

FAQs – Interim Changes to Perinatal and Paediatric Pathology Services

Updated: January 2020

1. What is the background to the interim changes to perinatal and paediatric pathology services?

Following the resignation of the sole paediatric pathologist at Belfast Health and Social Care Trust, significant efforts have been made to retain a service within Northern Ireland - including repeated recruitment drives both nationally and internationally.

The Health and Social Care Board (HSCB) approached every NHS provider of paediatric pathology services across the UK, as well as those in the Republic of Ireland (RoI). Regrettably, no organisation was found that could provide continuity through an in-reach service to Northern Ireland for the provision of hospital perinatal and paediatric post-mortems.

To ensure that families can still access a service, interim arrangements remain in place to provide paediatric pathology services at Alder Hey Children's NHS Foundation Trust in Liverpool.

The interim service with Alder Hey Children's NHS Foundation Trust commenced on 3 January 2019.

The Health and Social Care Board (HSCB) and Public Health Agency (PHA) have commenced a full evaluation of the service to capture the experiences of parents and staff who use the service, as well as gathering the views of the funeral undertakers and the staff at Alder Hey.

Over the last year, the HSCB, PHA and Trusts have been liaising closely with key charities and with families who have been affected by bereavement to ensure the arrangements are as sensitive and dignified as possible. A lot of work has been undertaken, and thorough oversight continues, to ensure that any baby who requires a hospital consented post-mortem, as well as their family, are treated with the utmost care, respect and compassion throughout the journey.

The HSCB and PHA fully recognise that having to travel to Alder Hey to access paediatric and perinatal pathology services may add to the distress experienced by families at a devastating time in their lives. We are reassured that from the initial feedback we have received, parents have felt supported by the service.

Parents are also receiving the results of the post-mortems more quickly than before, which is particularly helpful for those families wishing to use the information to inform their family planning.

We remain committed to the provision of a local service in the longer term and access to a high quality service will remain a priority. Significant efforts have been made to try and retain a service within Northern Ireland, and an open-ended recruitment process with an agency specialising in international recruitment is ongoing. However, the national and international shortage in paediatric pathologists is fully recognised.

Discussions between the Departments of Health in NI and ROI, exploring the potential options for an all-island network model for providing this service in the future, are also continuing. However, the feasibility of an all-island approach would only be deliverable in the longer term, due to current capacity constraints and the time required for new trainees to specialise in this area.

In the meantime, the HSC will work closely with the relevant Royal Colleges and training organisations to encourage and support training in this specialty in the future.

2. Why have services been moved outside of Northern Ireland on an interim basis?

The paediatric pathology service is valuable in providing answers for families as to why a baby or child may have died, as well as detecting and diagnosing obstetric and paediatric conditions. It is particularly important for the planning of future pregnancies.

The consultant paediatric pathologist working in Northern Ireland left his post in the Belfast HSC Trust early in 2019. Despite repeated recruitment drives, nationally and internationally, the post remained unfilled. A significant proportion of consultant pathology posts are vacant across the UK, so this problem is not unique to Northern Ireland.

To address the challenges in the interim period, we contacted all centres across the UK and ROI that currently provide a perinatal and paediatric pathology service to explore the possibility of securing support to retain a local service in Northern Ireland, especially for the provision of post-mortems.

Regrettably, despite all possible efforts, it was not possible to provide a local service in the short term. The changes are on an interim basis and the HSC will continue to explore all avenues to provide a local service.

We are also currently assessing the feasibility of using new emerging technologies, for example, non-surgical post-mortems, which could potentially provide parents with many of the answers they need, and which could be provided locally. This work will continue.

In the meantime, it is vital that parents in Northern Ireland still have access to a post-mortem service. Therefore, in line with approaches taken to support other small highly specialist clinical areas, interim arrangements have been put in place to provide paediatric pathology services at Alder Hey Children's NHS Foundation Trust in Liverpool.

While it is recognised that having a service outside of Northern Ireland, even on an interim basis, is not what we would wish, working closely with Alder Hey is providing a more robust service in the interim period and delivering results to families more quickly. Feedback to date has been very positive.

3. Have you exhausted all possibilities to retain a local service in Northern Ireland?

We remain committed to the provision of a local service in the longer term and access to a high quality service will remain a priority. Significant efforts have been made to try and retain a service within Northern Ireland, and an open-ended recruitment process with an agency specialising in international recruitment is ongoing. However, the national and international shortage in paediatric pathologists is fully recognised.

Perinatal and Paediatric pathology is a very small specialist area. In 2016, the Royal College of Pathologists in a survey of the workforce identified 70 consultant posts across the UK, so the challenges are not unique to Northern Ireland.

In 2018, the HSCB also corresponded with every NHS paediatric pathology service provider across the UK, as well as those service providers in the ROI. No organisation was found that could provide an in-reach service to Northern Ireland for the provision of hospital perinatal and paediatric post mortems.

Discussions between the Departments of Health in NI and ROI, on exploring the potential options for an all-island network model for providing this service in the future, are also continuing. However, the feasibility of an all-island approach would only be deliverable in the longer term due to current capacity constraints and the time required for new trainees to specialise in this area.

In the meantime, the HSC will work closely with the relevant Royal Colleges and training organisations to encourage and support training in this specialty in the future.

Also, we are currently assessing the feasibility of using new emerging technologies, for example, imaging, minimally invasive and non-surgical post-mortems, which could potentially provide parents with many of the answers they need, and which could be provided locally. This work will continue.

4. What transport arrangements are being put in place for any baby or child who requires a post-mortem?

There has been a lot of work ongoing to ensure that any baby or child who requires a post-mortem is treated with the utmost respect, dignity and sensitivity throughout their journey.

The HSC will organise and pay for travel arrangements, including transport, accommodation and subsistence, in line with support currently provided for families with children travelling outside of Northern Ireland for procedures.

Most babies who travel to Alder Hey for a post-mortem travel on the ferry in the compassionate care of Belfast Health and Social Care Trust's undertaker.

There is an option for parents to accompany their baby, either on the ferry or by plane. To date only a small number of parents have opted to travel with their baby.

Bereavement midwives, bereavement co-ordinators, pathology, mortuary and other clinical staff in Northern Ireland and Alder Hey will work together to ensure that families receive support and care throughout their journey. Families will be provided with written information,

including contact phone numbers and 24/7 support will be provided during the period of time babies are in the care of Alder Hey.

In addition, a range of resources have been developed with the help of parents and support groups to explain the process to parents to help inform their decision. These are available routinely to parents who have lost a baby where a hospital consented post-mortem is an option. They are available by clicking [here](#).

5. What would you say to families distressed by this decision?

We recognise that the loss of a baby or child is one of the most devastating events that can ever happen to a family. Families are always given a choice of whether or not to proceed with a hospital based post-mortem.

We fully accept that the prospect of the post-mortem being performed outside Northern Ireland may compound the distress experienced by families. It would absolutely be our preferred option to be able to provide this service locally but, due to circumstances outside our control, that is not possible at this point in time.

6. Have parents, charities and support groups been consulted in the design of the interim service?

Over the last year, the HSCB, PHA and Trusts have been liaising closely with key charities and with families who have been affected by bereavement to ensure the arrangements are as sensitive and dignified as possible. A lot of work has been undertaken, and thorough oversight continues, to ensure that any baby who requires a hospital consented post-mortem, as well as their family, are treated with the utmost care, respect and compassion throughout the journey.

A range of resources have been developed with the help of parents and support groups to explain the process to parents to help inform their decision. These are available routinely to parents who have lost a baby where a hospital consented post-mortem is an option. They are available by clicking [here](#).

7. Will post-mortems take longer under the new interim arrangements?

Alder Hey has a full paediatric pathology team which enables their post-mortem service to be delivered without interruption. This team has agreed to work with us to ensure an expedited service to support traditional funeral times in Northern Ireland. Under this new interim arrangement, the post-mortem service will be completed within a maximum of 36 hours.

Under the service with Alder Hey, parents are also receiving the results of the post-mortems more quickly than before, which is particularly helpful for those families wishing to use the information to inform their family planning.

BACKGROUND

8. What is perinatal/ paediatric pathology?

The primary purpose of a hospital perinatal and paediatric pathology service is to conduct post-mortem examinations. The majority of paediatric post-mortems in Northern Ireland are babies who are stillborn, as well as miscarriages from second trimester and babies who survive only a short time after birth. It also includes, much more rarely, hospital post-mortem examinations of older babies and children. Parents will always be given the choice on whether or not they wish to proceed with a hospital paediatric post-mortem examination.

The identification of any obstetric or paediatric conditions contributing to death may be of great value to families in planning of future pregnancies.

The service also includes the pathological examination of biopsies or tissue and organ samples to support accurate diagnosis for children's cancer and surgical services (the surgical aspect of the service remains in Belfast Health and Social Care Trust).

9. What services were provided in Northern Ireland?

The Belfast Trust provided a perinatal and paediatric pathology service on a regional basis across Northern Ireland until the beginning of January 2019.

Parents will always be given the choice on whether they wish to proceed with a hospital post-mortem examination.

Post-mortems ordered by the Coroner, where the circumstances of the death falls under Section 7 of The Coroners Act (Northern Ireland) 1959 are undertaken locally. This service is provided outside of the HSC through a separate contract with the Department of Justice outside the remit of HSC.

Due to limited local consultant paediatric pathologist capacity, the microscopic examination of placentas is currently provided outside Northern Ireland in Alder Hey Hospital, Liverpool.

Paediatric pathology services to diagnose cancer in children are provided locally by appropriately trained adult consultant pathologists in line with national guidance, and this will continue.

10. How many consultants/staff are required to run the service?

Ideally two to three paediatric pathologists (minimum of two) would be required to provide a robust and comprehensive paediatric pathology service in Northern Ireland. Smaller teams are very vulnerable to collapse and function best as part of a larger clinical team or network where possible.

11. Does any other region provide this type of service?

The Isle of Man currently has a contract in place with Alder Hey to provide a similar service.

12. Could the hospital post-mortem service be carried out under the same contract as Coroner ordered post-mortems?

No. Coronial post-mortems are required for a small number of babies and children each year (approximately 20). The responsibility for providing the coronial post-mortem service rests with the Department of Justice and is outside the remit of HSC.

13. What will happen to parents who do not consent to their baby or child being sent across to England for a post-mortem?

Other than in Coroner's cases, the decision to have a post-mortem will ultimately rest with parents. Families will be supported and guided in their decision-making process and every effort will be taken to ensure that all of their questions are answered.

14. How will this affect staff working in paediatric pathology in Belfast Trust?

Staff at the Belfast Trust will continue to play a key role in supporting the service and ensuring that any baby or child who requires a post-mortem is treated with the utmost respect, dignity and sensitivity throughout their journey.

15. Is there any prospect of the service being provided in Northern Ireland in the future?

The HSC will continue to actively pursue all options in order to re-establish a local service.