

1. What is the latest position in relation to interim changes to perinatal and paediatric pathology services?

Health and Social Care (HSC) is very aware that changes to paediatric and perinatal pathology services may add to the distress experienced by families at a devastating time in their lives, and this is extremely regrettable.

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), however, 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 could still access a service, interim arrangements are now 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 and families have been supported in their decision to transfer babies or children for hospital consented post-mortem.

An open-ended recruitment process with an agency specialising in international recruitment is also ongoing. In the meantime, we are working closely with families, staff, charities and other partners to take every possible step to ensure that any baby or child who requires a post-mortem is treated with the utmost respect, dignity and sensitivity throughout their journey now and in the future. Families will have our full support when facing these very traumatic circumstances.

Looking at the medium to longer term, health officials from Northern Ireland and the RoI will investigate the feasibility of an all-island approach to the delivery of paediatric pathology services. Senior Department of Health officials had preliminary discussions with counterparts from the Irish Republic's Department of Health on exploring the potential options for an all-island network model for providing this service in the future.

It is important to acknowledge at this stage that any potential solution is unlikely to be deliverable in the immediate future, due to current capacity constraints in RoI, and the time required for new trainees to specialise in this area.

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

2. Why are services being moved outside of Northern Ireland on an interim basis?

The paediatric pathology service is valuable for families who want to know 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 their 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 for Northern Ireland.

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 over the coming months.

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.

An open-ended recruitment process with an agency specialising in international recruitment is ongoing. Looking at the medium to longer term, health officials from Northern Ireland and the ROI will investigate the feasibility of an all-island approach to the delivery of paediatric pathology services.

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 a much larger centre such as Alder Hey provides a more robust service in the interim period. Importantly, there are opportunities under the new arrangements to enhance the service, and provide families with the results of pathology findings more quickly.

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

Significant efforts have been made to retain a local service. Any changes are only being made on an interim basis at this stage.

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, 15 of which are currently vacant (approximately 1 in 5), so the challenges are not unique to Northern Ireland.

Belfast HSC Trust has advertised for a perinatal and paediatric pathologist four times since July 2015. This has included an international recruitment drive. Additionally, the Trust has an open-ended recruitment process with an agency which specialises in international recruitment. While the Trust will continue to try to recruit to this post, the focus has been to secure an interim arrangement that will ensure the perinatal and paediatric pathology service is able to continue uninterrupted.

The Health and Social Care Board (HSCB) has 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.

Looking at the medium to longer term, health officials from Northern Ireland and the ROI will investigate the feasibility of an all-island approach to the delivery of paediatric pathology services. The issue has been discussed by Chief Medical Officers and senior officials from both Health Departments, however, it is important to acknowledge at this stage that any potential solution is unlikely to be deliverable in the immediate future, due to current capacity constraints in ROI, 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 speciality 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 over coming months.

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

Work continues to ensure that any baby or child who requires a post-mortem is treated with the utmost respect, dignity and sensitivity throughout their journey. Babies or children will be transported by air or by sea, and we have been liaising closely with families who have been affected by bereavement, key charities and our staff, to ensure the arrangements are as sensitive and respectful as possible.

5. Will parents be able to travel over to England with their baby or child and what support arrangements will be in place?

For those parents who consent to post-mortem, parents or family members will be supported in travelling with their baby or child if they wish to do so.

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.

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 information and support, and will have access to 24/7 telephone support when their baby arrives at Alder Hey.

6. 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 asked to make the difficult decision of whether to proceed

with a post-mortem in order to fully understand the circumstances of death, which may have implications for future family planning.

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.

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

The HSC has been liaising closely with key charities and with families who have been affected by bereavement to ensure the new arrangements are as sensitive and respectful as possible. A lot of painstaking work has been undertaken, and scrupulous oversight continues, to ensure that any baby or child who requires a hospital consented post-mortem is treated with the utmost care and compassion throughout their journey.

This engagement will continue over coming months, as we closely review, evaluate and make any necessary changes to the service.

The death of a baby or child, at whatever age, is a devastating event for families. It is hugely important that those parents who choose to have a post-mortem are fully supported throughout the whole process and have clear and helpful information to inform their decisions.

All families and staff alike will want to be assured that every care will be taken to ensure that any baby or child who requires a post-mortem is treated with the utmost respect, dignity and sensitivity throughout their journey.

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

Alder Hey has a full paediatric pathology team which will enable 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. Travel time will be additional to this and we have been engaging with staff, charities, and other key stakeholders to put in place the most appropriate and timely travel arrangements.

The reason for carrying out a post-mortem is primarily to provide answers to parents as to why their baby or child has died. It may also support planning for and care during future pregnancies. The post-mortem findings are provided in a medical report which, under the proposed interim arrangements, will be available much quicker than is currently possible with only one Consultant Paediatric Pathologist.

Currently, it takes between three to six months for the medical report to be available to parents and families. Under the new arrangements, there is a guarantee that almost all post-mortem reports will be available within two to three months.

BACKGROUND

9. What is perinatal/ paediatric/ pathology?

The primary purpose of a hospital perinatal and paediatric pathology service is to conduct post-mortem examinations. The great majority of paediatric post-mortems in Northern Ireland are babies who are stillborn, as well as late miscarriages 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.

10. What services were provided in Northern Ireland?

The Belfast HSC 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.

11. 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.

12. How many paediatric post-mortems are carried out in Northern Ireland each year?

Currently about 240 hospital post-mortems are provided for babies and children in Northern Ireland every year. Parents or families have consented to these post-mortems. The majority of these cases are babies born without signs of life, many in the earlier stages of pregnancy, before they would be expected to be able to survive independently.

13. 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.

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

No, the responsibility for coronial post-mortems rests with the Department of Justice, outside the remit of HSC.

In relation to paediatric pathology, this is also a much smaller service - there are around 20 paediatric post-mortems carried out each year by the coronial service.

15. 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.

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

Staff at the Belfast HSC 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.

17. 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.