

Cabinet Secretary for Health and Sport

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Health and Sport Committee
The Scottish Parliament
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Dear Lewis

As you will be aware, further to the BBC Scotland Disclosure documentary which aired on 24 June, several parents from the paediatric haemato-oncology service at NHS Greater Glasgow and Clyde (NHS GGC) subsequently expressed their concerns about the lack of communications and engagement with them prior to the programme. Consequently, Fiona McQueen requested that a special meeting of the QEUH Oversight Board Communications and Engagement Sub-Group be convened in order to consider the concerns raised by families.

Professor John Cuddihy, Family Representative on the QEUH Oversight Board collated feedback received from several families. Professor Craig White, Communications Lead and Chair of the QEUH Communications and Engagement Subgroup, forwarded the relevant feedback to the Co-Chairs of the QEUH Independent Review, NHSGGC and the Members of the Communication and Engagement Sub-Group respectively for responses.

Professor White also posted an update on the closed Facebook group from the Lead of the Expert Panel for the case note review, Professor Mike Stevens, on 3rd of July, along with a note outlining the above actions. I have enclosed a copy of the letter from Professor Stevens here for your information. He also emailed separately parents who were in touch but not members of the Facebook group; this includes Ms Kimberly Darroch and Ms Victoria Freeman.

Professor White has also been liaising with Lord Brodie QC, Chair of the upcoming Public Inquiry into the construction of the Queen Elizabeth University Hospital Campus (QEUH), Glasgow and the Royal Hospital for Children and Young People and Department of Clinical Neurosciences (RHCYP/DCN), Edinburgh, to advise on the work undertaken in support of family communication and engagement to date and assist with future requests in the context of the Inquiry.

I trust such actions will provide you with the assurance that I am doing all I can to make sure the families feel this government is acting upon the serious issues and great distress caused to them by the events, past and present.

JEANE FREEMAN

July 2020

Expert Panel Update for Families of Children and Young People included in the Queen Elizabeth University Hospital Case Note Review

I am aware of the concerns expressed by many of the families whose children who are being, or were previously treated by the Paediatric Haematology, Oncology and Bone Marrow Transplant (BMT) Service at the Royal Hospital for Children (RHC) and the Queen Elizabeth University Hospital (QEUH). Specifically, concerns that focus on the possible risk of infection arising from the hospital environment. These concerns must be even more keenly felt by those of you whose children have been identified for inclusion in the Case Note Review and I write now to provide you with an overview of our work and an update of our progress.

1. Membership of the Expert Panel

I have been asked by the Cabinet Secretary for Health and Sport to chair an independent panel of three people, all senior clinicians. I am Emeritus (retired) Professor of Paediatric Oncology at the University of Bristol and a Consultant Paediatric Oncologist at the Bristol Royal Hospital for Children. I am joined in this work by Professor Mark Wilcox, Professor of Medical Microbiology at the University of Leeds, and by Gaynor Evans, a senior Infection Prevention and Control Nurse who was until recently Clinical Lead for the Gram-negative Bloodstream Infection Programme at NHS Improvement in England.

We are responsible to Professor Marion Bain who was appointed by the QEUH Oversight Board at NHS GGC as the Executive Lead for Infection Prevention and Control and through whom we report to Professor Fiona McQueen, Scotland's Chief Nursing Officer, who is chair of the Oversight Board.

2. Purpose and Terms of Reference

The purpose of the Case Note Review is to review the medical records of all children and young people diagnosed with 'qualifying' infections (see definition below) and who were under the care of the paediatric haematology oncology BMT service at RHC and QEUH between 1 May 2015 and 31 December 2019. As an independent Expert Panel, we are being asked to answer the following specific questions:

- i. How many children in this specified patient population have been affected, when, and by which infection?
- ii. Is it possible to associate these infections with the environment of the RHC and the QEUH?
- iii. Was there an impact on care and outcomes for the children affected in relation to the infections they experienced?
- iv. What recommendations should be considered by NHS GGC – and, where appropriate, by NHS Scotland more generally – to address issues arising from these incidents and to strengthen infection prevention and control in future?

3. Patients to be included in the Review

With the help of Health Protection Scotland (and now Public Health Scotland), the Panel has agreed a classification of relevant infecting organisms and we will review the case notes of all children and young people defined as follows:

- i. Those with a Gram negative environmental bacteraemia (blood stream infection) - most patients fall into this group. The term 'Gram negative environmental' defines a large number of a specific type of infecting organisms.
- ii. Other environmental infections. There are a small number of other types of infection which may be associated with the environment but this includes is only a small number of cases, some with blood stream infection and some with similar infections found at other sites.
- iii. Cases identified for inclusion for special reasons. There is a small number of children who do not fulfil either of the two categories above but where, for reasons agreed by the Oversight Board, a review by the Panel is considered appropriate.

Currently, we have identified 85 patients whose records will be reviewed and some have had more than one 'qualifying' infection episode.

4. Data extraction

Members of the Expert Panel will not be directly involved in extracting data from the case records held at NHS GGC although we have agreed and defined the data items that we require to make our assessment. The task of extracting the data will be undertaken by two teams – one coordinated by a special group within Public Health Scotland and a second clinical team (led by a senior nurse with special expertise in reviewing clinical safety data). These two teams will provide us with information about the infection itself, how it was treated, and what happened as a result. It will also provide us with information about where, on the RHC and QEUH site, each child or young person was cared for. This may help us, for example, to identify if there are any links between the same infection in different patients treated in the same parts of the hospital site. We are also working with Public Health Scotland and NHS GGC to secure access to all relevant environmental data to help us understand the context for the different infection episodes. In that context, we will take on board the issues that Professor John Cuddihy recently and helpfully has raised on behalf of the families, as far as is possible.

5. The Panel Review

The Panel will discuss and assess every infection episode in every case identified for the review. In doing so, we are trying to answer the following questions:

- 1) Does the type of infection identified fall within the criteria for the Case Note Review?
- 2) Are the data available to us sufficient to complete the review as intended and for us to reach a conclusion?
- 3) Is it possible to link this infection episode with the environment of the RHC / QEUH?
- 4) Was there an impact on patient care and outcome in relation to the infection?
- 5) If so, how serious was this impact?
- 6) What lessons might be learned from each episode of infection?
- 7) Are there any other points we have identified arising from our review on which we wish to comment?
- 8) Where submitted, what response are we able to make to the questions or comments submitted by the parents of the child / young person concerned?

6. Panel Working and Timescale

Given current circumstances and the impact of the Covid-19 pandemic on all health care systems, the members of the Panel, the staff supporting data extraction and those coordinating the process of the review, have been working remotely using video conference technology. Many of those involved are also directly contributing to work relating to Covid-19 both in Scotland and in England. This has undoubtedly slowed the pace of progress and affected the likely timeframe for the completion of this work. Although the Case Note Review was announced by the Cabinet Secretary for Health and Sport in January this year, the submission of a final report will not be possible within the original timescale of the next few months, as originally

envisaged, but we are reviewing how quickly progress can be made and will provide an update on timescales as soon as we can.

7. The Final Report

In writing our report we recognise our responsibility to provide the best answers we can to the questions asked of us, and to give our clearest assessment to you and all other stakeholders in this process.

We are very conscious of the extent to which the issues that led to the commissioning of this review have been reflected in the media and we are particularly aware of the need for us to avoid being influenced by views expressed by others in reaching our own conclusions.

Our report will not include the case details of individual patients in a way that allows them to be identified by others. However, as you know, we intend to provide reporting to individual families about their children, where requested, and we will update you on plans for this in due course.

The Final Report will be provided to the Cabinet Secretary for Health and Sport and will be published by the Scottish Government.

I hope this update is helpful. If you have not yet submitted comments on the review of your child for consideration by the Panel, it is not yet too late to do so. Please continue to do so through Professor Craig White.



Michael Stevens