THE SCOTTISH HOSPITALS INQUIRY

Opening Statement for the affected Core Participants: the parents and representatives of the children affected by their treatment at QEUH

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1. Introduction

1.1 My name is Steven Love QC and I appear along with my learned friend, Mr Gavin Thornley, on behalf of the 54 core participants who are represented before this Inquiry by Messrs Thompsons, Solicitors.

1.2 Those whom we represent are either patients, parental representatives of the patients or immediate family members of the patients who were, or are still being, treated on the children cancer ward and in the neo-natal unit at the Queen Elizabeth University Hospital in Glasgow. They formed the campaign group "Families for Healthy Hospitals" which greatly influenced and framed the Terms of Reference for this Inquiry

1.3 On behalf of those whom we represent we thank the Chair for affording us the opportunity to make this opening statement on behalf of them.

1.4 As will become clear, their children were admitted to hospital for treatment for serious illnesses such as leukaemia and other cancers and they reasonably expected that the best possible medical care and treatment would be provided for their children in a suitably safe and clean hospital environment. What they in fact faced was a catalogue of problems as a result of the hospital environment, the hospital water supply and the conduct of medical staff there.

1.5 The Queen Elizabeth University Hospital was supposed to be a state of the art or 'super' hospital with enough beds to hold in excess of 1,600 patients. It opened for patients in April 2015. The evidence from the parents and representatives which you

will hear lays bare the truth about their experiences of the circumstances surrounding the treatment of their loved ones at that hospital.

1.6 A significant number of children suffered infections during the course of their treatment at the hospital and, tragically, several of those children died as a result.

1.7 In recent times we have read detailed and lengthy statements taken by the Inquiry Team from those we represent and they paint a harrowing picture.

1.8 It seems from what is said on those statements that parents were frequently kept in the dark about the problems with the water supply and ventilation at the hospital. They were not informed about the cause of the infections suffered by their children, when it appears to be clear that the hospital knew that many of the infections were closely connected to the water supply and ventilation systems.

1.9 There was a lack of candour and a failure to obtain informed consent about the administration of drugs including the use of prophylactic antibiotics and their impact. Parents were told they had to use bottled water rather than the water from the taps yet their children were still being showered in the same water that they were not being allowed to drink. They were reassured by staff that it was acceptable to shower their child in the water and then let them brush their teeth in it.

1.10 There were significant numbers who suffered infection from 2017 onwards and of which the hospital must have been, or it seems was, aware.

1.11 The parents of the children affected want answers for what happened, what went wrong and why. Many of them have lost all faith in the hospital itself as a safe place to treat their children.

1.12 This Inquiry will, we hope, go towards:

(i) Establishing the truth of what happened and why

(ii) Bringing any past and ongoing wrongs to light

(iii) Learning lessons about the protection of patients and the families of patients who rely on the NHS for safe and appropriate treatment

(iv) Exploring the duty of candour owed to patients and their families

(v) Calling those responsible for any failings to account and providing them with an opportunity to: (a) acknowledge and accept their responsibility for any wrongs that

were done by them and/or on their watch; and (b) apologise for their failings and the consequences of those failings

1.13 The core participants appreciate the extent to which the Chair has made it clear that the stories of parents and representatives should be heard at the outset of this Inquiry and they welcome the opportunity to be able to speak about what, for many of them, has been a hugely traumatic period in their lives and that of their children.

1.14 They have been invited to identify and describe any particular problems that they encountered and to talk about the emotional impact on them and their children. There are accounts of parents being left with long-standing emotional illnesses as a result of their experiences.

1.15 Having a child treated in hospital is a stressful experience for any parent or family member at the best of times, and it should not be the case that it is made to be more stressful, traumatic and upsetting by the conduct and circumstances at the hospital itself. Parents could not believe that the hospital environment was, as far as they were concerned, making their already sick children more ill. For many of them whose child had leukaemia, the infections were worse than the cancer itself.

1.16 In this Opening Statement I would like to address:

(i) The purpose of this Public Inquiry and its Terms of Reference

(ii) The clients and their experiences

(iii) The physical and emotional effects on child patients and their families; and

(iv) Expectations and the future

2. The purpose of this Public Inquiry and its Terms of Reference

2.1 The Inquiry has been set up and its terms of reference have been fixed.

2.2 The Inquiries Act 2005 within which it will be conducted affords room for interpretation of what the Inquiry is meant to achieve, what kind of Inquiry it seeks to be. Useful Guidance can be obtained from a House of Commons Briefing Paper entitled Statutory Commissions of Inquiry: the Inquiries Act 2005 (30 January 2018, number SN06410). This suggests that a public inquiry, such as this, may serve a number of purposes. We think that these objectives merit some consideration as we start this opening part of the Inquiry.

2.3 It is recognised that there will be further substantive hearings in due course dealing with the remaining Terms of Reference and we reserve the right to make an opening statement, if advised, at the commencement of those hearings.

2.4 The relevant facts must be established.

2.5 We expect the Inquiry to ensure that the relevant facts are fully and fairly investigated without fear or favour. Those relevant facts will be exposed to public scrutiny.

2.6 Core elements of the evidence in this opening substantive hearing will come from patients and families. They will be asked to identify and describe any particular issues or problems they encountered during the course of treatment at or involvement with the hospital.

2.7 A purpose of a Public Inquiry such as this is to achieve accountability, blame and retribution.

2.8 Those whom we represent are aware that both individuals and organisations are responsible for what has happened to them. They wish to see truth and to see justice done for themselves and for their loved ones. They wish those individuals and organisations to be held accountable for what they have experienced and had to endure.

2.9 It is accepted that a fundamental purpose of this Inquiry is for the experiences of and consequences for those whom we represent to be heard and heeded. They need and deserve to be listened to.

3. The clients and their experiences

3.1 At the Procedural Hearing on 22nd June this year, Counsel to the Inquiry made it plain that he intended to begin the substantive hearings by hearing and recording the evidence of patients and their families. He did so indicating that, as a starting point, the focus would be on Term of Reference 8.

3.2 Term of Reference 8 requires this Inquiry: "To examine the physical, emotional and other effects of the issues identified on patients and their families (in particular in respect of environmental organisms linked to infections at the QEUH) and to determine whether communication with patients and their families supported and

respected their rights to be informed and to participate in respect of matters bearing on treatment."

3.3 It seems to us that it is entirely right and proper to the open the substantive hearings in this Inquiry with the evidence of patients and families as the starting point. It is crucial to those whom we represent that questions in connection with issues that are important to them as individuals are asked and answered.

3.4 Their stories and their perceptions of what happened to them and their loved ones is an appropriate starting point. This is entirely right and proper and will allow the Inquiry to ingather the evidence of patients and their families with a view making use of it in the Inquiry's further investigations.

3.5 The individuals whom we represent come from all walks of life, all social classes, all backgrounds and all age groups. Although their stories are different, they are united by some common themes that I will turn to in due course.

3.6 They required to seek medical care for their ill, vulnerable children when they needed it most.

3.7 They all put their trust and faith in the NHS. They trusted the doctors and nurses to whom they turned. They trusted their expertise and honesty. They trusted that their loved ones would receive the best care available in a safe environment.

3.8 It seems, from the statements that we have had the opportunity to review, that they were let down.

3.9 They have been left with their faith and trust in the NHS shattered as a result of poor communication, evasiveness and a lack of openness, candour and honesty.

3.10 They want answers. Why did they experience what they did? What could have been done to prevent those experiences? What can be done to ensure that nothing like it ever happens again?

3.11 Patients and their families ought to have been protected, involved and given informed choices. They ought to have been told the truth.

3.12 The Inquiry will hear that they were not.

3.13 The impact of what they experienced has to be understood and appreciated. This Inquiry needs to provide an opportunity for individuals' stories to be told. Those we represent plainly need that to happen for them to be able to move on.

4 The physical and emotional effect on child patients and their families

The Inquiry must pay attention to the following issues:

Problems with the water

4.3 Parents will be giving evidence to the Inquiry about the problems with the water supply at the hospital. They will tell the Inquiry about how they were told not to use the water from the sink taps in the children's rooms for drinking and how bottled water was supplied by the hospital. The children were hooked up to lines providing lifesaving treatment and medication for them. These lines became infected on numerous occasions. Children were put on antibiotics and in many cases the parents were not advised that their child was going to go on an antibiotic regime before it commenced.

4.4 Nursing staff were blamed for the infections.

4.5 Parents were blamed for bringing infections into the hospital.

4.6 The parents could see that they were not allowed to drink the water, but they were not told why not. They still showered their children in the same water, which their children and them were not allowed to drink. Filters were placed on the taps in the child's bedrooms and on the showers but, if the child was moved to another ward, the filters were sometimes not present. Parents and children watched as staff poured substances down the sink and the drain in the showers. Children became seriously ill from certain types of infections which the hospital knew or ought to have known were closely connected to the water supply in the hospital. It is a tragedy that some children died and that others were pushed close to that as a result of the infections they suffered. Many more children suffered severely as a result of the infections. That suffering was over and above the suffering caused by the very difficult medical treatments they were having for cancer and other serious illnesses.

4.7 Nursing staff and the doctors were aware of the infections and the link with the water supply, but there was almost total failure to explain the situation to parents. When this did happen it was through guarded conversations with nursing staff who were clearly in fear of risking their own positions. That sort of pressure on nursing staff can only have come from those in senior management at the hospital. Unless and until the hospital provides an explanation to this Inquiry, the parents have quite

understandably assumed that the hospital knew about the water supply problems for some time before the infections started and failed to do anything about it. This has undermined the faith of the parents in how the hospital cared for their child and them.

Ventilation

4.8 It is a common thread in the stories of the parents that the bedrooms were far too hot or sometimes far too cold.

4.9 The temperature controls did not work properly or at all in many cases. Fans were provided in the rooms by a charity which helped to some extent until one day they were all suddenly removed. The rooms occupied by child patients were hot and stuffy.

4.10 After the patients were moved to Ward 6A of the adult hospital, air filter machines appeared on the ward and then were placed into the bedrooms of the children. Mould had been found in the bathrooms. The doctors and microbiologists appeared to be concerned about the risk of infection and the potential for adverse effect on transplant patients. It seems that one parent was told that the filters were placed in the bedrooms with a view to trying to disperse the spores coming from the mould and thus reduce any contamination. This state of affairs for what is supposed to be a "super clean" environment shocked parents.

4.11 There was a strong smell of sewage on entering the hospital and in the bedrooms on the wards. The smell of excrement was not constant but would come in waves. It was nauseating for the both children and their parents. It was to the point that it could be tasted and not just smelt.

4.12 The showers in the bathrooms attached to the bedrooms did not have proper ventilation.

Cleanliness

4.13 The bedrooms were only cleaned once a day by cleaners.

4.14 This was seen to be in contrast to the rooms being cleaned three or four times a day at the 'old' children's hospital at Yorkhill. The rooms at the new hospital were cleaned quickly involving a quick mop and wipe. The same cleaning equipment was

used from room to room with no attempt to control the risk of infection transmission between the rooms. Parents frequently cleaned the rooms themselves.

4.15 Soiled nappies and bowls of vomit and stained bedding were left for long periods at a time in the rooms and the bathrooms.

4.16 There were no obvious attempts by the hospital staff to keep the rooms, including the staff/parent kitchen, spotlessly clean and disinfected.

4.17 The impression was that the bare minimum was carried out in terms of cleaning the rooms and the wards. The small number of cleaners and the reduced cleaning rota from the previous children's hospital must have resulted from a decision of someone in senior management at the hospital. It is hoped this Inquiry will provide some answers and explanations for the parents.

4.18 Parents frequently cleaned the rooms themselves, because they were so concerned about the state of the cleaning process they were witnessing on a day to day basis.

Drainage

4.19 The showers in the bathrooms of the bedrooms did not drain away properly and the floors became flooded frequently so that towels had to be used by the parents to try and dry the floor and stop waste water from spilling into the bedrooms.

4.20 Regularly there was a stench of sewage in the bedrooms.

4.21 One of the senior consultants advised the parents that there was a problem with the drains.

4.22 On one occasion sewage was seen coming up through the tiles in the area of the atrium of the hospital.

Communication

4.23 Individually the parents felt that they were kept in the dark about the reasons why their children were getting infections. There was a lack of understanding of what the parents and the children were going through. The level of communication from the doctors and nurses about what was happening with their individual child and how the issues with the hospital were adversely affecting was felt by the parents to be very

poor. Parents felt they were talked to in a condescending manner if they asked questions or queried what was happening.

4.24 The lack of transparency and openness about the problems with the water and ventilation in the hospital completely undermined the trust and confidence that the parents should have been able to have in the treatment, the medical staff and the hospital.

4.25 There was no proper explanation from the hospital staff about the reason for the sudden closure of ward 2A and 2B. This was against a backdrop of increasing numbers of infections amongst the children and worries over the water supply and the drainage. Again there was no proper explanation when air filter machines were installed in the ward the children were moved to.

4.26 Although some parents did receive a generic letter providing notification, some parents found out about the closure of ward 2A and B through the media and social media and not through the hospital - a total failure of communication with the parents of the children. There were instances of parents turning up for treatment with their child and finding the ward empty and full of workmen. As a result of the breakdown in communication from the hospital the parents relied on information from the media about what was happening at the hospital.

4.27 Children were given antibiotics as a preventative measure without any explanation to the parents as to why this was happening. When questioned about this there are examples of parents being told that it was for their cancer treatment or for an underlying problem, which has been shown to be false. This gives the impression of institutional lack of honesty.

4.28 There appears to have been no attempt by the management at the hospital to keep the parents informed about the ongoing problems, which clearly adversely affected their child.

4.29 When the media became aware of the severe problems at the hospital, parents were quizzed by staff to try and find out whether they had communicated with the press. This created a bad atmosphere when the focus should clearly have been on the medical treatment of the children. The parents felt intimidated by the manner in which they were treated.

4.30 It seems that Facebook pages were monitored for criticism. Parents frequently had to rely on the press to provide updates.

4.31 Confidential information about the treatment and death of one child appears to have been passed to the media by a member of staff at the hospital. The parents complained to the hospital, but there has been a failure to fully inform them about the outcome of that investigation and explain how and why it occurred. This type of breach of confidentiality and trust surely demands a level of interaction with the parents that the hospital has not even come close to.

4.32 There has been a failure to take responsibility for what has happened. This is illustrated by some of the statements highlighting examples where the parents and family members felt that they were being blamed for introducing infection onto the wards. Blame was also placed on the cleaners for the infections.

Facilities

4.33 Televisions in the bedrooms did not work properly. There was no consideration of the emotional impact of children being isolated in their bedrooms for days on end. There were insufficient play rooms and areas where the children could escape from their bedrooms. This became particularly acute after the move to ward 6.

4.34 There was no apparent consideration or effort to provide facilities for the different age groups of children which meant that the needs of certain age groups of children were largely ignored.

4.35 Following the move to ward 6 the facilities for the parents were very poor. There were no kitchen facilities for the parents who had to rely on staff for assistance. If their child needed a drink of milk, they had to ask staff and wait. Often the requested item wouldn't come or it would be the wrong item because staff were so busy. Parents couldn't leave the bedrooms in 6A because of infection control. The level of cleanliness was low. No thought seems to have been put into the welfare of the parents who were staying with their child 24/7.

Duty of candour

4.36 There have been cases identified of a lack of candour and honesty by doctors, including one of failing to inform parents that one of the principal causes of death of their child was infection acquired during treatment at the hospital. This has led to the impression of an attempt to hide or cover up the infection and the likely cause.

4.37 Underlying much of the treatment of children and parents at the hospital is a failure to properly advise the parents about the treatment of their child and the reasons for that. This goes to the heart of the relationship between doctor and patient. It highlights the lack of respect for the rights of the patient and their parents to be properly informed and for consent to treatment, including administration of drugs to child patients, to be informed and properly obtained.

4.38 The Inquiry ought to give consideration to the issues of patient autonomy and the risks posed by a 'doctor knows best' paternalism. Many of those whom we represent were made to feel stupid or overanxious.

Complaints

4.36 The statements indicate that there have been numerous issues about complaints made by parents that have on many occasions been ignored or overlooked by the hospital. Given the severity of the situation, particularly over the period in 2018 and 2019, the parents did not feel that their complaints were being listened to. That is a fundamemtal part of the process and the failure of the hospital to properly address the complaints of the parents is something that needs to be answered during the course of this Inquiry.

The statements of the parents cover a number of other issues that includes the following:

Refusal or delay to provide medical records.

Staffing levels for both nursing and cleaning staff appearing to be inadequate for nursing care and cleaning.

Provision of medication, which includes examples of over or under dosing of patients as a result of staff being too busy with room moves which has led to painful consequences for the child patient.

Physical construction issues, such as mould in bathrooms, windows falling out at the from of the hospital and part of the roof falling off.

Internal bedrooms facing onto the atrium being noisy at night and too bright seriously impairing sleep of the child and parents with them in the rooms

Funding applications for treatment being ignored and contradictory advice.

5 Expectations and the Future

5.1 As stated above, it is appreciated that further substantive hearings will be held in due course focussing on the terms of reference and issues such as the construction of the hospital and its associated amenities.

5.2 This Inquiry must focus on past events with an eye to the future.

5.3 It should be recognised that decision making must be understood from a patient's perspective.

5.4 Those whom we represent have fears for the future. What happens if after this Inquiry their child relapses and has to go back? Will they be treated worse? Will their child receive substandard care? How can this fear be allayed?

5.5 There must be transparency as to whether senior members of the NHS Board were feeding ambiguous or even false information to junior staff to disseminate to patients and parents with a view to alleviating concerns that were growing. Was there a deliberate cover up?

5.6 There must be investigation into the response of the NHS Board and Scottish Government to the concerns that were raised about the operation of the hospital.

5.7 Public confidence requires to be rebuilt or restored and that can only be achieved if matters are fully, properly and openly investigated.

5.8 The public requires to be reassured that lessons can, have been and will be learned.

5.9 There requires to be a specific apology in due course for what went wrong and the consequences.

5.10 Healthcare professionals need to be reassured. They should be encouraged to feel able to voice concerns without fear of repercussion.

6 Conclusion

6.1 The 54 individuals who have asked us to represent them have engaged with this Inquiry process with confidence that it can, and the hope that it will, deliver on its terms of reference and meet their objectives. If the Inquiry is not about them, and people like them from all over Scotland, who is it about and who is it intended to benefit?

6.2 Parents who have provided statements to the Inquiry have found the whole process to be reassuring. It has been a clear demonstration of the Inquiry's commitment to exploring and discovering the truth. They have found that the statement takers and witness engagement team have been supportive and kind, have given the families the time and space they need to discuss the most traumatic events in their lives and have ensured that statements have been all-encompassing. For that we are very thankful to the Inquiry Team and the empathy and understanding shown by them in the course of their investigation.

6.3 We are committed and look forward to working further with the Inquiry Team in this and subsequent substantive hearings, knowing that those we represent will, perhaps for the first time, see full investigation, transparency, respect, trust and honesty.

We are grateful for the opportunity to make this opening statement.