. The use of scanning as a non-invasive alternative to full post-mortems for some cases in England and Wales was brought to the Committee's attention through her written evidence.

The Committee heard from practitioners in Lancashire about the use of scanners as an alternative to full post-mortems. This service was established to address the decreasing number of pathologists in the area and has been cost-neutral to the local authority.

Tissue sample handling

For hospital post-mortem examinations in Scotland, small tissue samples taken for microscopy and diagnostic purposes are automatically retained as part of the medical clinical record. The Scottish Government's submission of 15 November 2021 explains that "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."

Mrs Stark found that it was difficult to find out where tissue samples were being stored and struggled to have the samples returned to her. In explaining why the samples are important, Mrs Stark said –

"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."

Mrs Stark has called for Scotland to adopt the process in England and Wales whereby the next of kin are offered a choice of how they wish for tissue samples to be handled.

In England and Wales, the next of kin are given three options –

- 1) The hospital should retain any samples EITHER as part of the deceased's clinical record only OR for use in education and training.
- 2) The hospital should lawfully and sensitively dispose of any samples (which may include cremation).

- 3) The samples should be reunited with the body prior to the body being released for a funeral (which may delay funeral arrangements).
- 4) The samples should be returned to the family for a separate funeral at your own expense.

When asked about the <u>challenges raised by The Royal College of Pathologists</u> concerning tissue sample return Dr James Adeley, Senior Coroner in Lancashire, stated that –

"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."

Ann's personal experience has illustrated to the Committee where there are areas for improvement in pathology services and the Committee remains grateful for her work on this petition.

Sustainability of pathology services

The Committee heard concerns that pathology services do not have enough resources, with issues including the affordability of providing services and and recruitment and retention of staff.

Dr Adeley explained that -

"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."

The Committee is aware that without sustainable pathology services for the future, improvements such as the ones suggested by the petitioner will be challenging to deliver. The Royal College of Pathologists' submission of 10 January 2022 raised this issue, stating that –

"...there are significant pressures on pathology, post mortem and forensic services across Scotland with grossly inadequate facilities and staffing levels being the reality of current provision. The recent failure of the Crown Office and Procurator Fiscal Service procurement exercise to identify compliant bidders for forensic services across Scotland, even from existing providers of such services, highlights the difficulties already faced. Introduction of further complexities to the system would therefore need to be carefully thought through before any legislative changes are considered, especially given the current limitations in the services provided."

The Committee recommends that any delivery model should be designed to facilitate the continuous and long-term improvement of pathology services.

The Official Report of the meeting has been published and a recording of the meeting is also available to view online.

The Committee would be grateful to receive your response electronically, in Word format, by no later than **Thursday 5 September 2024**. Please note that <u>written submission guidance</u> is available and your response will be processed in accordance with the Parliament's policy on the treatment of written evidence.

The Committee notes that due to the lack of clear ownership over the issues raised in the petition, it is not clear which Ministerial portfolio this petition belongs to. Therefore, if you are required to issue a joint response please do so.

The Committee asks that this deadline is met to allow sufficient time for the petitioner to comment on your written response and for consideration of the petition to continue as timetabled. Should you be unable to meet the above deadline, I would be grateful if you could advise the Committee's clerks that this is the case as soon as possible.

On behalf of the Committee, thank you for your assistance.

Yours sincerely,

Jackson Carlaw MSP

Convener