SCOTTISH HOSPITALS INQUIRY

HEARING DIET 12-23 JUNE 2023

CLOSING SUBMISSIONS ON BEHALF OF JOHN AND MOLLY CUDDIHY AND LISA MACKAY

INTRODUCTION

The Glasgow 2 Hearing included both oral and written evidence from witnesses who are employed by Greater Glasgow and Clyde NHS and who are responsible for the care of patients in the Queen Elizabeth University Hospital (QEUH) and the Royal Hospital for Children (RHC). Oral evidence was heard from clinicians and nurses who provided front line care to the children and families affected by the issues under investigation by the Inquiry and also from managerial staff.

Core Participants to the Inquiry have been provided with a Closing Statement drafted by Counsel to the Inquiry Alistair Duncan KC and Victoria Arnott. That Closing Statement contains a number of questions to which Core Participants are invited to provide responses. These questions are answered below.

Before addressing the directed questions posed by Counsel to the Inquiry, we wish to address the issue of the departure of Counsel to the Inquiry, the impact of same for the Inquiry progressing and other issues arising from the evidence considered as part of the Glasgow 2 hearing.

DEPARTURE OF COUNSEL TO THE INQUIRY

News that both Senior and Junior Counsel to the Inquiry had resigned came both as a shock and of great concern to the Core Participants, who are patients and their families, that we represent (hereinafter referred to as “our clients”). Both Mr Duncan and Ms Arnott have carried out their duties in such a way as to generate a great deal of trust and respect. The trauma experienced by our clients during their time as patients of QEUH/RHC was, as evidence in Hearing 1, devastating. However, for the clients that we represent, the serious and ongoing ill-health that has resulted from infections contracted whilst they were in-patients within the hospital, and which they and indeed others, believe were caused by an unsafe hospital environment, has resulted in that trauma being a continuing lived experience. Whilst the prospect of having a Public Inquiry was very much welcomed, it was done so with great trepidation and concern. The prospect of having to “re-live” what was regarded as the worst period of their lives and to share the resulting fears and distress with strangers, including those who had been appointed as Counsel to the Inquiry, caused additional anxiety. In addition, there was hope that the Inquiry would fully investigate all matters arising from the Terms of Reference and provide much needed clarity on what had occurred, why it had occurred and what, if anything, would have prevented

the events and consequences suffered by our clients and prevent any recurrence in future. Through their empathy, dedication and expertise, Mr Duncan and Ms Arnott had provided our clients with the confidence that all relevant issues would be fully investigated, without fear or favour. Their departure has caused considerable distress. There is additional concern as to how replacement counsel can be appointed and discharge their duties effectively within a reasonable timescale. Our clients are acutely aware of the volume of work and the resulting knowledge that has been accumulated by Mr Duncan and Ms Arnott since their appointment on 7th September 2020. It is of great concern that the task faced by replacement counsel:- to accumulate the necessary knowledge and understanding, and to effectively discharge the Terms of Reference of the Inquiry - is possibly insurmountable or, if it is to be achieved, will inevitably negatively impact on the Inquiry's progress.

Of conciliation to our clients is the clear direction provide by outgoing Counsel to the Inquiry as to areas for further investigation. It is hoped that incoming Counsel will use this road map.

CORE PARTICIPANTS RESPONSE TO SECTION 21 NOTICES

The Remit and Terms of Reference of the Inquiry were announced to the Scottish Parliament on 15 June 2020 by the Cabinet Secretary for Health and Sport, Jeane Freeman MSP. At that point the remit and terms of reference were in the public domain. It is useful to remind oneself of the Remit:

"The Inquiry will determine how issues relating to adequacy of ventilation, water contamination and other matters adversely impacting on patient safety and care occurred; if these issues could have been prevented; the impacts of these issues on patients and their families; and whether the buildings provide a suitable environment for the delivery of safe, effective person-centred care."

Given that the remit, terms of reference and appointment of Counsel to the Inquiry all took place in 2020 it is of great concern that the Closing Statement in respect of Glasgow 2 makes repeated reference to information, that almost exclusively, would be held by Greater Glasgow and Clyde NHS, not being available to the Inquiry. Examples of this are found throughout the closing submissions and what follows is one example:

> Para 206. "It may be helpful to understand the basis upon which a link is not accepted by GGC (and whether other CPs have a position on that). In that regard, it may be important to understand what investigations including water sampling and testing was done at the time and upon which reliance is placed. A similar investigation may be appropriate in relation to other infections from this time, for example Stenotrophomonas (particularly as regards the question of whether testing was done contemporaneously with or soon after infections emerged)."

GGC have stated in their previous submissions that there is no evidence of a link between the vast majority of patient infections and the hospital environment, albeit that in a couple of cases, such a link

has been accepted by GGC. Para 206, above, indicates that GGC have failed to produce evidence that may support such a proposition. To ensure that both the public and Core Participants will retain confidence in the Inquiry, to fulfil its Remit, there should now be transparency as to whether documentation relating to "what investigations including water sampling and testing was done at the time and upon which reliance is placed" (para 206, above) has been produced to the Inquiry in response to a section 21 Notice. If, as suggested, that documentation and other relevant evidence has not been produced then, in the first instance, the failures to respond to any Section 21 Notice should be robustly responded to. The recent response by Lady Hallett in the UK Covid Inquiry to the refusal/delay by a former Prime Minister to produce evidence is an example of effective enforcement. Second, it would be appropriate for GGC (and other relevant Core Participants) to be asked to produce a position statement in respect of the link between patient infection and the hospital environment, and the other issues of "missing information" identified at Paras 254, 273 and elsewhere. That position statement should append supporting contemporaneous evidence that contradicts the evidence before the Inquiry, including that of clinicians and patients, which evidence that the hospital was not a safe environment for patients and that there is a link between the hospital environment and patient infections.

Professor John Cuddihy has provided the following statement, reflecting on his own response when Molly contracted Mycobacterium Chelonae and other children were suffering from infections whilst in-patients, to be included in these closing submissions. "I have consistently asked for investigations to be conducted into what was unfolding in order to ingather evidence to either prove or disprove. Absence of evidence is not evidence of absence and if one does not look, or in the case of GGC, test the water, you will never have any evidence to prove or disprove whether this is the source of contamination. Add to that the passage of time and the changing form of bacterial infection, even if you test at a later date and find the rare pathogen, it may not be identical."

In the event that there is no evidence to be produced by GGC, either due to, for example, there not being any evidence to support water testing and maintenance, then GGC should produce a clear statement to that effect. Blanket denials are not evidence.

QUESTIONS POSED BY COUNSEL TO THE INUIRY

Chapter 1: - The QEUH and RHC

(1) Do CPs accept that that the account of the evidence is accurate? ***Yes***
(2) Do CPs accept that the evidence itself is accurate (in material respects)? ***Yes***
(3) If the answer to (1) and/or (2) is in the negative, what is the reason for disagreement and what is the CP's position?

Chapter 2: - The Cancer Journey - diagnosis and treatment of paediatric cancer

(1) Do CPs accept that that the account of the evidence is accurate? ***Yes***
(2) Do CPs accept that the evidence itself is accurate (in material respects)? ***Yes***
(3) If the answer to (1) and/or (2) is in the negative, what is the reason for disagreement and what is the CP's position?

ADDITIONAL COMMENTS

Para 75- vulnerability to infection. Witnesses repeatedly highlighted the risk from infection, "infection was the single biggest risk to their child's life".
It seems, therefore, that this is the basic premise on which GGC senior management should have been operating, given that infection is the single biggest risk to the lives of those children in wards 2A and 2B. It is inconceivable that such risk was not on any risk register; the sources of such infection (water, ventilation etc.,) were not on any risk register. The fact that the Director General Health, supported by the then Health Minister, escalated NHS GGC to level 4 of the performance framework on matters relative to Infection, Prevention, and Control, highlights a corporate failing in prevention and protection of those children from the risk of infection.

Para 94- whilst agreeing with the evidence provided, it important to reflect on Gram Positive Bacteria on case, by case, basis. Mycobacterium is a rare pathogen, known as the silent bacteria, very difficult to identify and extremely difficult to treat. The treatment process is not formerly recognized with no agreed protocol for doing, such is the rarity. The impact and implications from contracting this are life threatening, life changing and will impact on future treatment options. Nontuberculous mycobacterial infection is contracted from drinking contaminated water or the bacteria can also enter the body through a break in the skin, such as a puncture wound that gets contaminated with water or soil. Contaminated water from flooding bathrooms could infect patients with feet/body wounds or lacerations.

Para 96- In addition to the 'impacts' listed the following can be added: cancellation/postponement of surgery, delays in radiotherapy and resulting reduced clinical options at a later date, impacting mortality.

Chapter 3: - Infections and mitigation of infection risk

(1) Do CPs accept that that the account of the evidence is accurate? ***Yes***
(2) Do CPs accept that the evidence itself is accurate (in material respects)? ***Yes***
(3) If the answer to (1) and/or (2) is in the negative, what is the reason for disagreement and what is the CP's position?

CHAPTER 4: The history of concern-

Questions aimed at establishing the history of concern

(1) Is it accepted that the narrative set out below provides a materially accurate summary of the evidence provided to the Inquiry – whether that evidence be in witness or in documentary form – about the history of concern? ***Yes, however, see the following sections of Professor Cuddihy's Inquiry statement which is additional evidence before the Inquiry.***

(2) Does the narrative provide, for the period it covers, a materially accurate account of contemporaneous expressions or examples of concern about the hospital environment and about infection link or risk?

Yes, however, see the following sections of Professor Cuddihy's Inquiry statement which is additional evidence before the Inquiry.

(3) Insofar as any aspect of the narrative is said not to have been part of the history of concern at the time what is the basis for that challenge?

N/A

(4) What if any additional expressions or examples of concerns ought to be included in the narrative and considered for further investigation?

See the following sections of Professor Cuddihy's Inquiry statement which highlights the various external reports evidencing an unsafe environment.

Responses to concern

(5) Does the narrative and the timeline set out a reasonably comprehensive history of the response by GGC and other organisations to concerns that the built hospital environment gave rise to a risk of infection on the part of vulnerable patients?

It is not possible for our clients to answer this question with any certainty as GGC has not been transparent in its response to concerns that the built hospital environment gave rise to a risk of infection. In communication, for example, patients and families have given evidence of being reassured that the QEUH had a separate water supply before their children were decanted from the RHC. Similarly, in respect of physical response, there is no evidence that recommendations from external bodies such as DMA Canyon or Innovated Designs (Report of 24 October 2018) were acted upon nor that there was internal effective comprehensive testing by qualified individuals to assess the safety and suitability of the ventilation or water system for immunocompromised patients.

(6) Should consideration be given to other measures; and if so which ones?

GGC should produce evidence or position statements that evidence their response to concerns that the built hospital environment gave rise to a risk of infection on the part of vulnerable patients.

Objective validity for concerns

(7) At any point since patients arrived in the QEUH/RHC, has the water system given rise to an increased avoidable risk of patients being exposed to infections?

Yes

(a) Is it accepted that the 2015 DMA Report identified deficiencies in the water system that without remediation had the potential to give rise to such a risk?

Yes

(b) Were these deficiencies addressed prior to the report being "discovered" around June/July 2018?

No and there is no evidence of comprehensive testing by qualified individuals across the estate. Indeed, there is evidence of water tanks being padlocked and therefore inaccessible to testing.

(c) Did the events of March/April 2018 identify widespread contamination of the water supply throughout the RHC and QEUH per the evidence of Professor Gibson and the Full IMT Report of 13 April 2018?

Yes

(d) Did that contamination have the potential to be harmful to vulnerable patients coming into contact with untreated or unfiltered water?

Yes

(8) At any point since patients arrived in the QEUH/RHC, has the ventilation system given rise to an increased avoidable risk of patients being exposed to infections?

Yes

(a) Does the Innovated Designs Report of 24 October 2018 identify any features of the ventilation system on Ward 2A that could have increased the risk of infection to patients?

Yes

(b) Did the features of the ventilation system discussed in the SBAR of12 November 2018 present an increased risk of infection to patients?

Yes

(9) Finally, for GGC, NSS and the Scottish Government specifically: which if any of the infections identified in the history of concern, are accepted as having been caused by an aspect of the built hospital environment; which aspect of the environment?

All

(a) To what extent does the answer to this question depend upon the availability and use of genomic investigation?

This answer is based upon the lived experience of the families, patients and the evidence that has been made available to the Inquiry which has not been contradicted by evidence other than a blanket denial by GGC.

(b) Insofar as it is being relied upon, is genomic investigation being used as a means for excluding or for confirming causal links to the environment?
The answer to this is unknown.

(c) Does the utility of genomic investigation depend upon the availability of suitable environmental testing?
The answer to this is unknown.

(d) In what way and over what period did water testing within the QEUH and RHC evolve (as regards regularity, location and nature of pathogens considered)?
The answer to this is unknown.

(e) Who sat on the Cryptococcus sub-group and did it come to an agreed view on each of the hypotheses under consideration?
The answer to this is unknown. It is of note that as the crisis at GGC developed, clinicians who were highlighting any concerns, were increasingly marginalised or removed from any groups that were either scrutinising the incidence of infection or developing responses to the crisis.

Reference is made to the following sections of Professor Cuddihy's Statement to the Inquiry, relating to events in June 2018 onwards when his daughter Molly contracted Mycobacterium Chelonae. This evidences the Cuddihy's history of concern and how this was communicated in the first instance with recourse to Chief Medical Officer for Scotland (the letter to the Chief Medical Officer and the reply from Dr Jennifer Armstrong, are contained within appendix One). The Chief Medical officer's conduct thereafter, along with the Cabinet Secretary, validated those concerns. Those concerns were then supported by the Director General and Scottish Government decision to escalate to level 4 of the NHS Board Performance framework, with emphasis on communication and engagement, Infection, Prevention and Control and Effective Governance. They stated that NHSGGC conduct presented 'Significant risks to delivery, quality, performance and safety, and therefore senior level external support required'.

"83. I embarked on my own due diligence of internal protocols relative to Hospital Acquired Infection, Infection Management Teams, Investigation of bacterial outbreaks and internal governance for such. I began to look for answers to many questions and could then see an absolute divide between clinical and corporate information management and disclosure and more specifically, communication and

engagement. Indeed, in June 2018, I sent my first letter of concern to Dr Catherine Calderwood, Chief Medical Director for Scotland. The letter, 'A Parents Concern" proved the catalyst for prolonged and detailed communications with numerous individuals within NHSGGC, Scottish Government, Statutory Authorities; including Children's Commissioner, Crown Office and Procurator Fiscal Service and various other corporate entities associated with the developing crisis. I am willing to share all such communications and reports with the Public Inquiry from June 2018 until the present time, should this be of assistance. I have ingathered hundreds of documents, emails, pictures and associated reports that reflect my investigations.

…

98. Following initial examination of the ward 2A, media reporting carried comments from NHSGGC stating that they would take the opportunity to upgrade the ventilation system on the wards but maintained a position that the environment was safe. This public statement was at odds with reports I had accessed from an independent expert company, INNOVATED Design Solutions who, in October2018 following detailed examination of the existing air conditioning system inward 2A, stated that the original design philosophy was not intended for immune suppressed patients. Further, the existing strategy would appear only likely to promote risks associated with uncontrolled ingress of infectious aerosols to patient areas. The report went on to state that air change rates were not in accordance with recommendations; no identified agreement to any deviation from recommended guidance; numerous deficiencies and inadequacies; with significant modification/replacement being necessary. In conclusion the report states that failure of this system gave rise to the risk of infection. They recommended that not only should the air-conditioning system in ward 2A be replaced, they stated that it was probable that these issues applied to other air handling units across the hospital.

99. This was at a time when NHSGGC were aware of the emergence and significance of the 'lost' 2015 DMA canyon report, first submitted to NHSGGC electronically and by hard copy in May 2015. The 2015 report highlighted a raft of very concerning issues with water management and bacterial control resulting in a number of high risks being identified, including no formal management structure, written scheme or communication protocols; and filters having been bypassed introducing debris into the system.

100. In addition, DMA Canyon provided a further report in 2017, during which they expressed significant concern that ALL recommendations including those HIGH RISK recommendations from 2015 had never been implemented. They further detailed concerns with regard to the filtration system, bypassed due to issues with pumps and filter sets, which would introduce contamination, debris and (potentially bacteria) into the system. As tanks had not been cleaned, even since recommendations in 2015 to do so, any material or contamination then present, could potentially have been flushed into the system and have colonised parts of the system. The report also made reference to positive tests for bacteria in 2017 indicating potential bacterial control issues. However, this report, a statutory requirement, was also 'lost'.

101. Remarkably a third DMA Canyon report, compiled in January 2018 as a gapanalysis reflective of legionella requirements, seems also to have been 'lost' as no-one makes any reference to the fact that the report highlighted significant concerns across estates with individuals responsible as 'authorised persons' being untrained and unqualified to carry out their role. DMA Canyon recommended 'corrective action as a matter of immediate urgency". However, rather than implement the immediate urgent recommendations, the report was once again lost, exposing my daughter and every other child to significant risk!

102. I find it incredulous therefore that the GGC management maintained that the environment was safe and were simply taking the 'opportunity' to upgrade the ward!"

Chapter 5: - Impacts

(1) Do CPs accept that that the account of the evidence is accurate? ***Yes***
(2) Do CPs accept that the evidence itself is accurate (in material respects)? ***Yes***
(3) If the answer to (1) and/or (2) is in the negative, what is the reason for disagreement and what is the CP's position

The evidence of impact considered to date indicates that no impact assessment relative to those young people from the Schiehallion Unit was ever completed. The evidence from Glasgow 1 and Glasgow 2, lays bare the trauma endured by everyone, not least of all the children and young people affected.

From evidence provided an options appraisal was completed by Mr Redfern, at least in part, which demonstrates a level of understanding, at senior management level of the need to identify a suitable environment for those vulnerable children, displaced from Schiehallion in September 2018. We also heard evidence of the vital importance for holistic care, as detailed in the evidence of Dr Murphy when he explained " *the 21st century paediatric cancer journey is not just about cure or not cure; it is about the experience of the patient whilst undergoing treatment*."

No documents or information have been produced that evidence proper consideration having been given to the impact that a change in policy, or implementation of measures would have on that experience of those children and young people up to the age of 18 who were patients in Wards 2A and 2B. This absence indicates a failure by GGC, the seriousness of which is exacerbated when one considers the provisions contained in the Scottish Government Child Rights and Wellbeing Impact Assessment (CRWIA) Guidance. Article 4 of the United Nations Convention on the Rights of the Child (UNCRC) requires governments *'to undertake all appropriate legislative, administrative and other measures for the implementation of the rights recognised in the UNCRC'.* CR[W]IAs were introduced by the Scottish Government as one of the general measures of implementation under the Convention.

The UN Committee on the Rights of the Child recommends that all levels of government - national, regional and local – should complete a CR[W]IA as part of their policy development.

The CR[W]IAs follow normal impact assessment practice and use two frameworks in the assessment:- the UN Convention on the Rights of the Child (UNCRC), which the Scottish Government, along with other duty bearers, such as NHS GGC, are required to respect, protect and fulfil, and the child wellbeing indicators developed as part of the GIRFEC approach to children's services provision in Scotland. GCC has produced no evidence that a CR[W]IA was completed in relation to their response to the incidence of infection of immuno-compromised children. A completed CR[W]IA would have provided evidence that NHS GGC identified, researched, analysed and recorded the anticipated impact of the displacement of those children and their subsequent wellbeing.

The absence of any evidence of any sort of assessment, demonstrates NHS GGC lack of consideration and their laissez faire attitude to the identification, management and mitigation of risk. There is no evidence that those children were demonstrably at the centre of their decision making, resulting in their physical, emotional, psychological and social deterioration during their three years being pushed from one make-shift ward, to another.

It is also important to recognise the impact of the bacterial infections themselves and as witnesses described, the long-term consequences of a particular therapy on a particular growing individual. Clinicians have to factor in those long-term consequences of treatment to the individual patient. It is hard enough when dealing with cancer, but when clinicians are then presented with infections from rare pathogens, the impact on them and their patients increased considerably. It is the case that those rare pathogens identified in water and in patients have had long term, devastating impact on their vital organs. Molly Cuddihy, having been treated for her cancer, contracted Mycobacterium Chelonae a rare pathogen, also identified in another patient and found in the water and water systems across the NHS GGC estate. Impact of the bacterial infection, was months and months of a cocktail of intravenous antibiotics, proving more devastating than the cancer itself. She now requires a double organ transplant, liver and kidney. This brings home the stark reality and true impact of the failures by NHSGGC to adequately protect patients, such as Molly, from the likelihood of infection, from an environment that has been shown to have exploited her known vulnerability during her cancer journey.

CHAPTER 6: Communication

(1) Which organisations had responsibility for directing or had input into communications during the periods covered in the above narrative?

The Inquiry should consider the work of the Oversight board and the communication and engagement sub-group, created to consider the concerns of the Director General and Cabinet Secretary relative to Communication and Engagement.

As regards practicalities

*(2) Is it accepted that the practical arrangements for communication were as described***?**

In part, however, reference is made to Professor Cuddihy's statement to the Inquiry. For a comprehensive picture of communication, the Inquiry should also consider evidence from the Chair of Communication and Engagement Sub Group, Professor Craig White, as well as the Chair of the Case Note Enquiry and Communication and Engagement Sub Group, Professor Mike Stevens.

(3) To what extent did those practical arrangements operate successfully?

In part, as the process developed, elements of briefing by Jamie Redfern were well received on the ward.

(4) Is it accepted that the practical arrangements for communication were to any extent sub-optimal? If not, why not? ***Yes***

(5) Is it accepted that changes were made between 2018 and 2019 to improve the arrangements for communication; what were they and to what extent were they effective? ***No.***
Reference is made to Professor Cuddihy's statement to the Inquiry and in particular, the BBC Disclosure Scotland program which evidence that any learning/improvement in communication between 2018/2019 was not maintained.

(6) What are the current practical arrangements for communication should an event of a similar nature reoccur? **Unknown.**

(7) What more is needed to complete the investigation into the arrangements for communication?
Take evidence from members of the communication and engagement sub-group, set up as a result of being placed into level 4 of the performance framework. The creation of the sub-group evidences that communication and engagement by GGC was considered sub-optimal. In addition, the Chair of the Case Note Review should provide evidence to answer questions in this regard.

As regards effectiveness

(8) What comments do CPs have to make on the discussion on the effectiveness of communications as regards: timing of communication; content of communication; and media briefing?
Reference is made to the comments contained within Professor Cuddihy's statement.

(9) Are the criticisms made by witnesses justified? **YES**

(10) What more is required to complete an evaluation of the effectiveness of communication? **Consideration of the findings from the communication and engagement sub-group and a review of corporate communications in GGC to ensure compliance with recommendations. Recent media coverage of the conduct of the Director of Communications and the Communications department leaves one to conclude that there is an organizational culture problem that needs to be investigated.**

As regards standards of communication

(11) What ought the hallmarks of good communication in the healthcare setting to be? **Openness, transparency, inclusiveness, timeous engagement and honesty.**

(12) What is the threshold for communication about the cause of an infection?
When considering the Duty of Candour, causation itself should not be a factor, although if known, should be shared.

(13) Was there a duty of candour conversation / communication with the Cuddihy family until prompted by Professor Cuddihy's email to Mr Redfern
No.

was it intended that there should be one
It* was the intention of the Chair of the IMT as agreed by members present, but this was countermanded, for reasons unknown**. ***This matter requires further investigation with the witness Dr Theresa Inkster.

who had responsibility for that
NHSGGC-CEO-Jane Grant*;*

what is the explanation for that not happening?
Jane Grant must be asked that question at a future hearing.

Chapter 7:- Present day Schiehallion Unit

(1) Do CPs accept that that the account of the evidence is accurate? ***Yes***
(2) Do CPs accept that the evidence itself is accurate (in material respects)? ***Yes***
(3) If the answer to (1) and/or (2) is in the negative, what is the reason for disagreement and what is the CP's position.

It is considered important to reflect on the arrangements for providing assurance and confidence around the re-opening of Schiehallion Unit. It is not suggested that there is evidence to believe that there are current issues with the Schiehallion unit, however the Oversight Board recommendations led to the creation of NHS ASSURE. It is suggested that evidence should be obtained from NHS Assure to ascertain if:

NHS ASSURE were involved in the provision of assurance and confidence to the NHS GGC Board and Scottish Government prior to the Schiehallion Unit re-opening?
If not, why not?

The answers to these questions will demonstrate if GGC are a 'learning organisation' and one who welcomes scrutiny enabling independent assurance and confidence around the commissioning process.

The answers will also shed some light on the decision to de-escalate NHSGGC from level four to level 2, having satisfied all recommendations from the various investigations and inquiries. Was the de-escalation based on evidence that the previous "concerns" had been fully and effectively addressed? If NHS ASSURE did not engage in the commissioning process and re-opening of the Schiehallion unit, as per Scottish Government terms of reference, who provided assurance and confidence to the First Minister with regards to the Schiehallion Unit?

CONCLUSION

Whilst the Inquiry's progress and fulfillment of its Terms of Reference face a number of very significant challenges, we continue to seek to support the Inquiry as fully as we can. Professor Cuddihy has provided a personal response to the Submissions, which is contained in Appendix Two.

Going forward we hope that all Core Participants will fully co-operate with the Inquiry and facilitate rather than inhibit the Terms of Reference being fulfilled. We wish to close by thanking again, Alistair Duncan KC and Victoria Arnott, Advocate, for their hard work and professionalism during their time with the Inquiry.

Clare Connelly, Advocate

APPENDIX ONE

Official Sensitive

Dear Dr Calderwood

I hope you will forgive my direct approach to you. I was kindly given your details by Paul Carberry who I am aware, emailed you earlier to advise of some concerns I have.

My daughter was diagnosed in January of this year with Ewing Sarcoma and is currently under the charge of Dr Sastry at Royal Hospital for Children, Glasgow.

Since her diagnosis she has embarked on an extensive cycle of chemotherapy, which has resulted in a number of side effects including neuropathy and severe mucositis. This has resulted in her being treated as an in-patient within Ward 2A over the majority of the last six months.

In March of this year bacteria was identified within the ward and allegedly sourced to the water supply resulting in considerable disruption, changes to ward hygiene procedures and instruction to refrain from drinking and washing in water from domestic water supply servicing the ward.

In addition, medical intervention resulted in anti-biotics being given to those children with compromised immune systems, including my daughter.

As you will no doubt agree this proved to be a very difficult time with considerable impact on my daughter. Indeed, we, as a family were extremely worried and concerned as to the safety and well-being of our daughter whilst being treated within the hospital ward. You will be aware of the media reporting at that time and discussion within the Scottish Parliament debating chamber with the Minister for Health Shona Robison making a statement and an apology to the patients and families concerned.

In addition, a comment, attributed to the NHS Glasgow was also widely reported in the press as follows

*"As a result, it is hoped that the full water supply will return to normal within **48 hours** after appropriate testing has been carried out..."*

It may interest you to know that bottled water continues to be supplied with temporary filters fixed to the washbasin taps and shower head.

You will imagine my distress and extreme concern when in May this year a further outbreak of bacteria, this time, according to media reports and following alleged comments from an NHS employee, the source was identified as the drains within Wards 2A and 2B.

Indeed, media reporting on 5 June 2018 provided

"As the wards affected treat patients whose immune system is compromised, we have taken these immediate steps to apply a chemical disinfection to the drains and to inform the families of the situation."

"We have also taken the extra precaution of prescribing antibiotics to a few patients who are at risk of infection and we are sorry for the disruption this has caused to our young patients and their families in wards 2A and 2B at this time."

My distress increased even further when I learned that my daughter had contracted Mycobacterium Cholonae, resulting in significant medical intervention with the removal of her "Hickman line" used to deliver the chemotherapy required to treat her cancer. My daughters condition during this period deteriorated significantly and since the identification of the bacteria she has been on a concoction of intravenous anti-biotics, which we have been advised will be required for at least one month followed by oral anti-biotics for a further year.

The impact and implications for my daughter have been hugely significant with the doctors, responsible for her care, being placed in an impossible position of deciding whether to resume her chemotherapy, which will result in the reduction of her immune system, at a time when bacteria, threatening the life of such a vulnerable patient, remains within the ward environment. Conversely, a decision not to resume chemotherapy increases the risk of her cancer spreading.

When one reflects on the statement of the NHS employee, made without any consultation with ourselves, viz: -

"...extra precaution of prescribing antibiotics to a few patients who are at risk of infection..."

This does not reflect the accuracy of the circumstances and seeks to underplay the critical nature of the infection within the ward. Indeed, the statement continues

*"we are sorry for the **disruption** this has caused to our young patients and their families in wards 2A and 2B at this time."*

This comment seems to further play down the critical nature of this incident. There has been no mention of the medical intervention, the critical requirement to provide anti-biotics, the distress, anguish, worry and pain caused. This is more than "disruption"!

In an effort to find out exactly what has been ongoing within this acute children's ward and to receive some sort of explanation as to why my daughter has contracted this bacterium, and to seek assurances that she will be safe within the ward, I requested to speak with the Infection Control Lead Dr Teresa Inkster. I am afraid to say that she did nothing to allay any of my fears, on the contrary my discussions with her left me concluding that there was a lack of command and control, no communication, no apparent dialogue between medical staff and infection control, a total lack of understanding of the fact that there continues to be an apparent issue with the water supply, something she disputed with me. In fact, when I asked as to why a deep clean was not carried out in March when the first bacteria were identified,

her response, amongst others was to ask if I was aware how much an HP Deep clean costs!! You will no doubt appreciate my response which was to ask what value does the NHS Glasgow place on the life of a vulnerable patient?

Over the last few weeks I have researched, spoken with a number of individuals and conducted due diligence in respect of the processes and procedures that should have been adopted once an infection has been identified. I have also observed every day "organisational chaos" within the ward with a total break-down of faith, trust and honesty, lack of coordination and absence of leadership. I have observed new patients being treated within other wards, outpatients advised not to visit ward 2A; "deep clean" followed by "deep clean", signage on water fountains and advice not to drink water from the taps, already fitted with filters. In all the circumstances my perception is that no-one has a "grip" of this crisis.

I have been left contemplating whether I should seek to remove my child from this ward however, the outstanding medical care at the hands of the clinical team under the leadership of Dr Sastry has resulted in me deferring this decision meantime. However, Dr Sastry, with all his skill, cannot and should not be held accountable for that which he is not responsible; ensuring that existing bacteria is removed from the water supply and drainage system and initiating effective infection control measures to prevent a recurrence of this crisis which has placed lives and that of my daughter, at significant risk.

May I respectfully request, as a matter of urgency that you afford me some time to speak with you and articulate my extreme concerns for the safety and well-being of my daughter whilst within an NHS Glasgow and Clyde Hospital. The lack of leadership is directly impacting on her safety, health and well-being and that of other seriously ill and vulnerable young patients.

I look forward to hearing from you by return.

Yours sincerely

Professor John Cuddihy

[redacted]

Greater Glasgow and Clyde NHS Board

Letter to be sent by email.

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Date: 23rd July 2018
Our Ref: JA/BOB/PC01

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Dear Professor Cuddihy

I have been passed a copy of a letter you sent to Dr Catherine Calderwood, Chief Medical Officer for Scotland, regarding concerns about your daughter, Molly, who until recently was an inpatient in the Royal Hospital for Children (RHC). I was keen to write to you directly, to ensure that you were aware that I have taken your letter very seriously, and to convey that I am keen to do all that we can to help.

I was so sorry to read about how ill Molly is. I realise that this must be worrying enough, and I deeply regret that concerns about the water supply made an already difficult and upsetting situation for your family worse. As Molly is 16, she is old enough to give consent about patient confidential information, which means I would need her permission to correspond to you about her care and treatment. However, I will do my best in this email to share what I can within the confines of this, and I would also like to say to you at the outset that we would be more than happy to convene a meeting to discuss your concerns if you would find that helpful. If Molly consents to this, this would mean we could discuss your concerns in depth, and we would ensure that senior colleagues from the Women and Children's clinical and managerial team were in attendance.

Whilst I cannot go into detail about Molly's clinical care, I can respond to some of your more general points about infection control. I would like to assure you that the Board followed both our local NHS and Scottish Government policy and procedures for the issues with the water, but I am nonetheless very sorry that your impression has been poor. I can completely appreciate why reference to this issue being a 'disruption' would be so provoking, as clearly it means so much more than that to the families of patients who are very unwell. For that, I sincerely apologise.

An Incident Control Team was appropriately set up under Chair of Dr Teresa Inkster who is the Board's Lead Infection Control Consultant. This team included formal involvement from Health Protection (HPS) and Health Environment Scotland. There were also a cross section of senior personnel from various parts of NHS Greater Glasgow and Clyde routinely present including doctors, nurses, pharmacists and managers. All meetings had a formal minute recorded and an action plan established and completed, and this action plan was developed to prevent harm to patients, while at the same time trying to identify the root cause of what the problems were. Throughout these meetings, clinical staff were asked to report on any specific patient concerns.

Formal communications were established including to the NHS Board Chief Executive Team and to the Scottish Government. The status of the incident being managed was routinely scored against a recognised system using formalised criteria for such purposes. Throughout the process, there was strong communication between key stakeholders.

Systems were in place to promote positive engagement between clinical staff and patients, parents and families to keep all informed of what was happening. I note this in the context of the difficult circumstances for how patients had to be treated and the general environment and restrictions of the ward at this time.

At ward level various actions were put in place to support medical and nursing staff working on the floor. This included roster of additional nursing staff, enhanced infection control support and provision of additional domestic and estate input. This is all documented through infection meetings.

I have noted all that you wrote about the reluctance of completing a Hydrogen Peroxide Vapour (HPV) clean in March 2018 when the initial outbreak in the ward was declared. There is guidance on the use of HPV. Dr Inkster did, when she met you, refer to the guidance and noted barriers to routine implementation in Scottish hospitals. However, I am sorry if this in any way came across as insensitive, as this would not have been the intention.

HPV is not a recognised method for decontamination of a water system. It was therefore not considered within the referred to guidance as a required strategy at this time to deal with the problem faced. An agreed action of the infection control team was to have filters located on all tap and shower heads. This action was an industry approved preventative measure to the water issue faced and as a result of it (alongside a systematic program of chemical dosing) problems with the water supply to the ward were successfully addressed. The filters remain in place, and at this time, no bacteria of the nature identified in ward 2a around March 2018 have been identified.

In May 2018 there was an increased incidence of enterobacter bacteraemias in the ward. This is a different type of bacteria which is not grown from the water supply and has a very different hypothesis. You correctly refer the cause of this to bacteria identified in the drains/sinks in the ward. All drains/sinks were appropriately cleaned and refitted with specific parts to minimise the problem reoccurring. It was at this time HPV was deemed the appropriate follow up strategy to use as part of a thorough environmental clean of the ward, and this was duly authorised by the Board Executive Team.

To date these various approaches have been collectively successful and the ward is now functioning normally, although as a precaution enhanced infection control and domestic measures remain in place.

I realise that your primary concern is, understandably, for Molly, and so I very much hope that I have managed to reassure you that we have approached this issue in a coordinated and transparent way, in line with recognised guidance and policies, and that the situation was closely monitored. I would like to reiterate my offer for the senior team to meet with you if you would find that helpful, as I am keen we do all we can to restore your faith and confidence.

Kind regards

[redacted]

Jennifer Armstrong
Board Medical Director
NHS Greater Glasgow & Clyde

APPENDIX TWO

Professor Cuddihy Closing Statement- Comments

General

I am encouraged with the depth and scope of this closing statement, which reflects a level of scrutiny, balanced observation and consideration of the evidence presented.

Whilst, we petitioned for this Public Inquiry, we were acutely aware of the additional trauma this would bring for our daughter and those other children and their families. It has been clear that the trauma, endured during the cancer journey has been acutely felt by the 'Schiehallion family' who have supported us on this difficult and at times, what has seemed, an insurmountable climb.

However, this additional burden was recognised by Counsel to the Inquiry, who have consistently fostered an atmosphere of trust whilst showing empathy and understanding throughout. This has enabled witnesses to be heard but more importantly listened to. The Public Inquiry has, so far, afforded a voice to those who were not listened to by NHS GGC, patients, staff and families. The Inquiry can only consider the evidence that they have available to them and the detail within this closing statement reflects this evidence to date. It is testament to the openness and transparency promoted by the PI and so welcomed by my family.

I do however have concerns following the departure of Counsel to the Inquiry, which came as a shock to everyone. They invested time and effort with families, gaining a level of understanding of the complexities of this case whilst recognising the human cost. Regardless of what the outcomes of the Inquiry maybe, I for one had a confidence in the integrity of the process to date, which in no small part was down to Counsel to the Inquiry. However, my trust and confidence in the Public Inquiry has been dented but I hope that through proactive communication, engagement and recruitment of replacement Counsel, that trust can be rebuilt and confidence regained.

Whilst reflecting on the last few years, I am acutely aware of the impact on those current children and their families, recently diagnosed. I would like to say to them and their families, this was not an easy decision for any of us. You have the most wonderful clinicians possible, available to you. They do magical things. They feel your pain and endure much during the journey and sometimes they themselves need our support.

I hope that our efforts in bringing about a Public Inquiry, will be seen as positive example of that support, a necessary step in our/your journey, ensuring that those children who will sadly follow and endure that climb to the top of the mountain, do so with reduced risk, where possible.

The provision of the new Schiehallion unit should be seen as a legacy to the trauma endured by everyone, staff, families, whistle-blowers and especially those children so cruelly denied a safe and secure environment by those entrusted to deliver on such. This trauma has resulted in, what we have been told, is a vastly improved environment, which I am sure will re-energise the Schiehallion family in their support for children yet to embark on their cancer journey.

Conclusion

As mentioned in the closing statement, this inquiry is about issues unconnected to the provision of clinical care that may have risked undermining the belief that the cancer journey can be completed successfully. Indeed, it is our absolute belief, that this unimaginable journey can be further supported with the provision of what is now heralded as a world class environment, befitting our world class clinicians and the most precious of things, our sick children.

It is incredibly humbling to see the efforts of patients, their families, those ‘advocates’ in the form of those clinicians who have spoken out, often at personal as well as professional cost, and the relentless campaign for justice, recognised with the provision of a refurbished Schiehallion unt.

However, sadly, in order to ensure such world class environment, there has been terrible human costs; the exposure of our sick children to a catalogue of corporate failures, individually and collectively that increased the risk of infection; some sadly, having paid the ultimate price, others, scarred physically, emotionally and mentally for the rest of their young lives. All have suffered the impact and implications of being treated in an unsafe environment that eroded their already, depleted quality of life.

NHS GGC, through their failures, corporately undermined the belief that the cancer journey could be completed successfully. They continue to undermine this belief through their repeated failure to accept responsibility for a series of catastrophic failures. Indeed, as evidence has shown, the environment was unsafe with a succession of independent experts exposing increased risk from water, water systems and ventilation. Yet they continue to defend the indefensible, to deny the undeniable and create a narrative that the current media coverage risks undermining the belief that the cancer journey can be completed successfully for our children.

Our clinicians, reflecting on their years of experience, have been left unable to reconcile this crisis through a lack of informed, evidence-based narrative from their own organisation, as to why? This is a further failing on the part of NHS GGC.

However, the very fact that the infected wards were ‘shut down’ requiring of a multi-million-pound refurbishment to replace the ventilation and water systems, is the clearest evidence you will ever find of a corporate failing that led to the exposure of our children to increased risk of infection.