

**From understanding to implementation: Meeting the needs of families  
and individuals affected by post mortem organ retention**

Executive Summary of the Final Report  
for the Department of Health  
and the Retained Organs Commission

On behalf of the Research Team

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### **What was the reason for the research?**

The lack of consent for the retention of organs following post mortem, across many NHS Trusts, came to the public attention during an investigation into the care of children receiving complex cardiac surgery at the Bristol Royal Infirmary [1]. This finding triggered investigation into the practice of Alder Hey Children's Hospital [2], other NHS Trusts and coroners' services where it was also found that hearts and other organs were routinely removed at post mortem, and stored, without the explicit consent of the next-of-kin.

Many families made enquiries about a family member, adult or child, who may have had organs retained at post mortem. A large number of these families have been given information by the NHS. Where families asked for the return of retained organs and tissues for respectful disposal, this has taken place.

Some families are still waiting for information and for returns to take place. This process has caused grief and distress for many families. Some have been critical of the way the NHS has responded to their need for information and support in making an enquiry about organ retention.

### **What were the aims of the research?**

1. To identify and prioritise the support needs of families and individuals affected by organ retention.
2. To describe the role played by support groups, the effects of their intervention and the needs of those providing support.
3. To describe the range of support services offered by the NHS, the impact of their interventions and the needs of those providing these services.
4. To identify examples of 'best practice' that are responsive to the immediate and continuing needs of families and individuals affected by organ retention.

### **Who took part in the research?**

Forty family members whose children's organs had been retained. Three Chairpersons of family support groups and their volunteers. Eighteen NHS staff from two participating NHS Hospital Trusts and one Primary Care Trust. Researchers also had limited access to the Retained Organs Commission archive of enquiry records.

### **How was the research carried out?**

Family members were recruited to the study either via letters sent by two of the support groups or the two participating NHS Hospital Trusts. The third support group informed its members about the study through their newsletter. NHS staff were recruited via the Trusts.

Face-to-face or telephone interviews were carried out with family members and NHS staff. Three focus groups, attended by 17 family members, were held in Liverpool and Manchester. A focus group for eight family members planned for Birmingham was cancelled due to sudden changes in the circumstances of four families. The remaining four were interviewed in their own homes. Four family members from the South of England completed the focus group scenario items, in writing, and returned this to the researchers.

The researchers analysed ten enquiry records held by the Retained Organs Commission, where families had given consent for them to do so.

## What are the main findings of the study?

### Aim 1. The needs of the families and individuals affected by organ retention.

- A constant, pervasive theme throughout the research was families' dissatisfaction with the care they received at the time of their baby or child's death. Learning of organ retention appeared to plunge families into a resurgence of their grief and a cycle of serial loss: the loss of their baby or child at the point of death, the loss of their belief in the wholeness of their baby or child, the loss of any emotional stability that had been achieved over the intervening years and a loss of trust in the NHS and NHS staff. Organ retention has left some families dealing with emotions stimulated by a renewal of their grief related to poor bereavement aftercare.
- The removal of choices at the time of post mortem left family members feeling angry and some feeling guilty. These emotions have been superimposed on their grief, amplifying the distress and disbelief felt on learning about post mortem organ retention.
- The delays experienced by families in gaining information, the mishandling of information and the lack of a meaningful apology for what had been done to their children and to family undermined individuals' trust in the NHS, and in particular the health professions.
- Health professionals sometimes mistakenly offered families counselling in response to their distress instead of information, which is what they required. Assessment of the families' bereavement needs must distinguish between the information families desire and other forms of bereavement support such as counselling. Family members and individuals need to understand the circumstances of the death and the details of results from any further investigations such as post mortem, in advance of counselling being offered to them. If counselling is offered at the wrong time [from the point of view of the bereaved person], bereaved individuals may feel that their informational needs are not being addressed and that their emotional stability is being questioned.
- Assessment of what individual parents need in relation to discussing post mortem and gaining post mortem results could maximise the potential for families to be satisfied with the care provided.
- Families who continued to return to NHS Trusts and the Commission in light of what the Trusts and the Commission feel is 'complete disclosure' of information and completion of the enquiry did not believe the information provided by the Trust about the disposal of organs and the 'certitude' that nothing else remained. This belief was reinforced by 'poor record keeping', 'erroneous responses' and a belief that Trusts with major archives would be unwilling to reduce them. Families believed that due to a lack of evidence of 'changes in attitudes' within the NHS there were still things hidden from them. This could have been in the form of information or present practices. Families did not believe what they were 'told' by Trusts as what they were 'told' in the past was 'untrue', 'limited' or 'paternalistic'. Their experience of erroneous responses in the past had undermined trust in what was being said. Families were seeking proof. Some families had issues resulting from their bereavement that remain unresolved such as specific beliefs regarding the after-life and the need for the body to be whole. Importance may be attached particularly to the heart, brain and eyes. Families were angry and were seeking retribution as an acknowledgement of their pain and what was done to their baby or child. Families remained overwhelmed by their feelings of distress and anger and did not know whom to turn to and so returned to Trusts and the Commission.

**Aim 2. The role of support groups, the interventions they offered and the needs of the volunteers within the support groups.**

- Support groups were set up by parents of children whose organs had been retained at post mortem.
- The aims of the support groups were to:
  - 1] To provide practical assistance to families.
  - 2] Lobby for a national public enquiry into organ retention.
  - 3] Campaign for a change in the law to make unconsented organ retention illegal.
  - 4] Keep families up to date with the wider national picture by establishing help-lines, websites and newsletters.
- Support groups were a primary resource for families. They provided the information families needed to carry out an enquiry and the knowledge and questions they needed to challenge NHS staff.
- Support groups provided information in relation to potential, and later, actual litigation against Trusts and finally the NHS.
- Support groups were the medium through which families kept up to date with the huge amount of information being delivered by agencies involved with organ retention.
- Handling hundred of calls and requests for practical and emotional support had a huge impact on the lives of volunteers providing this support to families. Volunteers combined their day-to-day lives with their support group work, often taking calls late into the night. Requests for assistance from the Retained Organs Commission were, in the eyes of the support groups, ignored.
- The needs of support group volunteers included the need for financial assistance and administrative support and access to 'professional services' to offer guidance in respect of helping the most distressed families.
- Initially groups achieved their aims with no financial or administrative support from the Retained Organs Commission or the Department of Health.
- The emotional needs of the volunteers, within the groups, who provided support to the families via telephone or by responding to letters or e-mails, were met by other volunteers, family and friends.
- Support groups were concerned about what 'independent' help would be available to those families who had not yet made or had not yet completed enquiries [to their own satisfaction] when the Retained Organs Commission ceased to operate in March of 2004.

**Aim 3. The range of support services offered to the families by the NHS, the impact of these services and the needs of those NHS staff providing these support services?**

- Initially there was a gross miscalculation of how serious the issues surrounding post mortem organ retention would be. This seemed to be based on NHS staff undervaluing the importance of organ retention to the public, and more particularly to the affected families.
- Leadership, in relation to the philosophy underpinning decision-making and provision of services made available to families, initially, came from within Trusts, as there appeared to be little available at National level.
- Pathologists in particular felt blamed for what was accepted practice across the medical profession, and unsupported by some of their colleagues and the government.
- Responding to enquiries called for a huge investment of resources in relation to person hours, developments of effective information databases, preparing and reviewing new documentation and initiating changes in practices, all of which had to be provided from existing budgets.
- Individual NHS staff involved in the organ retention enquiries at times felt ‘overwhelmed’ by the volume and content of calls.  
Their needs included:
  1. The acknowledgement of the Trust management that organ retention was a serious issue and that they were contributing an important role.
  2. Peer support, which was facilitated by working as a member of a multi-disciplinary team.
  3. Limited exposure to dealing with helpline enquiries and the opportunity for debriefing sessions.
  4. The provision of psychological support for those who wished to access it.
- Some helpline staff felt that medical clinicians did not acknowledge their role in organ retention and were unwilling to be fully involved in the enquiry procedures.
- NHS staff felt that they had learnt a lot from the experience of organ retention and particularly from the phone calls that families made to them. These calls contributed a greater understanding of the needs of the newly bereaved, the needs of those who were asked about post mortem, and the impact that the loss of a baby or child had on the individual and extended family.

#### **Aim 4. To identify examples of ‘best practice’.**

- The publicity about organ retention provided an opportunity for some families to resolve ongoing bereavement concerns, gain important information and put right issues that had constrained their existence for many years.
- A model of response that was based on openness and honesty, which was proactive and sought to gain the truth for individuals, appeared to facilitate an environment in which families could gain the answers to the questions that were raised by post mortem organ retention.
- All the examples of best practice share the common quality of individual needs assessment.
- Most examples of best practice were linked to a member of NHS staff’s personal commitment of care that encompassed a view that avoided ‘paternalism’ and sought to learn from the mistakes of the past.

#### **What do the findings of the study tell us?**

This research has shown that families can no longer be dismissed, as before. The findings indicate that at the time of death parents and relatives need to be given the opportunity to be involved in choices about the care of their baby or child: they need to be involved in choices about what happens to their baby or child after death and they need support in making those choices.

An effective bereavement service needs to recognise the role of family in illness and death and not seek to marginalise them in decision-making [3]. Enabling family members to talk openly about issues and make choices when facing bereavement, helping them to explore where they are in this changing process, while recognising that they may not have the language or experience to make informed choices, will assist families in feeling fully involved in decision-making.

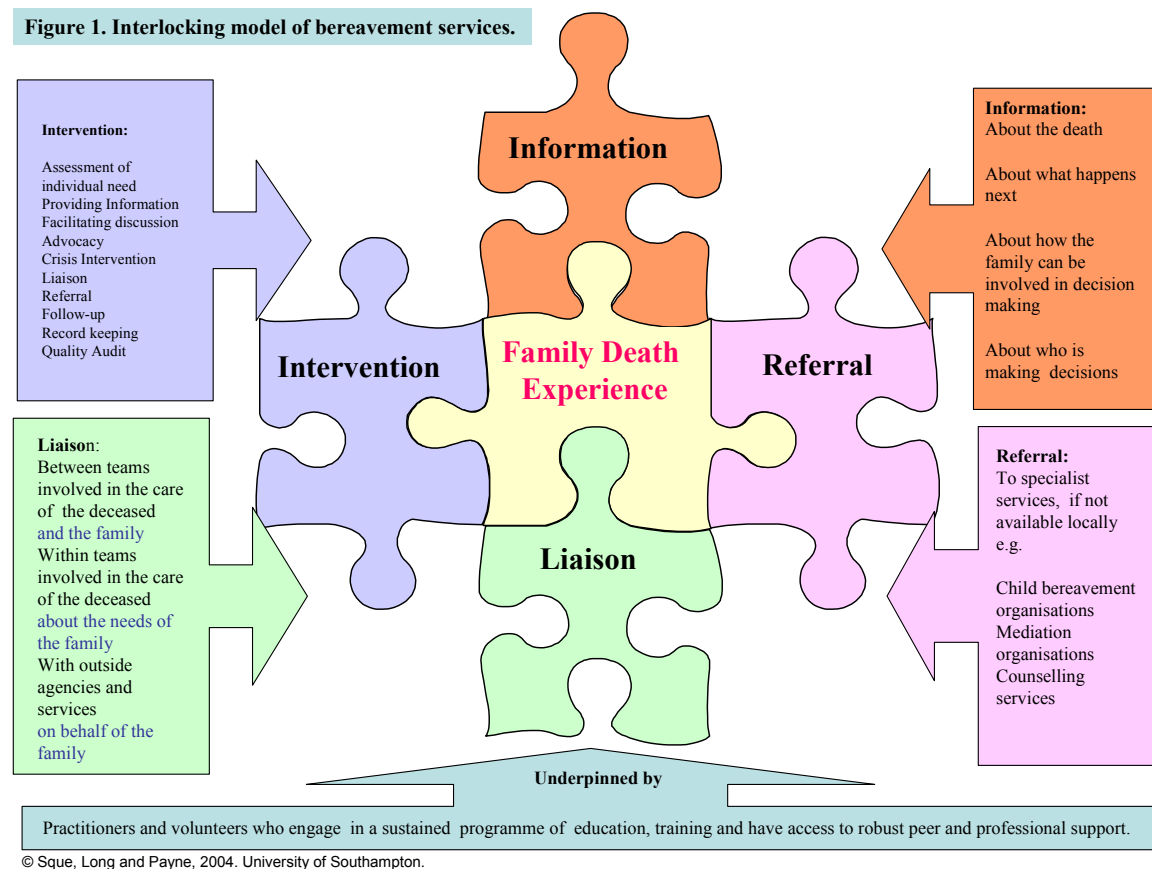
NHS staff and voluntary organisations need to progress their bereavement services to meet the needs of families affected by organ retention, however to meet these demands they require robust systems of education, training, peer support and professional support.

Parkes [4] and Payne et al. [5] suggest that the best people to help provide social support to those who have experienced loss, are those that share the common experience of that certain type of loss, as only they can provide the support of ‘friends’, who have some insight into the experience. This aspect of support was clearly reflected within the aims and actions of the support groups. They acted as ‘listening friends’ to family members as well as providing guidance and advice.

## What are the recommendations?

Organ retention can be part of a family's bereavement experience so our recommendations necessarily encompass the implementation of supportive bereavement care and services. Organ retention was also shown to have the ability to affect and disrupt relationships within the family, which makes it essential to make the family the central focus of care. Cohesive bereavement services are therefore required. These services should be based on choices for the family that begin at the bedside of the dying person and extend seamlessly from the care facility into the community. Where the death occurs in the community equitable bereavement services should be available.

Future service provision could be best guided by a model of an Interlocking Bereavement Service [Figure 1].



In this model bereavement services offer families the opportunity to be involved in all aspects of end of life decision-making. These decisions are best supported by multidisciplinary bereavement teams offering a range of skills and who are trained to assess individual need, liaise within and between teams, intervene when needed and provide referral to specialist services where appropriate. However, the ability to effectively support families can only be achieved by practitioners and volunteers who are involved in a sustained programme of education and training and have available to them robust systems of peer and professional support. The model for an Interlocking Bereavement Service was developed from three constructs drawn from the data concerned with Choice, Change and Support.

**Choice** - The findings in this report indicate that at the time of death parents and relatives need to be involved in choices about the care of their baby or child. They need to be involved in choices about what happens to their baby or child after death and they need support in making those choices. In view of all that had resulted from post mortem organ retention, families also need change to take place.

**Change** - In the attitudes within the health service that excluded and possibly still, exclude family members from involvement in care and decision-making and which are based on views that family members are not able to be involved in decision-making due to their lack of knowledge or intelligence. Richardson [6] has urged the need for a change in perception so that medical practitioners view the public as intelligent collaborators who have a role in improving the nation's health provision and the development of medical science.

**Change** - In the law that is underpinned by a legal framework that clearly outlines the rules and regulations within which post mortem organ and tissue retention can be carried out. The legal framework should encompass and clearly explicate the role of coroners and their duty of care to bereaved family members.

**Change** - In the way that health professionals are educated about, trained for, organise and provide bereavement services. A philosophy of 'involvement in choice' would be a good starting point upon which to base educational initiatives to help achieve changes in attitudes and behaviour that must happen if practices are to change. However, De Wit and Van Dam [7] have cautioned that improving the knowledge of health professionals does not mean there will necessarily be a change in their behaviour. Without changes in attitudes and behaviour there can be no lasting improvement in the services provided to bereaved parents and relatives. A change in attitudes and behaviour would facilitate the provision of 'interlocking bereavement service' that assesses individual need and provides support that extends from the hospital or care facility into the community.

**Support** - In the future, hospital bereavement services should encompass a range of potential scenarios and be flexible enough to provide: assessment of need based on personal circumstances, crisis intervention, peer support, education and support in relation to practical advice, guidance and written information. The model illustrates a proactive service that reaches out to bereaved people, who are often too exhausted by their grief to make voluntary contact, and which has the resources to provide the 'attention', 'time' and 'care' that is required to carry out individual needs assessment [8]. It must also be flexible enough to incorporate referral on to agencies such as social care, psychiatric teams, support groups and other outside agencies, where they can offer an effective intervention. Such a service needs to have the appropriate quality monitoring and should seek to give support to other hospital staff in managing the events surrounding death.

**Support** - Needs to be provided by a team approach, involving personnel from various disciplines within the NHS; a team who are prepared for their role in terms of education and ongoing development; a team that has well defined aims in what is needed to provide a quality bereavement service; a team with strong leadership and a philosophy based on involving families in end of life decision making. Such developments will benefit bereaved families and would also facilitate an environment in which the potential for distress among its members is reduced. A team approach would also contribute to a 24 hour service as dying is not dependent on daylight.



## Conclusion

As the pool of families involved in organ retention is growing, not only in the UK, but also in other countries, the ongoing needs of these individuals offer an opportunity to develop appropriate, responsive and proactive services, which are fully informed by the experiences of bereaved families. Logistic and policy issues both in health and social care support are best informed by a recognition of ‘unmet’ needs in relation to poor information giving and a culture of ‘defensiveness’ encountered by families. As all families and individuals will experience the death of a loved one the lessons learned here can extend beyond the boundaries of clinical interest to facilitate an interlocking, supportive bereavement service in which families and health professionals can have trust and pride.

This study has shown without doubt the distress and emotional pain that was wrought upon bereaved families through the inadequacy of consent for post mortem and the resulting retention of organs and tissue from their babies and children and the difficult memories of NHS staff, who were involved in supporting them in their enquires. Whilst it may never be possible to remedy the suffering of these families and individuals it is hoped that the organ retention crisis will be pivotal to the creation of effective, interlocking bereavement services and to the wider acceptance that NHS staff need to abandon outdated concepts of ‘paternalism’ and join with families in creating a legacy whereby organ retention can never happen again.

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