Scottish Hospitals Inquiry

Closing Statement by Counsel to the Inquiry

Hearing Diet: 20 September 2021 to 5 November 2021

Introduction

- On 19 January 2021, Lord Brodie announced that oral hearings of the Scottish Hospitals Inquiry would commence with an examination of the experiences of patients who, while receiving care within the Queen Elizabeth University Hospital campus in Glasgow and within the Royal Hospital for Sick Children and Department of Clinical Neurosciences in Edinburgh, were affected by issues covered by the Inquiry's Terms of Reference.
- 2. The volume of evidence provided to the Inquiry was large. In advance of the hearings, a total of 44 people provided detailed and often lengthy witness statements. In the case of 32 of these people, this was supplemented by oral evidence given at a diet of hearings that took place between 20 September and 5 November 2021¹. The quality of the oral evidence was notably high. Without exception, every witness who gave evidence spoke with conspicuous grace and courage.
- 3. To have attempted in this closing statement to set out a record of every witness's evidence would have resulted in a document too lengthy and cumbersome to be of any use. The evidence has been approached thematically; and the focus has been on ensuring discussion of all key themes. Therefore, where individual patient cases are mentioned, that is for illustrative purposes only; no patient's story should be seen as being singled out as deserving of closer attention than any other.
- 4. Particular prominence has been given to paediatric haemato-oncology patients in Glasgow. As they represented the preponderance of the evidence provided

¹ A list of witnesses is attached at Appendix 1. Witness statements and transcripts of evidence can be found on the Inquiry's website, although certain evidence was provided subject to Restriction Orders and redaction.

to the Inquiry, that was inevitable. Concentrating the analysis in one particular area has the advantage of permitting a particularly close look at issues raised under the Terms of Reference. But all witnesses, including those who are not within this cohort, and including those whose evidence was given in closed sessions or is redacted, can rest assured that their evidence has been carefully considered. It is hoped that the still very lengthy nature of this closing statement speaks for itself as regards that.

- One thing must be emphasised about the evidence at the very outset. The stated purpose of the recent hearing was to enable the Inquiry to obtain evidence of patient and family <u>perceptions</u>. Very fairly, and in keeping with that approach, no Core Participant sought to challenge or test anything said in evidence; and, mostly, the questions on behalf of the Inquiry took the same approach. In particular, it was emphasised to witnesses before giving, and during, their evidence that they should not be overly concerned about precise dates. It is hoped that this had the advantage of creating an environment in which patients and families felt able to tell their stories. But it does mean that no one should read this closing statement as setting out a series of facts that can simply be accepted. Instead, it should be seen as an attempt to capture the various concerns which, on the evidence heard, require to be investigated further.
- 6. On the other hand, on many of the most important issues before the Inquiry, the evidence of witnesses was clear and constant. It is hoped that this can be recognised by all Core Participants, and that to assist the Inquiry in its further work, they will give consideration to whether any matters are capable of agreement. In order to assist, and in keeping with Direction 4, Core Participants are directed to the questions which follow the summaries of the evidence for Glasgow and for Edinburgh and to the timeline at Appendix 2.

PART 1: GLASGOW

Summary of the evidence and conclusions

7. The length of this submission has already been acknowledged. In order to assist Core Participants in providing an informative response within the timescale stipulated by the Chair, the submission begins by setting out its conclusions in somewhat longer form than would be usual in an executive summary. Once again, it is to be recalled that what follows should not be treated as proposed findings of fact but as a summary of witness perceptions.

Theme 1: The diagnosis and treatment of cancer

The diagnosis of childhood cancer marks the beginning of an arduous journey. The illness and its treatment present a number of significant physical and emotional challenges. The level of care provided by the Schiehallion Unit clinical and nursing teams is held in the highest esteem by patients and families. But the extent to which the treatment journey is bearable, and perhaps even the extent to which it is successful, will depend upon a number of factors beyond this. The quality and safety of the hospital environment is one factor. The bond of trust between patient and care team is a further factor. Each of these is at the heart of the issues for the Inquiry.

Theme 2: The QEUH campus and the Schiehallion Unit

(ii) Before the emergence of a number of serious concerns, the Schiehallion Unit within the RHC was perceived as enabling the provision of world class clinical care in a suitable and supportive setting. The Unit demonstrated key features required to make the cancer journey more bearable and more hopeful. These features helped create and nurture a network of support; they kept children connected to their families, to their childhoods and thus to life. Both during inpatient and outpatient care, this network of support, allied to the care protocols provided by staff, provided a shelter, referred to by some witnesses as the Schiehallion Umbrella. All of this enabled a vital bond of trust between parents and the staff to whom they had entrusted the care and the lives of their children.

Theme 3: Standalone issues within the hospital environment

(iii) Quite apart from the serious concerns raised by witnesses about key building systems, and about infection and communication, patients and families attending the RHC and the QEUH report having encountered a large number of additional issues with the hospital environment. These range from those that on the face of it presented a real risk to patient health and safety (such as the infection risk from flooding bathrooms and the risk of injury from glass panels falling from height) to those that are apt to have made the cancer journey harder (such as malfunctioning televisions and temperature controls and the pervasive smell of sewage). These issues appear also to have contributed to a loss of confidence in the hospital, and a view that the Glasgow hospital was not the state of the art facility that had been billed.

Theme 4: Concerns relating to key building systems and the hospital environment up to 18 September 2018

- (iv) An escalating pattern of concerns about water and drainage is consistently reported by patients and families within the Schiehallion Unit up until its relocation in September 2018. There is more limited evidence of concerns about ventilation during this period. While there is some evidence of concerns on the part of patients and families about water and drainage as far back as 2015/2016, it was only in 2017 that these became more widespread and more serious (and not only within the Schiehallion Unit). That year there were a number of reported infections within the hospital.
- (v) Despite attempts by the Scottish Government and by Greater Glasgow Health Board ("GGC") to provide reassurance, evidence of issues with the water supply and with drainage only increased in the eyes of patients and families during 2018. That evidence included a number of very serious infection incidents, including some where clinical staff and/or managers appeared to acknowledge a link between the infection and the hospital environment.

Theme 5: Impacts of environmental concerns on Wards 2A and 2B

(vi) Quite apart from the impact of infection itself, concerns about key building systems caused a number of other serious disruptions to life on Wards 2A and 2B, which impacted on patients and families. Children were thought to have been placed in isolation more than would be usual. Cleaning appeared more extensive than usual. Of itself that was disruptive. Patients were decanted to other wards. That in turn presented a risk of children being placed in areas where infection control was not perceived to be at the level within the Schiehallion Unit and where there was a concern about receiving care not attuned to the particular needs of immunocompromised patients. Concerns about the building systems grew with time and undermined trust.

Theme 6: The closure of Wards 2A and 2B

- (vii) The evidence suggests that communication around the decisions to close Wards 2A and 2B and to relocate to Ward 6A was perceived to be, at best, inconsistent and, at worst, non-existent. In many cases, this was the cause of significant distress to some witnesses. People tended to learn of the move via the media. The few witnesses who indicated prior notice of the decision to close the ward, indicated that they understood it to be a response to an infection outbreak. Such evidence as there was about official communication, indicated that GGC sought to explain the closure differently; they said they wished to undertake cleaning.
- (viii) Witness evidence suggested a perceived lack of risk assessment in the decision to relocate Schiehallion patients to Ward 6A in the adult hospital. While patients and families were relieved that in large part the Schiehallion teams had been relocated too, the unanimous view of witnesses was that Ward 6A was wholly unsuited to caring for paediatric cancer patients. At the time of writing, it is understood to remain the position that paediatric cancer patients are cared for on that ward.

Theme 7: Impact of the move to Ward 6A

(ix) The evidence painted a bleak picture of Ward 6A. Patients were said to have become institutionalised; several described the ward as being like a prison. The arrangements for accessing the ward were a cause of some anxiety, given the need to take immunocompromised children through areas where smokers, adult patients and other members of the public tended to gather or be present. The distance from other paediatric services was also a cause of concern, as was the absence of many of the vital facilities that had enabled children to be children and teenagers to be teenagers; and had fostered a support network for families.

<u>Theme 8 & 9: Concerns about environmental safety on Ward 6A; the impacts of those concerns</u>

- Reassurances that Ward 6A would be free of environmental concerns proved unfounded in the opinion of patients and families. The use of preventative medicine continued; evidence of infections continued. In December 2018, a child died. GGC confirmed the presence of Cryptococcus, a bacterium linked to soil and pigeon droppings, on Ward 6A. For some parents, matters seemed only to deteriorate after that. In 2019, one patient was infected by the same extremely rare bacterium that had infected another patient in Ward 2A the year previously. Ward 6A itself was closed, wholly or partially, on at least two occasions due to infection concerns. On one of those occasions, patients were decanted back to the RHC, the very environment from which they had understood they had been removed due to the risk posed to their safety.
- (xi) Overall, the impression was of an increasingly fraught and anxious situation which brought some parents close to breaking point. Once again, communication from GGC was not considered acceptable. Attempted reassurance by GGC staff that the water was "wholesome" did not square with what patients experienced and witnessed. Nor did it square with what some took to be indications of concern from staff. In the case of two patients at least, staff were taken to indicate to patients that they might be safer at home.

Theme 10: Healthcare Associated Infections

- (xii) The Inquiry has been provided with a substantial body of evidence said to indicate the possibility of links between serious patient infections and the built hospital environment. Some of that evidence proceeds on the basis of suspicion: links between infection are suspected or assumed to exist because of circumstantial evidence thought to support those links. That circumstantial evidence includes the various issues with key building systems already discussed; and it includes perceived increases in the incidence of line infections.
- (xiii) But not all the evidence of possible links between infection and hospital environment can be said to be based only on suspicion or assumption. Several witnesses say that they were told either by clinical staff or via reports provided by the Case Note Review ("CNR") that the possibility (at least) of a link had been established. Against that background, and given also the findings of the CNR, Core Participants may wish to consider the questions below.
- (xiv) The potential consequences of an infection for a vulnerable patient and for an immunocompromised child in particular can be very serious indeed. Some parents suspect infections linked to the hospital environment contributed to the deaths of their children. Parents witnessed with their own eyes and children experienced the consequences of an infection: rapid and terrifying deterioration; suffering; additional illness. In some cases, parents assumed that they were watching the final moments of their child's life.
- (xv) Children underwent additional surgeries as well as unpleasant and sometimes distressing procedures. They had their life saving cancer treatment disrupted, suspended and, in some cases, stopped altogether while they were treated for infection. They suffered serious, and sometimes permanent, side-effects from the infection treatment, which side effects in turn had the potential to reduce the options for further cancer treatment, should their illnesses return.
- (xvi) The physical and emotional effects of a serious healthcare associated infection are therefore obvious. But parents are concerned that the price of avoiding an

infection may also have been very high. Children were understood to have been given prophylactic medication to protect them against the hospital environment. Parents worry about the side-effects from these medications, and in some cases are concerned that some recognised side effects – for example hearing loss – have already arisen.

Theme 11: Communication

- (xvii) One of the reasons that some parents appeared worried about the use of prophylactic medication was, as they saw it, an absence of communication. An absence of clear communication was also alleged in relation to individual cases of infection and in relation to concerns more broadly about the risk of infection.
- (xviii) But overall, and beyond these two issues, concern about the approach taken by GGC and hospital management to communication was universal. Not a single witness identified a good example of communication by managers in relation to the perceived issues with the hospital building or infection risk. This contrasted with communication from doctors and nurses about clinical care. This was mostly considered to have been exemplary. But for many patients and families, communication about the building was communication about clinical care. Universally, it was considered to have been lacking. Responsibility for that was said to lie with management.
- (xix) As concerns about the hospital environment and the risk of infection emerged, it seemed to patients that GGC had no communication strategy. The responsibility to explain what was going on appeared to have been pushed onto clinical staff, something many witnesses considered inappropriate. Communicating with patients did not appear to be the priority; the media was usually seen to be the first port of call. It was said that communication tended to put a positive spin on things; it did not accord with what patients said they had experienced on the ground.
- (xx) Great concern was raised about the accuracy of GGC's communications to the media and, when it happened at all, to patients. Many if not all witnesses indicated a belief that GGC managers had not communicated with patients and

with the public openly and in good faith. Evidence was said to exist that supported this view: a consistent disparity between what was said publicly by GGC and what patients and families saw with their own eyes; a tendency on the part of GGC to put a positive spin on things in their communications; an allegation made by one father that a clinician had confessed that she had been instructed to lie to him; and evidence that GGC's actual awareness of issues (from contemporaneous expert reports on the safety of the water and ventilation systems within the hospital) was understood to conflict with what they had said publicly and to patients.

- (xxi) Given the seriousness of the allegation, it is important to emphasise again the limits of this closing statement. It must not be taken to accept that a lack of candour has been proved. But witnesses were very careful in how they framed their question on this matter. They were careful to emphasise to whom the question is addressed: managers not frontline clinicians. And they were careful to disclose the evidence that leads them to at least raise candour as a question.
- (xxii) It can therefore be concluded that the following question is responsibly asked by patients and families: did GGC managers fail to provide a candid account of the issues with the hospital building and the perceived risk of infection? Nothing would be so likely to undermine trust than a suspicion by patients and families that they were not being given the whole story. It is therefore also possible to conclude that they are entitled to an answer to their question.
- (xxiii) As should already be apparent, the vast majority of witnesses did not criticise the frontline clinicians and nursing staff responsible for the care of their children (or, indeed, their own care). Quite the opposite. Many witnesses chose to conclude their evidence by emphasising their thanks to frontline staff for the excellent level of care provided to them and for their efforts in saving the lives of their children. In deference to that approach, the present summary concludes on the same point.

Glasgow Questions

- 1. Do Core Participants accept that in the above summary, and in what follows, this closing statement accurately sets out the accounts given by witnesses (and if not can they identify where)?
- 2. At this stage, are Core Participants able to identify any areas of the narrative provided by the patient and family evidence that is capable of agreement?
- 3. On the particular question of infection risk, are Core Participants able to say whether they consider that there is evidence that either establishes or indicates links between infections and the built hospital environment.

THEME 1: THE DIAGNOSIS AND TREATMENT OF CANCER

- 8. Term of Reference 8 requires the Inquiry to examine the impact of issues affecting the hospital environment upon patients and families. But illness and the treatment of illness are of themselves impactful. That baseline of impacts requires to be identified and understood. Only then is it possible to consider whether and to what extent patients and families experienced additional or avoidable impacts linked to the hospital environment. It was for this reason that much of the evidence produced and led during the recent diet was concerned with understanding the nature of the conditions and treatment that brought people to the QEUH campus.
- 9. It is to be acknowledged that the Inquiry is not solely concerned with paediatric haemato-oncology patients, and that the patient and family stories provided to the Inquiry arise across a range of serious medical situations. The Inquiry's further work will be cognisant of this. But the fact of the matter is that most of the evidence provided to the Inquiry was concerned with the impact of the hospital environment upon paediatric cancer patients. It is appropriate therefore, in order to identify the baseline against which to go on and examine

additional or avoidable impacts, to begin by looking at the impact that cancer, and the treatment for cancer, has upon children and their parents.

The effect of diagnosis

10. The devastating effect of a cancer diagnosis was a universal theme of the evidence. Parents described the "ground opening up"; the "world crashing" around them; the future becoming a "complete unknown"². The lives people had previously known were immediately changed. In the case of the children themselves, it is no exaggeration to say that the lives they had previously known were lost at the point of diagnosis. Education, sport, music, friendship and even family relationships would not be what they had known before that point. Stevie-Jo Kirkpatrick and Molly Cuddihy provided first-hand evidence of these impacts.

Treatment

- 11. In due course, the Inquiry may seek expert medical opinion on the nature and impact of the treatments and procedures typically used in treating cancer. But it must be recognised that, in the body of evidence provided by patients and families, the Inquiry already has a significant amount of information about the perceived nature and effect of these interventions. From that evidence, the following picture emerges.
- 12. Cancer treatment comes in a variety of forms. Chemotherapy, radiotherapy, stem cell/bone marrow transplant and immunotherapy were all mentioned in the patient and family evidence. Surgical intervention was another feature of treatment cited. This was often major in nature³, involving significant post-operative pain management and care.
- 13. While reference was made to treatment protocols used throughout the UK for particular types of cancer (for example, Acute Lymphoblastic Leukaemia), the evidence indicated that the choice of treatment in an individual case depended on a range of factors specific to the patient. Individual plans might be the product of multi-disciplinary planning; where appropriate, advice (and even

² See, for example, the evidence of Colette Gough (am), transcript at page 12.

³ See, for example, the evidence of Professor John Cuddihy and Karen Stirrat.

additional treatment) could be sourced outwith Scotland. Plans were reviewed as treatment progressed.

- 14. Chemotherapy appears typically to have been given in cycles. Witnesses spoke of multiple 21-day rounds of chemotherapy involving the administration of treatment followed by a period in which the body would react and then recover enough for the cycle to begin again⁴. Treatment could last months or even years. Although the evidence covered a range of disease and treatment, one theme remained constant: cancer treatment and chemotherapy in particular can be terrifying and gruelling.
- 15. The toxicity of the chemotherapy drugs was evident from descriptions of the care with which they are handled by staff. Chemotherapy drugs were understood to attack fast growing cells, but not selectively⁵. The successful destruction of a tumour might be accompanied by a range of impacts upon other cells within the body. Hair loss was one aspect of that. Another was mucositis. This was described as an extremely painful and distressing condition, the management of which required powerful analgesia⁶. Other frequently mentioned side effects of treatment included gastrointestinal upset, weight loss, peripheral neuropathy, restricted mobility and fatigue. Witnesses provided evidence about the extreme side effects suffered by their children as a result of clinical trials involving high intensity chemotherapy⁷.
- 16. Quite apart from the consequences of the treatment itself, the sheer number of procedures undergone by patients was striking. Witnesses described frequent diagnostic procedures including bone marrow aspirates, lumbar punctures, scans, MRIs and blood tests. Whether for the purposes of treatment or diagnostic procedures, patients faced multiple general anaesthetics. Witnesses spoke of the "beads" collected by their children for each procedure undergone; by the conclusion of treatment, strings of beads could be many feet in length.

⁴ See, for example, the evidence of Denise Gallagher and witness statement of Professor John Cuddihy at paragraphs 30 to 32.

⁵ Witness statement of Molly Cuddihy at paragraph 82.

⁶ Evidence of Molly Cuddihy whose severe mucositis was described as being like a third degree burn inside the body.

⁷ See, for example, the evidence of Charmaine Lacock and Aneeka Sohrab.

- 17. Cannulas were described as a regular feature of tests and treatment. These were, for some young patients, a source of terror⁸. The development of needle aversion was spoken to by several witnesses⁹. Given the propensity for the veins of young cancer patients to collapse, the use of cannulas was particularly problematic and distressing. Hickman lines, central lines and port-a-caths were understood to provide a convenient alternative. They provided a means for nurses and doctors to access veins to administer medication (and to undertake other procedures such as taking blood samples or providing transfusions) without using cannulas.
- 18. Mention should be made of certain secondary side-effects of treatment. The first concerns food. Eating was a challenge for children undergoing treatment. But the food provided by the hospital was universally considered unpalatable (at best). As discussed below, this meant that a facility enabling parents to provide food that their children were able to eat was vital if the indignity of a feeding tube¹⁰ was to be avoided. The combined effects of appetite suppression and unpleasant hospital food threatened more than just the nourishment of the children on the ward; it threatened their ability to feel like children. It does not take a great deal of imagination to see that enabling the patient to feel like a child might itself be a vital part of successfully navigating treatment.

The hospital as home

19. One impact of cancer treatment was that for many patients the hospital "became home". Even during outpatient periods, there remained a tie to the hospital and the prospect of immediate return where temperature protocols required that. Witness 1 gave poignant evidence of his daughter's life. Most of that was spent in hospital. The hospital had in effect become the only home his daughter knew¹¹. Louise Cunningham described the effects of a childhood spent in hospital: her daughter "didn't know about running about with kids; she didn't know her ABCs", but she did know the names of the medications she required. Ms Cunningham's daughter was two at this point.

⁸ See, for example, the evidence of Charmaine Lacock and Aneeka Sohrab.

⁹ See, for example, the evidence of Cameron Gough.

¹⁰ Evidence of Molly Cuddihy, transcript (am) at page 17.

¹¹ Evidence of Witness 1.

20. This connection to the hospital resulted in further radical changes to the lives people had previously known. Families were split in two in order that one parent could care for the child in hospital while the other cared for siblings, sometimes for months on end. For those families without two active parents, the consequences could be even more severe¹². The impact of diagnosis, practical and emotional, extended throughout families to siblings, grandparents, aunts and uncles, all of whom had a role to play in keeping families afloat. The added challenge of maintaining an income against the background of these issues is obvious, and a number of witnesses provided evidence of this. While financial consequences paled in comparison to the worry of having a seriously ill child, the costs of travel, accommodation, childcare and sustenance over the period of treatment were significant concerns¹³.

Vulnerability to infection

- 21. A further impact from cancer treatment is that it renders those undergoing it extremely vulnerable to infection. Denise Gallagher, herself an Advanced Nurse Practitioner, described the effect of chemotherapy cycles on the immune systems of patients¹⁴. Chemotherapy lowers neutrophil counts within the blood which in turn reduces the body's ability to fight infection. During certain phases of chemotherapy patients become immunocompromised, and in some cases neutropenic (an extreme form of immuno-suppression). During the chemotherapy cycle, neutrophil counts drop and then recover resulting in differing degrees of immunosuppression during each cycle.
- 22. A consistent recollection among witnesses was of being informed by oncology consultants at the outset of their child's treatment that infection presented the most immediate risk to their child. Witnesses understood that infections themselves presented a life-threatening risk. Separately, treatment for infection involved the parallel risk that chemotherapy might be suspended to allow the body to recover its immune defence and fight the infection, aided by antibiotic

¹² Evidence of Aneeka Sohrab, transcript at page 95.

¹³ See, for example, the witness statements of Annemarie Kirkpatrick and of Sharon Barclay.

¹⁴ Witness statement of Denise Gallagher at paragraphs 12-13 and 45.

medication. Where the infection was isolated within a Hickman or central line, the result would be surgery to remove the line, which might in turn be followed by further surgery to fit a replacement line. A number of witnesses spoke to this occurring on multiple occasions.

- 23. The severity of the infection risk was illustrated clearly through the evidence heard in relation to the "temperature spike" protocol. Most witnesses spoke of temperature spikes as a relatively frequent occurrence during treatment. A temperature spike occurs when a patient's temperature reaches 38 degrees¹⁵. Although a temperature spike might be caused by the body's reaction to chemotherapy itself¹⁶, the protocol is to treat every spike as if it could be an infection. The strict instruction given to all parents was to bring the child to hospital immediately¹⁷. On admission to hospital blood cultures would be taken to screen for infection and antibiotics administered pending the results of those tests. If there was no indication of infection within 48 hours, the patient would be released. Evidence was, however, heard from a number of witnesses who portrayed the rapid and life-threatening deterioration which could occur if infection was present¹⁸. Witnesses described infections causing patients to experience "rigor",' a dangerous and distressing condition described as a "conscious fit".
- 24. Some witnesses indicated an understanding that there were two primary sources of infection risk. The first was infection in the community. Immunocompromised children were said to be at increased risk from common viruses, with Chickenpox posing a particular risk. The second was infection caused by the environment. A number of witnesses spoke of the lengths they went to individually in order to mitigate risks. Alfie Rawson and Charmaine Lacock spoke of closing down their family business to avoid contact with the public; they placed their family in a self-imposed lockdown. Professor Cuddihy recalled extreme cleaning at home and even the 'hibiscrubbing' of the family dog. Many witnesses spoke of hyper-vigilance in relation to cleaning and

¹⁵ Witness statement of Molly Cuddihy at paragraph 78.

¹⁶ Evidence of Denise Gallagher, transcript at page 32.

¹⁷ Described as the 'golden hour' by Molly Cuddihy; transcript (am) at page 49.

¹⁸ See, for example, see the evidence of Colette and Cameron Gough, Sharon Ferguson, and Professor John Cuddihy.

hygiene. For some parents, infection prevention was the only means of regaining a modicum of control over the situation facing their child. Mr Gough, for example, spoke of his contribution to infection control as being the only way he knew how to improve his son's odds of survival¹⁹.

The cancer journey

- 25. Cancer has been said to be a darkness; and the job of the oncologist has been said to be to retrieve the patient and guide them back into the light²⁰. Diagnosis marks the beginning of that gruelling and unpredictable journey. Patients and families make their way in hope if not expectation that their journey will end well; that they will "ring the bell". Success is not guaranteed. Even if remission is achieved, there may be long lasting and sometimes permanent effects, and even risk of illness, from the treatment. The spectre of relapse "scanxiety" is ever-present. Evidence was heard from two patients who themselves experienced relapses and had to begin their journeys again²¹. Bravery is an over-used term. Not in the case of these two young women.
- Over a period of five weeks, the Inquiry heard about many cancer journeys. No two stories were the same, but it became possible to recognise all too familiar challenges. Some of these challenges are among those discussed above: the brutal and apparently unavoidable physical and emotional impacts of trying to save a life threatened by cancer. Other challenges were of a different sort. They were not perceived by patients and families to be the inevitable or unavoidable consequence of cancer or its treatment. These perceived challenges form the subject matter of the Inquiry's Terms of Reference; they are discussed below. Before turning to them, it is necessary to mention one further common feature of the cancer journey.
- 27. This chapter of the submission began by referring to the dramatic life-changing nature of a cancer diagnosis. Parents described how terrifying that was, and how daunting the way ahead looked. From slightly different perspectives, two

¹⁹ Witness statement of Cameron Gough at paragraph 151.

²⁰ Observations attributed to Sir David Lane by Ken Currie on the inscription to his painting: *The Three Oncologists*, Scottish National Portrait Gallery.

²¹ Evidence of Stevie-Jo Kirkpatrick and Molly Cuddihy.

parents identified something that was implicit in the evidence of every one of those other witnesses. One father spoke of the "helplessness, fear and anguish" in having to hand over his daughter's care to complete strangers²²; another described his son as a "dead boy walking" unless he took that step²³. The thing that permitted both fathers, and all the other parents, to take that necessary step and every one that came afterwards was the same thing: trust.

28. The evidence of all witnesses laid bare the importance of trust. Whether speaking of trust in clinical care, or in the processes and procedures of that care²⁴, in the hospital environment or in those responsible for providing and managing that environment, it was implicit in what every witness said that trust is a – and perhaps the – necessary ingredient if patients and families are to take the first step of the journey and keep going. Much of this submission is concerned with whether that relationship of trust was enabled or was undermined.

THEME 2: THE QEUH CAMPUS AND THE SCHIEHALLION UNIT

- 29. In large part, the overall purpose of this submission is concerned with assessing whether the hospital environments in which patients founds themselves were perceived to be a help or a hindrance. Theme 1 sought to begin that analysis by identifying the particular demands placed upon paediatric cancer patients. Theme 2 seeks to continue the analysis by identifying the key provisions made within the hospital environment for addressing these demands. The discussion continues to concentrate upon paediatric cancer patients, and so the focus is upon the provision made for such patients within the Schiehallion Unit and elsewhere within the Royal Hospital for Children ("RHC") and the Queen Elizabeth University Hospital ("QEUH").
- 30. Once again, the Inquiry does not overlook the fact that the evidence heard covered a number of areas of the QEUH campus. Mention might be made, for example, of John Henderson, who provided a statement outlining his

²² Witness statement of Professor John Cuddihy at paragraph 25.

²³ Witness statement of Cameron Gough at paragraph 151.

²⁴ Witness statement of Professor John Cuddihy at paragraph 26.

experience on an adult ward in the QEUH in April 2015; of Theresa and Matthew Smith, and Carol-Anne Baxter who provided evidence of their experiences in the Neonatal Intensive Care Unit ("NICU"); and of Samantha Ferrier who spoke of her experience in the Maternity Unit and on Ward 3 within the RHC.

- 31. The evidence of each these witnesses has the potential to be relevant to the Inquiry's Terms of Reference. It is taken into account in the discussion of the themes below. But the fact of the matter is that the preponderance of the evidence heard concerned the provision made for the treatment of paediatric cancer. By focusing on the facilities provided for that group of patients, it is possible to assess whether, at least as regards those facilities, public perception supports the view that the QEUH delivered the aspiration referred to in the opening submission for GGC: the delivery of the highest standards of healthcare within a state of the art facility.
- 32. The QEUH campus is located in Govan to the south of the River Clyde. It sits on the site of the old Southern General Hospital ("SGH") and consists of a mixture of newly constructed buildings and buildings retained from the old SGH estate. The QEUH itself is a newly constructed adult hospital which replaced the adult hospital previously located on the SGH site. It is a substantial building comprising fourteen floors arranged in four wings around a central atrium²⁵. Sitting alongside it, on the west, is the newly constructed RHC²⁶. On the opening of the RHC in 2015, paediatric services were relocated there from Yorkhill Hospital ("Yorkhill"), situated in Glasgow's West End. The RHC has five floors in total and was described as being in the shape of a racetrack²⁷ arranged around a central atrium. The QEUH and RHC are connected by linking corridors. The existing SGH Maternity and Neo-Natal Units were retained although both are accessible via a link constructed between the RHC and the Neo-Natal Unit²⁸. The relocation of children's services allowed for the colocation of adult, paediatric and maternity/neo-natal services.

²⁵ SHI Bundle 2 – Material Illustrating Layout of QEUH and RHC, Glasgow ("Bundle 2").

²⁶ Bundle 2.

²⁷ Evidence of Cameron Gough, transcript at page 51.

²⁸ Bundle 2, page 5.

33. Evidence about the layout of the QEUH campus was provided by Cameron Gough under reference to a series of photographs and diagrams provided to the Inquiry by GGC²⁹. Mr Gough observed that closely situated to the north and north-west side of the campus is a waste water treatment plant³⁰. The QEUH and RHC have separate entrances but both face north towards the direction of the waste water treatment plant. The adult and paediatric A&E entrances are located to the rear of the QEUH and RHC. To the west side of the RHC is an outdoor playpark. Multistorey carparks are located to the east and west of the campus.

Yorkhill Hospital and comparison with the RHC

- 34. The Schiehallion Unit provides haemato-oncology and haematology services to paediatric patients. It was described by a number of witnesses as having a world class reputation³¹. But, before considering the evidence relating to the Schiehallion Unit as situated at the RHC, it is helpful, for comparison purposes, to reflect on the evidence provided in relation to its previous home within Yorkhill. Evidence was heard on this topic from three witnesses³² all of whom spoke with some affection for Yorkhill³³. The evidence suggested a hospital facility that could not be described as state of the art but was "functional" even if it was in need of a "facelift" ³⁴.
- 35. The expectation was that the Schiehallion Unit within the new RHC would continue to deliver the excellent service experienced in Yorkhill but in an enhanced way, further enabled by state of the art facilities³⁵. The evidence from every witness who provided evidence was that, in a variety of ways, this expectation was not perceived to have been met.
- 36. Even before issues emerged in relation to the hospital environment, some witnesses felt that, in certain respects, the new RHC did not compare

²⁹ Bundle 2.

³⁰ Bundle 2, page 7.

³¹ See, for example, evidence of Witness 6, transcript at page 21.

³² Witness 6, Annemarie Kirkpatrick and Stevie-Jo Kirkpatrick.

³³ Evidence relating to Yorkhill is also found in the witness statements of Kimberly Darroch, Christine Horne and Derek Horne.

³⁴ Witness statement of Witness 6 at paragraph 12.

³⁵ Evidence of Witness 6, transcript at page 21.

favourably to Yorkhill. The location in Govan was very different to Yorkhill's city centre location in Glasgow's West End. Public transport links to Govan were inferior. The canteen was located in the QEUH; it was not easily accessible for children nor was it practical for parents to leave their child for the length of time required to travel to it³⁶.

- 37. In contrast to Yorkhill, the new Schiehallion Unit had no dedicated clinic for Schiehallion patients. Witnesses were concerned about their immunocompromised children mixing with the general public³⁷. Unlike Yorkhill, Ward 2A had no double door entry system "to keep the air pure"³⁸. Overall, the unit at Yorkhill was more compact. The results of blood tests taken in the clinic were available in the day care ward in short order³⁹. This stood in contrast to the position described in the RHC where hours could pass before blood results were available, sometimes to the point that samples were no longer viable and the process had to be re-started⁴⁰.
- 38. The internal location of some bedrooms was not conducive to a restful night's sleep⁴¹. The central atrium, which housed the out of hours clinic, was a source of light and noise throughout the night. Some witnesses felt the curved racetrack design was impractical for nurses carrying out observations and that it was claustrophobic. One witness perceived there to be a loss of staff in the move to the RHC with a resulting loss of community⁴².

The Schiehallion Unit within the RHC

39. Despite these concerns, a significant body of evidence suggested that the Schiehallion Unit was a "happy" place which understood the medical and, significantly, the non-medical, needs of patients and families⁴³.

³⁶ Evidence of Witness 6, transcript at page 22.

³⁷ Witness statement of Annemarie Kirkpatrick at paragraph 18.

³⁸ Witness statement of Stevie-Jo Kirkpatrick at paragraph 18.

³⁹ Witness statement of Witness 6 at paragraph 13.

⁴⁰ Witness statement of Molly Cuddihy at paragraph 25.

⁴¹ Witness statement of Annmarie Kirkpatrick at paragraph 42.

⁴² Witness statement of Witness 6 at paragraph 29.

⁴³ See, for example, the evidence of Molly Cuddihy, Annemarie Kirkpatrick and Colette Gough.

- 40. Located within the RHC alongside the Schiehallion Unit were other paediatric services including the Paediatric Intensive Care Unit ("PICU"), the Clinical Decisions Unit ("CDU"), surgical wards, and clinics⁴⁴. The RHC itself was described as having a modern and bright appearance tailored for children. It boasted state of the art facilities such as a Medicinema⁴⁵.
- 41. The Schiehallion Unit was housed within Wards 2A and 2B. Ward 2A was the inpatient ward. Ward 2B housed a separate day care unit. Although next to each other, Wards 2A and 2B were accessed separately⁴⁶. Ward 2B contained four private treatment rooms and a four-bed bay for Teenage Cancer Trust ("TCT") patients⁴⁷. Ward 2A was located on the curve of the racetrack and was understood to contain a total of 26 single en-suite patient bedrooms⁴⁸, four of which were located in the TCT Unit at the far end of the ward.

Patient bedrooms

42. Patient bedrooms were equipped to provide accommodation for the patient and one parent/carer. The en-suite bathrooms were in a wet-room style, accessible for wheelchairs. Overall the rooms were described as modern and as having suitable decoration for child patients.

Bone marrow transplant rooms

43. Evidence indicated that some rooms on Ward 2A were designed specifically to provide ultra-clean environments⁴⁹ for patients who were particularly vulnerable to infection as a result of bone marrow transplants⁵⁰. These rooms had lobbies attached to them (described by some witnesses as "double-door rooms", "lobby rooms" and "VAC rooms")⁵¹. These rooms were understood to benefit from specialist ventilation arrangements⁵².

⁴⁴ Bundle 2.

⁴⁵ Witness statement of David Campbell at paragraph 36.

⁴⁶ Evidence of Cameron Gough, transcript at page 59.

⁴⁷ Witness statement of Molly Cuddihy at paragraph 41.

⁴⁸ Evidence of Cameron Gough, transcript at page 61.

⁴⁹ Witness statement of Denise Gallagher at paragraph 45.

⁵⁰ Referred to by witnesses interchangeably as stem cell transplants.

⁵¹ See, for example, the witness statement of Lynndah Allison at paragraph 25.

⁵² Evidence of Denise Gallagher, transcript at page 17; witness statement at paragraph 45.

Playroom and parents' kitchen

- 44. Ward 2A housed a playroom where children could socialise and participate in activities run by playleaders. The playroom was described consistently as a very important facility in the quest to help children feel normal through cancer treatment⁵³.
- 45. The parents' kitchen located on Ward 2A was also viewed consistently as another vital resource⁵⁴. Parents were able to feed their children what they wanted, when they wanted it. Parents were dealing with children who desperately needed to eat but who, through the effects of their treatment, were often reluctant or unable to do so. The ability to cater to these children was essential⁵⁵.
- 46. Almost every witnesses who had experience of the parents' kitchen spoke with some emotion of its importance as a place to access the support of other parents. It was a lifeline⁵⁶ and a place where parents could access practical advice and 'phenomenal therapy'⁵⁷. Some witnesses doubted how they would have coped without the support found in the parents' kitchen; it was there that "strangers became friends" and they discovered the Schiehallion "family".

Teenage Cancer Trust Unit

47. Although Ward 2A is a children's ward it provides care for children of a very young age through to young adults up to the age of 18⁵⁸. The TCT recognises the specific needs of teenage patients and funds, through charitable donation, facilities catering to those needs. Evidence was heard from two patients who praised the facilities provided by the TCT and the work of its inspirational support co-ordinator ⁵⁹.

⁵³ See, for example, the witness statement of Cameron Gough at paragraphs 209 and 210.

⁵⁴ See, for example, the witness statement of Colette Gough at paragraph 23.

⁵⁵ See for example, the witness statements of David Campbell at para 45; Witness 6 at paragraph 18.

⁵⁶ Evidence of Suzanne Brown at paragraph 18.

⁵⁷ Evidence of Cameron Gough, transcript (am) at page 60; evidence of Colette Gough, transcript (am) at page 17.

⁵⁸ Evidence of Molly Cuddihy, transcript (am) at page 13.

⁵⁹ Evidence of Molly Cuddihy and Stevie-Jo Kirkpatrick.

48. The stand-out facility was the TCT common room. Alongside entertainment facilities it had its own kitchen area and a large table which could be used for family meals or doing homework. Although seemingly innocuous, the table was described by Molly Cuddihy as a very important feature. Sitting with friends or family around the table encouraged patients to eat; it was the "last defence against a feeding tube". The TCT common room was a place for teenage patients to support each and to have difficult conversations that were too upsetting to have with parents.

Charities

49. The TCT Unit is only one example of the services provided by charities within the Schiehallion Unit. A number of witnesses⁶⁰ spoke to the work done by other charities within the ward including the provision of entertainment (in the form of clown doctors, magicians and visiting princesses), snack trolleys and play facilities. More practically, charities such as CLIC Sargent (now "Young Lives Vs Cancer") provided invaluable accommodation and other support services to parents⁶¹. The evidence indicated that the successful operation of the Schiehallion Unit depends heavily on charitable funding. Molly Cuddihy spoke of her own fundraising efforts through which she and a fellow patient and friend raised over £330,000 for the benefit of the Schiehallion Unit⁶².

The "Schiehallion Umbrella"

50. In addition to the facilities on Wards 2A and 2B, witnesses described special protocols and levels of tailored expertise that were found in the Schiehallion Unit but not on other paediatric wards. Mr Gough termed this "the Schiehallion Umbrella"⁶³. That is a useful term. An understanding of the Schiehallion Umbrella is relevant to an appreciation of the situation faced by patients and families when they were displaced from Wards 2A and 2B.

⁶⁰ See, for example, the evidence of Colette Gough, transcript (am) at page 33.

⁶¹ See, for example, the witness statement of Witness 3 at paragraph 34 (as published).

⁶² Funding the provision of a common room for children falling within the pre-TCT age group (the "Eight to Twelve Years Club" room) and the purchase of a blood analysis machine speed up the receipt of blood test results.

⁶³ Witness statement of Cameron Gough at paragraph 66.

- 51. Although the evidence in relation to the cleanliness of Wards 2A and 2B was not always consistent, a number of witnesses described cleaning protocols that were not observed elsewhere⁶⁴.
- 52. One thing that was consistent was the evidence in relation to the expertise of the staff on Wards 2A and 2B. Witnesses spoke of highly specialised nurses who administered medications with military precision, who understood the peril involved in a temperature spike⁶⁵. The service provided by the nurses on Wards 2A and 2B was described a "gold standard"⁶⁶. Witnesses spoke of the rapport which nursing, auxiliary, domestic and support staff built with patients and how that enabled them to cater for their individual needs⁶⁷. Similar praise was directed at doctors. That witnesses went to such lengths to emphasise this might be thought to suggest that there was little doubt that, within the Schiehallion family, patients were at the centre of the care provided⁶⁸.
- 53. Evidence was heard about the overall ethos of the Schiehallion Unit: to let children be children and teenagers be teenagers. It was vitally important that they were not "just cancer patients" and were not "defined by sickness" 69. There appeared to be a recognition that there was much more to the treatment of cancer in children than physical treatment. Emotional and psychological elements were viewed by many witnesses as critical to long term recovery.
- 54. Witnesses spoke of world class consultants and doctors who were leaders in their fields and who devised tailored treatment plans for each child. Most witnesses recalled receiving an abundance of information at the beginning of their child's treatment. Although some found this level of information overwhelming, others described the communication about treatment on Wards 2A and 2B as "clear, sensitive and candid" 70.

⁶⁴ Evidence of Colette Gough, transcript (am) at page 80.

⁶⁵ See, for example, the witness statement of Colette Gough at paragraph 104.

⁶⁶ Evidence of Cameron Gough, transcript at page 87.

⁶⁷ See, for example, the evidence of Suzanne Brown and Molly Cuddihy.

⁶⁸ Witness statement of Colette Gough at paragraph 34.

⁶⁹ Evidence of Cameron Gough, transcript at page 57.

⁷⁰ Evidence of Colette Gough, transcript at page 66.

- 55. Communication is a topic to which this submission returns but the evidence was clear that open, honest and transparent communication about treatment was vitally important for this particular patient group⁷¹. Parents were closely involved in care, both in hospital and at home; they became part of the care team⁷². The provision of information helped parents understand what lay ahead⁷³ and provided a sense of control at a time when cancer had destabilised their child's future. Most importantly, transparent communication built and maintained trust with the clinical staff to whom parents had been forced, through circumstance, to entrust the care of their child.
- Despite the increasingly challenging situation on Wards 2A and 2B in the months before September 2018, the majority of witnesses described their experience positively, at least in relation to the ethos of the Schiehallion Unit. Although relationships with clinical staff were not always easy, and were made more difficult by subsequent events, the majority of witnesses were at pains to thank the frontline clinical and nursing staff who did everything within their power to save the lives of their children.

THEME 3: STANDALONE ISSUES WITHIN THE HOSPITAL ENVIRONMENT

57. Theme 4 begins the discussion of a series of issues at the very forefront of the Inquiry's investigations: concerns about key building systems such as water and ventilation, about infection risk and about communication. But the concerns that witnesses expressed about the hospital environment extended well beyond these matters. At first glance, these further concerns might appear to be – relatively – less deserving of the Inquiry's consideration than those in the forefront. For two reasons, that would be a mistaken view. First, it is clear that the additional concerns identified by witnesses did impact upon the patient experience. Secondly, the existence of so many perceived problems might be thought useful in assessing, as many of the witnesses did, the overall health of the hospital building.

⁷¹ Evidence of Professor John Cuddihy, transcript (26 October 2021 (pm)) at page 34; witness statement at, for example, paragraphs 37, 144, 145; and evidence of Cameron Gough, transcript at page 93.

⁷² Evidence of Colette Gough, transcript at page 66.

⁷³ Evidence of Charmaine Lacock, transcript at page 11.

Interior Issues:

(i) Flooding

- 58. Flooding of en-suite bathrooms on Ward 2A happened regularly. Flooding was also reported on other wards: Aneeka Sohrab recalled flooding from the ensuite bathrooms in Ward 6A; and flooding of one kind or another was reported by Mark Bisset as having occurred on Ward 4B and within the PICU.
- 59. A number of witnesses described the way in which use of showers caused flooding incidents. Simply by way of example, reference is made to Mr Gough's particularly vivid description and accompanying diagram of the flooding of his son's VAC room on 26 August 2018⁷⁴. On that occasion, the flooding covered the whole of the bathroom area, including the toilet. It extended into the bedroom and lobby and eventually reached the corridor. Reference might also be made to the evidence of Suzanne Brown, who recalled water "inches deep" flooding into the ward corridor⁷⁵; and that of Denise Gallagher who recalled some degree of flooding in most of the rooms her son stayed in on Ward 2A⁷⁶.
- 60. Witnesses were concerned about the infection risks they thought might be caused by these flooding events. The reasons for that concern are obvious but were in any event spoken to in evidence. Mr and Mrs Gough were concerned that water flowing from the bathroom area into the bedroom was a threat to an immunocompromised child⁷⁷. Other witnesses observed that the en-suite bathroom was where stool and urine samples were kept prior to collection by nursing staff. Flooding occurred while these samples sat on the bathroom floor. Witnesses did not recall a specific cleaning response when flooding occurred, causing some parents to clean the rooms themselves. Witnesses were also concerned about the potential slip hazard caused by water on the bedroom floor⁷⁸.

⁷⁴ Evidence of Cameron Gough, transcript at page 97; diagram prepared by Mr Gough is attached to the witness statement of Colette Gough at page 164.

⁷⁵ Evidence of Suzanne Brown, transcript at page 29.

⁷⁶ Evidence of Denise Gallagher, transcript at page 91.

⁷⁷ Evidence of Cameron Gough, transcript at p98; evidence of Colette Gough, transcript at page 74.

⁷⁸ Evidence of Aneeka Sohrab, transcript at page 35.

61. Staff were aware of the problem with the en-suite bathrooms. It was perceived to be widespread⁷⁹. Witnesses expressed frustration that there were no apparent attempts to remedy this issue. To the extent that anything was done at all, extra towels were provided to families to create a barrier between the ensuite bathroom and patient bedroom⁸⁰. Mr Gough observed the flooding some three years after the RHC opened. Echoing questions that arise under Term of Reference 6, he said that this was an obvious issue, and he could not fathom why it had not been addressed. Mrs Gough recalled her father, a carpenter to trade, being shocked that in a "flagship hospital" this issue had not been identified by the "clerk of works".

(ii) <u>Temperature of rooms</u>

- 62. Witnesses were consistent in their evidence that the temperature of patient bedrooms was uncomfortable in that it was either too hot or too cold⁸¹. Although the rooms contained temperature control devices, they did not work. Again, this situation was acknowledged by staff. Bedrooms were hot and stuffy and because windows were sealed there was no other mechanism to cool the air. Although the evidence on this issue related mostly to Ward 2A, some witnesses described a similar issue on Ward 6A⁸².
- 63. The evidence painted a vivid picture of the impact of this issue on patients who were prone to temperature spikes. At the very least, a hot stuffy room was extremely uncomfortable particularly when patients were sick and sweaty and confined to their rooms for lengthy periods. Some witnesses went further and questioned whether the excessively hot temperature of the rooms might in fact have contributed to the apparent manifestation of temperature spikes⁸³. Evidence was heard that parents felt unable to cuddle their child because the excessive heat would cause discomfort⁸⁴. Mr and Mrs Gough recalled that the

⁷⁹ See, for example, the evidence of Aneeka Sohrab who recalled flooding in ward 6A.

⁸⁰ Evidence of Denise Gallagher, transcript at page 91; and evidence of Aneeka Sohrab.

⁸¹ See, for example, the evidence of Denise Gallagher who described the ward as 'hot and humid' (transcript at page 24); evidence of Colette Gough, transcript at page 58; witness statement of Sharon Barclay at paragraph 44 (rooms were freezing).

⁸² See, for example, the witness statement of Annemarie Kirkpatrick at paragraph 93.

⁸³ See, for example, the witness statement of Andrew Stirrat at paragraph 32.

⁸⁴ Evidence of Colette Gough, transcript at page 62.

impact of the temperature issue was so uncomfortable that they preferred to be in the VAC room where the en-suite shower flooded but the temperature controls worked.

64. Witnesses could recall no attempts at remediation. Parents took to improvising with cold flannels and frozen water bottles⁸⁵. One witness recalled the ward lights being turned off in an effort to reduce the temperature⁸⁶. Witnesses perceived the issue to be related to the air conditioning system and expressed surprise that the air conditioning did not work in a brand new hospital.

(iii) Window blinds

65. Evidence was consistent that there was an issue with the operation of window blinds in the patient bedrooms on Ward 2A. Blinds were said to be stuck in the open or shut position and could not be adjusted⁸⁷ because of their internal location, situated between two panes of glass.

66. The evidence was to the effect that the broken blinds added to the overall discomfort of the patient bedrooms. Patients could be stuck in hot stuffy rooms for lengthy periods with no access to daylight. Alternatively, those in internal rooms had limited ability to shut out the light from the atrium at night, affecting their ability to sleep⁸⁸. No attempts at remediation were reported.

(iv) Televisions

67. Each patient bedroom within Ward 2A was reported to contain a modern and apparently high specification television for use by patients. Televisions were seen by parents as an important facility to keep children entertained particularly those who were confined to their bedroom for lengthy periods. However, there was consistent evidence that the televisions in patient bedrooms did not operate as they should. Witnesses recalled televisions with no signal or with upside down pictures⁸⁹. The problem existed throughout Ward 2A. Some

⁸⁵ Evidence of Colette Gough, transcript at page 58.

⁸⁶ Evidence of Leann Young, transcript at page 29.

⁸⁷ See, for example, the witness statement of Annemarie Kirkpatrick at paragraph 29.

⁸⁸ Evidence of Stevie-Jo Kirkpatrick, transcript at page 13.

⁸⁹ Witness statement of Suzanne Brown at paragraph 20; evidence of Graham McCandlish, transcript at page 83.

witnesses reported similar issues in other wards within the RHC and on Ward 6A within the QEUH⁹⁰. Although most witnesses spoke of these issues arising during 2017 to 2019, one witness provided evidence that there were problems with the televisions at the RHC from the very outset⁹¹. Another, who attended the hospital in September 2021, reported that the issue persisted⁹².

68. The problems described with the televisions serve to illustrate the points made in the paragraph that commences this Theme of the submission. It would be wrong-thinking to dismiss as unimportant the complaints of patients about the televisions. That a functioning television might provide a vital connection to childhood, and a distraction from illness, is obvious. It is equally obvious why patients would find the apparent difficulty in providing such a relatively simple facility in a brand new hospital inexplicable, and why that and the other issues discussed in this Theme might lead to broader questions being asked.

(v) <u>Wi-Fi</u>

69. Wi-Fi connectivity was reported as being hit or miss⁹³. Witnesses acknowledged that, as with the broken televisions, poor Wi-fi might appear to be only an inconvenience but were consistent in emphasising the importance of being able to keep this particular patient group entertained and distracted from the challenges of their treatment. Wi-Fi access would also be important in maintaining access to education facilities (something highlighted during the Edinburgh evidence⁹⁴).

(vi) Plug points and battery packs

70. Witnesses reported that patient bedrooms had insufficient plug points to simultaneously power all of the machines that some patients were connected to. Although battery packs were available, these were reported to hold charge

⁹⁰ See, for example, the evidence of Charmaine Lacock.

⁹¹ Evidence of Witness 6.

⁹² Evidence of Lynn Kearns, transcript at page 63. Mrs Kearns reported that, likewise, temperature controls still did not work in September 2021.

⁹³ Evidence of Graham McCandlish, transcript at page 84.

⁹⁴ Evidence of Abhishek Behl.

for only a short period of time with the result that there was juggling required between power points and battery packs⁹⁵. These issues were said to result in interrupted sleep and a restriction on patient independence.

(vii) Power outages / Electrical failures

71. Electrical issues were reported elsewhere within the QEUH campus. Mr Bisset recalled a failure of the electrical system in the PICU which resulted in his daughter being moved rooms. Theresa Smith recalled flickering lights and power outages in the Neo-natal Intensive Care Unit ("NICU"). On raising her concerns about patient safety with staff she was concerned to learn of the reliance on back-up generators particularly for babies reliant on machinery for survival.

(viii) Ward entry buzzer

72. Evidence was heard that the entry buzzer to Ward 3A was out of order between at least October 2019 and the end of December 2019. Parents were unable to access the ward easily and would wait up to 30 minutes to be let into the ward by a nurse. Although seemingly a minor issue, issues like these, when left unresolved, have the potential to cause serious detriment to the patient and family experience. Evidence was heard from Samantha Ferrier about the difficulties she experienced in accessing the ward to visit her daughter in the last few months of her short life, and the anxiety that this caused 96.

(ix) Sewage leak

73. Annemarie Kirkpatrick recalled witnessing sewage coming up through floor tiles in the area of the link corridor between the QEUH and RHC in the autumn of 2018⁹⁷.

⁹⁵ Karen Stirrat recalled that battery packs used in ward 6A had 'Yorkhill' printed on them indicating that they were of some vintage. Evidence of Karen Stirrat, transcript at page 27. See also the evidence of Stevie-Jo Kirkpatrick, transcript at page 12.

⁹⁶ Evidence of Samantha Ferrier, transcript at page 32.

⁹⁷ Evidence of Annemarie Kirkpatrick, transcript at page 85.

Exterior issues:

(x) Cladding

- 74. Environmental concerns raised by the replacement of cladding at the RHC are considered further below. In mid-August 2018, witnesses recalled being awoken by workmen outside patient bedrooms who were working on the cladding at the RHC98. No advance notice of this building work was provided. Some witnesses recalled receiving a communication about the cladding works in mid-September 2018, after the works had begun. A note99 was issued to parents advising that "Due to ongoing cladding works on the QEUH site" they should access the RHC through the "Discharge Lounge" entrance of the QEUH.
- 75. The note in itself caused some concern. It stated that "Building materials can pose a risk of infection. Appropriate measures will be put in place to protect any child at risk as a precaution". The nature of those measures was not specified. The note was issued after cladding works were understood to have commenced. Professor Cuddihy expressed concern that he and his daughter were only advised to use an alternative entrance after they had entered the ward via the RHC entrance. After the fact communication did not serve to mitigate the risks posed to his daughter's health¹⁰⁰.
- 76. Witnesses did not report a clear understanding of the issue with the cladding. Many assumed it was being replaced following the Grenfell Tower tragedy¹⁰¹. The note provided to parents identified an infection risk linked to "building materials"¹⁰². Even without an understanding of the precise nature of the infection risk, the fact that cladding was being replaced at all was a concern to a number of witnesses particularly given that "the hospital had just been built"¹⁰³.

⁹⁸ Evidence of Leann Young who recalled seeing workman at [07:53].

⁹⁹ Copy attached to witness statement Colette Gough at CG/03. The note is dated 7 September 2018 but was stapled to another note dated 18 September 2018.

¹⁰⁰ Evidence of Professor John Cuddihy, transcript (26 October 2021 (am)) at page 96.

¹⁰¹ See, for example, the evidence of Alfie Rawson.

¹⁰² Evidence of Colette Gough with reference to CG/02 and CG/03.

¹⁰³ Evidence of Alfie Rawson, transcript at page 26.

(xi) Glazing panels

- 77. Evidence was heard to the effect that in July 2018, a "window" fell from the 10th floor of the QEUH and smashed on the ground close to the QEUH entrance. Many witnesses were aware of this event, and three in particular recalled being in the near vicinity either shortly before or shortly after the window fell¹⁰⁴.
- 78. Although some witnesses described the smashed glass as coming from a window, evidence was heard to the effect that in fact it was from a "decorative glass panel". Professor John Cuddihy described a letter he wrote to Ms Jane Grant, the Chief Executive of GGC enquiring about the falling window and seeking reassurance about the safety of the hospital. Professor Cuddihy recounted the response he received from Ms Grant¹⁰⁵:

"We are extremely sorry that you experienced a panel falling from the building on entering with Molly. It may be helpful to clarify that no windows have fallen out of the Queen Elizabeth University Hospital (QEUH) building, nor the Royal Hospital for Children (RHC) building; all double glazed units have remained intact without issue, the windows are safe. The glazing failure we believe you are referring to, is decorative glazing panelling, and this remains under investigation. If a failure occurs they are designed to shatter into tiny fragments which are much less likely to cause harm. We will let you [sic] the outcome of this investigation."

79. Professor Cuddihy did not find this response reassuring, on the basis, apparently, that someone hit by a falling sheet of glass, decorative or otherwise, might find little consolation in the size of the resultant fragments. Professor Cuddihy's broader concerns about communication are discussed below. But on this matter, he does not recall receiving a further update on the investigations into the glazing failure and understands through his own investigations that this was not an isolated incident.

¹⁰⁴ Evidence of Senga Crighton, Alfie Rawson and Molly Cuddihy.

¹⁰⁵ Evidence of Professor John Cuddihy, transcript (26 October 2021 (am)) at page 93; witness statement at paragraphs 239-242.

80. Mr Henderson, a patient in the QEUH in April 2015, provided a photograph of what he perceived to be loose seals around windows and glazed panels¹⁰⁶.

(xii) Roofs

81. Two issues were reported in relation to roofing failures. Mrs Kirkpatrick recalled seeing part of the roof blow off the QEUH building¹⁰⁷. Stevie-Jo Kirkpatrick recalled witnessing water pouring through the roof in the Zone 12 area of the RHC¹⁰⁸.

(xiii) Playpark

- 82. Evidence suggests that the rooftop playpark situated between the QEUH and RHC did not open for use in any meaningful way. Witnesses recalled that it may have opened occasionally but only after playleaders had cleared it of pigeon excrement and pigeon corpses¹⁰⁹.
- 83. There was no evidence of communication with patients and families about use of the playpark. One witness recalled her son being upset that he could see the playpark but could not access it¹¹⁰. Although there was a ground level playpark, it was located close to the carparks and where smokers congregated. The rooftop playpark would have been a "good safe space" for children to break up the day¹¹¹.

(xiiii) Smell from water treatment works

84. Term of Reference 10 requires the Inquiry to examine whether the choice of site was appropriate or gave rise to an increased risk of infections caused by environmental organisms. It is likely that the Inquiry will require expert input on this question. For present purposes it suffices to record that the evidence indicated consistent patient concerns about the risk of infection posed by the

¹⁰⁶ Photograph attached to witness statement of John Henderson at JH/01.

¹⁰⁷ Evidence of Annemarie Kirkpatrick, transcript at page 86.

¹⁰⁸ Evidence of Stevie-Jo Kirkpatrick, transcript at page 32.

¹⁰⁹ Evidence of Witness 6; evidence of Aneeka Sohrab, transcript at page 80.

¹¹⁰ Evidence of Witness 6.

¹¹¹ Evidence of Witness 6.

water treatment works, whether from airborne organisms or from underground water contamination through the drainage system¹¹². Many witnesses reported a high incidence of vermin (pigeons) on the QEUH campus. The link, <u>if any</u>, between the vermin reported and the water treatment plant is presently unknown.

- 85. Quite apart from concerns about infections, there was clear evidence that the smell believed to come from the water treatment works was deeply unpleasant. It was described as "rancid" and as being like "the smell of sewage" 113. Witnesses recounted that the smell was present both outside and inside the hospital building 114. One witness had a particular concern that she was able to smell it in a specialist isolation room within Ward 2A and asked, if the room had specialist filtration and ventilation, why was the smell perceptible 115?
- 86. The impact of the smell on patients within the Schiehallion Unit was particularly acute. These patients were already experiencing sickness and nausea caused by chemotherapy treatment. The smell only worsened those symptoms¹¹⁶.

Overall impact

87. The perceived impact of these issues ranged from acute concern for patient safety to a detrimental effect on the patient care. Witnesses accepted that others were an inconvenience but were manageable individually. However, taken together, families came to suspect and indeed believe that the QEUH campus was not the state of the art facility they had understood it to be. It was obvious to witnesses that there were problems with the hospital environment and yet few recounted efforts at communication from hospital management about these issues. What few attempts at communication were made, came after the fact and were not reassuring. This approach to communication

¹¹² See, for example, the evidence of Colette Gough and Denise Gallagher.

¹¹³ See, for example, the evidence of Haley Winter, Denise Gallagher, Colette and Cameron Gough, Stevie-Jo Kirkpatrick and Molly Cuddihy.

¹¹⁴ Évidence of Colette Gough, transcript (pm) at page 2. Mrs Gough recalled the presence of the smell within the PICLI

¹¹⁵ Evidence of Denise Gallagher, transcript at page 93.

¹¹⁶ See, for example, the evidence of Cameron Gough, transcript at page 53; evidence of Stevie-Jo Kirkpatrick, transcript at page 34.

appeared to continue even when serious concerns emerged about key building systems and their possible link to life threatening infections.

THEME 4: CONCERNS RELATING TO KEY BUILDING SYSTEMS AND THE HOSPITAL ENVIRONMENT UP TO 18 SEPTEMBER 2018

Introduction

- 88. One question about the RHC and QEUH has attracted more public attention and concern than any other: has the hospital environment exposed patients to the risk of life-threatening infection? Three building systems have predominated in that discussion: water, drainage and ventilation. Consistent with this, the evidence provided by patients and families revealed adverse experiences and concerns in relation to these systems. The purpose of this narrative is to provide an overview of these concerns and other concerns that witnesses thought had the potential to connect to infection risk.
- 89. The narrative relating to all of these concerns and their impacts is spread over Themes 4 to 9. The intention is to try and identify key events and their impacts in chronological order. Although the narrative once again focuses for reasons already explained upon the Schiehallion Unit, other wards are referenced where relevant.
- 90. Theme 4 focuses on events on Wards 2A and 2B up to 18 September 2018. Theme 5 considers their impacts. Themes 6 to 9 repeat that analysis for Ward 6A. While later chapters go on to look in detail at infection risk itself and at issues to do with communication, it has not proved possible to set out the chronological narrative in a meaningful way without touching on these matters to some extent too: for many witnesses it was from experiencing, or being aware of, infections that suspicions about the hospital environment began to be revealed. This has resulted in some repetition within the submission.

Events in 2015 and 2016

- 91. Later in this submission, consideration is given to information about key building systems dating from close to the time that the hospital opened. Notable among that material is a report prepared by a firm called DMA Canyon Ltd in relation to the hospital's water supply. On the evidence just heard, the existence of this material was only discovered by patients and families after the fact. There is no evidence that patients and families attending the hospital in 2015 and 2016 (and indeed for a long time after that) were aware of this and other similar sources of information about the hospital's systems. As discussed below, this material is relevant to consideration of the way in which GGC and perhaps the Scottish Government communicated with patients and families. It is not relevant to understanding how, at the time, problems with water and other building systems gradually revealed themselves to patients and families.
- 92. Evidence of events in 2015 and 2016 was not plentiful. What evidence there was suggested that issues with water may have been apparent to patients shortly after the QEUH opened. A patient in the adult wards within QEUH recalled the water being turned off for periods of time shortly after opening in 2015¹¹⁷. There was evidence to the effect that patients and families were warned against drinking tap water in the NICU¹¹⁸ and in Ward 2A¹¹⁹ in 2016. One witness recalled seeing filters on the taps and showers in Ward 2A during 2016¹²⁰.

Events in 2017

93. A number of witnesses reported that their children experienced line infections during 2017¹²¹. Consistent with this, a letter issued by Mr Kevin Hill, Director of Women's and Children's Services, GGC, in November 2019¹²² confirms that

¹¹⁷ Witness statement of John Henderson at paragraph 10.

¹¹⁸ Evidence of Karen Stirrat, transcript at page 4.

¹¹⁹ Evidence of Witness 6.

¹²⁰ Evidence of Witness 6.

¹²¹ See, for example, the evidence of Suzanne Brown and Louise Cunningham; see also Appendix 3.

¹²² See letter from Kevin Hill to parents dated 12.11.19 attached to the witness statement of Mark Bisset at page 55A.

concerns were raised by staff about the number of line infections occurring on Ward 2A in 2017.

- 94. The evidence included reports of individual infections in the early part of 2017¹²³. In April 2017, according to certain evidence, Ward 2A was placed in lockdown for a period of two to three weeks ostensibly due to an outbreak of Rhinovirus¹²⁴. Rooms required to be deep cleaned and patients were moved between rooms. Other evidence indicates some reluctance around the use of tap water in the NICU during the same month¹²⁵.
- 95. In July 2017, Kimberly Darroch's daughter suffered a line infection and a septic shower event. Her condition deteriorated and she died in August 2017. The death certificate is reported to record the presence of Stenotrophomonas Maltophillia. Lynndah Allison and Rachel Noon Crossan also reported line infections in in August 2017¹²⁶.
- 96. Towards the beginning of Autumn 2017 witnesses recalled being warned not to drink the water in Ward 2A or to use it for brushing their teeth. The same witnesses recalled the showers on Ward 2A being out of use for a number of weeks¹²⁷. Around this time, Ms Ferguson recalled being told that her son was being placed on Posaconazole to protect his lungs although he went on to develop a fungal infection in his chest in October¹²⁸.
- 97. In November 2017, Louise Cunningham's daughter contracted a line infection which she later discovered showed the presence of two different bacteria, Enterobacter Cloacae and Raoultella Planticola¹²⁹. By this stage, Ms Cunningham's daughter had experienced eight Hickman line replacements. Ms Cunningham recalled further deep cleaning of rooms and room moves around

¹²³ See the witness statement of Suzanne Brown at paragraph 30; see also the evidence of Theresa and Matthew Smith albeit relating to an infection suffered by their daughter in the NICU.

¹²⁴ Evidence of Louise Cunningham, transcript at page 13.

¹²⁵ Witness statement of Theresa Smith at paragraphs 39 and 46

¹²⁶ Witness statement of Rachel Noon Crossan at para 48; witness statement of Lynndah Allison at para 54 and 58.

¹²⁷ Evidence of Annemarie Kirkpatrick, transcript at page 40; and evidence of Stevie-Jo Kirkpatrick, transcript at page 16.

¹²⁸ Evidence of Sharon Ferguson, transcript at page 54.

¹²⁹ Witness statement of Louise Cunningham at paragraph 60.

this time¹³⁰. Cultures taken in December 2017 showed the presence of Enterobacter in Ms Ferguson's son¹³¹.

98. In late 2017, Mrs Kirkpatrick recalled the introduction of green caps for Hickman lines. They had been introduced due to the high incidence of line infections and the Infection Control Team's ("ICT") belief that nurses were not cleaning the lines properly¹³². Mrs Kirkpatrick recalled that green caps were not a feature of Hickman lines at Yorkhill, nor were they used at Dumfries and Galloway Royal Infirmary. The evidence about green caps on Hickman lines and the suggestion of their unique use within the RHC was spoken to by a number of witnesses. Witnesses also reported that the ICT team were on Ward 2A with increasing frequency in the later part of 2017.

Events in January to March 2018

- 99. In around February and March 2018 patients and families noticed obvious changes in the use of water on Ward 2A¹³³. Water coolers were removed, filters were placed on taps and instructions were issued to use bottled water even for cleaning¹³⁴. Witnesses reported seeing signs warning against the use of the water for drinking, and advising that showers should be run for a period before use¹³⁵. The ICT was said to have had an increased presence on Ward 2A during this time¹³⁶.
- 100. The instruction not to use water for washing continued into mid-March 2018. Portable sinks were provided on around 13 March 2018¹³⁷. A note was issued to parents informing them they could use the CLIC Sargent facility to have a shower¹³⁸. On 16 March 2018, families were informed that the water to the ward

¹³⁰ Evidence of Louise Cunningham, transcript at page 24.

¹³¹ Evidence of Sharon Ferguson, transcript at page 14.

¹³² Witness statement of Annemarie Kirkpatrick at paragraphs 31 – 35.

¹³³ See, for example, the evidence of Suzanne Brown, transcript at page 51.

¹³⁴ See, for example, the witness statements of Lynn Kearns at paragraph 31; witness statement of Sharon Ferguson at paragraph 109.

¹³⁵ Witness statement of Witness 6; see also the witness statement of Colette Gough at paragraph 152 in which Mrs Gough recalls seeing similar signs in August 2018 and of David Campbell at paragraph 43 who recalls similar signs in Ward 6A.

¹³⁶ Witness statement of Sharon Ferguson at paragraph 111.

¹³⁷ Witness statement of Lynn Kearns at paragraph 50; see also the photograph produced by Lynn Kearns at LK/02.

¹³⁸ Witness statement of Lynn Kearns, photograph of note at LK/03.

would be shut off altogether (understood by one witness to be for a second time although the date of the first shut down is not known)¹³⁹.

- 101. No witness recalled being given a clear explanation about the nature of the problem with the water, why they were not to use it or why it was being turned off. This is discussed further below. Ms Ferguson recalled a meeting with Professor Gibson, Mr Jamie Redfern (then one of the QEUH's General Managers) and another individual in March 2018 during which she raised concerns about the water on Ward 2A. Ms Ferguson recalled being informed that there was nothing wrong with the water and that it was tested often 140.
- 102. On 20 March 2018, Shona Robison, at that time the Cabinet Secretary for Health, Wellbeing and Sport provided answers to the Scottish Parliament in response to questions about "contamination" of the water supply to Ward 2A. Ms Robison referred to steps taken by GGC to address the issue and reported that no patient with a bacterial infection associated with the incident gave cause for concern. According to Professor Cuddihy, GGC, around the same time, issued a press release indicating that the full water supply would be returned to normal within 48 hours after appropriate testing had been carried out¹⁴¹. Sure enough, the evidence indicated that on 22 March 2018 the water supply to Ward 2A was turned back on¹⁴².
- 103. But in the eyes of patients and families (and possibly also those of the staff), concerns about the safety of the water supply had not been fully resolved. Filters remained on taps, and the instruction to use bottled water remained in place. Witnesses were informed by consultants on a one-to-one basis that their child was being placed on antibiotics to "protect them from the water" 143. Witness 1 recalled his daughter having two serious infections during this period 144. Another witness recalled rooms being sealed off and deep cleaned during this period 145. Although other evidence pinpoints the latter issue as arising later

¹³⁹ Witness statement pf Lynn Kearns at paragraph 51.

¹⁴⁰ Evidence of Sharon Ferguson, transcript at page 37; witness statement at paragraph 113.

¹⁴¹ Evidence of Professor Cuddihy, transcript (26 October 2021 (am)) at page 48.

¹⁴² Witness statement of Lynn Kearns at para 60.

¹⁴³ See for example the witness statements of Sharon Ferguson at paragraph 63; and evidence of Lynn Kearns, transcript at page 49.

¹⁴⁴ Evidence of Witness 1

¹⁴⁵ Witness statement of Suzanne Brown at paragraph 43.

on¹⁴⁶, the fact of the matter is that, for understandable reasons, and notwithstanding the reassuring words of Ms Robison and GGC, patients and families continued to entertain doubts about the safety of the water supply. Those doubts would only increase with the passage of time.

Events in April to July 2018

- 104. Environmental concerns on Ward 2A continued. Evidence indicated that Ward 2A was shut down for two weeks around Easter 2018¹⁴⁷. Senga Crighton recalled being informed by staff that the ward was closed to visitors in an effort to manage unexplained infections. A sign was placed on the door which read "Ward closed to <u>ALL</u> visitors, Parents only allowed in ward. Thank you!" 148
- 105. The Inquiry heard compelling evidence of a series of infection events during April and May 2018. Haley Winter recalled that between 28 April and 2 May 2018 her son had a line infection which was subsequently confirmed by the CNR to be Enterobacter Cloacae¹⁴⁹. Sharon Ferguson's son had a septic shock event on 14 May 2018 which was also confirmed to have been caused by an Enterobacter Cloacae infection¹⁵⁰.
- 106. Molly Cuddihy recalled experiencing temperature spikes on 13 April and 9 May 2018 which were suspected to be linked to an infection, although blood cultures taken at the time did not immediately reveal the nature of the infection. Ms Cuddihy experienced a third severe infection event on 31 May 2018 during which fluid resuscitation was required. On 1 June 2018, Ms Cuddihy was informed that the blood cultures taken on 9 May 2018 confirmed that she had contracted Mycobacterium Chelonae, an extremely rare gram-positive bacterial infection.
- 107. Witness 1 recalled that his daughter became extremely unwell with an infection having been in isolation on Ward 2A for a period of months¹⁵¹. Leann Young

¹⁴⁶ May 2018. In Jennifer Armstrong's response to Professor John Cuddihy's 2018 letter to Catherine Calderwood, Ms Armstrong stated there was no Hydrogen Peroxide Vapour cleaning during this outbreak of infections.

¹⁴⁷ Witness statement of Senga Crighton at paragraph 30.

¹⁴⁸ Witness statement of Senga Crighton. Photo of note attached at SC/01.

¹⁴⁹ Witness statement of Haley Winter at paragraph 74 and per attached timeline

¹⁵⁰ Witness Statement of Sharon Ferguson at paragraph 69.

¹⁵¹ Evidence of Witness 1.

recalled that in May 2018, her son contracted VRE (Vancomycin Resistant Enterococcus) and in June that he contracted Aspergillus¹⁵².

- 108. Witnesses did not recall receiving clear communication from hospital management about the infection outbreaks during this period or in relation to the methods being used to tackle them. But witnesses observed for themselves chemicals and crystals being poured down drains¹⁵³ and rooms being sealed off to be cleaned using Hydrogen Peroxide Vapour ("HPV")¹⁵⁴. One witness recalled being informed that the ward was under investigation for "environmental issues" 155. Some witnesses had an understanding that the pipes behind sinks were to be changed because "bugs were sticking to the plastic in the pipes"¹⁵⁶. Ms Ferguson recalled that on around 5 June 2018 she was given a piece of paper referring to a "new method of cleaning" on Ward 2A which she understood to relate to the HPV cleaning. On 7 June 2018, she recalled being handed a second note indicating that the drainage and chilled beams were being cleaned and that her son would be given antibiotics¹⁵⁷. Suzanne Brown recalled that leaflets were only handed out after events on the ward appeared in the news¹⁵⁸.
- 109. During this time frame, some witnesses recounted discussions with clinical staff about preventative medication¹⁵⁹. Denise Gallagher was informed by her son's consultant that he would be placed on Ciprofloxacin to guard against environmental infection although the nature of those environmental concerns was not explained. Ms Young recalled being informed that all children with "central lines" would receive Ciprofloxacin as a precautionary measure¹⁶⁰.
- 110. In June 2018, Professor Cuddihy wrote to the then Chief Medical Officer for Scotland, Catherine Calderwood, outlining his concerns about the environment on Ward 2A and about the rare infection contracted by his daughter¹⁶¹. This

¹⁵² Witness statement of Leann Young at paragraphs 20 – 22.

¹⁵³ Witness statement of Leann Young at paragraph 21.

¹⁵⁴ See, for example, the evidence of Sharon Ferguson, transcript at page 50.

¹⁵⁵ Evidence of Denise Gallagher, transcript at page 24.

¹⁵⁶ Witness statement of Leann Young at paragraph 25.

¹⁵⁷ Witness statement of Sharon Ferguson at paragraph 149.

¹⁵⁸ Evidence of Suzanne Brown, transcript at page 54

¹⁵⁹ See, for example, the witness statement of Denise Gallagher at paragraphs 10 and 70.

¹⁶⁰ Evidence of Leann Young, transcript at page 20.

¹⁶¹ Evidence of Professor John Cuddihy, transcript (26 October 2021 (am)) at page 83.

prompted a response from Dr Jennifer Armstrong, Medical Director of GGC, dated 23 July 2018. The letter has not yet been produced but its contents were spoken to by Professor Cuddihy in his evidence. Dr Armstrong sought to reassure Professor Cuddihy that the Incident Management Team set up by GGC would get to the root cause of the infections and that everything that was being done accorded with NHS guidance as well as relevant policies and procedures. Dr Armstrong explained that the March 2018 infection outbreak stemmed from a problem with water whereas the outbreak in May 2018 involved a problem with drains. The letter indicated that the issues with water and drains had been successfully resolved and that Ward 2A had returned to near normality with no new reported cases.

111. Dr Armstrong's assessment of matters did not accord with "the chaos" Professor Cuddihy was witnessing for himself on Ward 2A. It might be thought that the conflict between his view and that of Dr Armstrong was resolved when, two months later, Ward 2A was completely shut.

Events between August and 18 September 2018

- 112. The evidence relating to the period up to 18 September 2018 indicates that concerns about the water system persisted. The families of new patients on the ward recalled being warned of issues with the water¹⁶². One witness recalled continued treatment of the drains¹⁶³. Others recalled further issues with the water facilities such as taps being sealed off in the parent kitchen and the dishwasher being placed out of use¹⁶⁴. The news of the water issues was known outwith the RHC. Some witnesses spoke of staff in other hospitals informing them that there were issues with the water in Glasgow.
- 113. Witnesses also spoke of the continued presence of the ICT on the ward. Dyson fans which had been brought in to address the temperature issue were removed on the instructions of the ICT¹⁶⁵. One witness recalled a meeting between

¹⁶² See, for example, the evidence of Cameron Gough, transcript at page 94.

¹⁶³ Witness statement of Annemarie Kirkpatrick at paragraph 61.

¹⁶⁴ Witness statement of Annemarie Kirkpatrick at paragraph 61.

¹⁶⁵ Evidence of Annemarie Kirkpatrick, transcript at page 41.

parents and the ICT to discuss protocols and cleaning¹⁶⁶. Parents were instructed not to pour drinks down wash hand basins.

- 114. Formal communication from hospital management about the environmental issues on the ward was described by many witnesses as non-existent. Some recalled informal discussions with nurses and with domestic staff and among parents. One witness recalled expressing concerns about the water to a junior doctor and a response along the lines of "If this was my child, I wouldn't put her near the water either" ¹⁶⁷.
- 115. Further infections were reported during this period. One witness recalled a point in time when all five patients within the TCT unit were unwell; and two who were preparing to go home had contracted infections¹⁶⁸. Ms Ferguson's son contracted another line infection on 4 August 2018. At a meeting with Professor Gibson and Dr Theresa Inkster (microbiologist), Ms Ferguson was informed that her son had contracted an environmental bug called Stenotrophomonas.
- 116. In early September 2018, Mr and Mrs Gough's son experienced a life-threatening line infection which was subsequently confirmed to be Serratia Marcescens. At the same time, on around 6 September 2018, Mr and Mrs Gallagher's son developed an infection subsequently confirmed to be Stenotrophomonas. Mrs Gallagher recalled a troubling discussion with a nurse on Ward 2A. Mrs Gallagher observed a lot of activity around Room 23 and was aware that a child who had been in that room had recently died. On enquiring whether there was an issue with the room, the nurse's response was "you are closer than you know" 169.
- 117. On 17 September 2018, Mr and Mrs Gough met with their son's consultant and Dr Inkster to discuss their son's infection. Dr Inkster confirmed that the infection was linked to a bug in the drains and that their son was one of six children who contracted infections that weekend. At a meeting with Professor Gibson, Mr Redfern and Dr Inkster, Mrs Gallagher was also informed that there was a

¹⁶⁶ Evidence of Aneeka Sohrab, transcript at page 22.

¹⁶⁷ Evidence of Charmaine Lacock, transcript at page 94.

¹⁶⁸ Witness statement of Annemarie Kirkpatrick at paragraph 60.

¹⁶⁹ Evidence of Denise Gallagher, transcript at page 58.

- problem with the drains on Ward 2A. The decision to close Wards 2A and 2B was announced on 18 September 2018 and is considered in Theme 6.
- 118. It bears notice that reports of infection continued right up to the closure of Ward 2A on 26 September 2018. Charmaine Lacock and Senga Crighton recalled their children experiencing infections in the days leading up to the closure¹⁷⁰.
- 119. Although the concerns reported during this period related predominantly to water and drainage, a small group of witnesses raised concerns about ventilation and mould on the ward. Mrs Gallagher observed a vent which was 'popped' out and appeared to be undergoing testing. Mrs Barclay recalled seeing 'dust' blowing out of an air vent onto a patient bedroom¹⁷¹. Annemarie and Stevie-Jo Kirkpatrick recalled being told by the TCT support co-ordinator of an issue with ventilation on the ward. Professor Cuddihy recounted learning of the discovery of significant levels of mould in the en-suite bathrooms caused by failure in the seals between the wall and floor¹⁷².

THEME 5: IMPACTS OF THE ENVIRONMENTAL CONCERNS ON WARDS 2A AND 2B

120. Self-evidently, the most serious impacts arising from events on Wards 2A and 2B are those related to infections sustained or understood to have been sustained by patients. Those impacts are considered within Theme 10. However, the evidence disclosed a number of other physical and emotional impacts affecting patients and families.

Disruption of the water supply

121. Initially, witnesses were not overly concerned about being told not to drink tap water. They found the instruction to run the showers before use curious; it caused some to think about Legionella but overall these were not matters of significant concern. Concern emerged with the appearance of filters on taps

¹⁷⁰ Witness statement of Charmaine Lacock at paragraph 41; witness statement of Senga Crighton at paragraph 58

¹⁷¹ Witness statement of Sharon Barclay at paragraphs 40 and 48.

¹⁷² Witness statement of Professor John Cuddihy at paragraph 246.

(and showers) and with the dousing of drains with chemicals. The only communication about these matters came by way of passing comment from staff or workmen. Absent a clear statement from GGC about what was wrong with the water or drainage system, rumours circulated 173 and concerns grew. It was obvious that there was a problem, but patients and families were left to speculate about what it might be. Overall confidence in the water supply fell. Witnesses reported extreme concern that a state of the art healthcare facility could not achieve that most basic of healthcare facilities: a functioning water system 174.

- 122. The most acute disruption to the water system occurred in March 2018 when witnesses recalled being informed firstly that they could not wash using the hospital water supply (effectively depriving patients of hot running water) and then that the water supply was being shut off altogether. Lynn Kearns provided a powerful description of the effect of these events upon her son who, following a spell in PICU, had an endotracheal tube removed on 10 March 2018¹⁷⁵. That was a distressing and messy event. All her son wanted to do was to have a hot shower. Mrs Kearns' son waited seven days for a hot shower, and even then was only able to have one because he was given a day pass to go home. In the interim, Mrs Kearns was provided with a small basin of water and then a portable sink with which to wash her son. Neither solution was adequate, and only contributed to her son's loss of dignity. Matters deteriorated when the water was turned off altogether and patients were instructed to use bed pans.
- 123. As mentioned above, parents were instructed that, if they wished to have a shower, they could take a taxi to the CLIC Sargent facility located outwith the hospital grounds. Some witnesses did not consider this a realistic option because of the time during which their children would be left alone.
- 124. The water supply was restored on 22 March 2018 but no explanation was provided as to why the water was now considered safe. Mrs Kearns recalled that, in the absence of an indication to the contrary, her family assumed the

¹⁷³ See, for example, the evidence of David Campbell, transcript at page 30.

¹⁷⁴ See, for example, the evidence of Suzanne Brown, transcript a page 67; and witness statement of John Henderson at paragraph 10.

¹⁷⁵ Evidence of Lynn Kearns, transcript at page 33.

water was safe to use¹⁷⁶. Other witnesses remained concerned about the safety of the water supply. Suzanne Brown's son had used the hydro pool on the ground floor of the RHC to help ease muscle pain caused by his treatment; she stopped this in early 2018 when concerns about the water supply emerged. She recalls feeling guilty about exposing her son to a risk of infection¹⁷⁷. This feeling of guilt was echoed by a number of witnesses who felt that they had exposed their children to risk just by using the water. Parents were in a *Catch 22* situation: washing their children was necessary to ward off infection; but washing them was apparently perceived to risk exposing them to that very thing.

125. The disruption to the water supply also affected staff on the ward. Nurses and doctors were instructed to leave the ward to use the bathroom or to wash their hands. One witness recalled the water supply being shut down without warning being given to doctors on the wards. She recalled that one particular consultant, who was fastidious about handwashing, was frustrated and concerned about the potential infection risks posed by the situation¹⁷⁸. Witnesses were concerned that the job of staff on the ward was hampered by the lack of a reliable water supply.

Parents' kitchen

126. Evidence was heard to the effect that issues with the water supply and concerns about infection control placed the parents' kitchen out of use for periods of time. During these periods, the ability of parents to cater to a child's food requirements became limited; and the sanctuary for parents the kitchen offered was not available.

HPV cleaning of rooms

127. Witnesses recalled significant disruption caused by the deep cleaning of rooms.

Room cleaning resulted in frequent room moves in which patients and their belongings were moved from room to room. There was evidence that room

¹⁷⁶ Witness statement of Lynn Kearns at paragraph 54.

¹⁷⁷ Witness statement of Suzanne Brown at paragraphs 77 and 122.

¹⁷⁸ Evidence of Molly Cuddihy, transcript (am) at page 60.

moves could result from patient requirements for specific room types but the perception was that the high frequency of room moves was linked to HPV cleaning. David Campbell recalled the appearance of people living out of suitcases¹⁷⁹. Aneeka Sohrab recalled moving rooms hundreds of times; on some occasions she would leave the ward for a short period and return to find that her daughter was not in the room where she left her¹⁸⁰. Patients and their families were unable to settle and staff time was taken up assisting with moves.

Ward moves

- 128. A serious concern expressed by a number of witnesses related to displacement of Schiehallion patients to other wards within the RHC. Witness perception was that displacement was a result of a lack of capacity on Wards 2A and 2B contributed to by room cleaning and other building issues. Molly Cuddihy recalled that during the HPV cleaning all patients who did not have to be on the ward were moved to other wards¹⁸¹.
- 129. It should be acknowledged that some witnesses who described experiences on other wards were there because of the expertise available on those wards (for example, neurological or surgical wards). It should also be noticed that some witnesses described positive experiences on other wards¹⁸².
- 130. However, one consistent theme was that the "Schiehallion Umbrella" did not travel effectively to other wards. Parents identified two perceived concerns: the risk of infection and a lack of specialised care. Mr and Mrs Gough provided clear and detailed evidence of the nature of these concerns¹⁸³ which was supported by a number of other witnesses. Cleaning protocols did not travel to other wards. In some cases, even basic cleanliness was not achieved¹⁸⁴. Immunocompromised children mixed with non-immunocompromised children. Some witnesses spoke of a rule that Schiehallion children should always be

¹⁷⁹ Evidence of David Campbell, transcript at paragraph 15.

¹⁸⁰ Evidence of Aneeka Sohrab, transcript at page 38.

¹⁸¹ Evidence of Molly Cuddihy, transcript (pm) at page 5.

¹⁸² Karen Stirrat, for example, spoke highly of her and her son's experience on the neurology ward.

¹⁸³ Evidence of Cameron Gough, transcript at page 105.

¹⁸⁴ Evidence of Colette Gough, transcript at page 82. Mrs Gough recalled discovering dried brown matter on the bed rail of the patient bed.

placed in a VAC room when on other wards, but if there was such a rule, it was not applied consistently. Witnesses described how infection risk concerns led to an isolating and lonely existence on other wards.

- 131. Witnesses did not recount a consistent position in relation to the water supply on other wards within the RHC. Some recalled seeing filters or being provided with bottled water. Others had the opposite experience and formed the impression that other wards were unaware of the risk posed to immunocompromised children by the water within the RHC.
- 132. The parallel concern related to a perceived lack of experience of dealing with patients with the highly specialised requirements of the Schiehallion patient group. Most witnesses were careful to emphasise that no criticism was intended of staff themselves; but the simple fact was that those staff members did not have experience of the particular demands of caring for paediatric haemato-oncology patients. For example, staff on other wards did not have an understanding of the requirement for precision medication or of making frequent observations. They did not have the same skill set in relation to use of cannulas, Hickman lines and port-a-caths. Staff on other wards appeared to lack understanding of the nature of temperature spikes and the speed at which the condition of Schiehallion patients could deteriorate. When life threatening deteriorations did occur, parents did not have confidence that staff on other wards were in control of the situation. Parents perceived that their children were placed at increased risk when they were outwith Wards 2A and 2B.
- 133. The overall effect of these concerns was to erode parents' trust in the safety of the hospital environment for their immunocompromised children. It was a deeply unsettling experience for parents who had built up trust in the processes and procedures of the Schiehallion Unit. Mr Gough described bringing a 'crash bag' on every visit to the hospital. It contained items such as bottled water and cleaning materials to enable Mr and Mrs Gough to cater for every eventuality. Mr and Mrs Gough recalled reaching a stage, later in 2018, where they switched from wishing that their son would be home for Christmas to just wishing that, if he was in hospital for Christmas, he would at least be in the Schiehallion Unit.

<u>Infection control protocols</u>

- 134. As mentioned already, during the period under discussion, witnesses perceived an increased ICT presence on Ward 2A¹⁸⁵; and a heightened awareness of infection and prevention control measures coupled with increasing pressure on nursing and domestic staff. Some witnesses formed the impression that ward staff felt they were being blamed for infection outbreaks. There was a perceived deterioration in the relationship between the ICT and ward staff who were becoming increasingly frustrated at the situation. Blame was also directed at parents who were instructed not to pour left-over drinks down sinks in the patient bedrooms¹⁸⁶, and were reprimanded for not immediately disposing of the packaging from a new toy ¹⁸⁷.
- 135. Witnesses recounted a change in infection control protocols. Parents were no longer allowed to assist with certain day to day tasks like obtaining fresh bed linen for their child or in taking samples to the sluice room. This led to a perceived increased workload on staff. Some witnesses recounted multiple stool and urine samples gathering in bathrooms awaiting collection¹⁸⁸.
- 136. One witness described an overall drop in the mood of the ward as protocols became stricter. Even patients felt that they had done something wrong¹⁸⁹. Ms Cunningham recalled one particularly distressing event where she was instructed that almost all of her daughter's possessions had to be removed because they were viewed as contaminated. Ms Cunningham's daughter had to give up almost all of her toys, teddies, cards and art work. Even after the room was deep cleaned, only minimal possessions were allowed back in the room. Toys were replaced with the assistance from a charity¹⁹⁰.

¹⁸⁵ Evidence of Louise Cunningham, transcript at page 22.

¹⁸⁶ See, for example, the evidence of Aneeka Sohrab, transcript at page 80.

¹⁸⁷ Evidence of Alfie Rawson, transcript at page 10.

¹⁸⁸ Evidence of Leann Young, transcript at page 32.

¹⁸⁹ Evidence of Louise Cunningham, transcript at page 54.

¹⁹⁰ The John O'Byrne Foundation.

Source isolation

- 137. Source isolation was a regular feature of the evidence. It was described as a procedure which would be implemented when there was a particular concern about the risk of or from infection: i.e. whether posed by one patient to others on the ward or vice versa or perhaps where there was thought to be a general risk of cross-contamination on the ward (for example, in the event of a viral outbreak). Patients placed "in source" were required to remain in their bedrooms for days or weeks at a time. Although parents could leave the room, they were not permitted to use communal facilities such as the parents' kitchen. Visiting was restricted. It was, in effect, a mini-lockdown.
- 138. Among the witnesses, there was a consistent perception that the use of source isolation increased during 2017 and 2018. Witness 6 and Mrs Kirkpatrick recalled that, although source isolation was a feature when their children were in Yorkhill, it was more prevalent on Ward 2A. Some witnesses recalled periods when almost the whole ward was "in source".
- 139. The Inquiry is not presently in a position to reach any conclusions about whether patients were 'in source' more frequently than would ordinarily be the case. But that was the perception of many witnesses. What was also evident was that many parents and children became wearied by the use of source isolation. It made an already challenging situation worse. Children and parents alike felt isolated. Some witnesses painted a bleak picture of being stuck in a dark, hot and stuffy room, with no means to entertain their sick child (because there was no working television or Wi-Fi).
- 140. Parents were particularly frustrated at what they perceived to be a lack of communication in relation to source isolation. Some recalled that stickers were simply placed on bedroom doors with no further explanation. This added further to mounting anxiety about what was happening on the ward. Parents did not know if the use of source isolation was linked to suspected environmental infections, part of a new infection control protocol or the specific needs of their child.

Communication

141. A clear and constant theme was that communication during this period was lacking. This in itself impacted upon patients and families. Witnesses could not recall being provided with a clear explanation for these events. It was obvious that something was wrong. Information was gleaned from general discussion on the ward among parents and ward staff. Some witnesses could recall nurses and consultants mentioning "environmental issues" and "bugs". Overall though the picture was one of mounting anxiety and concern which was not successfully allayed. Absent clear communication from GGC, parents and staff were left to speculate about the safety of the ward. Professor John Cuddihy summed up the experience in a way which reflected the tenor of the evidence from most witnesses¹⁹¹:

"This left me angry, concerned, anxious and distrusting of the hospital at a time when I needed to have absolute trust as my daughter's health depended upon it. There was a lack of openness, transparency and honesty".

THEME 6: THE CLOSURE OF WARDS 2A and 2B

142. In September 2018, a decision was taken to close Wards 2A and 2B and to move patients to adult Ward 6A in the QEUH. The evidence revealed four related concerns: (i) the basis for the decision to close the Wards; (ii) the basis for the decision to decant to ward 6A; (iii) the communication around the closure; and (iv) the arrangements for the move. Theme 6 examines these concerns and Theme 7 considers the impact of the move to Ward 6A on patients and families.

The decision to close Wards 2A and 2B

143. Only a small number of witnesses recall having any advance notice of the possibility that Wards 2A and 2B might close. The impression formed by those witnesses was that the decision to close Wards 2A and 2B was a reaction to

¹⁹¹ Witness statement of Professor John Cuddihy at paragraph 238.

an outbreak of infections around 6 and 7 September 2018. Denise Gallagher met with Mr Redfern, Dr Inkster and Professor Gibson around the latter date to discuss the infection contracted by her son. Mrs Gallagher asked those present what they intended to do given that this was the third outbreak of infections that year. Although it was accepted that there was a problem with the drains, Mrs Gallagher did not recall being given a clear answer. On 17 September, Mr and Mrs Gough met with their son's consultant and Dr Inkster to discuss their son's infection. It was accepted that the infection was linked to the drains. They were informed that investigations were ongoing and that there was a proposal to close the whole Schiehallion Unit.

144. On 18 September 2018, the decision to close Wards 2A and 2B was announced together with the intention to move patients to an "adult ward" in the QEUH. A typed note dated 18 September 2018 and titled "Ward 2A and 2B Update" was provided to Mr and Mrs Gough¹⁹². It began:

"We appreciate that you have been experiencing disruption whilst we have introduced an enhanced cleaning programme. As you may be aware we initially experienced a build-up of material (known as biofilm) in the sink drains in Wards 2A and 2B. This is the same sort of biofilm we get in domestic sink drains but as the patients in these wards are being treated for cancer their immune system is compromised and they are more susceptible to infection."

The note goes on to explain that the "new cleaning product" is a temporary solution and that Wards 2A and 2B will be transferred temporarily to "another ward" in the QEUH while a permanent solution is identified. That would also "...provide an opportunity for drainage and technical experts to undertake a comprehensive investigation and complete any remedial works required".

145. This note suggests that the basis of the decision to close the Wards was driven by the need for a new cleaning regime. That did not align with Mr and Mrs Gough's understanding: that the reason for the closure was an actual outbreak of infection coupled with serious concerns about the risk of further infection.

¹⁹² Attached to the witness statement of Colette Gough at CG/02.

The decision to move to Ward 6A

- 146. It is unclear when the decision to move to Ward 6A was taken. Evidence suggests that, as at 20 September 2018, options were still being considered¹⁹³. Few witnesses had any understanding of the apparent rationale for choosing Ward 6A over other locations. Some witnesses had formed the impression that the decisions to close the ward and decant patients to Ward 6A was a reactive, 'knee jerk' decision. Professor Cuddihy said that he had entertained serious concerns about the decision¹⁹⁴. He spoke of a meeting he had with Mr Redfern and Dr Inkster in September 2018 after learning of the planned move. To his mind, the closure confirmed that, contrary to what he had been told by Dr Armstrong, Ward 2A was not safe.
- 147. Professor Cuddihy therefore welcomed the closure of the ward but sought assurance that the alternative arrangements would be safer. The response was that an options appraisal had been performed and various options considered. Professor Cuddihy's understanding of the options appraisal was as follows ¹⁹⁵. The preferred option was to move the Schiehallion Unit to another ward within the RHC. However, that option had been ruled out, implying to Professor Cuddihy that moving to another ward within the RHC was deemed unsafe. Further options included moving to another haemato-oncology unit elsewhere in Scotland. That too was discounted, on the basis that it would have left patients without other critical services provided within the RHC. A mobile facility had been considered but was discounted as impractical. The solution eventually identified was to move patients to an adult ward in the QEUH.
- 148. Professor Cuddihy enquired about the safety of the environment on Ward 6A. He recalled being informed that it would be modified in order to improve its suitability for accommodating immunocompromised children. He was told that Ward 6A had a separate water supply from the RHC, albeit point of use taps filters would still be installed as an extra precaution. Although Professor Cuddihy was reassured at the time, he came to doubt the assessment of the

¹⁹³ Evidence of Denise Gallagher, transcript at page 70.

¹⁹⁴ Evidence of Professor John Cuddihy; transcript (26 October 2021 (pm)) at page 7.

¹⁹⁵ Evidence of Professor John Cuddihy, transcript (26 October 2021 (pm)) at page 7.

Ward 6A's suitability even as modified. Through his subsequent work with the Oversight Board, he requested sight of any risk assessments prepared relative to the move and any general continuity plans for the displacement of immunocompromised children in particular. He also asked whether Scottish Government, Child Rights and Wellbeing Impact Assessments were completed. Professor Cuddihy was informed that an SBAR (Situation, Background, Assessment, Recommendation) was prepared but was not provided with copies of any impact assessments or continuity plans. Professor Cuddihy's perception is that these documents do not exist.

Communication in relation to the closure of Wards 2A and 2B

- 149. The evidence suggests that communication around the decision to close Wards 2A and 2B was perceived to be, at best, inconsistent and, at worst, non-existent. In many cases, it was the cause of significant distress to some witnesses. There is evidence that a written communication was handed out to some families (the note referred to by Mrs Gough). Although the note is dated 18 September 2018, that is not necessarily indicative of the date on which it was issued¹⁹⁶. There was a clear line of evidence that witnesses learned of the closure for the first time through press reports, text messages from friends and neighbours and from social media¹⁹⁷ on 18 and 19 September 2018. Leann Young recalled receiving a written communication on 20 September 2018 two days after seeing the story on the news.
- 150. A number of witnesses recalled the shock and anger caused by learning of the closure on the news or from third parties. They could not fathom why the families of children being treated on the ward (whether in 2A or as day patients in 2B) were not the first to learn of the closure; patients and families were the people most directly affected and yet the media had been given priority access to the information. Some witnesses recalled that they had been on Ward 2A itself the day before the announcement, but had been given no indication of

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¹⁹⁶ Stapled to the note is another note dated 7 September 2018 relating to cladding works. This suggests that the dates printed on written communication are not necessarily indicative of the dates on which they were issued.

¹⁹⁷ See, for example, the evidence of David Campbell, Leann Young, James Gallagher and Charmaine Lacock.

what was to come¹⁹⁸. Charmaine Lacock expressed disbelief that she and her daughter, an inpatient, were on Ward 2A itself on 18 September 2018, and yet she learned of the closure from a text message.

- 151. Discovery of the closure via press coverage caused some families extreme anxiety. Mr Gallagher's son was due to undergo a life-saving bone marrow transplant on Ward 2A. The family was concerned that a delay in his transplant would result in the loss of his donor. There were also practical concerns about travel, employment, expense and childcare arrangements which had to be considered if the transplant was to take place elsewhere. When Mr Gallagher met with Mr Redfern on 20 September 2018 (at Mr Gallagher's request), he was provided with an assurance that his son would receive his transplant in Glasgow.
- 152. At a general level, witnesses recalled that, aside from press reports and the note handed out to some families on the ward, most communication about the closure and subsequent decision to move to Ward 6A came from one-to-one meetings with individual consultants. Conspicuously absent was a clear and comprehensive statement from hospital management or GGC about what was happening and why. One witness recalled that Mr Redfern and a senior nurse were sent by management to be "the bearers of bed news" (at least to those families who were present on the ward). However, they had not been provided with the information necessary to enable them to answer questions or allay concerns. Their message was that Ward 6A would be "a lot better" and that the move would only be "for a couple of months".

Arrangements for the move

153. The move to Ward 6A took place on 26 September 2018. The overall impression of witnesses was that the arrangements for the move lacked planning and strategy²⁰⁰. One witness described it as "organised chaos"²⁰¹. From Professor Cuddihy's perspective, there was no evidence of an existing

¹⁹⁸ Witness statement of Leann Young at paragraph 40.

¹⁹⁹ Evidence of Molly Cuddihy, transcript (pm) at page 8.

²⁰⁰ Evidence of Cameron Gough, transcript at page 137.

²⁰¹ Evidence of Leann Young, transcript at page 42. See also witness statement of Witness 5 at paragraph 9.

continuity plan providing for the transfer this extremely vulnerable patient group²⁰².

154. Witnesses were consistent in their evidence of what happened on the day of the move. Patients were moved in their beds accompanied by a team of people including nurses, auxiliaries and porters. One witness recalled being alarmed that her daughter was accompanied by a doctor with oxygen in a backpack; this suggested the existence of risk²⁰³. Each patient's furniture was labelled and moved. Nurses packed up and then unpacked the ward (although third party contractors may also have been involved). Overall, the impression was that the move absorbed a huge amount of resource. There was a perception by some that patient care was affected; nurses were busy and exhausted and could not provide the same high level of care they were used to providing²⁰⁴.

THEME 7: IMPACTS OF THE MOVE TO WARD 6A

155. Patient and family concerns about key building systems, the environment and infections continued on Ward 6A. These concerns and their impacts are considered within Themes 8 and 9. But quite apart from these matters, there was a clear line of evidence that Ward 6A was considered unsuited to the provision of paediatric cancer care, and that the move to Ward 6A was therefore detrimental in itself. Theme 7 records the Inquiry's understanding of the evidence heard on that matter.

The Journey to Ward 6A

156. Concerns about the new arrangement begin with the route which patients were required to take to reach Ward 6A. Although Ward 6A could have been accessed through the RHC, patients and families had been advised in September 2018 that they should use the QEUH Discharge Lounge entrance (due to risks posed by ongoing cladding works). The Discharge Lounge entrance was described by as an unpleasant place. It was a congregation point

²⁰² Evidence of Professor John Cuddihy, transcript (26 October 2021 (pm)) at page 7; witness statement of Professor John Cuddihy at paragraph 255.

²⁰³ Witness statement of Charmaine Lacock at paragraph 56.

²⁰⁴ Evidence of Leann Young, transcript at page 44.

for smokers (and, as one witness indicated, individuals with addiction issues²⁰⁵). Molly Cuddihy recalled that, as a vulnerable patient undergoing treatment for cancer, passing through a crowd of smokers was an unsettling experience.

157. Once into the QEUH building, patients had to use the public lifts to travel to Ward 6A (although it was understood that latterly a dedicated lift arrangement was put in place). The public lifts were a source of some anxiety for patients and families who were hyper-aware of the need for cleanliness. Use of these lifts required immunocompromised children to mix with the general adult population of the QEUH²⁰⁶. The lifts themselves were described as being unclean.

Description of Ward 6A

- 158. Ward 6A is located on one of the 'wings' of the QEUH. Mr Gough spoke to its layout under reference to a diagram provided by GGC²⁰⁷. The day care unit (formerly Ward 2B) was situated at the far end of a long straight corridor which housed inpatient bedrooms. The location of day care was a further source of anxiety for families. Children attending day care with suspected infections or viruses such as Chickenpox were required to pass through the inpatient section of the ward which housed immunocompromised patients.
- 159. Ward 6A was understood to be a general adult ward comprising single en-suite bedrooms. It had no specialist ventilation or VAC rooms. Paediatric patients requiring bone marrow transplants were allocated rooms on the adult BMT Unit on Ward 4B. This in itself was a sub-optimal solution. Ward 4B had limited space and was an adult ward which was not designed to cater for children or to accommodate their families²⁰⁸. Similarly, Ward 6A was not designed to cater for children and families. Rooms did not contain a pull-down bed; camp beds were provided but were uncomfortable and took up space in the room during

²⁰⁵ Evidence of David Campbell, transcript at page 41.

²⁰⁶ See, for example, the evidence of Cameron Gough, transcript at page 142; evidence of David Campbell, transcript at page 43.

²⁰⁷ Bundle 2, page 41.

²⁰⁸ Evidence of Mark Bisset, transcript at page 54.

the day. Although a minor point, the décor of the rooms was dull and not designed for children.

The patient family experience on Ward 6A

- 160. Witnesses were grateful that Schiehallion staff moved with the Unit. However, in many other respects the Schiehallion experience did not compare to that evident when the Unit was located in RHC. Absent from Ward 6A were the parents' kitchen, playroom and TCT Unit. The loss of these facilities was felt keenly by patients and families. Parents lost the practical advantages of a kitchen facility on the ward and the ability to feed their children as needed. Travelling to the central atrium of the QEUH to heat food up in a communal microwave was not viewed as a realistic or safe option. Parents could ask nurses for a glass of water or cup of tea but were reluctant to add to their workloads²⁰⁹. Significantly, parents lost the important support network formed through interactions with other parents. They lost their respite²¹⁰.
- 161. Children lost the use of the playroom²¹¹. A table and chairs was set up in a corridor but this rather inadequate solution was considered a health and safety hazard. Parents were concerned about the infection risk posed by passing day care patients and about obstruction caused in the corridor²¹². Play leaders had no storage and were spread too thinly in their attempts to provide an individual service to patients in their rooms. From a physical perspective, some parents were concerned that the increased time spent in bedrooms was detrimental to the battle against muscle atrophy faced by these patients. Mrs Kirkpatrick recalled suggesting to nurses that a frequently-empty meeting room could be turned into a playroom but was told that would not be possible because it was used as a meeting room for doctors.

²⁰⁹ Evidence of Denise Gallagher – nurses went from looking after 20 patients to 50 people including patients and their families (transcript at page 50).

²¹⁰ Evidence of Alfie Rawson, transcript at page 23.

²¹¹ Although it is understood that a playroom may now have been installed.

²¹² Evidence of Aneeka Sohrab, transcript at page 48.

- 162. Children lost access to the Medicinema and Radio Lollipop located in the RHC²¹³. Charity access to the ward was restricted which meant that patients and families lost out on many of the important services provided by charities²¹⁴.
- 163. The TCT unit was lost entirely. Patients were not allowed into each other's rooms. Without access to a common room, teenage patients were, in effect, "confined to barracks". The teenage support network was lost. Molly Cuddihy recalled that, despite his best efforts, the TCT support co-ordinator was unable to operate effectively in this new set up.
- 164. Overall witnesses painted a bleak picture of life on Ward 6A. Stevie-Jo Kirkpatrick described it as a depressing and lonely place²¹⁵. Molly Cuddihy said that, for her, being "sick" is a mindset and Ward 6A put her in that mindset. It was on Ward 6A that she "gave in" to a feeding tube²¹⁶. Parents recounted a similar effect on their younger children who were stuck in their rooms with limited entertainment and few opportunities for socialising. Children became "institutionalised"²¹⁷ in a ward that was described as feeling like a "prison"²¹⁸. The means of normalising cancer were gone; children became defined by illness; they changed from being "kids with cancer" to being "cancer kids"²¹⁹.

Links to the RHC

- 165. Although the Schiehallion Unit moved to Ward 6A, all of the other paediatric services remained in the RHC including the clinics, the pharmacy, dental service, surgical wards and PICU. Some witnesses expressed a general concern about the length of time it took to travel between the two buildings²²⁰.
- 166. A striking illustration of the concern about the distance between Ward 6A and the RHC was provided by Mrs Kirkpatrick²²¹. Following admission to Ward 6A on 24 December 2018, Stevie-Jo's condition deteriorated, requiring rapid

²¹³ Evidence of David Campbell, transcript at page 50.

²¹⁴ Evidence of Colette Gough, transcript (pm) at page 63.

²¹⁵ Witness statement of Stevie-Jo Kirkpatrick at paragraph 52.

²¹⁶ Evidence of Molly Cuddihy, transcript (pm) at page 16.

²¹⁷ Evidence of Colette Gough, transcript (pm) at page 12.

²¹⁸ Evidence of Denise Gallagher, transcript page 56.

²¹⁹ Evidence of Cameron Gough, transcript at page 145.

²²⁰ See, for example, the evidence of Aneeka Sohrab, transcript at page 47.

²²¹ Evidence of Annemarie Kirkpatrick, transcript at page 46

transfer to the PICU. The PICU crash team, consisting of at least 6 people (doctors, nurses and porters), ran from the PICU in the RHC to Ward 6A carrying a significant amount of equipment. They were exhausted upon reaching Ward 6A, and Mrs Kirkpatrick doubted that they would, physically, be in a position to perform resuscitation if required. There followed a discussion about how to effect the transfer from Ward 6A to PICU and what to do in the event that Stevie-Jo crashed and required resuscitation en route.

167. Initially, the plan was to use the dedicated (adult) patient lifts, but the PICU team's access card did not work on lifts in the QEUH. A decision was then made to use the public lifts which required the entire group, now consisting of around 10 people, to take a public route through the QEUH to reach the RHC. It was thus necessary for the team to discuss and plan what to do in the event of Stevie Jo crashing in a public area. All of this discussion took place in the presence of Mrs Kirkpatrick and Stevie-Jo. Mrs Kirkpatrick observed that the PICU team were frustrated and concerned about the situation. Unsurprisingly, Mrs Kirkpatrick described this as a terrifying experience.

Length of decant to Ward 6A

168. By December 2018, it was clear to patients and families that the decant would be for more than the two months initially indicated. While one witness could understand that the decant to Ward 6A was intended as only a temporary move, he was surprised that more was not done to improve the situation once it became obvious that it would require to provide a longer-term situation²²². As at the date of this submission (3 December 2021), the Inquiry understands that Wards 2A and 2B remain closed and that patients remain in Ward 6A.

²²² Evidence of Cameron Gough, transcript at page 163.

THEME 8: CONCERNS ABOUT ENVIRONMENTAL SAFETY ON WARD 6A

Events in September to December 2018

- 169. In early December 2018, families were made aware that the Schiehallion Unit would remain in Ward 6A for a further year. Some witnesses recalled a briefing to the effect that GGC was "taking the opportunity" provided by Wards 2A and 2B being closed to "upgrade the ventilation" 1223 in those wards. That statement is considered further below in Theme 11. Meanwhile on Ward 6A, concerns about infections continued. Evidence was heard to the effect that preventive medications continued to be prescribed to children from an early stage on Ward 6A²²⁴. Mrs Gallagher recalled a HEPA (high-efficiency particulate absorbing) filter being placed in her son's room on around 4 December 2018 after he became unwell.
- 170. Shortly after this, in December 2018, a patient on Ward 6A died. Some witnesses understood this death to be linked to a Cryptococcus infection²²⁵. Witnesses expressed an understanding that Cryptococcus could be linked to pigeon droppings (a link acknowledged in Ms Grant's letter dated 23 January 2019)²²⁶. On 30 December 2018, Mrs Gallagher's son was admitted with a line infection (Staphylococcus Epidermidis)²²⁷. One witness reported that in December 2018 she saw Rooms 11-13 being closed off in connection either with building works or with the discovery of mould.²²⁸ Another witness recalled being moved rooms as a result of poorly sealed panels within the patient bedrooms giving rise to an infection risk²²⁹.

Events in January 2019

171. The evidence suggests that Ward 6A was under scrutiny during the first half of January 2019. Witnesses provided further evidence of seeing HEPA filters on

²²³ Evidence of Professor John Cuddihy, transcript (26 October 2021 (pm)) at page 18; witness statement of Alfie Rawson at paragraph 57.

²²⁴ Witness statement of Charmaine Lacock at paragraph 177.

²²⁵ See, for example, the witness statement of Professor John Cuddihy at paragraph 117; the witness statement of Charmaine Lacock at paragraph 94.

²²⁶ Letter attached to the witness statement of Colette Gough at CG/04.

²²⁷ Witness statement of Denise Gallagher at paragraph 40.

²²⁸ Witness statement of Charmaine Lacock at paragraphs 94-95.

²²⁹ Excerpts of the witness statement of Witness 4 at paragraph 19.

the ward²³⁰, and of receiving a leaflet about preventive medications (Posaconazole)²³¹. There was a perceived lack of confidence on the part of staff that the decant to Ward 6A had resolved the concern about infections²³². Molly and John Cuddihy recall medical staff advising them that, although Molly had undergone major surgery, she would be safer recuperating at home than in Ward 6A²³³.

- 172. During this period witnesses recalled press coverage in relation to the death of the patient who had contracted Cryptococcus²³⁴. However, communication from GGC did not come until 23 January 2019 when a letter was issued by the Chief Executive of GGC, to parents²³⁵. Mrs Gough recalled that this was the first "formal" letter to be issued to parents on GGC headed paper. The letter begins by acknowledging that parents will already have seen press coverage about "two isolated cases of an unusual infection...and about the ongoing control measures which have resulted in no further cases". Ms Grant apologised for "any anxiety this may have caused". The letter explains that the incident was being actively managed and that the "likely source [was] detected and dealt with immediately". It stated that (unspecified) "additional control measures" had proven effective because there had been no other cases. The letter continues that "During our detailed investigations into these isolated cases, a separate issue was identified regarding shower room sealants issues [sic] that are now being urgently repaired. Whilst this is being repaired some patients have been moved to another ward area".
- 173. Mrs Gough's impression was that this was only written in response to anger from patients about what they had seen on the news. The identification of yet another environmental concern in the shower rooms was not reassuring²³⁶. Mr Gough recalled that the discovery of this further issue brought him close to breaking point. His family could just about cope with cancer, but he felt they

²³⁰ Witness statement of Annemarie Kirkpatrick at paragraph 97; and witness statement of Colette Gough at paragraph 134.

²³¹ Witness statement of David Campbell at paragraph 82.

²³² Witness Statement of Molly Cuddihy at paragraph 124; and of Professor John Cuddihy at paragraph 129.

²³³ Witness statement of Professor John Cuddihy at paragraphs 129 to 131; transcript (26 October 2021 (pm)) at page 38.

²³⁴ Witness statement of Charmaine Lacock at paragraphs 98 and 104,

²³⁵ Letter is attached to the witness statement of Colette Gough at CG/04.

²³⁶ Witness statement of Colette Gough at paragraph 134; transcript at page 161

were being hit on all sides by environmental issues which posed a danger to their son and hampered staff trying to do their jobs²³⁷.

- 174. Evidence suggested that Ward 6A itself was closed and decanted during January 2019 as a result of environmental concerns. Witnesses recalled the ward being moved back to the RHC where inpatients were situated in the Clinical Decisions Unit and day care patients were sent to Ward 1A. This move concerned Professor Cuddihy; it took him back to whatever analysis had been done at the time of the initial move to Ward 6A and his understanding that the appraisal had ruled out the RHC as an unsafe environment for this patient group 238 .
- 175. Mrs Kirkpatrick recalled a meeting with Professor Gibson and a doctor from microbiology to discuss her concerns about the environment on Ward 6A. She was not reassured to be told that her vulnerable daughter was as safe inside the hospital as she was outside it. The following day, Professor Gibson suggested that Stevie-Jo should be transferred to Dumfries and Galloway Royal Infirmary to keep her safe²³⁹.

Events in February and March 2019

Evidence was heard in relation to a number of further infections during this period²⁴⁰. Charmaine Lacock's daughter contracted three infections, a grampositive line infection (Staphylococcus Warneri), a life threatening Pseudomonas infection and then a fungal infection (Candida)²⁴¹. Stevie-Jo Kirkpatrick was diagnosed with Mycobacterium Chelonae²⁴², the second incidence of the extremely rare infection in the paediatric patient group within a year.

²³⁷ Witness statement of Cameron Gough at paragraph 247.

²³⁸ Witness statement of Professor John Cuddihy paragraphs 135 and 136; transcript (26 October 2021 (pm)) at page 44. ²³⁹ Evidence of Annemarie Kirkpatrick, transcript at page 80; witness statement at paragraph 101.

²⁴⁰ Including one infection in the NICU – witness statement of Carol-Anne Baxter at paragraphs 10-11.

²⁴¹ Witness statement of Charmaine Lacock at paragraphs 107 – 114.

²⁴² Although the source of the infection was subsequently traced back to an operating theatre where Stevie-Jo had line removal surgery in January 2019.

Events in April to August 2019

- 177. Infection concerns continued through the summer of 2019. Mr Bisset's daughter attended Ward 6A as an outpatient for two days on 10 and 11 June 2019. She was admitted to the Royal Hospital for Sick Children in Edinburgh with an infection (Putida Pseudomonas) on 12 June 2019²⁴³. Mr Bisset's daughter went on to develop two life threatening infections, Adenovirus and Aspergillus, while she was a bone marrow transplant patient in Ward 4B. She was admitted to the PICU for a number of weeks.
- 178. There is evidence of a further outbreak of infections in August 2019. Ms Ferguson recalled a meeting being called to discuss these infections²⁴⁴. She also recalled being provided with a letter indicating there were two different infections on Ward 6A but that they were not linked to the environment²⁴⁵. Evidence indicates that at around this time, Ward 6A was closed to newly diagnosed patients and infusional chemotherapy patients²⁴⁶.

Events between September 2019 and November 2020

- 179. Evidence was heard of a further serious fungal issue on Ward 6A²⁴⁷. A long-term leak was discovered in the staff kitchen which caused a significant build-up of mould. In November 2019, Molly Cuddihy developed a type of fungal pneumonia (PCP pneumonia) which Ms Cuddihy's consultant suspected she developed because she was not on the antifungal prophylaxis being prescribed to other patients²⁴⁸.
- 180. At a meeting among parents, hospital management and GGC representatives, parents were informed that the hospital water supply was "wholesome" 249. This explanation did not satisfy some parents who questioned why their children

²⁴³ Witness statement of Mark Bisset at paragraph 103.

²⁴⁴ Witness statement of Sharon Ferguson at paragraph 87.

²⁴⁵ Witness statement of Sharon Ferguson at paragraph 124.

²⁴⁶ Letter from Kevin Hill to parents dated 12 November 2019 and posted to Closed Facebook Group, see witness statement of Mark Bisset at page 55A.

²⁴⁷ Witness statement of Professor John Cuddihy at paragraphs 176 and 248; transcript (26 October 2021 (pm)) at page 41.

²⁴⁸ Witness statement of Molly Cuddihy at paragraph 136.

²⁴⁹ See, for example, the evidence of Karen Stirrat, Alfie Rawson and Colette Gough.

were still on preventative medications²⁵⁰. Karen Stirrat recalled being informed by her son's consultant that, although the tap water was safe, environmental concerns remained.

- 181. On 12 November 2019, a letter from Kevin Hill to parents was published on the Closed Facebook Group²⁵¹. This indicated that environmental test results from Ward 6A were "satisfactory" and that the water supply was "safe and effective".
- 182. Concerns about the environment persisted. On 18 November 2019, Ms Ferguson was informed that her son had contracted Acinetobacter²⁵². In January 2020, Molly Cuddihy was advised by nurses to push for admission to Ward 4B over Ward 6A for her stem cell transplant on the basis that it had better ventilation²⁵³. In November 2020, Aneeka Sohrab's daughter contracted a pseudomonas infection²⁵⁴.

THEME 9: IMPACTS OF ENVIRONMENTAL CONCERNS ON WARD 6A

- 183. The evidence indicated that the impacts on patients and families of the environmental concerns on Ward 6A were of a similar nature to those described in relation to Ward 2A (Theme 5). They are not repeated in detail here. The consequences of infection concerns are considered in Theme 10.
- 184. At a practical level witnesses recalled building works and room cleaning leading to capacity issues. This led to displacement to other Wards where patients and families experienced the consequences of the absence of the "Schiehallion Umbrella" Witnesses perceived that the use of source isolation was prevalent on Ward 6A.
- 185. Families experienced disruption caused by the closure of Ward 6A in January 2019. The consequences for newly diagnosed patients who could not access the Schiehallion Unit in the autumn of 2019 are presently unknown.

²⁵⁰ Witness statement of Karen Stirrat at paragraphs 129 – 132.

²⁵¹ Contained at Appendix 2 of Mark Bisset's witness statement at page 55A.

²⁵² Witness statement of Sharon Ferguson at paragraph 125.

²⁵³ Evidence of Molly Cuddihy, transcript (pm) at page 41; witness statement at paragraph 140.

²⁵⁴ Evidence of Aneeka Sohrab, transcript at page 89.

²⁵⁵ See, for example, the evidence of Cameron Gough, transcript at page 86.

- 186. What little communication there was in relation to the environmental issues did not reassure patients and families. Witness were understandably doubtful of reassurances. They had been assured that Ward 6A would be a safer environment than Ward 2A for their children, an assurance contradicted by their experiences. As discussed below, the continued disconnect between communication and experience further fractured trust between witnesses and hospital management. It also strained relationships between parents and clinical staff who could not provide the answers they sought²⁵⁶.
- 187. Overall, the impression was of an increasingly fraught and anxious situation which brought some parents close to breaking point.

THEME 10: HEALTHCARE ASSOCIATED INFECTIONS

Introduction

- 188. The Inquiry's Terms of Reference take in the whole history of the hospital: from initial concept through to present day condition. One thing narrows what would otherwise have been an exceptionally broad investigation. At all points, the Inquiry's remit is to focus its examination on those issues that had, or have, the potential to impact adversely upon patients and families.
- 189. Term of Reference 8 provides emphasis to one impact in particular: infection. This is as it should be. Infection and its perceived link to the hospital environment was, by some way, the most serious concern identified in the patient and family evidence. The concerns raised went further than simply drawing attention to the serious consequences of such an infection (the Term of Reference 8 question). The evidence given also raised questions about the reporting of as well as the possible failure to report properly healthcare associated infections, thus engaging Terms of Reference 4 and 9.
- 190. It is proposed to consider the question of infection under reference to the following matters: (i) the incidence of infection where there are said to be

²⁵⁶ See, for example, the evidence of Charmaine Lacock who recalled difficult discussions with clinical staff but acknowledged that her anger was borne of frustration at the lack of communication from hospital management.

suspected links to the hospital environment; (ii) the direct impacts caused by infection; (iii) secondary impacts; and (iv) preventative medications.

The incidence of infection and suspected links to the hospital environment

- 191. It is again to be emphasised that, at this stage, the Inquiry seeks only to understand the nature of the concerns identified by witnesses. In relation to these concerns, it is neither appropriate nor possible to venture conclusions without Core Participants being given the opportunity for comment and without further investigations being made. Accordingly in what follows, the intention is once more simply to set out witness perceptions.
- 192. But two things should be noticed about these perceptions. The first is the sheer volume of evidence on this subject provided by witnesses. Appendix 3 to this submission lists families from the present group of witnesses who raised a concern about the impact of an infection or infections upon their child. A perceived link (or the possibility of a link) between an infection and the hospital environment was raised in the case of some 25 patients.
- 193. It is further to be recalled that this cohort may simply be a subset of a wider body of evidence. Reference is made in particular to the CNR. It identified some 84 children as having been affected by (a total of 118 episodes of) infection. In the case of 76 of those episodes, the CNR was satisfied there was at least a possible link to the built environment. Of that number, the CNR considered that in the case of 37 episodes the infection was "most likely" linked to the hospital environment.
- 194. However, witnesses to the Inquiry identified two matters that indicate that these findings by the CNR must also be put in their proper context; that they are not to be taken as setting out a concluded position on the full extent of environmentally linked infection in RHC and QEUH since the opening of the hospital. First, as alluded to in evidence, the CNR's remit was limited (to paediatric patients who experienced (mainly) gram negative bacterial infections during a particular timescale) ²⁵⁷. Second, the CNR team identified a number of

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²⁵⁷ See, for example, the witness statement of Aneeka Sohrab at paragraph 59.

significant data gaps in the information provided by GGC. Professor Cuddihy provided evidence that touched on this²⁵⁸. These data gaps appear to have hampered the work of the CNR. They say that it left the team "unable to interpret the true extent of relatedness between patient and environmental isolates"²⁵⁹.

- 195. The second point to be made is as follows. No medical evidence was led in relation to any of the infection incidents referred to in evidence. Witnesses spoke with varying degrees of knowledge and certainty about infections they understood to have been experienced. At one end of the spectrum are those who <u>suspect</u> an infection and <u>suspect</u> a link to the hospital. But at the other end are those who say they were advised by GGC at the time or were subsequently apprised by the CNR that their child had indeed suffered an infection and that to some extent the infection was linked to the hospital environment.
- 196. Witnesses reported a range of infections. Reference was made to gram negative and gram positive bacterial infections, fungal infections, and viral infections. A significant proportion of the evidence related to "line infections" which were understood to be infections in the blood contracted via Hickman Infections reportedly associated with Hickman lines included lines. Pseudomonas. Stenotrophomonas, Enterobacter Cloacae. Serratia Marcescens, Staphylococcus and Mycobacterium Chelonae. Other types of infections were also reported including infections such as Aspergillus, Cryptococcus, Pneumonia, PVL-MSSA and viral infections such as Adenovirus and RSV.
- 197. The evidence indicates that, even where the source of an infection has not been confirmed, many parents strongly suspect a link to the hospital environment. Some witnesses recalled contemporaneously suspecting such a link based on what they had witnessed and experienced within the hospital. Reference was made, for example, to an understanding of higher than normal rates of line infection²⁶⁰. Other witnesses formed suspicions with hindsight based on what

²⁵⁸ Witness statement of Professor John Cuddihy at paragraphs 298-303; and the similar concerns raised by Mr and Mrs Gough.

²⁵⁹ QEUH and RHC Case Note Review Overview Report, March 2021, at page 7.

²⁶⁰ See, for example, the witness statement of Annemarie Kirkpatrick at paragraph 32.

they saw in the media, heard from others, or saw in formal reports²⁶¹. Where suspicions exist, most relate to the water supply, the drains or the ventilation system.

198. Beyond those cases where a link was only suspected, the evidence suggested a substantial number of cases where witnesses understood a link actually to have been established. Reference was made to three infection "outbreaks" 262 on Ward 2A during 2018 and at least one on Ward 6A during 2019. The evidence also indicated a number of individual cases where staff were understood to have advised patients and families that a link between the hospital environment and the infection in question had been established. The following formed that understanding from what they were told by medical staff: Molly Cuddihy, Mr and Mrs Gough, Stevie-Jo Kirkpatrick, Denise Gallagher and one witness who gave evidence in a closed session. Some of these had their understanding confirmed by the CNR. An additional group say that it was only upon receiving their individualised reports from the CNR that they learned for the first time of the possibility of a link of some kind between infection and environment: Kimberly Darroch, Charmaine Lacock and Alfie Rawson, Witness 1, Aneeka Sohrab, Louise Cunningham, Mark Bisset, Haley Winter, Rachel Noon Crossan and Sharon Ferguson.

Other perceived infection risks

199. It may be important to note that witnesses provided evidence of a range of issues which they perceived might pose a risk of infection but which were not linked directly to the built environment. Consideration of these matters could, in due course, be significant when it comes to assessing the strength or otherwise of suggested connections (or at least direct connections) between the built environment and infection risk. Reference is made in particular to evidence about cleanliness in the hospital.

²⁶¹ See, for example, the witness statement of Kimberly Darroch at paragraph 94.

²⁶² However, that might be defined by GGC or others.

- 200. Complaints about the cleanliness of the floors in Ward 2A were commonplace²⁶³. Although some witnesses reported that cleaning in Ward 2A was "gold standard", others felt that it was not sufficiently thorough²⁶⁴. Dust was reported to accumulate in inaccessible places as a result of the design of the building²⁶⁵. Although the bulk of the evidence was of good hygiene practices on Ward 2A, some concerns about handwashing were reported²⁶⁶. Particular concerns were raised about areas outwith the Schiehallion Unit. Other wards were felt to be less stringent about cleanliness and hygiene. On Ward 3, brown matter was observed on a bed frame²⁶⁷. Pigeon droppings were observed at the hospital entrance and in corridors within the building itself²⁶⁸.
- 201. Other infection risk concerns were raised in relation to routes taken by immunocompromised children within the RHC and QEUH²⁶⁹. Risks were perceived in relation to Schiehallion patients mixing with other children when in the RHC clinic space and when they had to travel through the adult hospital to reach Ward 6A. There were also consistent concerns raised about the route taken by day care patients through Ward 6A. Parents were informed of an infection risk posed by cladding works at the RHC entrance.
- 202. There is at this stage no evidence of the relative contribution, if any, of these concerns to the infection risks posed by the key building systems.

The direct impact of infection

203. The often devastating effect of infections on patients and families, whatever their cause, is indisputable. Reference should be made to the witness statements and transcripts to understand this fully. Evidence was heard in relation to the life-threatening nature of infections on this vulnerable patient group. Families witnessed children suffering and rendered seriously ill by

 $^{^{263}}$ See, for example, the evidence of Witnesses 1 and 2 who reported having to clean the floors with wipes $\underline{\text{after}}$ cleaners had been in.

²⁶⁴ Witness statement of Steven Kirkpatrick at paragraph 61.

²⁶⁵ Witness statement of Annemarie Kirkpatrick at paragraph 131.

²⁶⁶ Excerpts of the witness statement of Witness 2 at paragraph 13.

²⁶⁷ Evidence of Colette Gough, transcript at page 82

²⁶⁸ Witness statement of Carol-Anne Baxter at paragraph 37.

²⁶⁹ See, for example, the evidence of Professor John Cuddihy, David Campbell, Annemarie Kirkpatrick and Colette and Cameron Gough.

infection; a number of others suspect that infection led to or at least contributed to the death of a loved one.

- 204. That infections pose a life-threatening risk cannot be in doubt. Mr and Mrs Gough provided evidence of the effect of a line infection on their son who, within the space of 48 hours, suffered two near death experiences. Mr Bisset's daughter was close to death on five separate occasions while in the PICU suffering from infections. On each occasion, her family was summoned to say their goodbyes and on one occasion, Mr Bisset was presented with the unimaginable prospect of having to decide whether to turn off his daughter's life support machine.
- 205. The trauma, emotional as well as physical, of a serious infection incident is unquestionable. A number of parents and both patient witnesses vividly described this. Parents spoke of the horror of witnessing 'rigor' followed by the rapid deterioration of their child's condition. Some described fearfulness among the care team, as they witnessed doctors and nurses "taken to the threshold of their abilities" 270 by their efforts to save patients affected by infections 271. Unsurprisingly, witnesses described being haunted by these events even years afterwards 272.
- 206. Quite apart from these resonating emotional traumas, patients can be left with long lasting physical impacts from the infections themselves. Stevie-Jo Kirkpatrick, for example, had been left with permanent scarring from a Mycobacterium Chelonae infection. The infection remains in her system and although it is currently dormant could recur²⁷³.

Secondary impacts

207. The evidence disclosed a range of secondary impacts resulting from infections, some of which were themselves life-threatening. Two secondary impacts

²⁷⁰ Evidence of John Cuddihy, transcript (26 October 2021 (am)) at page 59.

²⁷¹ For example, the evidence of Cameron and Colette Gough, Professor John Cuddihy, Mark Bisset, Annemarie Kirkpatrick to name only a few.

²⁷² See, for example, the evidence of Colette Gough and Annemarie Kirkpatrick.

²⁷³ Evidence of Stevie-Jo Kirkpatrick, transcript at page 29.

predominated: interruption to cancer treatment and the impact of treating the infection itself.

- 208. A number of witnesses described the conflict between continuing with the administration of chemotherapy, which lowers the body's immune response, and commencing the treatment of infection which depends on a strong immune response bolstered by antibiotics. This dilemma was often resolved in favour of suspending cancer treatment, resulting in delay, or even complete loss, of chemotherapy treatment in a number of cases²⁷⁴. Stevie-Jo Kirkpatrick faced an acute example of this difficult balancing act. She was advised by her clinical team that her best hope of combatting a rare infection²⁷⁵ was to stop chemotherapy and to allow her body's immune system to tackle it. Between the effects of the infection itself and the early cessation of chemotherapy, Ms Kirkpatrick lost many months of her planned chemotherapy treatment.
- 209. The cancer treatment of patients has been affected in other ways. Molly Cuddihy had life-saving surgery postponed twice, for a total of six months, as a result of the same rare infection. Her chemotherapy plan was altered. The impact did not stop there. The prescription of extremely strong antibiotics to treat the infection affected her heart and kidney function. When her cancer returned, her treatment options were limited as a result²⁷⁶.
- 210. Infections frequently resulted in additional surgeries. Removal of a Hickman line required two surgeries under general anaesthetic to remove and then replace the line. In the interim, patients faced the distressing prospect of treatment and testing by cannula. Mr and Mrs Gallagher's son endured the unnecessary removal of his appendix as an indirect result of a Stenotrophomonas infection (which the CNR, apparently, confirmed was probably linked to the hospital environment). The appendix was suspected as being the cause of abdominal pain. Only after an appendectomy was an infection confirmed. Mr and Mrs Gallagher's son had to undergo two further surgeries to remove and then replace his line.

²⁷⁴ See, for example, the evidence of Stevie-Jo Kirkpatrick, Molly Cuddihy, Witness 1, Senga Crighton and Leann Young to name but a few.

²⁷⁵ Mycobacterium Chelonae.

²⁷⁶ Evidence of Molly Cuddihy, transcript (pm) at page 35.

- 211. Overall, it is clear that line infections had the potential to impact seriously on quality of life for young patients. For those patients whose lives were curtailed by cancer, the impact of multiple infections, multiple surgeries, and prolonged time in hospital is obvious.
- 212. The effects of infections extended beyond these detriments to physical health. Patients and families had their time in hospital prolonged, sometimes by months²⁷⁷. This brought with it further effects on the lives of all involved (for the reasons outlined in Theme 1). Particular concerns were noted about the impact on teenage patients at a critical time of their education²⁷⁸.

Preventative medications

- 213. A recurrent concern among patients and families in their evidence was the provision of preventative medications (understood to be preventative antibiotics and anti-fungals). While the evidence suggested that prophylactic medication can sometimes be a feature of standard chemotherapy protocols, a consistent body of evidence indicates that, in the RHC and QEUH, patients were provided with preventative medications to protect them from perceived potential risks associated with the hospital environment²⁷⁹. The medications most frequently mentioned in this respect were Ciprofloxacin and Posaconazole. Others were also mentioned²⁸⁰, but in some cases witnesses were not certain whether these medications formed part of existing treatment plans.
- 214. A number of witnesses suspected that these medications had physical side effects although most acknowledged that their suspicions had not yet been confirmed. Gastrointestinal concerns were most frequently reported²⁸¹. Ms Ferguson perceived that her son suffered significant hearing loss²⁸². Parents were concerned about the possibility of long-term side effects from what they understood to be powerful drugs.

²⁷⁷ See, for example, the evidence of Molly Cuddihy.

²⁷⁸ Evidence of Stevie-Jo Kirkpatrick and Molly Cuddihy.

²⁷⁹ See, for example, the evidence of Professor John Cuddihy, Sharon Ferguson, Denise Gallagher, Karen Stirrat and Leann Young, all of whom recalled discussions with consultants about the use of medications to protect patients against the risk of infection from the environment.

²⁸⁰ For example, Ambisome, Caspofungin and Septrin.

²⁸¹ See, for example, the evidence of Aneeka Sohrab and Leann Young.

²⁸² Evidence of Sharon Ferguson, transcript at page 59.

Communication about infections and preventative medications

- 215. If accurate, the evidence to the Inquiry would suggest that the hospital took a fairly varying approach to communication with patients about infection. Individual witnesses spoke of being called to meetings with consultants, microbiologists and sometimes Mr Redfern to be informed of a link between their child's infection and the hospital environment²⁸³, or that the specific source had been identified through sampling²⁸⁴. Other witnesses recalled being informed of the name of the infection contracted by their child but not of its likely source²⁸⁵. Some recalled being informed by hospital staff that their child had an infection (frequently a "line infection") but could not recall being told the name of the infection²⁸⁶ or given any indication of its likely source. Some went further and said that they detected a reluctance on the part of clinical staff to comment on the likely source of an infection²⁸⁷. Witnesses spoke to discovering the names of infections from medical records and from reports issued by the CNR.
- 216. The overall tenor of the evidence suggests that where parents were not informed of the name of an infection, its nature or its possible source (environmental or otherwise), this bred suspicion, anxiety and distrust. These feelings escalated as concerns about the hospital environment developed thorough 2018 and 2019. Parents saw alarming press reports and carried out their own research on the internet. In the absence of information from the hospital, they reached their own conclusions²⁸⁸. Conversely, some witnesses who had not had contact with the hospital for years, and who had no cause to suspect an infection linked to the hospital, recalled the distress of receiving an CNR report raising the possibility of such a link²⁸⁹.

²⁸³ See, for example, the evidence of Mr and Mrs Gough, Mr and Mrs Gallagher, the Kirkpatrick family, Molly and John Cuddihy.

²⁸⁴ See, for example, the evidence of Annemarie Kirkpatrick, transcript at page 80.

²⁸⁵ See, for example, the witness statement of Kimberly Darroch at paragraph 75, and the evidence of Charmaine Lacock, Sharon Ferguson and Mark Bisset.

²⁸⁶ See, for example, the evidence of Leann Young, Sharon Ferguson, Aneeka Sohrab, Louise Cunningham and Haley Winter.

²⁸⁷ See, for example, the witness statement of Charmaine Lacock at paragraph 111.

²⁸⁸ See, as an example, the evidence of witness statement of Kimberly Darroch, Christine Horne and Derek Horne.

²⁸⁹ Evidence of Louise Cunningham, transcript at page 68; witness statement at paragraph 82.

- 217. Some witnesses reported additional frustration that the hospital had not done more to investigate the source of their child's infection. As already mentioned, they perceived failure, bolstered by the findings of the CNR, to carry out adequate sampling²⁹⁰. In two cases, the parents of a baby who died described being informed of the presence of an infection only after receipt of the results of a post-mortem report²⁹¹. Even then, one family say that they perceived a reluctance on the part of GGC to investigate the cause of the infection and to communicate with them about it. They say that they felt that they were, and continue to be, 'stonewalled'²⁹².
- 218. A lack of co-ordinated communication about infections and infection risk from GGC was consistently perceived. It was said to be increasingly obvious to witnesses throughout 2018 and into 2019 that there was a persisting issue around infection. Yet, they could recall no clear overall acknowledgement of the situation by GGC. Instead, the sparse communication parents spoke to having received was said to be either devoid of reference to infection events or made only tangential reference to the vulnerability of the patient group to infection.
- 219. There was a similar flavour to the evidence about communication relating to preventative medications. Overall, the concerns related to a lack of transparency about the rationale for prescription of these medications and of their potential risks. Some witnesses formed the impression that preventative medications were part of their child's treatment for cancer. Others recalled vague reference to "protection from water" or "protection from the environment". On the whole, witnesses did not recall being fully informed of the purpose of prophylactic medication or its potential side effects²⁹³.
- 220. Some witnesses indicated agreement, in hindsight, with the rationale behind the prescription of preventative medications: the protection of their child from risks present in the environment²⁹⁴. These witnesses separated concerns about

²⁹⁰ Evidence of Colette Gough and Professor John Cuddihy.

²⁹¹ Evidence of Theresa and Matthew Smith and of Carol-Anne Baxter.

²⁹² Witness statement of Theresa Smith at paragraph 127.

²⁹³ See, for example, the evidence of Charmaine Lacock, transcript at page 75; evidence of David Campbell, transcript at page 67.

²⁹⁴ See, for example, the evidence of Denise Gallagher, transcript at page 45; evidence of David Campbell at page 69.

the existence of those environmental risks and the steps taken by clinicians to mitigate against them. Ms Lacock recalled her alarm on discovering the nature of Posaconazole on the internet. She understood it to be a powerful medication usually prescribed for only short periods at a time. However, even with that understanding, Ms Lacock said that had the reasons for its prescription and its risks been explained clearly at the outset, she would probably not have objected to it²⁹⁵.

221. It should be recorded that there was also evidence of families being informed about the use of preventative medications for reasons linked to the environment. Some witnesses recall being informed in March 2018 by clinical staff that immunocompromised children were being prescribed medication to "protect them from the water" 296. Similar communications were reported in May 2018 and June 2018 about medications to protect children from "the environment" 297. Reports of similar communications continued through 2019. 298 What appears to have been considered lacking from those communications was a full explanation of the nature of the environmental issues 299. It was that perceived lack of transparency which led to suspicion and distrust.

THEME 11: COMMUNICATION

<u>Introduction</u>

222. Communication is relevant to a number of the Inquiry's Terms of Reference. It is referred to expressly in Term of Reference 8 in the context of patients' and families' rights to be informed and to participate in matters bearing on treatment. Evidence provided by patients and families about communication may also bear upon Terms of Reference 4, 5, 6 and 9.

²⁹⁵ Evidence of Charmaine Lacock, transcript at page 78.

²⁹⁶ See, for example the witness statements of Sharon Ferguson at paragraph 63; and Lynn Kearns at paragraph 54.

²⁹⁷ Witness statement of Denise Gallagher at paragraph 70; witness statement of Leann Young at paragraphs 24 and 75.

²⁹⁸ David Campbell recalls a leaflet being produced in January 2019 (witness statement at paragraph 82); witness statement of Karen Stirrat at paragraph 113. Ms Stirrat recalled that parents were called to a meeting and provided with a leaflet relating to preventative medication.

²⁹⁹ Witness statement of Denise Gallagher at paragraph 70.

- 223. Theme 1 of this submission emphasised the importance to patients and families of being able to trust in the clinical and care team and in the hospital environment. It is self-evident that communication is the bedrock of that relationship of trust. This was repeatedly laid bare or spoken to by parents in their evidence³⁰⁰. Parents explained how effective and transparent communication helped them, if not completely anticipate, then at least try to manage what was an inherently uncertain, traumatic and prolonged experience. Each patient who gave evidence explained this too. As one of them demonstrated so powerfully, even when things went badly wrong effective communication was still possible and remained key to preserving trust³⁰¹.
- 224. Accordingly, communication is an important issue for the Inquiry, not just in its own right as an issue expressly raised by the Terms of Reference, but also as an indicator and possible cause of adverse impacts.
- 225. Unfortunately, concerns relating to communication were a consistent theme of the evidence. Predominately, these related to the hospital environment, healthcare associated infections and preventative medications. Although much of this has been touched on already, Theme 11 attempts to pull the evidence together in the hope of explaining its importance and identifying where input from Core Participants may be of assistance.

Patient and family perception of clinical communication

226. The Inquiry has not yet had the benefit of hearing from the clinical staff whose responsibility on any given day it may be to tell parents that their child has cancer. But the Inquiry has heard enough to understand that those initial difficult exchanges simply presage a series of further difficult discussions. It is obvious that providing accurate information tailored, both in content and in tone, to the individual must be an exceptionally difficult task. It is equally obvious that, as lives hang in the balance, clinicians and nurses do not have the luxury of time in choosing their words. Nor is it to be assumed that all patients and families

³⁰⁰ As did Molly Cuddihy, a patient herself.

³⁰¹ Evidence of Professor John Cuddihy and Molly Cuddihy.

will have the same capacity to understand; or that they will meekly nod and listen. A number of witnesses candidly accepted that they had been prepared to ruffle feathers where they felt protecting their children required that.

227. And yet, almost without exception, most witnesses praised the communication they received from doctors and nurses about cancer treatment³⁰². Bad news – even admissions of things having gone badly wrong – were capable of being communicated without undermining the relationship of trust. It is possible the Inquiry will find useful guidance in that evidence, when it comes to assess what GGC chose to say about the issues facing the hospital and their impact upon patient safety and care.

The different features of successful communication

228. Professor Cuddihy identified a number of the considerations that will be important to consideration of the way in which the hospital communicated with patients³⁰³. He placed particular emphasis upon the corporate duty of candour (i.e. the duty on GGC not simply that on individuals). In due course, the Inquiry will consider in more detail that duty as well as the other obligations upon clinical staff in relation to communication. In the meantime, it may be of assistance to set out the issues that were identified in the evidence.

Patient and family concern about communication on the part of GGC

Communication about the environment

229. It is important to emphasise one thing at the outset. Information about the hospital environment was viewed as no less critical by witnesses than information about treatment. In a very real sense, communication about the hospital environment was just one aspect of clinical communication³⁰⁴.

³⁰² See, for example, the evidence of Colette and Cameron Gough and of Professor John Cuddihy.

³⁰³ Evidence of Professor John Cuddihy, transcript (27 October 2021 (pm)) at page 33. The questions being: (i) who do we need to communicate to; (ii) what information do we need to communicate; (iii) why do we need to communicate it; and (iv) by what means do we communicate it?

³⁰⁴ See, for example, the evidence of Molly Cuddihy, transcript (pm) at page 48.

230. Notwithstanding its importance, and notwithstanding the obvious questions that arose, communication about the environment was described by a remarkable number of witnesses as 'non-existent'³⁰⁵, and as contrasting sharply with communication about treatment. Witnesses did not consider that the approach to communication was patient centred when it came to the building. It may be helpful to examine that criticism under reference to three questions: who was the messenger; to whom was the message conveyed; what did the message say?

Who was the messenger?

- 231. The perception of many witnesses was that the job of providing information about the building had been devolved to clinical staff. Professor Cuddihy considered that GGC and/or the hospital managers appeared to have given the responsibility for communication and crisis management to the Incident Management Team tasked with investigating infections³⁰⁶.
- 232. While some frustration was directed to the quality of communication by clinical staff about the building, witnesses were, in the main, of the view that it was not the job of nursing and clinical staff to explain what was going on with the hospital. Most witnesses viewed that obligation as sitting with the hospital management team and with GGC³⁰⁷. Many witnesses considered that in any event staff on the wards simply did not possess the necessary information. Others were concerned that staff knew something but were not permitted to relay that information to them³⁰⁸.
- 233. Overall, whilst it was acknowledged that the selection of the appropriate conduit for communication might be a nuanced issue, the perception was of a complete lack of a communication strategy on the part of management and GGC³⁰⁹.

³⁰⁵ See, for example, the evidence of Charmaine Lacock, transcript at page 101.

³⁰⁶ Evidence of Professor John Cuddihy (26 October 2021 (am)) at page 79; witness statement at para 337.

³⁰⁷ References to the Health Board and to 'management' were used interchangeably by some witnesses.

³⁰⁸ Witness statement of Denise Gallagher at paragraph 98.

³⁰⁹ Evidence of Professor John Cuddihy, transcript (27 October 2021 (pm)) at page 34.

To whom was the message communicated?

- 234. The evidence of patients and families indicates a perception that communication with them was not the priority of GGC; the media appeared to them to be the first port of call. This is perhaps best illustrated by GGC's communication at two crisis points: the closure of Wards 2A and 2B and the first closure of Ward 6A. According to the evidence, the press were aware of the closure of Wards 2A and 2B before patients and families using those facilities. The letter dated 23 January 2019³¹⁰ from the Chief Executive assumed that parents would already be aware of events on Ward 6A from the press. The letter was perceived to have been issued in response to press coverage and was not seen as being a proactive attempt to keep parents informed³¹¹.
- 235. Some witnesses recalled occasional meetings between parents and management³¹² or Infection Control doctors. Otherwise, the evidence suggests that in person meetings were on an individual basis when requested by parents³¹³ who wished to discuss specific concerns. This was perceived to lead to an imbalance in the level of information provided to individual parents³¹⁴. One witness recalled that during the period of extreme anxiety on Ward 6A in January 2019, she called for an open meeting with GGC, rather than with the clinical team. The request was refused³¹⁵.
- 236. While no conclusion is suggested at this point, there is no denying that the overall impression created by the witness evidence was of a piecemeal and reactive approach. In the eyes of witnesses this resulted in the means of communication in relation to concerns about key systems including fundamental questions such as whether it was safe to drink the water depending on *ad hoc* and contradictory messages from clinical staff, from

³¹⁰ See Witness Statement of Colette Gough at CG/04.

³¹¹ Evidence of Colette Gough, transcript (pm) at page 22.

³¹² For example, the meeting with Mr Redfern about the closure of Wards 2A and 2B (Molly Cuddihy), a meeting to discuss infection control procedures (Aneeka Sohrab) and a meeting to discuss the use of preventative medications in August 2019 (Karen Stirrat).

³¹³ For example, evidence of Denise Gallagher, transcript page 70; and the evidence from Professor Cuddihy relating to meetings he requested during 2018 and 2019.

³¹⁴ Evidence of Aneeka Sohrab, transcript at page 82.

³¹⁵ Evidence of Charmaine Lacock, transcript at page 73.

random and uninformative written communications³¹⁶ and from stories in the media.

What was communicated?

- 237. The perception of witnesses was that what little information was provided to them was not transparent and did not align with what they were experiencing. Reference might be made to the "Ward 2A and 2B Update" note dated 18 September 2018 and to the letter to Professor Cuddihy about the falling "glass panel". It was evident that witnesses considered that there was more than a hint of something self-serving in the approach of GGC and the hospital managers.
- 238. In contrast to the position taken by clinical staff, there appeared to be a reluctance by GGC and the hospital management team to convey bad news or even uncertainty. No doubt, there will be evidence to be heard about the balance to be struck between providing a candid account and not unnecessarily alarming or undermining confidence. But the resilience of patients and families is not to be underestimated. Ms Lacock explained that, although she would not have been happy to learn of a problem with the water supply, she would have understood the dangers faced by her daughter and felt empowered to mitigate risk³¹⁷. Mr Gallagher expressed a similar sentiment: early, transparent communication with parents could have maintained trust³¹⁸.
- 239. Evidence was heard about the perceived inaccuracy of information communicated by GGC and hospital management. Some witnesses alleged dishonesty on the part of staff. It seems likely that not everyone who made this allegation really intended to suggest that clinical staff in particular deliberately or recklessly told untruths. Such allegations are unsurprising response where parents are angry and frustrated that the explanation from staff does not square with the concerns patients are seeing with their own eyes.

³¹⁶ Examples are attached to the witness statement of Colette Gough.

³¹⁷ Evidence of Charmaine Lacock, transcript at page 78.

³¹⁸ Evidence of James Gallagher, transcript at page 54.

- 240. But allegations of lack of candour by hospital managers and GGC cannot be dismissed so easily. During his evidence, Professor Cuddihy was pressed to explain why he was unable to accept that what he perceived to be inaccurate and uncandid messaging from GGC was at least provided in good faith. He was asked whether one explanation may have been that the Board had not known what to say given that they might have perceived themselves to have been dealt a terrible hand of cards by the contractors; he was asked whether he considered that a desire not to alarm patients might have provided an explanation for some of the communication deficiency he perceived. He said he was presently unable to accept these explanations³¹⁹.
- 241. Once again, the limit of this submission is to be emphasised. No view on the correctness of what Professor Cuddihy said can properly be offered at this point; indeed, he said himself that he would like nothing better than to be proved wrong. But one thing can be said: there is a proper basis for the question he raises; and he, and others, are correct that a clear explanation for the way in which GGC told patients the story of the hospital is called for.
- 242. Four factors in particular suggest that the question about a lack of candour is responsibly raised. First, there is the sheer amount of reported inconsistency between, on the one hand, the commentary provided to the media and to patients and, on the other, the reality of what patients describe as having actually witnessed and experienced. Secondly, the reported tendency to put a positive spin on events might risk creating the impression that a self-serving approach to communication was indeed being taken. Thirdly, Professor Cuddihy described a serious incident during which he understood a clinician to acknowledge that she had been instructed to lie to him. He understood this to have been compounded by an inaccurate entry to an IMT minute. This incident appeared to be followed, on Professor Cuddihy's account, by a less than fulsome attempt by GGC to get to the bottom of what he had alleged. That was notwithstanding his having escalated his concern to the very top of the GGC

³¹⁹ Evidence of Professor John Cuddihy, transcript (27 October 2021 (pm)) at page 35.

management structure. The events in question are detailed in Professor Cuddihy's witness statement³²⁰ beginning at paragraph 340.

GGC's awareness of issues affecting water and ventilation

- 243. Professor Cuddihy and Mr Rawson provided the Inquiry with information about a fourth factor that might be thought to point towards it being reasonable for patients to ask whether GGC deliberately chose to tell patients less than they knew. As mentioned earlier, in March to July 2018, GGC and the Scottish Ministers provided assurances about the situation in the hospital³²¹. Professor Cuddihy and Mr Rawson (and indeed others) subsequently learned of evidence, the existence of which, is said to call into question the accuracy of these assurances.
- 244. Professor Cuddihy referred to three water safety reports prepared on behalf of GGC by DMA Canyon Ltd in 2015, 2017 and 2018. On his reading of these reports, DMA Canyon Ltd identified serious concerns about the safety of the water supply in 2015³²² (the "2015 Report") and made recommendations about steps which should be taken by GGC to address those risks. In its 2017 report, DMA Canyon Ltd recorded concerns that its recommendations had not been implemented and about the management of the water supply generally.
- 245. Once again, this submission offers no concluded view on any of this. Examination of what GGC actually knew, and the implications of the DMA Canyon Ltd reports, are for later. But, as was discussed during the evidence, this issue has already been considered by the Oversight Board. That discussion suggests that the 2015 report, although provided to staff within Estates and Facilities, was subsequently "lost". It is not apparent from the evidence just heard what that term is to be understood as meaning. In that context, Professor Cuddihy drew attention to his understanding that the 2015 report had been the

³²⁰ Witness statement of Professor John Cuddihy at paragraph 340; evidence, transcript (26 October (pm)) at page 56.

³²¹ Evidence of Professor John Cuddihy, transcript (26 October 2021 (am)) at page 47.

³²² Summarised at paragraphs 99 and 100 of the witness statement of Professor John Cuddihy; transcript (26 October 2021 (am)) at page 8.

subject of email correspondence among Estates and Facilities, the Microbiology Department and the Water Safety Group in mid-2015.

- 246. Nor did Professor Cuddihy suggest that he was able to explain what the reference in the Oversight Board report to the 2015 report having "surfaced" in March 2018 was intended to convey. He broadly understood this to refer to its emergence in the context of a review carried out by Health Protection Scotland³²³. Through his involvement on the Oversight Board, he understood that in March 2018 GGC conducted an internal investigation as to why the 2015 report was not actioned. The outcome of that investigation is not known. In July 2018, GGC are said to have made an action plan to address DMA Canyon Ltd's recommendations, although to Professor Cuddihy's knowledge that action plan has yet to be completed. Professor Cuddihy perceives this sequence of events to be at odds with GGC's communication about the water supply during 2018 and 2019³²⁴.
- Mr Rawson identified a similar issue in relation to ventilation. A number of 247. witnesses identified concerns about GGC's public communication in December 2018 which indicated that in light of the closure of Wards 2A and 2B, they were "taking the opportunity to upgrade the ventilation system" ³²⁵. Professor Cuddihy pointed to a report prepared for GGC by Innovated Design Solutions Ltd in October 2018 which concluded that the installed ventilation system in Wards 2A and 2B was not designed to cater for immunocompromised patients.³²⁶ In Professor Cuddihy's assessment, GGC's knowledge of this issue could not be reconciled with its public statement. Mr Rawson questioned the state of GGC's knowledge about the suitability of the ventilation system at an even earlier stage. He understood that, in July 2015, a problem was identified with the ventilation system in the adult bone marrow ward (4B) resulting in the decant of patients away from that ward³²⁷. There was no corresponding action in relation to the RHC in 2015 and yet Mr Rawson understands that the ventilation system has since been entirely replaced.

³²³ Evidence of Professor Cuddihy, transcript (27 October 2021 (pm)) at page 19.

³²⁴ Evidence of Professor Cuddihy, transcript (27 October 2021 (pm) at page 34.

³²⁵ See, for example, the witness statement of Cameron Gough at paragraph 164.

³²⁶ Witness statement of Professor John Cuddihy at paragraph 98.

³²⁷ Evidence of Alfie Rawson, transcript at page 40; witness statement at paragraph 57.

Further aspects of communication

Meeting with GGC and hospital management in November 2019

248. In November 2019, a meeting was convened between parents and representatives of GGC and hospital management. Witnesses reported that the Chairman of GGC, Mr Tom Brown, provided a reassurance that the water was now "wholesome". But some witnesses were not reassured standing the continued use of filters on taps and preventative medications. Mr Rawson recalled leaving the meeting with a large number of unanswered questions about the safety of the hospital environment, a sentiment echoed by a number of attendees³²⁸.

Scottish Ministers

249. There was a limited amount of evidence heard in relation to the involvement of the Scottish Ministers. References was made to the statement made to the Scottish Parliament on 20 March 2018 by Shona Robison, the then Cabinet Secretary for Health. The reassurance about the safety of the water was perceived, with the benefit of hindsight, to have been inaccurate³²⁹. Evidence suggested that, from the family perspective at least, the next substantive involvement of the Scottish Ministers came in the second half of 2019 when parents met Jeane Freeman, the new Cabinet Secretary for Health. Although some witnesses were frustrated that Ms Freeman was unable to provide them with immediate answers to their questions, most felt she listened to their concerns before agreeing to find the "answers they deserved" 330.

Oversight Board

250. On the whole, witnesses did not have a high degree of knowledge of the work of the Oversight Board. They (mostly) acknowledged the work of Professor Craig White and the Communications and Engagement Sub-Group. The

³²⁸ Evidence of Alfie Rawson, transcript at page 42.

³²⁹ Evidence of Professor John Cuddihy, transcript (27 October (am)) at page 4.

³³⁰ See, for example, the evidence of Charmaine Lacock, transcript at page 105.

evidence suggested that some witnesses found the establishment of the Closed Facebook Group to be helpful, although others were distrustful of it on the basis that it was administered by GGC staff. An example of the nature of communication posted to the Closed Facebook Group is attached to the witness statement of Mr Bisset³³¹.

251. Professor Cuddihy's view was that the work of the Communications and Engagement Sub-Group did, at least initially, have a positive effect on the approach to communication within GGC. However, he doubted whether there had been meaningful change in the communications culture at GGC when the BBC aired its Disclosure programme entitled "Secrets of Scotland's Super Hospital" in June 2020³³². Although GGC took time to communicate with staff and to provide a response to the BBC, it took no steps to alert patients and families to the programme; it seemingly had no appreciation of the distress and anxiety the programme would inevitably cause to that group.

The impacts upon patients and families of the perceived deficiencies in communication

- 252. The impacts of communication failures are recorded throughout this submission. In essence, witnesses felt that there was no evidence of a patient centred approach in relation to either the content or manner of communication. Accurate and transparent information was not made available at the time when it was most needed. Families had many questions but few answers on matters relating to the lives of their children. Communication failings contributed to the anxiety felt by patients and families, who were already facing the most challenging periods of their lives.
- 253. A number of witnesses had sympathy for the position they perceived staff to be in. Communication about the building environment had been pushed on to frontline staff by management who had "disappeared and left them to deal with

³³¹ Witness statement of Mark Bisset, beginning at page 55A.

³³² Evidence of Professor John Cuddihy, transcript (27 October 2021 (pm)) at page 5; witness statement of Professor John Cuddihy at paragraphs 285 to 291.

the fallout"³³³. Some witnesses felt strongly that it was not the job of oncology consultants to field questions about the hospital environment or to be involved in a public relations exercise; their sole focus should be on saving the lives of children³³⁴. Parents also expressed frustration that their precious appointment time with consultants was taken up with discussions about the environment. Consultants should not have been put in the position of answering questions from families who had seen stories about the hospital in the press³³⁵.

- 254. The combined effect of a lack of information and clinical staff being left to field questions appeared to put a strain on relationships between parents and staff. Parents were frustrated by the lack of information and staff were "burnt out" one witness perceived that some parents were being provided with more information than others; information was only provided to those who pushed for it and she simply did not have the energy of than one witness recalled nurses encouraging parents to go to the press to try to get answers of the hospital environment when the fight they should have been focussed on was against cancer?
- 255. The overall tenor of the evidence was that communication failures at the very least contributed to a fracturing of trust between patients and families on the one hand and "the hospital" on the other. When asked how they felt about the hospital now, the response from witnesses was universally negative. Many expressed dread at the thought of returning. That dread was not directed at the care provided by clinical and nursing staff but at the perceived risks posed by the hospital environment to patients. That in itself indicates that the concerns of patients and families persist and that communication from GGC, or elsewhere, has not allayed or managed those concerns.

³³³ Witness statement of Denise Gallagher at paragraph 101.

³³⁴ Evidence of Charmaine Lacock, transcript at page 104

³³⁵ Evidence of Charmaine Lacock, transcript at page 104; witness statement at paragraph 171.

³³⁶ Witness statement of Denise Gallagher at paragraph 101; and witness statement of Steven Kirkpatrick at paragraph 66.

³³⁷ Evidence of Aneeka Sohrab, transcript at page 82.

³³⁸ See, for example, the witness statement of Steven Kirkpatrick at paragraph 66.

PART 2: EDINBURGH

Introduction

- 256. Evidence was provided by six witnesses who had experience of the Royal Hospital for Sick Children ("RHSC") and Department of Clinical Neurosciences ("DCN") prior to their relocation to new hospital facilities located on the site of Royal Infirmary of Edinburgh at Little France. Five witnesses supplemented their witness statements with oral evidence³³⁹.
- 257. The issues engaged by the Edinburgh evidence are narrower in scope than those relating to the QEUH. At their centre is the delay in opening the new Royal Hospital for Children and Young People ("RHCYP") and new Department of Clinical Neurosciences as a result of concerns about the safety of those facilities. In contrast with the situation in Glasgow, patients and families were impacted not by the new hospital facilities themselves but by the last minute decision to postpone their opening and thereafter by the prolonged use of outdated facilities and equipment. Whilst the majority of the evidence focused on Term of Reference 8, it also touched upon issues connected to Terms of Reference 1, 6, 7 and 12.
- 258. Though the evidence provided in relation to Edinburgh was smaller in quantity than that relating to Glasgow, the quality was equally high. Witnesses gave their evidence in a conspicuously fair and balanced manner, and with great dignity. The Inquiry is grateful to them for providing the human context to the story of the Edinburgh hospitals.

Executive Summary

259. The evidence relating to Edinburgh is also arranged thematically. Core Participants are invited to address the questions which follow the Executive Summary. Given the restricted scope of the Edinburgh evidence, there is no timeline recording key dates. That should not prevent any Core Participant who

³³⁹ A list of witnesses is attached at Appendix 1. Witness statements and transcripts of evidence can be found on the Inquiry's website.

considers that a timeline would assist a proper understanding of the Edinburgh evidence from preparing one.

Theme 1: The RHSC and the DCN

(i) The fact that new hospital facilities were commissioned at all suggests that the old hospital facilities were nearing the end of their useful lives. That was indeed the tenor of the evidence heard. The RHSC and DCN functioned but fell far short of facilities which supported the provision of modern, state of the art healthcare.

Theme 2: Delayed opening of the new RHCYP and DCN

(ii) Although witnesses understood the opening of the new RHSC and DCN to have been delayed on previous occasions, the decision to delay the opening of the new facilities on 4 July 2019 was sudden and came only days before the transfer between facilities was due to take place on 9 July. The evidence indicates that families who had close ties to the hospitals did not feel well informed about the delayed move; the reasons for it; or the progress made towards moving to the new facilities. Families felt forgotten about in the construction dispute which followed.

Theme 3: Impact of the delayed move

(iii) The impact of the last minute decision to delay the move to the new facilities was felt keenly by patients and families. Parents who had been reassured that their child's care would be improved by the facilities and equipment in the new hospital were returned suddenly to a state of anxiety and uncertainty. Staff at the RHSC faced a huge logistical challenge in reviving a hospital facility that had all but closed. The culture at the DCN was reportedly affected, which in turn had a trickledown effect on patients. In the longer term, families remained in outdated facilities for a prolonged time.

Theme 4: Perceptions of the new RHCYP and DCN

(iv) Unsurprisingly, families observed a world of difference in the new facilities when they eventually opened. State of the art equipment is housed in a modern fresh hospital building. Parents were reassured that, rather than just proceeding to open the new facility, time was taken to resolve issues that might have affected the safety of their children. Yet, doubts remain about the safety of the new hospital facilities given the involvement of the same contractor in both the Edinburgh project and that in Glasgow.

Edinburgh Questions

- 1. Do Core Participants accept that in the executive summary, and in what follows, this closing statement accurately sets out the accounts given by witnesses (and if not can they identify where)?
- 2. At this stage, are Core Participants able to identify any areas of the narrative provided by the patient and family evidence that is capable of agreement?

THEME 1: THE RHSC AND THE DCN

260. Evidence was provided by five witnesses³⁴⁰ about the hospital facilities at the RHSC and from one witness³⁴¹ in relation to the DCN whilst located at Edinburgh's Western General Hospital. Overall, the impression of witnesses was that the hospital buildings and facilities were outdated and in dire need of upgrading. They were not consistent with the provision of modern healthcare³⁴².

RHSC

261. The RHSC had a city centre location in the Sciennes area of Edinburgh.

Although it was accessible by car, parking could be difficult and expensive³⁴³.

Witnesses described the hospital as an old Victorian-era building³⁴⁴. Most

³⁴⁰ Lesley King, Abhishek Behl, Mark Bisset, Lynndah Allison and Haley Winter.

³⁴¹ Peter Landale.

³⁴² See, for example, the evidence of Peter Landale, transcript at page 12.

³⁴³ Evidence of Lesley King, transcript at page 11.

³⁴⁴ See, for example, the evidence of Lesley King and Mark Bisset.

evidence related to Ward 2 which housed the paediatric haemato-oncology department, but evidence was also heard in relation to Ward 7 (neurology)³⁴⁵ and the wider hospital facilities.

- 262. Ward 2 was described as being a single long corridor in the style of a Nightingale ward³⁴⁶. It contained six individual rooms (also described as "cubicles") for inpatients and had an open bay containing a further two beds for overnight stays and four-day care beds³⁴⁷. The open bay area afforded little privacy to patients or families³⁴⁸. The ward also contained a small Teenage Cancer Trust area comprising two or three patient beds and a common sitting area with two chairs where teenage patients could receive treatment³⁴⁹.
- 263. The evidence was consistent that the individual patient bedrooms provided a sub-optimal setting for the needs of child cancer patients. The six individual patient rooms were described in detail by Lesley King and Mark Bisset. They observed that the rooms varied in quality with each room having its own unique advantages and disadvantages³⁵⁰. The rooms were glass fronted and even with blinds offered little privacy. Room 6 was seen as the 'high-end' room. It was a larger room with an en-suite bathroom containing a toilet and a bath. Room 5 had a toilet facility (not an en-suite bathroom) but no window to the outside world. Rooms 1, 2, 3 and 4 had windows but no bathroom or toilet facilities. Room 1 was large but was located next to the treatment room and was noisy. Some rooms were freezing in the winter to the point that Mrs King recalled sellotaping a window shut to stop the draft³⁵¹. Conversely, rooms were far too hot in the summer.
- 264. Most rooms were too small particularly for children requiring multiple drips and pieces of medical equipment. If two nurses were present in the room it was overcrowded³⁵². Mr Bisset, a wheelchair user, observed that room 6 was the

³⁴⁵ Evidence of Abhishek Behl.

³⁴⁶ Witness statement of Lesley King at paragraph 12.

³⁴⁷ Witness statement of Lesley King at paragraph 12.

³⁴⁸ Evidence of Lesley King, transcript at page 15.

³⁴⁹ Witness statement of Lynndah Allison at paragraph 17 and evidence of Lesley King, transcript at page 21.

³⁵⁰ Evidence of Lesley King, transcript at page 17.

³⁵¹ Witness statement of Lesley King at paragraph 13.

³⁵² Evidence of Mark Bisset, transcript at page 29.

only room large enough for him to manoeuvre in his wheelchair. This restricted his ability to stay overnight with his daughter³⁵³.

- 265. The evidence indicates that the bathroom facilities on the ward were far from ideal for either patients or families. Only two patient rooms had a private toilet for patients. All other patients had to use two shared toilets and a bath at one end of the ward. There was a commode available on the ward but even if it was available when needed it would not fit easily into all of the patient bedrooms³⁵⁴. Given the effects of chemotherapy treatment, the prospect of sharing a bathroom was distressing especially for older children who felt the loss of privacy acutely³⁵⁵. Parents were not permitted to use the ward bathroom facilities and had to leave the ward to go in search of a public bathroom.
- 266. Evidence was heard in relation to accommodation and other facilities for parents. Camp beds were available but, due to limited space in patient rooms, other furniture had to be moved into the corridor every time the camp bed was set up³⁵⁶. PJ's Loft provided accommodation, washing, kitchen and laundry facilities, but it was some distance from the ward and was itself in need of updating³⁵⁷. PJ's Loft was not accessible at all to Mr Bisset as it did not benefit from lift access³⁵⁸. There was a CLIC Sargent facility near to the RHSC, but it moved to a new site close to Little France in anticipation of the opening of the new facilities³⁵⁹. The evidence indicated that although the RHSC had a canteen, it was awkward to access and, indeed, impossible to access for Mr Bisset because it too was located up a flight of stairs with no lift access³⁶⁰.
- 267. It is perhaps indicative of the age and state of the facilities that Ward 2 was home to "Speedy", the ward mouse³⁶¹.

³⁵³ Evidence of Mark Bisset, transcript at page 18.

³⁵⁴ Evidence of Lesley King, transcript at page 15.

³⁵⁵ Witness statement of Lynndah Allison at paragraph 19.

³⁵⁶ Evidence of Lesley King, transcript at page 21.

³⁵⁷ Witness statement of Lesley King at paragraph 16

³⁵⁸ Evidence of Mark Bisset, transcript at page 26

³⁵⁹ Evidence of Mark Bisset, transcript at page 27 and Witness Statement of Haley Winter at paragraph 90.

³⁶⁰ Evidence of Mr Bisset, transcript at page 23.

³⁶¹ Witness statement of Haley Winter at paragraph 83.

268. Standing in sharp contrast to the evidence about the hospital facilities, was the evidence about the nursing staff. One witness described the nursing staff on Ward 2 as 'magnificent'³⁶². They were responsive and meticulous and it was "incredible to see that level of quality project management" in the care they provided.

The DCN

269. The evidence relating to the old DCN was in a similar vein³⁶³. It was an older building and lacked the facilities that would be expected in a modern healthcare setting. Bathrooms were rudimentary and were shared among entire wards. It was not uncommon for toilets to be out of order requiring patients to use bed pans, an experience which caused distress to Mr Landale's son³⁶⁴. Rooms were inadequately sized and "nothing worked" as it should. Waiting room areas were inadequate. Mr Landale understood that the DCN had been identified as a facility in desperate need of upgrading since 2007³⁶⁵.

Equipment

270. Evidence was also provided in relation to the medical equipment available at the RHSC and DCN³⁶⁶. Although functional, witnesses perceived equipment as being dated and most certainly not state of the art. Mr Landale described having to hand-write data produced by a monitoring machine because it could not be extracted in any other way³⁶⁷.

THEME 2: DELAYED OPENING OF THE NEW RHCYP AND DCN

271. It is important to note that the witnesses who provided evidence in relation to Edinburgh were not "ad hoc" visitors to the hospitals. The nature of the conditions suffered by their loved ones meant that they were in regular need of inpatient and outpatient care. Each of these families had close ties to the hospitals.

³⁶² Evidence of Lesley King, transcript at page 31.³⁶³ Evidence of Peter Landale, transcript at page 12.

³⁶⁴ Evidence of Peter Landale, transcript at page 15.

³⁶⁵ Evidence of Peter Landale, transcript at page 21.

³⁶⁶ Evidence of Abhishek Behl and Peter Landale and Lesley King.

³⁶⁷ Evidence of Peter Landale transcript at page 32.

272. Families understood that the new hospital facilities were due to open in early July 2019. Evidence suggests an awareness of previous delays to the opening of both the RHCYP and the new DCN, albeit witnesses did not speak to those prior delays in detail³⁶⁸. But it was clear that, as of the beginning of July 2019 families, and staff, believed that they were, finally, on the verge of leaving the old facilities behind.

Events in the run up to the planned move in July 2019

- 273. There was clear evidence of great anticipation among patients, families and staff about the move³⁶⁹. Staff had been on tours of the new facilities. Nurses were excited about the new resources that would be available. Auxiliaries told parents about the new parents' kitchen, the en-suite bathrooms and parent accommodation. The cleaning staff raved about how much easier it would be to keep things clean.
- 274. Parents understood that the facilities and equipment at the new hospital would enable enhanced medical care for their children. Mr Behl recalled doctors speaking with excitement about the advantages of the world class MRI machine located in the new facility when compared with the existing MRI machine in the RHSC³⁷⁰. Mrs King understood that her daughter would be safer from infection in the RHCYP because she would have access to an isolation room with specialist ventilation, a facility not available in the RHSC³⁷¹.
- 275. As at the beginning of July 2019 preparations for the move were at an advanced stage. Medication and supplies had been packed up and moved to the new hospital. Nurses had planned the logistics "excellently" so that they were running the ward with only the bare minimum needed to function³⁷². The hospital shop had closed. All of the toys and old resources which were not

³⁶⁸ Evidence of Peter Landale, transcript at page 27; witness statement of Haley Winter at para 88 and witness statement of Lesley King at paragraph 48.

³⁶⁹ Witness statement of Lesley King at paragraph 45.

³⁷⁰ Evidence of Abhishek Behl, transcript at page 33.

³⁷¹ Evidence of Lesley King, transcript at page 56.

³⁷² Witness statement of Lesley King at paragraph 54.

moving to the new hospital had been disposed of³⁷³. Patients and families wrote 'goodbye' messages on the walls³⁷⁴.

Announcement of the delay

- 276. The announcement of the delayed move on 4 July 2019 was sudden and unexpected as far as families were concerned. Mr Behl recalled that his daughter had been discharged from the RHSC the day prior to the announcement and yet his wife learned of it through social media³⁷⁵. Families who were on the ward that day were informed of the delay by nurses³⁷⁶. Others learned of the delay through press reports³⁷⁷. It was a consistent theme of the evidence that witnesses were informed only of the delay itself and not of the reasons for it. Nurses were unable to provide any further information³⁷⁸.
- 277. Witnesses could not recall being provided with formal written communication about the delay or its cause³⁷⁹. There was an effort made at in-person communication with those present in the RHSC in the immediate aftermath of the announcement. Mrs King recalled that the "Chief Executive" visited Ward 2 the day after the announcement and was available to speak to parents (although she did not speak to him herself). The following day, Jeane Freeman, the Cabinet Secretary for Health, visited the hospital albeit the purpose of that visit was unclear ³⁸⁰.

Communication

278. It was a clear theme of the evidence that witnesses did not feel well informed about the delayed move when it was announced. There is a distinction to be drawn between those who were present in the RHSC and DCN on the date of the announcement and those who were not. Evidence was heard that families within the RHSC were informed that the move was not happening as planned

³⁷³ Witness statement of Lesley King at paragraph 54.

³⁷⁴ Witness statement of Haley Winter at paragraph 89; evidence of Abhishek Behl, transcript at page 28.

³⁷⁵ Evidence of Abhishek Behl, transcript at page 51

³⁷⁶ Evidence of Mark Bisset, transcript at page 31; evidence of Lesley King, transcript at page 61.

³⁷⁷ Evidence of Peter Landale, transcript at page 28.

³⁷⁸ Evidence of Lesley King, transcript at page 61.

³⁷⁹ See, for example, the evidence of evidence of Abhishek Behl, transcript at page 51; Lesley King, transcript at page 64.

³⁸⁰ Evidence of Lesley King, transcript at page 63.

in person by nurses. There was no evidence of direct communication with those not present in the hospital buildings on that particular day³⁸¹.

- 279. Witnesses were fair in acknowledging the last minute nature of the decision to delay the move and the effect that may have had on its communication³⁸². However, the evidence indicates that communication did not improve in the days and weeks following 4 July 2019. One witness observed that there was no formal line of communication. Families obtained information through the media or through discussions with other parents and staff on the wards³⁸³. Mr Behl recalled receiving a letter a few weeks after the announcement informing him that his daughter's next appointment would be at the RHSC rather than at the RHCYP. However, the nature of the letter was of an appointment letter. It explained nothing about the delayed move or the reasons for it³⁸⁴.
- 280. Witnesses could not recall being told the reasons for the delay by hospital management, NHS Lothian ("NHSL") or through the Scottish Government³⁸⁵. Witnesses gained a general understanding through media coverage that the new facilities were 'not fit for purpose'³⁸⁶.
- 281. Mr Behl was a member of the RHSC Family Council, a group which had provided input to the planning of the new RHCYP from the patient and family perspective and which met regularly with representatives of NHSL to discuss the project's progress. However, even the Family Council received no formal communication about the delayed move. Following the announcement on 4 July 2019, meetings with NHSL representatives continued but Mr Behl did not recall the Family Council being provided with any more information about the reasons for the delay than had been in the media³⁸⁷.
- 282. Families did not feel informed about progress towards opening the new facilities. Updates were "off the cuff" remarks from staff on the wards³⁸⁸. Mr

³⁸¹ See, for example, the evidence of Peter Landale and Abhishek Behl.

³⁸² Witness statement of Lesley King at paragraph 81.

³⁸³ Evidence of Lesley King, transcript at page 74.

³⁸⁴ Evidence of Abhishek Behl, transcript at page 51.

³⁸⁵ Evidence of Lesley King, transcript at page 94.

³⁸⁶ Evidence of Lesley King, transcript at page 74.

³⁸⁷ Evidence of Abhishek Behl, transcript at page 61.

³⁸⁸ Evidence of Lesley King, transcript at page 96.

Landale, whose family was in the hospital less frequently, could recall receiving no direct communication about when the new facilities might open. Mr Landale referred to the website for the DCN but to his great frustration it continued to advertise that the DCN was moving to new facilities in "2015". This messaging remained on the website right up until the DCN moved to its new home in July 2020³⁸⁹. Mr Landale eventually learned of the opening date for the new DCN in the press. But his concerns about NHSL's messaging were exacerbated by the self-congratulatory nature of the NHSL press release which heralded that the DCN would be "delivered ahead of time" in the summer of 2020³⁹⁰.

- 283. Some witnesses recalled seeing the Cabinet Secretary for Health discussing the issue in the media. Mrs King was particularly frustrated with what she observed from Scottish Parliament discussions and comments to the press on the issue³⁹¹. Mrs King's impression was of "mud-slinging" among politicians about a construction project. Absent from the dialogue was consideration of the impact of the delay on the provision of healthcare for child patients. Mrs King was concerned that the focus was on the risks of the new hospital, not those posed by the old one³⁹².
- 284. It bears notice that some witnesses were careful to clarify that they agreed with the decision to delay the opening of the new hospital facilities³⁹³. They were frustrated that the delay was required but understood the necessity for it if there was a risk posed to the health of patients by the hospital building. One witness described being aware of the issues with the QEUH and RHC and of her relief that the decision was taken not to open the RHCYP³⁹⁴. However, overall, witnesses assessed communication with them by hospital management, NHSL and the Scottish Government as lacking³⁹⁵. For those on the wards, staff served as an informal conduit for information. Otherwise, families were left to

³⁸⁹ Witness statement of Peter Landale at paragraph 30.

³⁹⁰ Evidence of Peter Landale, transcript at page 55.

³⁹¹ Witness statement of Lesley King at paragraph 80.

³⁹² Evidence of Lesley King, transcript at page 97; witness statement of Lesley King at paragraph 80.

³⁹³ See, for example, the evidence of Lesley King and the evidence of Mark Bisset.

³⁹⁴ Evidence of Lesley King, transcript at page 100.

³⁹⁵ See, for example, the witness statement of Lesley King at paragraphs 80 and 81.

glean what information they could from the media. The result was uncertainty, speculation and rumour³⁹⁶. Families felt left behind.

THEME 3: IMPACT OF THE DELAYED MOVE

285. The impacts which are described in Theme 3 are those said by witnesses to stem from the last minute need to change course from opening the new hospitals, and from the prolonged time spent in outdated facilities.

Impacts on treatment

- 286. The evidence did not suggest a link between the delay and a significant detrimental impact on medical treatment, at least not to the knowledge of the witnesses from whom evidence was heard³⁹⁷. Apparent from the evidence however was the creation of increased anxiety about the ability of the old hospital facilities to support the healthcare needs of patients.
- There was a clear line of evidence that in the run up to July 2019 families had 287. become acutely aware that the existing facilities were lacking. Parents learned from doctors about the state of the art equipment available at the new hospital and how far ahead it was of the equipment currently used to treat patients. Mr Behl understood that his daughter would benefit from the MRI machine available within the new DCN. As a result of the delay, his daughter did not have access to that machine at the time she needed it³⁹⁸. Mrs King spoke powerfully of her comfort in being told that the new facilities had rooms with specialist ventilation that would improve her daughter's chances of avoiding infection. When she learned that those facilities would not be available to her daughter, she and her husband were "flattened" and "scared" Mrs King described the last minute attempts to prepare an isolation room within the RHSC but she was nevertheless aware that these arrangements did not offer the same protection to her daughter as those which should have been available to her in the new RHCYP.

³⁹⁶ See, for example, the evidence of Lesley King and the evidence of Abhishek Behl.

³⁹⁷ See, for example, the evidence of Lesley King, transcript at page 68.

³⁹⁸ Evidence of Abhishek Behl, transcript at page 64.

³⁹⁹ Witness statement of Lesley King at paragraph 51.

- 288. Mrs King also spoke of the efforts made by clinicians to plan the next phase of her daughter's treatment around the hospital move. High dose chemotherapy would render her daughter extremely vulnerable to infection. After much debate, a move to Glasgow was ruled out. Doctors decided instead to schedule the treatment so that Mrs King's daughter would be at the lowest risk point in the chemotherapy cycle on 9 July 2019, the date of the planned move. In order to achieve that objective, the beginning of the cycle was delayed by one week; doctors had to balance the risk of waiting to begin the treatment against the risk posed by the move⁴⁰⁰. The impact of the delay on Mrs King's daughter was therefore two-fold: her treatment was delayed by one week unnecessarily and she did not benefit from the enhanced protection that should have been offered by the specialist isolation room facilities in the RHCYP.
- 289. The last minute nature of the delayed move presented a huge logistical challenge for nurses and ward staff. The impression was of a hospital on the verge of closing which suddenly had to be brought back into operation. Staff had to ensure the treatment of existing patients continued uninterrupted and that they had sufficient supplies and equipment to cope with the new set of patients they expected to see at the new hospital⁴⁰¹. Mrs King's perception was that, at least initially, there was logistical uncertainty caused by not knowing how long the delay would last. Staff did not know if they had to repatriate all equipment and supplies or only what was needed for a couple of weeks⁴⁰². There was hesitancy about removing equipment from the new hospital because it was in "clean" rooms. Mrs King was careful to note that despite all of this, her daughter continued to receive a high level of nursing care⁴⁰³.

Impact on patients and families

290. The evidence indicated that, for a period following the delay, the RHSC existed as a bare medical facility⁴⁰⁴. Families were deprived of the amenities which were designed to help them cope with prolonged periods in hospital. The

⁴⁰⁰ Witness statement of Lesley King at paras 42 to 44; evidence of Lesley King, transcript at page 49.

⁴⁰¹ Witness statement of Lesley King at paragraph 52.

⁴⁰² Evidence of Lesley King, transcript at page 70.

⁴⁰³ Witness statement of Lesley King at paragraph 53.

⁴⁰⁴ Evidence of Lesley King, transcript at page 70.

playroom was closed, and toys had been disposed of⁴⁰⁵. Eventually toys were replaced with the help of a charity but that took time. The hospital shop had closed, meaning that families had to leave the hospital to buy food and drinks⁴⁰⁶. The CLIC Sargent facility was now located at the new hospital site and was less easily accessible.

- 291. Mr Landale painted a similar picture of the situation at the DCN following the move. He spoke of the efforts to keep the old DCN facility going. His impression was that, in the months following the delay, some budget was released for repairs and decoration. However, the constant movement of people and ongoing works meant it was not a restful place to be⁴⁰⁷. Painters were also called into the RHSC to paint over the goodbye messages written on walls by patients and families⁴⁰⁸.
- 292. Delaying the move at the last minute had an emotional impact on patients and families. There had been a great build up to the move. Mrs King spoke of her young daughter being "crushed" when she found out it was not happening. She had been told about the wonderful new facility built just for her. It was one positive thing to focus on during the horrors of cancer treatment and to have it taken away was very upsetting⁴⁰⁹.
- 293. Beyond the immediate challenges presented by the last minute delay, patients and families had to cope with outdated facilities for much longer than should have been the case. The nature of those facilities is described in Theme 1. The DCN is understood to have transferred to the new hospital building in the summer of 2020, approximately one year after the planned move. The move to the RHSC took longer, with patients transferring in March 2021, some 20 months later than the planned move in July 2019⁴¹⁰.

⁴⁰⁵ Evidence of Abhishek Behl, transcript at page 30; witness statement of Lesley King at paragraph 54.

 $^{^{\}rm 406}$ Evidence of Abhishek Behl, transcript at pages 30 and 40.

⁴⁰⁷ Witness statement of Peter Landale at paragraph 56.

⁴⁰⁸ Evidence of Abhishek Behl, transcript at page 28.

⁴⁰⁹ Evidence of Lesley King, transcript at page 99.

⁴¹⁰ Although the evidence indicated that these were not the first delays.

Impact on staff

- 294. Although the Inquiry has not yet heard directly from staff, witnesses were clearly struck by what they perceived to be the impact of the delay on staff. At a practical level, staff had to deal with challenging logistics whilst maintaining high levels of patient care⁴¹¹. Mrs King observed that the staff were "stellar" but were let down by the facilities in which they had to operate⁴¹². Mr Behl observed that the RHSC had benefitted from little maintenance in anticipation of the move to a new building. It fell to staff to keep the "makeshift" RHSC going⁴¹³. Mr Behl praised staff who were affected by the delay but continued in their efforts to "keep the place running…despite the challenges of the environment"⁴¹⁴.
- 295. Mrs King observed that staff were also affected in their personal lives. Staff had changed their transport and childcare arrangements. Some had even moved house in anticipation of the move⁴¹⁵.
- 296. Mr Landale reported a change in the culture at the DCN following the delay. He observed that there were fewer nurses available and the staff were "stretched" 16. Temporary nurses were more prevalent and there was less consistency in the level of care provided. Mr Landale met with the Deputy Chief Executive Officer of NHSL, Mr James Crombie, in February 2020 to discuss what he perceived to be low morale and a poor culture at the DCN caused by the delay. However, he formed the impression that Mr Crombie's sole focus was on the opening of the new facility rather than the existing situation at the DCN 17.

⁴¹¹ Witness statement of Lesley King at paragraph 53.

⁴¹² Evidence of Lesley King, transcript at page 92.

⁴¹³ Witness statement of Abhishek Behl at paragraph 45. A similar sentiment was expressed by Mr Landale.

⁴¹⁴ Witness statement of Abhishek Behl at paragraphs 45 and 46.

⁴¹⁵ Witness statement of Lesley King at paragraph 52.

⁴¹⁶ Evidence of Peter Landale, transcript at page 36.

⁴¹⁷ Witness statement of Pater Landale at paragraph 90.

THEME 4: PERCEPTIONS OF THE NEW RHCYP AND DCN

- 297. Unsurprisingly, those witnesses who had experience of the new hospital facilities compared them favourably to the old facilities. Mr Bisset described the new RHCYP as clean and fresh and said that his daughter is more at ease there⁴¹⁸. Mr Behl reported a "world of difference" between the old and new facilities⁴¹⁹. Accommodation for patients and families is improved, and the machinery is state of the art⁴²⁰.
- 298. Yet, although feelings about the safety of the new hospital are broadly positive, lingering doubts remain. Mr Bisset, for example, reported an increased sense of safety because he knew time had been taken to fix the problems at the new facility⁴²¹. However, he continued to harbour concerns from the fact that the same contractor had been involved in the Glasgow and Edinburgh projects⁴²². Ms Winter expressed a similar concern⁴²³.
- 299. Mrs King recounted that her anger at the delay turned to relief as she learned that there was a flaw in the ventilation serving the specialist isolation rooms due to house her daughter. On hearing about the possible effect of the building environment on patients at Glasgow, and knowing that both projects involved the same contractor, she felt that her family "dodged a bullet". However, Mrs King reported that she did not have confidence in the management of the project in Edinburgh. She questioned why checks did not identify the problems earlier, and she suggested that had they done so the impact of the delayed move would have been reduced⁴²⁴. Mrs King also questioned the experience and ability of the Health Board to manage a project as complex as the building of a new hospital. She said:

"[T]he health board only builds a hospital once every 50 years or so, how much experience do they have within the health board of this kind of project? It seems

⁴¹⁸ Evidence of Mark Bisset, transcript at page 133.

⁴¹⁹ Evidence of Abhishek Behl, transcript at page 48.

⁴²⁰ Evidence of Abhishek Behl, transcript at page 49.

⁴²¹ Evidence of Mark Bisset, transcript at page 134.

⁴²² Evidence of Mark Bisset, transcript at page 134.

⁴²³ Evidence of Haley Winter, transcript at page 42.

⁴²⁴ Witness statement of Lesley King at paragraph 89.

to be a classic case of public sector organisations trying to project manage something they don't have much experience in. There must be lessons to be learned⁴²⁵."

The Closing Statement of

Alastair Duncan QC, Counsel to the Scottish Hospital Inquiry

Victoria Arnott, advocate, Junior Counsel to the Scottish Hospital Inquiry

3 December 2021

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 $^{^{\}rm 425}$ Evidence of Lesley King, transcript at page 103; witness statement of Lesley King at paragraph 90.

APPENDIX 1: LIST OF WITNESSES

	Name	Glasgow/Edinburgh	Oral evidence / statement only
1	Cameron Gough	Glasgow	Oral evidence and statement
2	Colette Gough	Glasgow	Oral evidence and statement
3	Lynn Kearns	Glasgow	Oral evidence and statement
4	Suzanne Brown	Glasgow	Oral evidence and statement
5	Graham McCandlish	Glasgow	Oral evidence and statement
6	David Campbell	Glasgow	Oral evidence and statement
7	Annemarie Kirkpatrick	Glasgow	Oral evidence and statement
8	Stevie-Jo Kirkpatrick	Glasgow	Oral evidence and statement
9	Witness 6	Glasgow	Oral evidence and statement
10	Sharon Ferguson	Glasgow	Oral evidence and statement
11	Charmaine Lacock	Glasgow	Oral evidence and statement
12	Alfie Rawson	Glasgow	Oral evidence and statement
13	Leann Young	Glasgow	Oral evidence and statement
14	Denise Gallagher	Glasgow	Oral evidence and statement
15	James Gallagher	Glasgow	Oral evidence and statement
16	Witness 1	Glasgow	Oral evidence and statement
17	Witness 2	Glasgow	Oral evidence and statement
18	Karen Stirrat	Glasgow	Oral evidence and statement
19	Aneeka Sohrab	Glasgow	Oral evidence and statement
20	Senga Crighton	Glasgow	Oral evidence and statement
21	Molly Cuddihy	Glasgow	Oral evidence and statement
22	Professor John Cuddihy	Glasgow	Oral evidence and statement
23	Lynndah Allison	Glasgow / Edinburgh	Statement only
24	Louise Cunningham	Glasgow	Oral evidence and statement
25	Samantha Ferrier	Glasgow	Oral evidence and statement
26	Witness 4	Glasgow	Oral evidence and statement
27	Theresa Smith	Glasgow	Oral evidence and statement
28	Matthew Smith	Glasgow	Oral evidence and statement
29	Mark Bisset	Glasgow / Edinburgh	Oral evidence and statement

30	Haley Winter	Glasgow / Edinburgh	Oral evidence and statement
31	Lesley King	Edinburgh	Oral evidence and statement
32	Peter Landale	Edinburgh	Oral evidence and statement
33	Abhishek Behl	Edinburgh	Oral evidence and statement
34	Sharon Barclay	Glasgow	Statement only
35	Rachael Noon Crossan	Glasgow	Statement only
36	Kimberly Darroch	Glasgow	Statement only
37	Christine Horne	Glasgow	Statement only
38	Derek Horne	Glasgow	Statement only
39	Witness 3	Glasgow	Statement only
40	Andrew Stirrat	Glasgow	Statement only
41	Carol-Anne Baxter	Glasgow	Statement only
42	Witness 5	Glasgow	Statement only
43	Steven Kirkpatrick	Glasgow	Statement only
44	John Henderson	Glasgow	Statement only

APPENDIX 2: TIMELINE OF KEY EVENTS - GLASGOW

Date	Event	Issue	Witness
2015			
April 2015	Water supply to QEUH interrupted.	Water	John Henderson
April/May 2015	Report prepared by DMA Canyon Ltd provided to QEUH Estates and Facilities Department.	Water	Professor John Cuddihy
2016			
2016	Rare Mycobacterium Chelonae infection identified in paediatric haemato-oncology patient.	Infections	Professor John Cuddihy
2016	Restrictions on drinking tap water within the NICU and Ward 2A. Filters on taps in Ward 2A.	Water	Karen Stirrat; Witness 6
2017			
February 2017	Report of Staphylococcus line infection on Ward 2A.	Infection	Suzanne Brown
March 2017	Concerns raised by staff on Ward 2A about high instance of line infections.	Infection	GGC post to Facebook Group. Appendix to statement of Mark Bisset
April 2017	Power supply to NICU interrupted. Back-up generators required.	NICU Power supply	Matthew Smith Theresa
	Restrictions on use of tap water in the NICU.	Power supply Water	Smith
	MSSA-PVL infection in the NICU.	Infection	
April 2017	Ward 2A shut down for infection control reasons.	Ward 2A closure	Louise Cunningham
		IPC	
August 2017	Investigations into two cases of Stenotrophomonas. Death of Schiehallion patient. Death certificate lists Stenotrophomonas Maltophilia.	Infection	GGC post to Facebook Group. Appendix to statement of Mark Bisset

	Further line infections reported. Enterobacter Cloacae identified as cause of at least one line infection.		Lynndah Allison; Rachel Noon Crossan; Kimberley Darroch
Autumn 2017	Restrictions on use of water on Ward 2A for both drinking and washing. Increased presence of ICT on Ward 2A. Sinks doused and wash hand basin removed. Preventative medication prescribed to protect against the 'environment'.	Water IPC Preventative medication	Stevie-Jo Kirkpatrick; Alfie Rawson; Annemarie Kirkpatrick; Sharon Ferguson
October 2017	Second DMA Canyon Ltd report prepared and provided to Estates and Facilities Department.	Water	Professor John Cuddihy
Late 2017	High incidence of line infections, including Enterobacter Cloacae infection. Green caps introduced for Hickman lines due to concerns about line infections. Deep cleaning of patient rooms on Ward 2A.	Infection Deep cleaning IPC	Louise Cunningham; Sharon Ferguson; Annemarie Kirkpatrick
2018			
Jan 2018	DMA Canyon Ltd "Gap Analysis" prepared.	Water	Professor John Cuddihy
February / March 2018	Escalating concerns about water supply on Ward 2A. Signs warn families to run showers before use and not to drink tap water. Bottled water is provided for drinking. Subsequent instructions issued not to use the showers and to use bottled water for washing. Plastic basins provided. Bacteria are identified. Preventative medications are prescribed to immunocompromised children. Filters are installed on taps. Increased ICT presence on Ward 2A.	Water Infections Preventative medication IPC	Suzanne Brown; Molly Cuddihy and others. Lynn Kearns LK/01 (photo)
13.03.18	Portable sinks provided on Ward 2A.	Water Communication	Lynn Kearns LK/02 (photo) LK/03 (note)

	Written note provided to parents informing them that they could shower at Marion House.		
16.03.18	Written note provided to parents on Ward 2A informing them that the water supply to Ward 2A would be shut off "again". Water supply is shut off completely.	Water Communication	Lynn Kearns
20.03.18	Shona Robison, Cabinet Secretary for Health, makes a statement to the Scottish Parliament in response to questions about "contaminated water" in the QEUH. GGC issue a press release on the same topic.	Scottish Ministers Communication	Professor John Cuddihy
22.03.18	The water supply is restored to Ward 2A and patients are permitted to shower. Filters remain on taps. Patients are instructed to use bottled water for drinking.	Water	Lynn Kearns; Professor John Cuddihy
March 2018	Report prepared by DMA Canyon Ltd in 2015 "surfaces".	Water	Professor John Cuddihy
Approx. Easter 2018	Ward 2A is shut to visitors as a result of unexplained infections. No visitors are allowed for around two weeks.	Ward 2A closure Infection / IPC	Senga Crighton SC/01 (photo)
April / May 2018	Further outbreak of infections on Wards 2A and 2B. Infections are thought to be linked to drains. Multiple infections reported by witnesses during April and May 2018. Some, but not all, are linked to Enterobacter Cloacae bacteria. Preventative medications are prescribed to patients. Some parents are informed these are to protect against "environmental issues" and that the ward is "under investigation". Continued instruction not to use tap water for drinking.	Drains Infection Preventative medications Water	Professor John Cuddihy Examples include: Haley Winter; Sharon Ferguson; Molly Cuddihy; Denise Gallagher
May / June 2018	Drains on Ward 2A are treated with chemicals. Work is carried out on wash hand basins in Ward 2A to replace sinks traps and pipework. Drains in showers are not replaced at this time.	Drains IPC	Professor John Cuddihy; Leann Young

	HPV room cleaning introduced.		
01.06.18	Rare Mycobacterium Chelonae infection on Ward 2A. Diagnosed from blood cultures taken on 9 May 2018.	Infection	Molly Cuddihy
05.06.18	Parents on Ward 2A are provided with a note explaining the "new method of cleaning" in relation to drains. Chilled beams are also mentioned. Press release issued relating to drain cleaning on Ward 2A. It notes that as an "extra precaution" some patients have been prescribed preventative medications. GGC apologises for the "disruption" caused.	Drains Chilled beams Communication	Professor John Cuddihy; Sharon Ferguson
June 2018	Letter from Professor Cuddihy to the then Chief Medical Officer for Scotland, Catherine Calderwood, outlining concerns about outbreaks of infection on Ward 2A in March and May 2018.	Communication	Professor John Cuddihy
July 2018	A large glass panel falls from height close to the entrance of the QEUH. The Chief Executive of GGC, Jane Grant, responds to a letter from Professor Cuddihy about this incident reassuring him that "windows" are safe and that what fell was a decorative glass panel designed to shatter on impact. Ms Grant agrees to let Professor Cuddihy know the outcome of the investigation into the glass panels.	Glass panels Communication	Professor John Cuddihy
July 2018	GGC completes a plan to address the recommendations in the report by DMA Canyon Ltd dated 2015.	Water	Professor John Cuddihy
23.07.18	Letter issued from the Medical Director of GGC, Dr Jennifer Armstrong to Professor Cuddihy providing assurance about the safety of Wards 2A and 2B.	Communication	Professor John Cuddihy
August 2018	Instructions continue to be provided not to drink tap water on Wards 2A and 2B. Filters remain on taps.	Water	Charmaine Lacock; Denise

	Reports of infections continue.	Infection IPC	Gallagher; Annemarie
	Dyson fans are removed from the ward due to infection prevention and control concerns.	IPC	Kirkpatrick; Sharon Ferguson;
	Drains are still being treated with chemicals. HPV room cleaning continues.	Drains	
13.08.18	Scaffolding erected at RHC in connection with cladding works.	Cladding	Leann Young
August 2018	Meeting with parents to discuss infection prevention and control protocols.	IPC Communication	Aneeka Sohrab
07.09.18	Note to parents informing them of alternative	Cladding	Colette
	access arrangements to RHC due to ongoing cladding works. Note is not issued to all parents on 07.09.18.	Communication	Gough; Professor John Cuddihy
			CG/03 (note)
September 2018	Meeting among Professor Cuddihy, Mr Redfern and Dr Inkster to discuss concerns about a lack of proactive communication and risks posed by the discharge lounge entrance, cladding and falling glass panels.	Communication Building risks	Professor John Cuddihy
Early to mid- September 2018	Line infection incidents on Ward 2A. Parents of affected children are called to one to one meetings to be informed of likely link between infections and drains on Ward 2A. Infections include Stenotrophomonas and Serratia Marcescens.	Infection Communication	Cameron Gough; Denise Gallagher
17.09.18	Infection outbreak involving 6 patients on Ward 2A.	Infection	Colette Gough
	Closure of Wards 2A and 2B is under	Communication	
	consideration although there is no general communication with families to that effect.	Closure of Wards 2A and 2B.	
18.09.18	A number of families learn of the closure of Wards 2A and 2B from news reports, social media and text messages.	Closure of Wards 2A and 2B. Communication	· '

			Charmaine Lacock
18.09.18	A written note entitled "Ward 2A and 2B Update", dated 18.09.18, refers to disruption caused by a new cleaning process intended to deal with	Closure of Wards 2A and 2B.	Colette Gough; Leann Young
	Biofilm in drains. It explains that because Wards 2A and 2B house immunocompromised children, the wards will be transferred to another ward in the QEUH whilst a permanent solution is identified.	Communication	CG/02 (note)
	Not all families receive this note on 18.09.18 despite its date.		
Mid-end September 2018	Meetings between some families and Dr Inkster / Mr Redfern. Meetings are at the request of individual families who express concern about the closure of the Wards.	Closure of Wards 2A and 2B.	James Gallagher; Professor Cuddihy
		Communication	,
	At one such meeting, Professor Cuddihy is informed that Ward 6A has a different water supply from Wards 2A and 2B but that precautions would be taken to prepare Ward 6A to receive Schiehallion patients in any event. He is told that an SBAR has been prepared.	Suitability of Ward 6A	
23 – 26 September 2018	Further line infections reported in immediate run up to the closure of Ward 2A.	Infection	Senga Crighton; Charmaine Lacock
26.09.18	Closure of Wards 2A/2B and move to Ward 6A		
September 2018	Preventative medications are prescribed to patients transferred to Ward 6A.	Ward 6A	Charmaine Lacock
		Preventative medications	
Autumn 2018	A problem is identified with inadequate seals around panels in patient bedrooms.	Wall panels	Witness 4; Denise
	HEPA filters are placed in Ward 6A.	HEPA filters	Gallagher
October 2018	Innovated Design Solutions report commissioned by GGC advises that the ventilation on Wards 2A and 2B is not suitable for immunocompromised patients.	Ventilation	Professor John Cuddihy

Nov/Dec 18	Sewage leak in Atrium / link corridor. Part of roof blows off QEUH.	Sewage leak.	Annemarie Kirkpatrick
Early December 2018	GGC briefing to the effect it is "taking the opportunity" of Wards 2A and 2B being closed to "upgrade the ventilation" and that the decant to Ward 6A will last for another year.	Ward 6A – long term Ventilation Communication	Cameron Gough and others
December 2018	Death of Schiehallion patient who had contracted Cryptococcus.	Infection Cryptococcus	
25.12.18	Difficulties encountered in urgent transfer of patient from Ward 6A to PICU.	Transfer Ward 6A to PICU	Annemarie Kirkpatrick
Dec 2018	Rooms are closed off for works or cleaning in Ward 6A. Line infections continue.	Ward 6A Room closures Infection	Charmaine Lacock; Denise Gallagher
2019			
Early 2019	Instructions given to drink bottled water in the Maternity Unit.	Maternity Unit Water	Samantha Ferrier
January 2019	Professor Gibson, Mr Redfern and Dr Inkster meet with family of patient who contracted Cryptococcus. A likely link to pigeon droppings is confirmed.	Infection Communication	
January 2019	Patients on Ward 6A are prescribed preventative medications. Handout issued to parents. HEPA filters are present on Ward 6A.	Preventative medications HEPA filters	Cameron Gough, Molly Cuddihy, Annemarie Kirkpatrick
19.01.19	Ward 6A inpatients are decanted to the Clinical Decisions Unit in the RHC. The day care unit is moved to Ward 1A within the RHC. Mould has been found in en-suite bathrooms as a result of flawed seals. The closure of Ward 6A is reported in the press. Some families find out about it that way.	Closure of Ward 6A Communication Ward 6A bathroom defects	Mrs Gough; Charmaine Lacock; Annemarie Kirkpatrick

		T	
	Parents request an open meeting with representatives of GGC/hospital management to discuss the issues which have arisen on Ward 6A but the request is refused.		
23.01.19	Letter from the Chief Executive of GGC, Jane Grant, to parents about the issues on Ward 6A. Parents are informed that the source of two unusual infections has been identified and dealt with. The letter also references a separate issue with bathrooms on Ward 6A requiring some patients to be transferred out of Ward 6A.	Communication Infections Ward 6A bathroom defects	Colette Gough CG/04 (letter)
February 2019	Ward 6A re-opens.	Ward 6A reopens	Professor John Cuddihy
Feb / March 2019	Concerns continue about the high incidence of line infections through to the summer of 2019.	Infections	Charmaine Lacock and others
March 2019	Rare Mycobacterium Chelonae in paediatric patient. Sampling confirms infection is linked to the hospital environment.	Infections	Annemarie Kirkpatrick
14.04.19	Samples on taken on Ward 2A (where no patients are resident) show Mycobacterium Chelonae in 4 locations.	Infections	Professor John Cuddihy
25.06.19	Minutes of IMT meeting record that until the recently identified case, there have been no paediatric cases of Mycobacterium Chelonae reported in last decade.	Infection reporting	Professor John Cuddihy
July 2019	Parents contact the office of Jeane Freeman, the Cabinet Secretary for Health to express concerns that the environment is putting patients at risk. Ms Freeman agrees to the request for a meeting.	Scottish Ministers	Charmaine Lacock
August 2019	Room moves and deep cleaning in Ward 3A.	Ward 3A Deep cleaning	Samantha Ferrier
August 2019	Further outbreak of infections in Ward 6A. Ward 6A closed to newly diagnosed patients and infusional chemotherapy patients.	Ward 6A closure	GGC post to Facebook Group. Appendix to

	Paediatric patient on Ward 4B suffers two infections.	Communication	statement of Mark Bisset
	Meeting with parents to discuss infection outbreak. Note issued to parents informing them that there are two different infections on Ward 6A and that patients are being prescribed preventative medications.		Sharon Ferguson; Karen Stirrat; Mark Bisset
08.08.19	Professor Cuddihy meets with Mr Redfern and Dr Inkster to discuss the failure to inform him of the new Mycobacterium Chelonae infection.	Duty of candour Communication	Professor Cuddihy
September 2019	Meeting between families and the Cabinet Secretary for Health, Jeane Freeman at Grand Central Hotel in Glasgow.	Scottish Ministers Communication	
Autumn 2019	Significant mould discovered in staff kitchen on Ward 6A thought to have been caused by a long term leak.	Ward 6A Mould	Professor John Cuddihy
September 2019	Closed Facebook Group set up to aid communication between GGC and families.	Communication	
04.10. 19	John Brown, Jane Grant and Jennifer Armstrong visit Ward 6A.	Communication	GGC post to Facebook Group. Appendix to statement of Mark Bisset
23.10.19	Professor Cuddihy meets with Professor Craig White and separately with Jeane Freeman and the Chief Nursing Officer, Fiona McQueen.	Oversight Board Scottish Ministers Communication	Professor Cuddihy
November 2019	Meeting among representatives from GGC, hospital management and parents. Parents are informed that the water supply is "wholesome". Patients continue to be prescribed preventative medications and filters remain on taps.	GGC Communication	Colette Gough; Karen Stirrat; Alfie Rawson
12.11.19	Meeting among Professor John Cuddihy, Professor John Brown, Dr Jennifer Armstrong and Jane Grant.	Communication	Professor John Cuddihy

12.11.19	Letter from Kevin Hill posted on Facebook Group. Addressed to Parents/Carers of patients on Wards 6A and 4B. Provides overview of timeline and of steps taken by GGC in relation to environmental issues and "enhancements" on Ward 6A. The water supply is reported to be "safe and effective".	Communication	GGC post to Facebook Group - Appendix to statement of Mark Bisset
23.11.19	Ward 6A reopens to new patient admissions following "a detailed investigation by the Incident Management Team and a review by Health Protection Scotland".	Ward 6A reopens. Communication	GGC post to Facebook Group - Appendix to statement of Mark Bisset
12.12.19	Professor Cuddihy meets with Mr Jonathan Best, Dr Scott Davidson, Dr Alistair Leonard.	Communication	Professor John Cuddihy
2020			
06.01.2020	Letter from parent to Chief Operating Officer Acute Services of GGC, Jonathan Best regarding use of prophylactics and environmental issues. Mr Best responds to say that he was not aware of any issues on wards before 2018 and that prior to 2018 there was no indication of any infections outwith the norm.	Infections Communication	David Campbell
June 2020	Independent Review published.	Independent Review	
June 2020	BBC airs Disclosure: "Secrets of Scotland's Super Hospital". Patients and families are given no advance notice of the programme.	Communication	Professor John Cuddihy
22.03.21	Final Oversight Board report published.	Oversight Board	
Spring 2021	Individual CNR reports issued.	CNR	

APPENDIX 3: TABLE OF WITNESSES WHO RAISED A CONCERN ABOUT INFECTION

	Name	Infection Type (confirmed or suspected)	Date(s)
1	Cameron Gough and Colette Gough	Serratia Marcescens	September 2018
2	Suzanne Brown and Graham McCandlish	Line infection. Possibly Staphylococcus	February 2017
3	David Campbell	Suspected infections	September to December 2018
4	Stevie-Jo Kirkpatrick, Annemarie Kirkpatrick and Steven Kirkpatrick	Mycobacterium Chelonae Listeria meningitis and unknown respiratory issues	January 2019 August to December 2018
5	Witness 6	Suspected infections	
6	Sharon Ferguson	Aspergillus Enterobacter Stenotrophomonas Acinetobacter	October 2017 to November 2019
7	Charmaine Lacock and Alfie Rawson	Staphylococcus Pseudomonas Candida	September 2018 to March 2019
8	Leann Young	VRE Aspergillus	May to June 2018
9	Denise Gallagher and James Gallagher	Stenotrophomonas Staphylococcus Epidermidis	September to December 2018
10	Witnesses 1, 2 and 3	Multiple line infections	
11	Karen and Andrew Stirrat	Multiple infections	March 2019 – December 2020

12	Aneeka Sohrab	Multiple line infections Pseudomonas	May 2018 to November 2020
13	Senga Crighton	Line infection	September 2018
	5 5		•
14	Molly Cuddihy and Professor John Cuddihy	Mycobacterium Chelonae Line infections	April to May 2018
		PCP Pneumonia	November 2019
15	Lynndah Allison	Multiple line infections	November 2016 to November 2017.
16	Louise Cunningham	Multiple line infections Enterobacter Cloacae and Raoutella Planticola	October 2017 to January 2018
17	Samantha Ferrier	Enterovirus Rhinovirus Norovirus	August 2019 to December 2019
18	Anonymised	Cryptococcus	December 2018
19	Theresa Smith and Matthew Smith	MSSA-PVL	April 2017
20	Mark Bisset	Adenovirus Aspergillus Putida Pseudomonas	June to August 2019
21	Haley Winter	Enterobacter Cloacae	April 2018
22	Sharon Barclay	Line infection RSV Norovirus Rhinovirus Astrovirus	May 2017 to October 2020
23	Rachael Noon Crossan	Streptococcus	June 2017 to August 2017
		Enterobacter Cloacae	

24	Kimberly Darroch,	Stenotrophomonas	August 2017
	Christine Horne and Derek	Maltophilia	
	Horne		
25	Carol-Anne Baxter	Staphylococcus	February 2019
		Sepsis	
		Klebsiella pneumonia	