

The background features a large, semi-transparent watermark of the University of Edinburgh crest. The crest is a shield with a blue field containing a white open book, and a red field containing a white building. The shield is surrounded by a blue and red border. The words 'EDINBURGH' and 'UNIVERSITY' are visible in a serif font, partially obscured by the crest.

Post Mortem Tissue Donation for Research: Experience of Approaching Bereaved Families

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Why are Brains needed for Research?

- To progress our knowledge of different diseases (Alzheimer's, Parkinson's, CJD and vCJD)

BUT

- Investigation of brain abnormalities requires control (normal) tissue for comparison

Current Sources of Brain Tissue for Research

- Hospital post mortem examinations (but numbers are declining)
- Neurosurgical biopsies (but amount of tissue is restricted)
- Donor programmes (but they tend to concentrate on specific diseases)
- Medico-legal post mortem examinations (but they are not consented for research)

Other Potential Difficulties with Medico-legal Post Mortem Examinations

- Approach to the family depends on Procurator Fiscal approval
- Concerns over approaching relatives at such a distressing time – inappropriate? Insensitive?
- Removal of research samples cannot interfere with defence PME or chain of evidence procedures

MRC Sudden Death Brain and Tissue Bank

- Set up in Edinburgh in 2005 with the approval of the Scottish Executive, Crown Office, Procurators Fiscal and Police Deaths Unit
- Approved by Lothian Ethics of Research Committee
- Main remit is to collect control (normal) brain tissue from medico-legal post mortem examinations

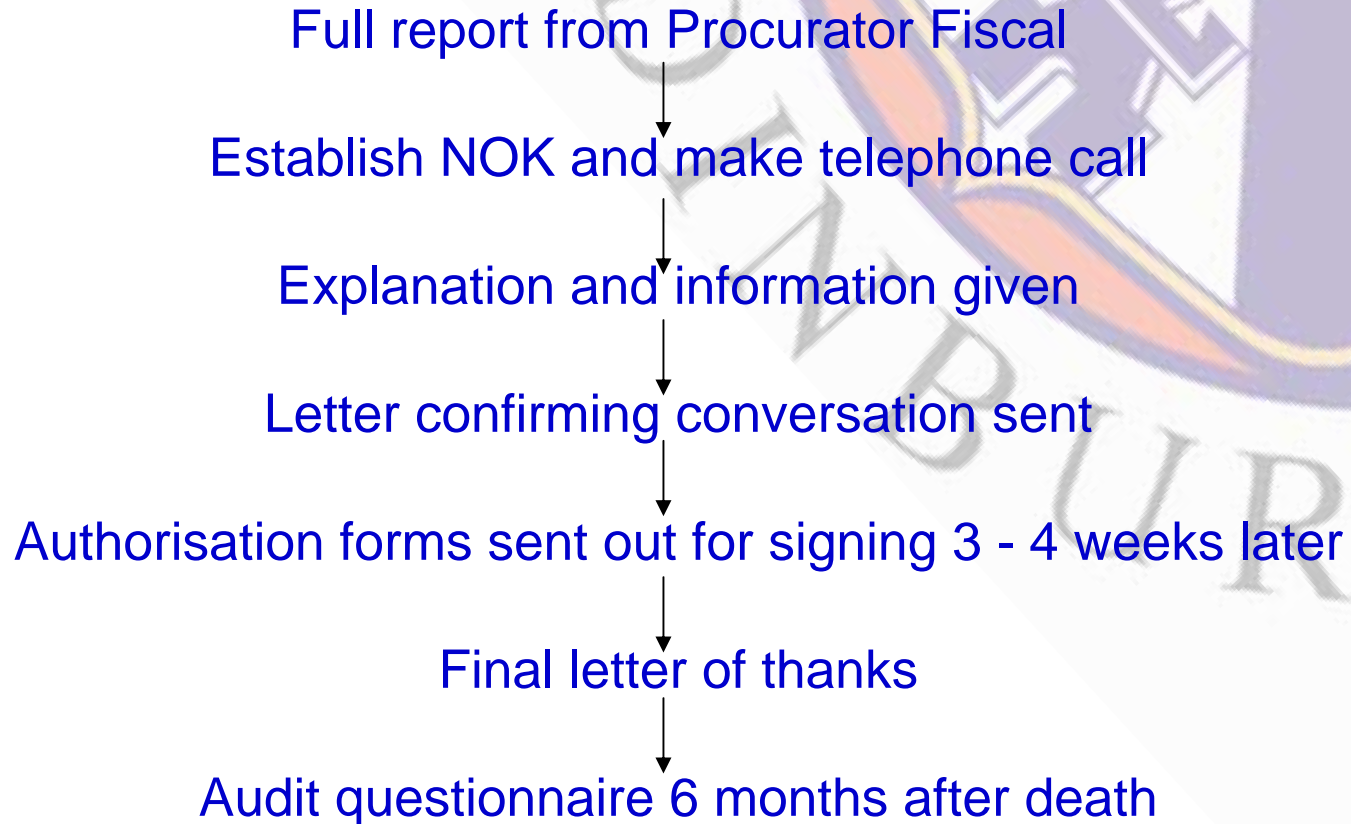
Aims:

- To establish a mechanism for seeking explicit authorisation
- To determine whether recently and suddenly bereaved families would be willing to donate tissue samples for research
- To audit the families' experience of the authorisation process
- To achieve a sufficient success rate to support the establishment of ***The MRC Sudden Death Brain and Tissue Bank***

Challenges:

- To develop an empathetic method for approaching bereaved families
- To provide adequate and appropriate information to allow families to make an informed decision
- To establish good working relationships and a communication network with police, procurator fiscal and mortuary staff

The Authorisation Process

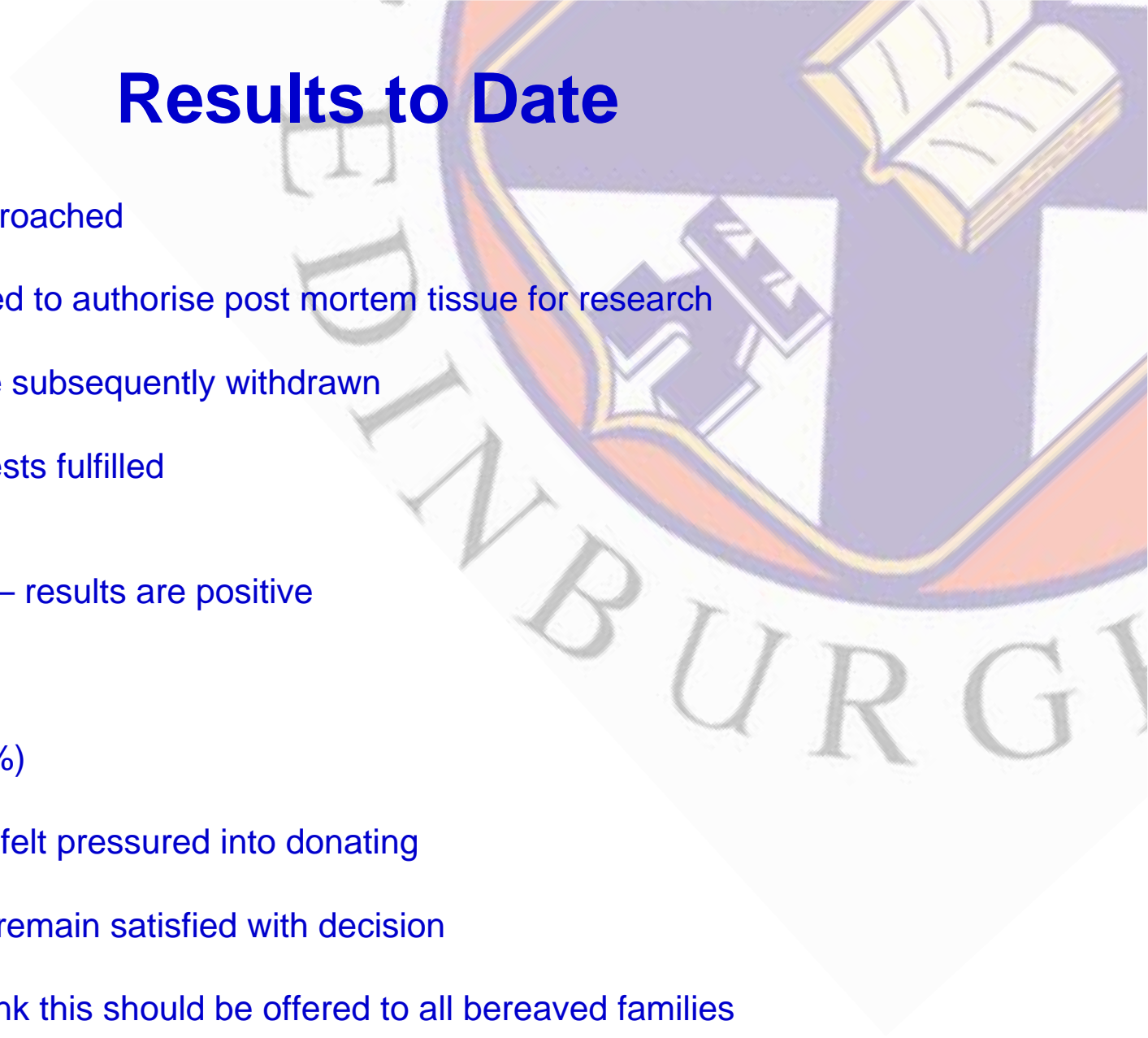


Results to Date

- 215 families approached
- 206 (96%) agreed to authorise post mortem tissue for research
- No families have subsequently withdrawn
- 110 tissue requests fulfilled

Audit Questionnaire – results are positive

- 109 sent
- 59 returned (54%)
- No respondents felt pressured into donating
- All respondents remain satisfied with decision
- Vast majority think this should be offered to all bereaved families



Comments from Families

- “It would be a waste to bury the body with the brain if there is the opportunity of it being useful in helping others in the future”
- “It was empowering to receive your telephone call offering this opportunity at such a desperate time”
- “If this helps only one person then it has been worthwhile”
- “I want to help with research and do something that may help others

Conclusion and Findings

- Despite the distressing circumstances of sudden bereavement, the vast majority of families are willing to authorise research activities
- The audit suggests that families are not further distressed by the request
- The act of donation for research may provide some comfort and meaning to unexpected death – families bereaved by suicide particularly supportive
- Comments and letters received from families confirm that the need for medical research is well understood
- Some families have voiced an interest in making a research donation in the future

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