Scottish Hospitals Inquiry

Witness Statement of

Dr Anna Maria Ewins

WITNESS DETAILS

1. My name is Anna Maria Ewins.

2. I am an Associate Specialist in Paediatric Oncology at the Royal Hospital for Children (RHC) on the Queen Elizabeth University Hospital (QEUH) Campus in Glasgow.

PROFESSIONAL BACKGROUND

3. When I first qualified as a medical doctor, I did two pre-registration jobs. My first six months were in surgery at Hairmyres Hospital, East Kilbride and then the next six months in medicine at the Glasgow Royal Infirmary. I then did a period of training in pathology at the Royal Infirmary. I applied for a job in paediatrics in 1994 and prepared for the membership exam during training posts.

4. In 1997, my current post arose at Yorkhill Hospital in Glasgow. As a speciality doctor post, it gave me the option of being able to stay in the one place. At that time, I had three small children, so the stability the post offered was very attractive to me. I gained my MRCP (UK) in 1997 and became a full member of the Royal College of Paediatrics and Child Health in 2004. In 2021 I sat the first ever EBMT (European Bone Marrow Transplant) exam to gain a Diploma and 5 year certification.

5. Research is an important part of the work of the department. I am a Principal Investigator in 2 Clinical Trials and Sub-Investigator on several other

departmental trials. I am co-author in a number of transplant-related research papers.

6. In the early days, I worked across all the areas of the unit, both benign and malignant haematology and oncology. I was an appointed Associate Specialist in 2006 with a focus mainly on stem cell transplantation. I am currently the only doctor in the unit whose remit is just transplant. There are several other doctors who also work in transplant; however, they have other additional responsibilities within paediatric haematology and oncology.

7. In addition to my specialist clinical work, I also perform one session a week as a sub-dean for undergraduate students who have a clinical attachment to Queen Elizabeth University Hospital. In my clinical role, I work very closely with Professor Brenda Gibson. Since 2014, we have had more doctors who have been appointed to spend time in transplant, so the team has grown quite a bit. As one of the more established doctors there, I am involved right across the spectrum of the job. For example, when we receive referrals in for transplants, I am involved in selecting donors and choosing what stem cell source we use. My involvement continues in every stage of the process from the planning of the transplant right through to follow up of patients who have been transplanted. I would also be involved in the day-to-day medical care of patients when they are having their transplant.

8. Although I am a senior doctor, my line manager in terms of leave and such practicalities would be Professor Brenda Gibson, who is the Clinical Lead in our department.

TYPES OF PATIENT TREATED

9. I am based in Wards 2A and 2B, known as the 'Schiehallion Unit', in the Royal Hospital for Children (RHC). We treat children from birth to the age of eighteen. The paediatric haemato-oncology unit within the RHC is the largest in Scotland. Although there are other haemato-oncology units such as Edinburgh, Dundee and Aberdeen, we provide a national paediatric stem cell

transplant service for all of Scotland. We also look after patients jointly with paediatric colleagues in Inverness and Dumfries.

10. We occasionally take children from elsewhere in the UK, because we are part of the UK wide paediatric stem cell transplant group. If a transplant bed cannot be found for a paediatric patient in Bristol or Nottingham for example, and if we have the capacity, then we would carry out that transplant. We are the only unit in Scotland which, on occasion, takes children from elsewhere in the UK such as Belfast, Sheffield, Bristol and Cambridge. We see ourselves as part of a wider UK and Republic of Ireland group who regularly meet virtually to discuss difficult cases. We also meet in person at least two times a year to audit our performances, to talk about difficult cases and develop themes if we recognise trends in diseases. We share a lot of information. Although we are, in some respects, a standalone unit in Scotland, we do feel well supported by a virtual network with whom we are constantly in contact.

TYPES OF TREATMENT NEEDED BY BMT PATIENTS

11. The RHC is a national centre for bone marrow transplantation. The two types of transplant you can have are autologous, when it's your own stem cells, and allogeneic, when it's from another individual. If a child needs an allogeneic bone marrow transplant in Scotland, they will come to us. Also, we are a centre for a treatment called MIBG (Meta Iodo Benzyl Guanidine). This process involves giving a radioactive drug to patients with a condition called neuroblastoma. MIBG is molecular radiotherapy. When a patient is given radiotherapy, the entire body is radiated, however with MIBG, a tracer is given to the patient which seeks out the parts of the body affected by the condition, and it delivers localised radiotherapy.

12. Ward 2A is the inpatient ward for paediatric haemato-oncology. There we treat children with blood disorders, malignant or benign. Ward 2B is the Day Care Unit. When we send patients home, we often bring them back to 2B for follow up infusions. Or, if the patient comes in unwell, they will come in

through 2B where they will be assessed and triaged and then transferred to the ward.

13. Benign diseases would be children with haemoglobinopathies such as sickle cell disease, thalassemia, which is a red cell disorder, clotting disorders, and anything which primarily affects the blood system. If a child is unwell enough to be in hospital with one of these conditions, they will likely come to Ward 2A. These children may require transplant. We also treat children with bone marrow failure; they don't have leukaemia, but their bone marrow isn't working properly. Another group of patients we treat are immune deficiency patients who may have inherited conditions which make them very susceptible to infection. We can provide a protective environment for those children too.

14. In the old days, my workload was mainly leukaemia but in the last 20 years or so it has expanded to include children with many other conditions. Malignant diseases would be disorders like leukaemia or lymphoma. In the unit we also treat children with solid cancers, such as bone tumours, brain tumours, neuroblastomas, kidney tumours, any sort of malignant disease or any disorders which may require treatment with cytotoxic drugs. Cytotoxic drugs are anti-cancer drugs that target and kill certain types of cells and stop or interrupt the cell reproduction. They are used in cancer chemotherapy to shrink and kill tumours. Children requiring anti-cancer drugs would be treated in our unit because it has specialist facilities for looking after children who become very immunocompromised by the treatment.

15. As a Bone Marrow Transplant (BMT) Specialist, I treat a broad category of patients. I treat patients with leukaemia and patients with inherited conditions who need a blood stem cell transplant. They may have a benign condition, but it could be life threatening or significantly impair quality of life to the point that it is worth risking a transplant.

16. In terms of the work I do on the transplant side, a patient will come to transplant if they're referred in from another centre, or if we recognise a

patient in our own service who needs a transplant. The rationale for transplant must come under a list of clinical indications. That is set out by British Society of Blood and Marrow Transplantation (BSBMT). They are the body who draw up agreed criteria, or "clinical indications" for transplant.

17. There are other conditions where transplant is a clinical option; maybe there are reasons why a patient may consider continuing with their current treatment or go to transplant. There are some conditions for which transplant is not recommended. It has to be a justifiable clinical indication, and we don't do it lightly. If the patient has a malignant disease, they must be in remission, because you cannot cure leukaemia with transplant if you still have leukaemia present when you go to transplant. We must complete a series of chemotherapy and we must have evidence the disease has responded adequately to benefit from transplant.

18. If a patient has a benign condition like an immune deficiency, their disease has to fall under the "clinical indication" category. We would discuss all our immune deficiency patients in a regional Network clinic with immunologists from Scotland and Newcastle. A decision would be made about whether the patient should be transplanted in Glasgow or in Newcastle. If it's suitable for our programme, the patient must be infection free. Everybody has to have a central venous line. They also have to have a baseline battery of tests which shows they are likely to stand up to the challenge of a transplant. We do a lot of heart, kidney and lung function tests just to see if we can pick out people who would not tolerate what we're proposing, or if we have to propose something less toxic.

19. We will try to find the best well-matched donor, and that involves working with colleagues at the tissue typing lab. If the donor is going to be a brother or a sister who is a child, we have to go through the HTA (Human Tissue Authority) for approval. The HTA needs to be satisfied that the child has not been coerced or in any way treated inappropriately in order to obtain their

stem cells. We then perform the bone marrow harvest from that child, in order to obtain stem cells for the patient.

20. To get to transplant, you need to give patients treatment that will render them incapable of rejecting the transplant. If you were to identify a well-matched donor and try and do a transplant on somebody who has not received conditioning treatment, they would reject it. Their body would recognise it as non-self. Even though it's matched at a reasonably good tissue level, the immune system is set up to recognise all proteins which are not part of you. Your immune system will react as if "that's not my protein, let's attack it.'

21. In order for a patient to accept cells from another individual, you have to wipe out the patient's immune system. Then, once you've put those cells in, you need to supress the immune system that has come from the donor to stop it from attacking the patient's tissues. The donor immune system is healthy, so it could get into the recipient's body and react as if it is in the wrong body. That is called graft versus host disease.

22. We immune suppress the patient to accept the graft. We also immune suppress the graft, the donor cells, to suppress graft-versus-host disease. There is a prolonged period of immune suppression to allow the transplant to take and for the transplant not to attack the patient.

23. Over the period when we immune suppress the patient, they have no white blood cells; they will be dependent on blood and platelet transfusions. They'll be exquisitely sensitive in the first month to bacterial infections and then after that first month, most of the infections we'll see will be viral or fungal. Transplant patients need to be nursed in a protective environment until we start to see neutrophils coming through.

24. Once we start to see neutrophils, we can allow the patient to go home, but they are still immune suppressed, and they could still get a bad viral infection that could make them very ill. If they've been transplanted for leukaemia, we keep monitoring to see if there's any signs of leukaemia re-occurrence and

that's most likely to happen in the first year post-transplant. Once you've got past that first year, we would be hoping that we have dealt with the leukaemia, as most relapses occur in the first 12-18 months after transplant. It's an anxious first year for leukaemia patients. For non-malignant patients, you can see complications like graft-versus-host disease and viral reactivations. They can lose their graft, and we need to monitor for that.

25. It's an intensive follow up programme for all our transplants. They can get very sick when they're in having the transplants because the conditioning treatment which makes the patient incapable of rejecting the stem cells causes havoc in their body.

26. To wipe out the immune system or wipe out the patient's own bone marrow, there are lots of what we call "off-target" effects; the conditioning treatment can be really toxic on the gut, especially for leukaemia patients who receive the toughest types of conditioning treatments. They often have troublesome tummy pain, vomiting and diarrhoea, no appetite. Patients will often be incapable of eating or drinking, so they'll need a tube in their nose to feed them. They might need to be fed intravenously, so a Hickman line is essential.

27. It's often a real challenge to get enough nutrition into sickly transplant patients. This often delays their discharge from hospital, because nutritionally they're not in good shape if they have been unable to absorb enough calories or nutrients for a period of weeks. Lots of complications can occur because of the treatments. For example, patients can get high blood pressure or renal impairment where their kidneys don't work as well as they did before transplant. You can get toxicities from all of the drugs we use singly and in combinations. Working in transplant, we have to be very alert to these complications.

28. This means we need the physical environment to be as safe as possible. That means keeping environmental pathogens to an absolute minimum. We must educate families and parents to behave in a way that reduces risk. We must

have staff who know the risks and recognise the potential exposure of patients to infection. It is an absolute minimum requirement that we have those safeguards in place.

29. You also need proximity to services which help you diagnose and treat the many complications of transplant: facilities like radiology, for when patients get fevers, and you need to obtain x-rays and scans. You need proximity to an ICU (Intensive Care Unit). This patient group uses ICU a lot, so you need to be co-located in a building with a Paediatric ICU. You need to have a relationship with colleagues on that unit which allows easy access for your patients, because when they get sick, you need to intervene early . The patients have complex needs, so you need quick access to specialists in the hospital who can deal with patients with this degree of complexity.

30. We are now located on the floor above PICU. We were in the adult hospital transplant unit for several years and that made me anxious, especially when we were transplanting babies, because we were physically quite a long way away from PICU. Thankfully that didn't adversely impact our patients, but it is the sort of thing you worry about. It’s one of these things you have to factor into an already complex situation.

31. There are differences between paediatric intensive care and adult Intensive care. In paediatrics, everything is size and weight based. When you are in adults ITU there are lot of standard doses for medications. Adults come in all shapes and sizes, but children have a much greater size and weight range, and they are physiologically more diverse at the extremes of age. We could be treating an 18-year-old who is 90 kilos and a two-month-old who is four kilos. We have to think about diverse physiological normal ranges which affects the basics like how we dose drugs and fluids, as well as nutritional needs. Children under ten kilos may have chemotherapy doses based on their weight in kilos, whilst for the same drug, children over ten kilos may receive a dose based on their surface area. Babies and children have relatively large heads and small airways, so if you have to intubate a patient, you need

specialists who are experienced at intubating small children. You need that range of expertise.

32. If I'm preparing a patient for a transplant, it takes, on average, eight days to give the conditioning treatment. It then takes two to three weeks for the patient to engraft once you've given the donor cells, so the conditioning treatment is given on day minus eight, the cells are given on day zero and engraftment occurs at between day 14 and day 21. The earliest your patient might go home would be about day plus 28, so if you add the eight days at the start on to that, it takes you to day 36, or a minimum 5–6-week admission.

33. The shortest time a patient would be in for from the beginning of transplant to discharge would be six weeks. That depends on whether there are any infections, whether the patient is able to take all the medicines required to keep them well, and whether they need any intravenous support. The quickest we would get a patient out from transplant would be six weeks, and that would be with a lot of day care support in place. A lot of patients will be in for longer than that because of all the potential complications.

34. Transplant is difficult. We are often dealing with the sickest patients outside of intensive care. We make patients very sick on the road to making them better. Transplant is often done as a salvage procedure, when there is little chance that continuing on chemotherapy will result in cure. The patient's only chance of cure might be a transplant, so the stakes are very high and that makes it a stressful area of working. You have to have a good team ethos. You have to feel as if the team is pulling in the same direction and, for that, you need physical space to build a team. You need to have a constant and ongoing education programme to keep your team functioning well, and to keep patients safe.

35. We also need to reflect on things that don't go well in addition to learning from things that do go well. We are keen to learn from, and adopt good practice from other centres, so we have to constantly share experiences and be open

to listening to the experiences of our colleagues in other paediatric transplant centres.

36. Sadly, in transplant, if you transplant a child for leukaemia, there is still around a 30 per cent chance the disease will return. This means that a lot of our patients go through a very difficult journey and then ultimately, they do not survive, because despite the treatment, we haven't cured the disease. Sometimes patients die because of complications of the transplant, despite all our efforts to treat complications early and aggressively. These events are hard to deal with because the patient has been through the transplant procedure with all the side effects, and the wider impact it has had on the last weeks and months for the child and the family. It causes you to reflect on why we haven't succeeded for that family. We need to be able to talk things through with colleagues when these tragic events happen. It is necessary to reflect on these events as professionals in our local and national meetings.

37. It's a difficult journey for staff and patients. We get to know families well because we often meet them at a time of crisis. The clinical team and the family must work as a team with a common purpose to help the child through a very difficult course of treatment. We cannot succeed without parents being in partnership with us. You learn to try to remain very professional with families because you might have to have a really difficult conversation in a few weeks' time. While you show a lot of empathy and humanity, sometimes you're going to be having conversations about stopping care or telling them the treatment hasn't worked. That is really difficult, but you have to be able to live with yourself after that. I suppose our approach is to offer a very professional service that is backed up with kindness as well as science and experience. We need to know the pitfalls, where and when they can occur, and be alert to them when they do occur.

38. I think we always proceed on the basis that the treatment is going to work but know that it might not. Even after doing this for 25 years, I find there are patients who, at the outset, we may not expect to tolerate treatment well, but who come through transplant and are cured, and others who suffer

unexpectedly from rare complications. I think one of the difficulties of moving site, away from Yorkhill to the new children's hospital, is that we remember all those patients: those who survived, and those who sadly didn't. I felt guilty about leaving them behind because physical places are markers that bring to mind patients; you remember their family and remember that day of happiness or sadness. That's only human. When you move to a fresh canvas, it lacks those reference points.

39. We deal with unknowns and uncertainty. I suppose when things are not going according to plan, it's difficult to deal with all that in addition to the routine work that you're doing. I think in the old building there were lots of informal spaces where you could go and have a moment. We lacked that after the move: the feeling that you could go and find a space to think.

40. I feel as if there was little regard given to how staff deal with this aspect of the job. The people who designed the spaces didn't think about those issues. If we can't deal with these issues, we end up snapping at somebody or not being able to function properly. I think acknowledging that need, and finding an outlet, is a healthier way to work.

THE RHC SCHIEHALLION WARD

41. In the new hospital we felt homeless to start with. It felt like lots of things that were challenging before were now huge challenges. Hot-desking on the ward did not work. If you wanted to dictate a letter, you couldn't take the notes out of the ward and the office block was in another building. It felt as if everything was more difficult than it needed to be. A lot of things became difficult purely because of logistics. You would get over to your desk and think, 'Oh no, I've left something over in the ward, I now have to walk back.' It's quite a distance away, so you could spend a lot of time walking back and forth, especially when we started, because you weren't familiar with the layout. Phone coverage was also poor, making it difficult to reach colleagues who were off site.

42. In Ward 2A we did have 26 beds. We lost some beds because there was repurposing of rooms. One has become a 'Tweenies' room, created to provide facilities for 8–12-year-olds where previously there was a gap, and another became a pharmacy room, so there are now 24 beds.

43. In terms of staff, in oncology we have three full-time consultants and one who is half oncology and half palliative care. There are 4 haematology consultants. There is a fifth haematology consultant who is responsible for the teenage leukaemia and lymphoma patients. His job is split between 2 sites: half of his time is looking after teenage patients at the Children's Hospital and the other half is looking after teenage and young adult patients at the Beatson. My own role is mainly part of the haematology team. I mainly cover transplant now.

44. We have another three speciality doctors who work across day care and the ward and also contribute to the middle grade on-call. In addition to me, there is also one other doctor who is retired but comes back for some sessions.

45. There are many nurses who work between the wards, I don't exactly know how many there are from day to day. A lot of recruitment goes on in nursing areas which leads to high turnover of staff.

46. In terms of junior medical staff, every six months we get adult haematology trainees who come in to do paediatrics. We also get paediatric trainees; they change around every six months or so. Every four months we get recently qualified junior doctors who rotate through the unit.

47. Structurally, we come under the Women and Children Directorate which was managed by Jamie Redfern. He has now been replaced by Melanie Hutton. If I ever have an issue that I feel is not something Prof Gibson can help sort out, I would speak to Dr Phil Davies. Phil is the clinical director, a consultant paediatrician who also has a managerial role, and he is our line manager for things like job plans or problems in the department. In view of his role as a respiratory paediatrician, we would often involve him in clinical situations too.

Phil would also be the interface between us and Alan Mathers, who is the Medical Director of Women and Children' Services

VULNERABILITIES OF IMMUNOCOMPROMISED PATIENTS

48. Many of the patients we treat are immunocompromised. This means their immune systems do adequately protect them from infection. Our patients are vulnerable because they are lacking important components of the immune response, so they tend to become more unwell with infection and illnesses are more prolonged.

49. Everyone is prone to infection from organisms their immune systems haven't dealt with before, even if you have a tip top immune system. Immunocompromised patients are more at risk of becoming severely unwell from things that would not normally make people unwell. That is because they lack the type of cells that can form an immune memory, make antibodies, or be a first line of defence when they meet an infecting organism.

50. There are complex reasons why people become immunocompromised, but most of the patients we deal with are immunocompromised because we've given them chemotherapy. They lack the first line of defence type cells called neutrophils. Neutrophils help you fight bacterial and fungal infections, so if you have no neutrophils and you get a bacterial infection, that bacteria can multiply quite rapidly in your bloodstream, and you can become very unwell.

51. Some other patients may have neutrophils but won't have any lymphocytes. Neutrophils are a group of cells which are produced in the bone marrow. They circulate around your blood stream. If you were to cut yourself and bacteria were to get at that breach in your skin, neutrophils would go there and essentially eat the bacteria.

52. Lymphocytes are the white blood cells that are important in making antibodies and fighting viruses. They are important in coordinating a response to viral infections.

53. Some of our patients can also be anaemic. In your blood you have red cells which contain haemoglobin and carry oxygen. You have platelets that stick; if you bleed, then these go to the site of a cut and they stick, so these are cells that stop you bleeding.

54. Also, when neutrophils congregate at the site of tissue injury, where there might be infection, they send a chemical signal to tell the rest of the immune system to come along because there is trouble. They can be responsible for releasing chemicals that alert the immune system by signalling, 'There's a problem, she's cut her finger, come and deal with this.' If bacteria are there, your immune system and your clotting system will heal that tear and, in the process, you might notice a collection of pus at the site of an injury. That is the result of neutrophils performing the function of destroying the invading bacteria. If it's dealt with properly, the pus will serve the function of destroying that bug. If the infection is overwhelming, you might get a big abscess which is an extension of a small pustule or spot. If the bacteria are still not being controlled, you could get septicaemia, which is when bacterial infection is not localised in your skin, your throat, or the lining of your gut, but has multiplied and has spread into your bloodstream.

55. Neutrophils are like the foot soldiers of the immune system. They get there, they deal with the problem, alert the rest of the immune system to a problem and they deal with bacteria. They also deal with fungus, because these are bugs that tend to land on surfaces, and neutrophils are good at dealing with these surface invaders. If you don't have neutrophils, you're susceptible to bacterial infections. Neutropenia can be a result of treatment or a primary illness.

56. In our unit there's a culture of thinking about neutrophils and lymphocytes. If you move outside of a haematology unit and you see a child with an infection,

you know that the expectation is that the child will get better. The doctors will look at the child and say, 'Well they've got a temperature, they're feeling a bit unwell but tell them to take paracetamol, and it is safe to send them home.' However, in our unit, we would think, 'Oh the child's got a temperature, but they've got no neutrophils, so we better look for the infection and while we're looking, before we know can confirm that they have an infection, we treat it.' We treat first, ask questions later - that's our approach to a fever or an unwell child. We assume infection is the problem because of the immunocompromised status of our patients.

57. That is a shift in thinking which is learned by our trainees. They must stop thinking in terms of a well child with a temperature and start thinking, 'This is a child who can't cope with infection.' This principle is to the forefront of our work. Even a very junior nurse in our unit would know that a fever in one of our patients is significant and must be reported up the chain and dealt with quickly.

58. That leads to a different culture as far as hygiene is concerned. We limit the number of people that can come in and see our patients. We give parents advice about hand hygiene and, in the case of transplants, we are very strict about who can come into the room and what can be brought into the room . We are also strict about what diet these children have because if you are neutropenic, you need to avoid certain foodstuffs.

59. We assume that every patient on the ward is immunocompromised to some extent. Transplants are the top of the immunocompromised tree and the patients with non-malignant conditions would be further down, but they'll still be compromised to some extent if they have lots of transfusions.

IMPACTS OF INFECTION

60. If a patient gets a line infection, we have to pause the chemotherapy to address the line infection. If they're not too unwell, we may resume it while

they're still on antibiotics, but we'll usually resume once we've proved that the blood culture is negative, and all the inflammatory markers are low. If the line has had to come out, then we must observe a period of time post-line removal before we put a line back in because we don't want to put it back in while there are bacteria circulating. That might delay chemotherapy by a week or so. If a patient is very unwell with an infection, then the delay might be longer than that. If a patient has ended up in ICU, they may be delayed by a week, or several weeks in the case of a fungal infection. Infections can delay the introduction or the reintroduction of chemotherapy. Infections can also delay transplant because we only go to transplant when the patient is clear of signs of active infection.

61. Infections can also result in two surgeries with two general anaesthetics. A surgery is needed to remove the line and a further surgery is needed to insert another line.

62. Infections can also mean a patient is exposed to antibiotics that can affect their kidneys or liver function. There are many potential toxicities of having line infections or any infection.

COMMUNICATION IN RESPECT OF HAEMATO-ONCOLOGY

63. In terms of communication to patients and families, we tell patients what medications the patient will be on and for what duration, for example, that they will be on certain medications for the next year. We make sure they have a supply and we're always checking to make sure they're taking them.

64. From a haemato-oncology perspective, we have a rigid code that we communicate through. We have SOPs (Standard Operating Procedures) that we follow, and transplant is heavily regulated and inspected by JACIE, the accreditation body that insists that you have a policy or a procedure for everything you do. That goes from the decision to do a transplant, how you choose a donor, how you condition the donor, and it covers every aspect of

the process. An important aspect of the process is that you meet with families to have a discussion about the appropriateness, otherwise, of transplant.

65. We also send the family a letter explaining the rationale for the transplant and the potential complications. It's based on a standard format, from a library of templates, to ensure that the necessary points are covered. However, the letter is tailored to the patient's individual circumstances. For example, if you have a patient who has had a lot of treatment and is coming into transplant with a fungal chest infection, that may alter the balance of risks, and the nature of the discussion around risks of treatment, and the letter will reflect the increased vulnerability to transplant related toxicity.

66. Another thing that that letter often reflects is the fact that patients may have been discussed at national, Scottish and UK-wide Multi-Disciplinary Team meeting (MDT). This will be included in the letter where appropriate. MDT meetings are where we will bring difficult cases, or when want agreement that a proposed course of action is an appropriate thing to do.

67. We also tell the families what the mortality risk of the procedure is, and you then justify that mortality risk. We will often say that there's a 5 to 10 per cent mortality risk just from the transplant procedure. It's quite a hard letter for a parent or patient to read. We list a lot of potential side effects. We sign that letter, we send it to the family, and then we invite the family back to go through a proforma consent form that ensures we obtain a signature to confirm that we've covered all the major issues in that letter, like infection, risk of infertility, risk of organ failure, risk of death, etc. Completion of the transplant consent paperwork is mandatory.

MITIGATING VULNERABILITIES AND RISKS BY USE OF DRUGS AND PROPHYLACTICS

68. As well as the cytotoxic drugs that I described earlier, we also use prophylactic medications to help manage the risk of infection. All leukaemia

patients get Septrin or Cotrimoxazole (the long name for Septrin) prophylaxis, to protect them against a particular type of pneumonia that you get when you have a very low white cell count.

69. When transplant patients are at the neutropenic stage, they are prescribed Ciprofloxacin. The purpose of Ciprofloxacin is to keep gram-negative bugs at a minimum. It is a prophylactic measure to prevent, or at least to try and minimise, translocation or movement of healthy gut flora into the blood stream. Ciprofloxacin is standard neutropenic cover for transplant patients; you are trying to prevent a predictable, but serious thing from happening.

70. They also receive Septrin, which is used in patients who have no white cells, to prevent opportunistic chest infections. It is given twice a day in the run-up to transplant and then you pause it, and you restart it once they've got a neutrophil count. Again, that would be standard practice and the patient could be on that for up to two years.

71. Usually when you give the Ciprofloxacin, the patient is not on Septrin, because we don't restart the Septrin until there is a neutrophil count. This is because it can drop the neutrophil count. There will therefore be a window when the patient is just on the Ciprofloxacin, but still in a HEPA-filtered positive pressure room, so the risk of opportunistic infection is low because of the protected environment. We don't usually restart Septrin until the patient is being discharged, because the type of bugs that Septrin protects you from are in ambient air.

72. Transplant patients also receive Acyclovir, an antiviral, until they are ready to be revaccinated. They are also prescribed an antifungal drug called Posaconazole. Posaconazole might be prescribed for any period of time from about three months to maybe 18 months. Transplant patients all have prolonged exposure to antimicrobials of various classes for various reasons.

73. Leukaemia patients receive antifungals during induction and Septrin all the way through treatment. A lot of the solid tumour patients will receive Septrin

during chemotherapy and they'll get antifungals during intensive bouts of chemotherapy. All the patients with hemoglobinopathy will get penicillin by mouth. They normally have no functioning spleen. Hemoglobinopathy describes sickle cell disease or thalassemia. It's not a malignant disease, but it's a genetic disorder of red blood cells that make you transfusion dependent, and all those patients will be on penicillin prophylaxis, taking it twice a day for the rest of their lives.

74. With leukaemia treatment, the induction phase is basically when you're trying to get rid of circulating leukaemia cells. That's the purpose of your first four or five weeks of treatment, and then you do an assessment at the end of that period, and you assess whether or not you've got your patient into an adequate remission. Their response to that phase will determine whether or not the patient is going to stay on chemotherapy and stay on the protocol they're currently on, or whether or not the treatment is going to be escalated to more chemotherapy or a transplant. Induction is that early phase of treatment. You start it with a disease burden and you end it, usually, with a low blood count, so the patient is quite vulnerable during that phase of treatment.

75. The phases that follow are called consolidation, intensification and maintenance. To summarise, you've got induction, when you aim to eradicate the disease, and consolidation of remission, followed by a period of treatment intensification, before a prolonged phase of less intensive maintenance when the patient would be an outpatient and attending nursery or school.

76. The prescription of particular prophylactics depends on the underlying disorder. The transplant patients get quadruple cover with Septrin, Acyclovir and Posaconazole and they'll get Ciprofloxacin or Penicillin depending on whether they have a neutrophil count. This is all to help prevent infection. In the case of transplants, you're doing it until the new immune system is fully up and running, so it's a protective thing and is standard practice.

77. We give Ciprofloxacin to cover the neutropenic phase of transplants. You've given the chemotherapy until the graft begins to make neutrophils. When we start seeing that the patient has a neutrophil count, we stop the Ciprofloxacin because usually, by this stage, their gut has also healed, so they're not at such a risk of gram-negative bugs getting into their bloodstream, so we start Penicillin. We don't have patients on Ciprofloxacin and Penicillin together, we replace one prophylactic with another in the form of penicillin.

78. As for side effects, Posaconazole is probably the most toxic of the drugs described. It can put your liver function off, and it can interfere with the metabolism of other drugs. It can interact with other drugs to give you abnormal heart rhythms. It's not very pleasant to take. You have to monitor the drug levels, so you have to get blood tests as you're upping and downing the dose.

79. Ciprofloxacin can also interact with other drugs. It can make you feel pretty poorly. Septrin is pretty well tolerated and is usually only taken three times a week. Acyclovir is well tolerated; it's a twice daily drug.

THE CENTRAL VENOUS LINE

80. In respect of administering chemotherapy, the preferred option is through a central venous line. This is a plastic line which is put in surgically through one of the big veins in the neck. The surgeons put them in. They make a very small incision usually above the clavicle to access one of the jugular veins. They then feed the line down through the jugular vein and it sits in the superior vena cava, which is the biggest vein in the body that comes into the right atrium, the low pressure chamber on the right side of the heart. If you kept feeding it down, it would eventually go into the right ventricle, but you don't want it in the ventricle, you want it either in the right atrium or the superior vena cava; it is in a big venous chamber.

81. The line has a tip, and that tip contains two channels. Inside the central venous line there are two lumens, which are the channels common to all

central lines, which allow blood or fluids to be delivered into the body. The surgeons tunnel it through the skin, and it comes out in the chest wall as a line, a single piece of plastic, that contains these two lumens. Then the line splits so you've got a red lumen and a white lumen. It's like two tubes within one single tube. It allows you take blood and give drugs without having to pierce the child, so it's great for painless access, but it is a foreign body that sits usually in the child's chest wall, and it is surgically inserted in theatre. After a child has completed their treatment, it's a tiny wee scar above the clavicle, so you might see a spot on the chest wall where it went through. The importance of tunnelling is that, if somebody pulls it, there's a bit of slack so that it doesn't dislodge too easily.

82. The benefits are administration of medication and drawing blood. It also has benefits in terms of resuscitation, as you can fill the patient up quickly if they look like they're collapsing as you've got access to the circulation right away.

83. Nearly all the patients with malignant diseases have these lines, and all the transplant patients will have them. It's essential to deliver the treatment they need. Children with cystic fibrosis might also have one for repeated antibiotic administration and children with kidney disease may also have a version of it for dialysis.

84. Sometimes patients talk about a 'wiggly'; with one of those you can see the line sitting outside the body.

85. A port-a-cath is just the same except it doesn't come through the skin, it sits under the skin instead, so the line doesn't divide in two. It has two lumens, so you can deliver two different drugs simultaneously. It coalesces under the skin as a metal box, with two chambers into which each lumen empties. What you would feel on the chest is a firm rectangular shape, and that's the metal box. You can stick a needle into it so it's almost like a needle of a badge. One lumen will empty in to one half of the box and the other lumen will empty into

the other half, a double lumen. A lot of ports are single lumen, so the line is just like that, and the port just empties into it.

86. A port is often used in younger children where you worry about them pulling the line out or maybe in children for whom who you anticipate needing access for a more prolonged period because you only need to flush a port every four weeks, whereas a central line needs to be flushed every week or it will clot or get infected. There is less maintenance for a port, and access to it is slightly different: you need to put numbing cream on so that the child doesn't feel the needle going in.

87. Access to these ports is almost exclusively the preserve of the nursing staff. They access the lines all the time and they are the experts and know how to manage them. It's something I would stay well clear of and would only do as a last resort. It is the same for central lines; the nurses are taught all the techniques about how to access them without causing infection.

88. There are some risks associated with these lines, for example, the surgeon might inadvertently cause a lot of bleeding in a very vascular area of the body. There are risks associated with surgery, including anaesthetic, and the risk that the line ends up in the wrong vein. Placement in the right atrium, or too far into the right ventricle, can interfere with heart valve function so it might have to be pulled back. In general, putting lines in can increase the clot risk of the patient, especially for teenage girls. It can increase clot risks away from the line such as in the head and elsewhere in the body.

89. Having a central line can cause infection, as you are breaching the skin to put it in. Your skin is full of lots of bacteria, so bacteria that normally lives at peace with you can enter your bloodstream because you've created a portal, a pathway via the plastic, into the bloodstream. It can become colonised with bacteria that normally are not pathogenic, so normally wouldn't cause disease, but when they get into your bloodstream, they can stick in places and cause abscesses or bacteraemia in the bloodstream and that can make you unwell, especially if you're neutropenic. Lines can increase infection risk.

PROTOCOLS

90. Haematology and oncology practice is very protocol driven. That's because a lot of our patients are treated on clinical trials, and these will define the group who will benefit from the trial and will define the chemotherapy or the radiotherapy treatment.

91. They will also define the supportive care, recognising that these treatments are going to be very immunosuppressive. A lot of protocols, for example, drug trial protocols, will involve the patients being given Cotrimoxazole, the Septrin preventative antibiotic, and other antifungals, and will mandate sometimes to give antibodies also. There are clinical trial protocols that try to standardise the type of care that all patients receive across the country and so will mandate specific treatments.

92. On top of that, we have our own protocols. We have SOPs and clinical guidelines I mentioned earlier, which will cover things like a patient having a fever with neutropenia or a patient having a fever when they've got a central venous line in and will cover the type of unusual infections you often see in the immunocompromised patients.

93. We have protocols to deal with unusual viral infections, fungal infections and that sort of thing, including situations such as having been in contact with viruses like chicken pox or measles. We have written policies that deal with these, because they do happen.

94. In terms of Standard Operating Procedures, the transplant programme has a menu of SOPs, and these will be inspected by external bodies such as JACIE (Joint Accreditation Committee of ISCT (International Society for Cell and Gene Therapy) and EBMT (European Society for Blood and Marrow Transplantation)) and the Health Technology Assessment (HTA), and they would expect us to have these documents in place. An example of the JACIE

standards is the one shown to me at Page 80 of bundle. I can confirm that page 147 of that JACIE document includes, at CM2.2, the standard that "*The Marrow Collection Facility shall provide adequate lighting, ventilation, and access to sinks for handwashing and to toilets to prevent the introduction, transmission, or spread of communicable disease*". We often share those SOPs with the hospital, so some of our SOPs will appear also as RHC clinical guidance.

95. There are periodic JACIE inspections where inspectors come to the Unit and go through all your documentation, interview staff, inspect your facilities and make recommendations about anything they're not happy with. They give you periods of time to correct anything. We have had very good JACIE inspections with minimal findings.

96. We should have had a JACIE inspection after the move from Yorkhill, but it was delayed because we were going to join with the adult Stem Cell transplant programme. The inspections should take place every five years and you should have an interim inspection every three years. If you change a facility, if you move, you're supposed to have an inspection within a year of the move. These routine JACIE inspections were, however, delayed because of the plan for the paediatric and adult programmes to apply for joint accreditation. As we share a processing facility it made a lot of sense for us all to do it at the same time. In the end the joint application did not happen, because the adult unit did not move across to the QEUH as anticipated and then the paediatric unit moved out of Wards 2A and 2B.

97. I think that there would normally be a JACIE inspection with a move of ward too, such as the decant from 2A and 2B. That didn't happen but I think it was because we thought we'd be back there by Christmas. It was difficult to do any sort of planning around inspections, because it's a lot of work and we were already in a kind of contingency scenario, which was stressful enough without taking on the JACIE Inspection.

98. The SOPs within the unit are accessible in a folder called Q-pulse, which is an app or program on the computer desktop that anyone who is part of the transplant programme has access to. However, they are also printed off and held in folios on the ward and in certain designated sites around the unit. They are also stored in electronic form. We send them to our Shared Care Centres, so if they are looking after one of our patients, we can refer them to the SOP, and they can look it up and find it.

99. A Shared Care Centre is a place where our patients might be cared for, where there might not be a specialist haematology-oncology team. For example, we might treat a patient from Inverness in the Schiehallion unit but they might later return to Inverness, or we might have leukaemia patients who end up being admitted to a district general hospital such as Crosshouse or Forth Valley. If a child is neutropenic because they are on chemotherapy and they develop a fever of over 38 degrees, the parents will usually call us for advice and will be advised that the child needs to be seen. If they live locally, they'll come to us in the RCH, but if they are closer to a district general hospital, they will go there instead. The staff in those hospitals are able to access our SOPs, such as the febrile neutropenia policy.

100. We would expect the Shared Care Centre to take blood cultures, check the blood count and start antibiotics, so the Febrile Neutropenia SOP includes an empirical antibiotic policy. The patient may not be neutropenic, but we still expect them to be treated as if they could be, until we know more information.

101. It's a minimum of 48 hours from when the blood culture is taken, until you can get a negative result, but in reality, it takes longer than that because sometimes samples don't go straight to lab. The microbiologists have an incubator which incubates the bottles and once the samples are put in there, that's when the clock starts ticking, so the 48 hours does not necessarily start when you take the sample, rather from the time they start incubating. At 48 hours, if nothing has grown, they'll tell us there's no growth after 48 hours. We'll keep incubating for five days, but 48 hours covers the vast majority of

infections. If a patient has a temperature of 38 degrees or above, we will keep them for 48 hours until we get the negative cultures, provided their temperature settles. If the temperature is still ongoing, then we keep monitoring the patient.

102. Sometimes if a child has a temperature spike, and we have issues with bed availability, it may mean that they have to be admitted or allocated a space elsewhere in the hospital. We have a target, which is not always achievable, of getting antibiotics to the child presenting with febrile neutropenia within about 30 minutes.

103. That can be a challenge out-of-hours when there's fewer staff around and if they're dealing with emergencies elsewhere. Clearly, this can cause anxiety for families with the child who has a temperature. We now try and address that by making them go through the emergency admission route. What used to happen in the old Yorkhill and when I first started was that, if a child came in febrile, the overnight on call middle grade doctor would come and review the patient and start the necessary treatments, such as antibiotics. The patient might go directly to the ward and they would have to wait for the medics covering the hospital to come and see them, so that could cause delay. Now they go through Accident & Emergency, and they'll be triaged. They should be triaged quickly, and A&E will have it in hand to have blood cultures and antibiotics started as they may have to wait some time to get to a bed on a ward.

104. The destination of the patient may be delayed because of other things going on in the hospital, so I know that's a cause of anxiety and dismay for families who present out-of-hours but it's a challenge in every hospital.

CLEANLINESS AND HYGIENE ON THE WARD

105. There are cleaning regimes on the Schiehallion ward. I am not familiar with the details as this is within the nurses' remit. However, I know that there is a schedule of cleaning when a patient vacates a room. I know that we can't just

re-admit into that room straight away; the room has to be cleaned down. Domestic staff follow instructions from the ward staff.

106. With regard to cleanliness and hygiene on the ward, I think the domestics do a great job. As somebody who worked as a domestic as a student, my view is that domestic staff are a crucial part of the clinical team. You can't run a service for immunocompromised people without having domestic staff helping on your team. You cannot open the ward if it's not clean. You can open a ward with minimal doctors, you could do it with reduced number of nurses, but you can't admit patients to beds if rooms are not clean, and if there is not a constant programme of cleaning. A criticism I have heard in the past is that the domestic staff are often moved around, so you don't get the same members of staff and that doesn't help build up a team ethos with medics and nursing staff.

107. I think the 2A and 2B ward domestic staff are not included enough. I don't think their voices are heard. I think they should have a voice in our unit meetings and should be identified as part of the unit.

108. Domestic staff interact a lot with families, they are in the rooms with families every day. They'll often come and tell you how families are coping with hospitalisation, and the families will often tell you about conversations they've had with the domestic staff, so they actually perform more than a cleaning role. They're often important to families because they don't talk about a child's leukaemia or illness, they introduce less threatening topics of conversation. I think they take a lot on and see a lot of stuff in our unit that they probably don't get a chance to discuss with clinical staff, which is a shame.

109. There are other processes we adhere to such as an ongoing rolling programme of hand hygiene awareness. It's part of your mandatory training that you watch the LearnPro module – GGC's online training system - on how to wash your hands and when to wash your hands. There are posters up everywhere about the five times when you need to think about washing your

hands, before and after you see a patient. With COVID, that's all been ramped up. There is also hand gel everywhere.

110. In the immunocompromised patient wards, we wear masks, an apron and gloves. I think that's also become standard with COVID in non-immunocompromised patients as well. It is pretty much standard practice now. We teach that to medical students who are not going to treat immunocompromised patients, to use PPE (Personal Protective Equipment).

SPECIALIST VENTILATION IN WARDS 2A AND 2B

111. In order for us to treat transplant patients effectively, there are structural differences in the rooms. To cover the neutropenic phase post-transplant, the rooms used are HEPA (High Efficiency Particulate Air) filtered. This means that the air going into the room passes through a mesh which would catch anything that's more than six microns, so the air is filtered. If you looked at them under a microscope, HEPA filters are basically quite a disorganised mesh, they're lots of interwoven fibres, and that's deliberate. The way that they're interwoven stops particles of greater than six microns getting through, so that will filter out a lot of bacteria and mould in the air. A lot of viruses are smaller than that so it's not quite so good at getting rid of viruses, however they will filter out any dust particles.

112. The rooms are also under positive pressure, which means the air has been pushed downward towards the floor and when you open the door on a positive pressure room, you feel the air pressure coming out. The idea is that if there's a positive pressure room, for the patient, the air they breathe is filtered. If someone walks into that room and sneezes, the positive pressure will tend to push the air downwards, not across onto the patient.

113. There are inbuilt safeguards in these rooms. In any standard room there will be ambient air with bacteria, fungus, and all sorts of particles, but most people have immune systems so it's not a problem. However, in an

immunocompromised patient's room, the air is filtered, and the positive pressure is designed to stop ambient bugs from infecting the patients.

114. In the Schiehallion Unit at RHC, my understanding is that the entire unit is now HEPA air filtered. We came from a ward in Yorkhill that was filtered and had double door entrances with filtered corridors, but when we moved to Schiehallion in 2015, the corridors were not filtered and only the transplant rooms were HEPA filtered with positive pressure.

115. However, what we have now is a unit that has HEPA filtration and positive pressure in the transplant rooms which is of a much higher specification than the non-transplant rooms. From a hygiene and risk point of view, the air quality in the new unit is of a standard that's probably not matched anywhere else in the world, as far as we can tell.

116. Again, there are standards recommended by JACIE, the overarching body that accredits transplant units, but they are recommendations rather than mandatory requirements. I believe the reason for that is that they don't want to prevent poorly resourced countries from doing lifesaving transplants.

117. The whole footprint of the ward is now filtered including the TCT (Teenage Cancer Trust) rooms. It's all double doored, and the five transplant rooms within the unit all have much higher positive pressure values and they also have anterooms, so there's a step down in pressure in the anteroom. And then the pressure in the corridors is less again, so you get this gradient in the air movement.

118. The way the anteroom works is, when you open the door from the corridor into the transplant room, you're first in the lobby, so you shut that first door behind you, then you open the door into the bedroom. If you're opening that door in the bedroom into the anteroom, it allows a step down in pressure. It's also an area where you can set things down, where you can put on your PPE and you can use hand gel.

119. When we transferred to the current hospital in 2015 all the transplant rooms had monitors on the outside of the rooms. They also had anterooms with big trough sinks in them. The corridor wasn't air filtered, so that took a bit of getting used to because when we moved in at first and they did air sampling, we needed to rely on the positive pressure and filtration in the room to keep those transplant rooms infection free or as infection free as possible, from any airborne bugs. We now have an entirely new ventilation system that covers the whole Schiehallion ward, so I think all the air that goes in is all HEPA filtered.

THE OLD YORKHILL HOSPITAL AND EXPECTATIONS OF RHC

120. I wasn't directly involved in planning the ward in the new hospital. There were meetings that went on at Yorkhill before the move and I recall going to one with people from GGC there. It was a meeting in a Board room with people sitting round the table and I was sitting round the edge of the room. I wasn't asked what we needed.

121. We were told we were getting like for like, so we were quite happy if that was the case because if it was going to be a new build, then things were not going to creak so much. Our expectation was therefore that we would have the same number of rooms and the same spec, only better.

122. Some time before the move, when we were still in Yorkhill, I sent an email suggesting that consideration needed to be given to the risk to our patients in terms of exposure to mould in the air as a result of moving to an environment where there might be ongoing building works or demolition of old buildings. This was because I remembered being in a previous role and hearing about the Cardiac Transplant Unit moving to the Royal Infirmary, which had building word going on. Cardiac transplant patients were immunocompromised, and they got a lot of fungal infections. The events were possibly 10 or 20 years ago and were well-publicised at the time. Based on this experience, I

questioned whether we might need to consider giving our patients anti-fungal prophylaxis.

123. I cannot find this email, and I cannot recall exactly when I sent it or to whom. It was someone who had expertise in this area. I recall being assured in response that anti-fungal prophylaxis would not be necessary. Although I did not entirely understand why this was not a risk, I accepted this response.

124. We did see some floor plans and I remember looking at them and thinking, 'There are no staff toilets there'. That was my first comment. I was then told to choose which patient rooms we were prepared to sacrifice to create staff toilets. It might seem a trivial thing to point out, but if you work in a unit with immunocompromised patients then there is a large number of staff who are working long shifts. We could be in the ward for in excess of 15 hours, so you do need to go to the toilet and you do want clean toilets. You tend to find that toilets out-with clinical areas, like in the canteen and elsewhere in the hospitals, are not so clean, so you want to feel reassured that your facilities are clean, that somebody's keeping an eye on them and that they're accessible. I don't think that that was taken particularly seriously because I was told there would be toilets in the corridors and that we could use those.

125. The good thing about the previous ward at Yorkhill was that there were toilets out-with the ward and out-with day care, so you weren't in a clinical area, but you were still within the unit. There were also two toilets on the ward, male and female toilets. When we raised the lack of toilets in the new plans, we were told that we were going to have a unisex toilet and that there would be one cubicle. We actually got two cubicles which, with such a massive staff, I thought was still poor. I didn't like the idea that the toilets were going to be very heavily used, but I felt that it fell on deaf ears. It was basically 'This is what you're getting.'

126. I can't remember exactly when that meeting was, but I do know that when we tried to ask for things we were told, 'No, the foundations are in,' so the

meeting took place before the building went up. That meeting was with people from GGC Health Board.

127. We were originally supposed to be on the first floor of the Children's Hospital, adjacent to ICU, theatres and radiology. Then we were told we were to be moved to the second floor. I don't know why, and we weren't consulted about that. We were a bit upset when we heard we were being moved because we liked the proximity to theatres, PICU and scanning departments. Transporting patients in lifts can be challenging and time consuming, so we had been pleased to have been originally placed on the same floor. Also, we were allocated very little space adjacent to the ward. The adjacent corridor had already been mostly allocated, and we were losing our seminar room which was where we held our ward meetings. We had multidisciplinary meetings there, we had teaching sessions, family days and it was always a room you could go into and speak to the families. It was a well-used facility, so we were a bit peeved that we lost that space to give it to people to use as offices.

OPENING OF SCHIEHALLION UNIT – FIRST IMPRESSIONS

128. On the day when we moved to the new hospital, we packed up the old Schiehallion and we had series of patients moving with staff. There were staff already on site to receive patients and there were staff staying behind to look after the existing patients.

129. We had stopped transplanting a couple of months previously because we didn't want patients to be severely immunocompromised and then having to get in a car or taxi or ambulance to move to the new hospital, so we had suspended the programme. However, there was one transplant patient who still required care who moved with us.

130. When we arrived at the new hospital, it was very different. We had been shown around it, I think about a month previously, but it's always difficult looking around an empty building. There had been no furniture and no beds in

it at that time. I was very enthusiastic about the move. I was not as apprehensive about changing location as some of my colleagues.

131. We did ask questions. Many months, or even a couple of years, before the move we asked whether we would be moving to a building site. The QEUH campus was still under construction when we moved. The car parks hadn't been put up and there were other things too. It certainly wasn't the finished article.

132. As transplanters, we were all aware of previous experience of new building issues, such as the time when the Cardiac Transplant Unit moved to the Royal Infirmary, which I described earlier.

THE SCHIEHALLION UNIT AT THE RHC

133. The new Schiehallion Unit runs along a curved corridor, with single bedrooms with en-suite wet rooms, a shower, a toilet and sinks adjacent to the patients' beds. There is also a parents' kitchen and a TCT room (which used to be a playroom for the smaller children), and a room for the 'Tweenies' as I described earlier.

134. The rooms on the outside of the curve have windows to the outside of the building and rooms on the inner part of the curve have windows looking into the atrium. That's the outpatient waiting area and it can be quite noisy at times due to the echoey nature of the atrium. There is also a 24-hour service area based in the atrium too, although that's more towards the main entrance.

135. If I'm being honest, I don't like the shape of the new unit. The curved corridors limit what you can see, whereas the ward at Yorkhill was one big, long, straight corridor where you could see everything. You could see where your colleagues were, and you could see stuff happening. If you were doing a long ward round, then you felt as if you were making progress, you weren't going up and down a curve, so I suppose from an organisational and operational

standpoint, the new unit took a bit of getting used to. When you're on this curve in the current Schiehallion Unit, you can't see who's around the bend. Also, if a buzzer or alarm goes off, it can be difficult to work out what room it is. I suppose the human brain likes to see the horizon and you feel like you don't know where the horizon is.

136. The design of the ward means that we have no idea what the climate is outside. It could be a blistering hot day in July or a cold day in December, you wouldn't know. You can see the daylight when you go into a patient's room, but you are not enjoying natural light when you are not in a patient's room.

137. That's a personal view and I realise that I'm very influenced by the previous environment I worked in. There's always the shock of the new and then you get used to it. I did find the new hospital very disorientating when we moved in because of the way it was laid out. Again, that was me just having to re-programme an old brain into thinking about where things were, as it was no longer in my head. I realised that in the corridors you could turn in any direction, you would always get to your destination eventually, but sometimes you ended up going the long way around the curve and that could get quite frustrating. I wasn't that enthusiastic about the curve because I think it makes ward rounds a bit more challenging.

138. The staff are mostly in quite a cramped, small room in the ward. There's an awful lot of us in there, so it often feels overcrowded. Plus, there's a big air conditioning unit on the wall, which was really noisy, so you couldn't speak on the phone when it was operating. I don't think they were thinking about the people that work in the hospital when they built it.

139. Another thing we noticed was that if you were standing outside a patient's room discussing a patient, you could be heard round the bend but wouldn't be able to see if anyone was within earshot, so you were losing an aspect of privacy. This problem arose partly because of the cramped accommodation that we had for staff. A lot of our conversations were conducted outside

patient rooms because in the staff room, with the air-conditioning, you couldn't hear the phone, and there were often so many people in it.

140. The medical staff had one other room on the ward which was against a back wall. It was windowless and, because it was adjacent to the MIGB room, which was lead lined as MIGB is a radioactive drug, you couldn't get phone signals in it, so it was really strange. You could be sitting in there and your phone would buzz and then you would run out into the corridor to have a confidential conversation. There was the risk that passing families could hear, but also that you could lose the call if you didn't answer it. In that aspect, it did feel as if nobody had really thought through the practicalities of working in there.

141. I think we all suffered from the fact that there wasn't much space for staff. This is a job where you often sadly have to take parents into rooms to explain things, to give bad news, to let really difficult conversations sink in. When we first took possession of the ward, I was in a meeting like that with a family and I didn't realise the light went out if you stopped moving. So, we were sitting there talking about a child's leukaemia, and the room was plunged into darkness, so we had to move our arms up and down to get them to come back on.

142. There was no purpose-built room for breaking bad news. We should have had something like that but we didn't. I don't think a great deal of thought went into the non-clinical parts of the wards. Overall, there are not a lot of confidential spaces, there aren't a lot of places for people like psychologists and social workers to come and speak to families. Space is at an absolute premium and that seemed a challenge all the time and made the job a bit harder for us.

143. As far as the temperature in the wards is concerned, I know that in the old Yorkhill it used to be tropical in the summer and very cold in the winter, so the new wards weren't as bad as that. We used to have patient rooms in Yorkhill that families would complain about as they would get too hot or cold, so the

climate in the patient rooms in the new hospital were better, but the staff spaces were cramped and difficult with the noisy air-conditioning units in place.

144. When we moved in, there wasn't a designated pharmacy space as far as I could tell. The pharmacy took over an internal room with no windows and which had a run of shelves where some pharmaceutical stock was kept. They had a bar stool-type of chair up against some worktops inside. They made the best of it, but pharmacy are integral to working in a unit like this. We use a lot of unlicensed drugs and drugs with what we would describe as a very narrow therapeutic index, so you have got to get it right. Often if you go too high or too low, you miss the target, so there are a lot of discussions with pharmacy. You can know what drug you want to use, but you need a pharmacist to tell you how you're going to deliver that and what you've got to watch out for, so our pharmacists are absolutely part of the team, and they need to be embedded in the team.

145. In Yorkhill, the pharmacists had a couple of rooms where they made up a lot of drugs and it was good, as you could just go there and shut the door. We had quite a close working relationship with the pharmacists in there because we interacted with them a lot. In the new hospital that became a cramped space, and you could see they got very frustrated at being in this cupboard, because they didn't have a door they could close. It wasn't ideal.

146. Following the refurbishment, they now have a better room, basically a patient room with a view of the atrium - it's much better.

ISSUES WITH THE BUILDING

147. The windows had internal blinds many of which stopped working. That was very frustrating because patients couldn't see the view. That sounds like a small thing, but when you're in a room for weeks on end it could play with your mental health. It's something I always say to families; you're going to be in

here for a number of weeks and things are going to get on your nerves, so talk to us early.

148. You can also get difficult dynamics on the ward. You've stuck an adult in a room, you've put them in the most stressful situation on earth and they're going to notice little ticks or things that people do. The situation can explode. You do see families who watch the nurses like hawks and get hypercritical. And it does occasionally explode, so that's why you need what I would call the soft stuff, to defuse situations.

149. Sometimes the TVs didn't work either. That's important if you're stuck in a room for weeks on end. That can be a tipping point. Also, the Wi-Fi was dreadful, though it has improved a bit.

150. I was also aware of toilets overflowing. That happened in a transplant room in Ward 4A when we were decanted and it was quite unpleasant.

151. I was also aware of issues with the cladding because of Grenfell. It had to be renewed. I remember we had to tell parents to take their children to another entrance because they couldn't use the usual entrance. Also, because the cladding was coming off, I think we extended the use of Posaconazole. We did something with antimicrobial prophylaxis, an anti-fungal preventative treatment to cover immunocompromised patients walking through an area where cladding was being removed. This was because our patients had to be in proximity to that work going on. In removing the cladding, you disturb the building, which will cause an increase in mould and a greater mould load in the ambient air. I think that was during the winter months of 2018.

152. We sometimes received communication about building issues in staff meetings. We then imparted some of that information to patients and families. That was sometimes done in clinics and sometimes by a pre-prepared letter. There was also a Facebook page, but I did not interact with that. In fact, none

of the medics did, because it was created by GGC. GGC used it to provide information to patients and families.

153. In addition, a lot of the senior nursing staff would have talked to patients. I know Prof Gibson spoke often to patients about things that were going on. There were so many instances where we had to pass information on, there were press releases, information updates and things circulating round the ward. It was an unprecedented situation.

154. There was also poor mobile reception too, so all these things just made life a bit more difficult. You had to walk about with your laptop because you couldn't always get on a computer on the ward, so I had to take my bag everywhere I went. That has improved and you just become more savvy about how to organise yourself because you have to find a way of making it work.

155. In terms of raising any of these issues as a problem, I think we brought it up at every staff meeting.

156. In general, it was just not a very well thought out environment for doing important work. I don't think there was enough recognition of the fact that for a lot of the work we do, for the difficult clinical work, you need a bit of headspace, some time and space and organisation.

157. We were forever complaining. I think to be fair to Jamie Redfern, he's got a listening ear and people bent his ear a lot, whether he could do anything about it or not. In my view, he acted in good faith to address our concerns, but there was a limit to what he could do, so we had to just get on with it.

ODOUR

158. There was always a thing about the smell. If you'd ever worked in the Southern General Hospital, you knew that the sewage could get a bit smelly. It's a historical thing though. I worked at the Southern General back in the early 1990s in the Neonatal Unit, and I loved working there, but the smell from

the water treatment works could be troublesome, especially in the warmer months. In the summer, you can open the windows somewhere, but there would be spells of the day where it would be particularly pungent. Although I wasn't looking forward to experiencing the smell again, I can't say that it was causing me any safety concerns.

ISSUES IDENTIFIED WITH THE VENTILATION SYSTEM IN 2015

159. My interaction with the RHC building started in June 2015 when I was involved in the first transplant we did. I was also involved in a lot of the things that we uncovered about Ward 2A as we started to use all the aspects of it. If you move into to a new house, you realise, this doesn't work, that doesn't work. Those snagging type things happened, but some of these issues were more than snagging.

160. I think we entered the building in the good faith that it was like for like and had been fully specified. We thought we would just move in and get started.

161. Before we moved in, we discovered that there were no HEPA filters in the transplant rooms, so they had to be installed retrospectively. I can't recall specifically if this was done just before or just after we moved across to the RHC but it was certainly done before our first transplant took place there, which was at the end of June 2015. I remember that the filters were flown over from Dublin over a weekend and installed very quickly.

DISCOVERY OF HIGH PARTICLE COUNTS IN 2015

162. Patients then moved in but before transplants started, we discovered a problem with high particle counts, so this would still have been around June 2015. The decision to do the particle counts was a legacy of our Yorkhill practices. Microbiology used to do a particle count of the corridor and the rooms in Yorkhill, but that was a HEPA filtered environment.

163. When we moved to the RHC, we were told that only the transplant rooms would be HEPA filtered and it wasn't a positive pressure environment. Having a high particle count in the corridor was not unexpected, therefore, because no measures were in place to reduce the particle count. Nevertheless, it was necessary to have an acceptable particle count in the rooms in which we were intending to treat immunocompromised patients, notwithstanding that JACIE does not mandate a specific particle count as a standard.

164. We discovered high particle counts on Ward 2A when we attempted to assess the quality of the environment. They discovered very high particle counts in the corridor of 2A and also the rooms, which was of greater concern. After the rooms were cleaned and disinfected, they still had high particle counts. That led to an inspection of the rooms which showed that a lot of things weren't as they should be.

165. There were lots of issues with the rooms. We discovered that some of the fixtures had not been properly sealed. We carried out smoke tests and they showed smoke around fixtures in the walls. If you're going to put positive pressure into the room and you've got sockets sunk into the wall, those sockets need to be sealed. Every fitment needs to be sealed otherwise particles will leak out of every breach in the plasterwork. Anything that goes through the plasterboard must be sealed. There were problems with seals around the light fittings in the ceilings and in fans and pipe chases. All these things have to be sealed or you're never going to eliminate high particle count. Those particles would not be coming through a HEPA filter, they were coming in from elsewhere, so that's air that's potentially laden with things that you wouldn't want to see in that environment.

166. Craig Williams was the Microbiology doctor whom I recall was heavily involved and he explained that the corridor was not filtered and was no different from a room in your house. The particle count was in fact even worse than a room in a house because of all the traffic passing through the ward corridor. There were people coming and going and moving furniture, which caused a lot of particle movement.

167. It took us a while to understand the implication of the corridor being full of particles. We had to keep the room doors shut because maintaining the positive pressure was important. This would be a concern in all the rooms but especially the positive pressure rooms and transplant rooms because of the nature of the patients being treated there. Other patients, like AML patients, are also very vulnerable to fungal infections.

168. The particle count issues were addressed quickly once Craig Williams was involved. There was a lot of reshuffling rooms while seals were made good but the particle levels reduced to an acceptable level before we admitted a transplant patient.

169. As far as I'm aware, particle counts are not conducted now. It's not my area of expertise. I know that they didn't happen during COVID, when we were in Ward 4B, because we did not want to have extraneous people on the unit. Somebody coming up from Microbiology to do a particle count could be a potential COVID contact for vulnerable patients.

DEVELOPMENT OF CONCERNS ABOUT THE ENVIRONMENT

170. In 2016, I remember we had a leukaemia patient who had very significant problems arising from gram-negative infections. In that case it was their response to infection that caused alarm bells to ring, rather than the infection itself. This seemed to be an exceptional case rather than indicative of a wider problem.

171. In 2017, I also recall an incident involving a Stenotrophomonas infection. A patient died as a result of contracting that infection. Stenotrophomonas is recognised as a potentially waterborne infection. It's an infection that we did see back in Yorkhill and I expect that most haematologists and oncologists will have met that infection before. It can contaminate water, and anything that happens to be sitting in water. However, it is also recognised that it can enter

the bloodstream via the patient's gut if the patient has Stenotrophomonas in their gut flora as a result of previous prolonged antibiotic use. There is more than one explanation when a patient contracts that infection. If you were to have a cluster of those infections occurring at the same time, you would question whether there was an environmental cause, but an individual case would not necessarily arouse suspicion. At this point in time, we were not aware of any evidence of a cluster. This was a year after the leukaemia patient described above. We were concerned about this particular case, but we did not suspect a wider problem at this time.

172. I recall that there was a transplant patient [redacted] who, before [redacted] came to transplant, had a huge number of infections. We had a transplant date for [redacted], and we had cells lined up and were good to go, but [redacted] got another gram-negative infection. We had to cancel [redacted] transplant twice to deal with those infections. This patient was a baby, [redacted], and the practice for babies was to bathe them in a plastic bath. They would obviously be naked in the bath and sometimes the ends of their central line would be in the water. I remember observing this baby during [redacted] bath and reflecting that this was likely why [redacted] was getting lots of central line gram-negative infections: there would have been gut bacteria on [redacted] bottom and this was getting into [redacted] line during [redacted] baths. There came a point in time where we started putting green caps on the end of lines, which allow you to immerse the central line ends in water, but this was before that was introduced. I stopped [redacted] from having baths, which was not a popular decision, but I felt that the infection risk was too important to ignore. [redacted] stopped getting central line gram-negative infections.

173. That was after the baby had [redacted] transplant and I accept that other things may have influenced the infections stopping. It may have been the fact that [redacted] now had a well-functioning immune system and there may have been other factors. However, gram-negative infections are more likely to come from bacteria you've got in your gut getting into your bloodstream, rather than something that somebody is giving to you or you're picking up from the environment. It's much more likely to be from yourself, especially if you've got

low blood count. My view at that time was that, as the decision to stop putting this baby in an immersive bath and do bed baths instead led to an end to [redacted] gram-negative infections, it wasn't the water that was the problem, it was how it was being used. I felt that there may be an explanation as to why that individual got so many infections.

INVESTIGATIONS ABOUT WATER SUPPLY AND POSSIBLE LINK TO THE ENVIRONMENT - 2018

174. In 2018, there was a cluster of three cases that caused me concern. We approached hospital management as a senior doctor body, the Schiehallion Consultants, to ask if we could have somebody from outside of the organisation come in to investigate it. We had a face-to-face meeting with Jonathan Best who came and spoke to us, and the hospital management agreed in principle that that would be a good idea. It would allay fear and answer questions, but that proved an impossible thing to achieve.

175. I think they did approach somebody in Northern Ireland, and they may have approached somebody in NHS England, but were unable to find a suitably qualified individual to conduct the investigation. What we anticipated was a microbiology investigation, intended to answer the question, 'Do we have an environmental infection problem, and can we identify a source?' We expected it to be conducted by a laboratory scientist with experience in investigating previous outbreaks. I believe there had been an outbreak in a neonatal unit in Belfast so I thought that someone with relevant experience could be found.

176. Though it was agreed in principle that external review would happen, I believe that in the end, an appropriate expert was not found.

177. Personally, I did not have any concerns about the water supply at that time. I was obviously listening to the concerns that my colleagues were expressing, but I was open minded about the cause of the infections.

178. The increasing concern about infections developed because of the variety of infections we were seeing. The displacement of the gram-positive infections by the gram-negative infections made us wonder whether we had a problem. This was coupled with the fact that we had moved, so people were thinking, 'What is happening here? Is there something different about the environment?'

179. There were lots of meetings, such as Incident Management Team Meetings (IMTs) where people put forward theories and theories were tested. I know they tested the water. We were shown a diagram of the water supply to QEUH, the Children's Hospital and Maternity Unit. I know water was sampled at the treatment works and at Govan Road and other places, and I'm pretty sure we were told that this water supply to the Children's Hospital was given a clean bill of health.

180. I also learned from those IMT meetings that there's no such thing as sterile water, that all water has bacteria in it, but there's a tolerability level and we were told that the water met that standard. It was also made known that no such scrutiny of the water supply of any other health institution had taken place, so we didn't have any benchmarking and there were no comparators. We did not have access to any test results and we did not have any sort of context, so we had to take the advice of the experts who told us the water quality was fine.

181. I attended one IMT meeting on 21 March 2018, which is described as the "water incident IMT". I think this was maybe in response to an incident where we had a transplant patient who came in unwell one weekend and needed resuscitation and her line taken out.

182. I think the purpose of the IMT meetings was to identify whether we had a problem, assess the scale of the problem and look into possible sources of infection. From a clinician point of view, I think our worry was always about our patients being at risk, because whilst these concerns were under

investigation and discussion, we were still trying to safely deliver a transplant programme.

183. We were bringing patients in from other hospitals to be transplanted while all of this was also going on. From our point of view, we were trying to get an idea of what the risk was and to see if we had any evidence that it was a systemic issue. We were trying to get a feel for what the scale of the problem was, to make sure we were adequately protecting our patients. That was always our overriding concern. Families were asking questions, 'Is this safe? Can we drink that?', so we needed to be able to give an honest account of what was happening in the organisation. If you're giving reassurance, you need to know where that reassurance is coming from.

184. I can recall tap and shower filters being fitted in all the rooms. Those were fitted with a view to filtering out any bugs that might have been in the water coming into the unit. They put filters on taps that weren't really designed for filters, so you were having to get your hands under a filter and your hands ended up closer to the drain as a result because the filters elongated the tap, so you were trying to keep your hands out of the drain.

185. There was definitely an impact on the staff, but we just rolled with the punches. I know a lot of our nursing staff were stressed and upset because they were having to explain the changes to families all the time, so they did a lot of the heavy lifting in that regard. They spend a lot of time in rooms with families, and this would often result in questions about water safety. They probably had to deal with a lot of the additional worries and concerns that the families had, on top of the families' obvious day-to-day anxieties for their child.

186. I'm assuming that the switch to using bottled water was also in response to the three cases of gram-negative infections that I mentioned. They were worried that the water was contaminated with gram-negative bacteria, so they supplied lots of bottled water and instructed us to wash our hands with it. It

was logistically difficult to wash your hands with bottled water. You still have to touch the bottle and unscrew it; it was a nightmare.

187. At that time, I remember parents being upset because they couldn't bath their children and the water wasn't warm. That was thankfully short lived.

188. I have been shown the Core Brief dated 22 February 2019 regarding an HPS report on water at the RHC and QEUH. [Reference (eRDM)] I recall a publication of an HPS water report. I wasn't involved in it, but it was something I was aware of.

189. I know they were sampling water from different water tanks and Scottish Water sampled the water supply before it got to tanks as well, and they published the results of that. From what I remember, the HPS investigation implied there wasn't a problem with what Scottish Water were supplying us with. All in all, I just remember thinking that there's not a problem with the water that's coming to us, and if there is a problem, it's happening somewhere else, maybe off where the main pipe comes in, but there wasn't a clear candidate location for something happening, from what I remember. I remember diagram boxes of where the water was stored before it came to us and there were no findings of high levels of contaminants in any source. I took some reassurance from the report. However, it seemed to rule stuff out without identifying what the problem actually was.

THE CLOSURE OF WARD 2A AND DECISION TO MOVE TO WARDS 6A/4B

190. The children and the ward were decanted around September 2018. There were ongoing concerns about gram-negative bacteria and it was felt that they were going to have to investigate the ward environment. I cannot recall the tipping point that led to the decision to move then, but I recall that the move was supported by the Infection Control doctor, Teresa Inkster. The priority was to move us to an environment that didn't contain the same risks that we were moving away from, to keep control measures going in the new environment and to have a look at the infrastructure of Ward 2A, to check all

the structural issues and things like the water and drains. It was intended to be a temporary measure, with the thought being that we would be back by Christmas, which turned out to be wrong.

191. I know that there were quite a lot of meetings where various options were considered. Those options included building a field hospital on the grounds of the hospital that was just for haemato-oncology patients and I know that management looked into getting temporary modular units that would sit in the car park or somewhere in the grounds and that would be our hospital. It got as far as working out what the logistics would be, how long it would take and what it would all cost. There was also talk of building a standalone haematology-oncology unit in the grounds of the hospital, attached by a link corridor. That was obviously going to be a more long-term solution.

192. Another option was a move to a site in the QEUH. I don't know if we ever considered moving to the Beatson but there were lots of options thrown around.

193. We would have been included in general discussion about the move but not in selecting a destination. I think that was hospital management, Infection Control and Estates. But the options were presented to us and in the end we moved to 6A.

194. I think Wards 6A and 4B were deemed suitable to receive the patients because Ward 4B is the adult transplant ward, and it already performed transplant for adults. I think that Ward 6A was a temporary holding ward for care of the elderly, so it seemed like they were a group which could be safely moved to an alternative location at Gartnavel Hospital. Ward 6A was also reasonably close to 4B.

EVENTS ON WARDS 6A/4B: LATE 2018 TO LATE 2109

195. When we moved into Wards 4A and 6B in September 2018, I understood we were only likely to be there up until that Christmas, but we ended up there for around two years and during that period there was a move to the CDU also. We moved to CDU in the New Year. I think that was probably because of fungal infection when, in December 2018, I think there were two instances of cryptococcus.

196. Everyone was involved in the move to CDU because it was a case of all hands-on deck, but primarily the senior nursing staff took the brunt of the work. They were organising it and physically doing everything, moving drugs and equipment, and telling you where to go. I can't say exactly how long we were in the CDU for, but it was a matter of weeks.

197. We would have had patients in Ward 4B at the same time and they would have remained there.

198. Wards 6A and 4B were not paediatric wards. I think we were always concerned about the move away from the paediatric specialisms and at night it was quite a long way from the on-call team who were available for sick patients. It was a distance to transfer patients from theatre or x-ray and immune-compromised patients were having to use the lifts in the busy concourse, beside other patients, families and general visitors. There were worries about our patients being in confined space with lots of other people.

199. In response to our concerns about access, a lift was decommissioned and set so that it was exclusively used by our patients. This happened reasonably quickly after the decant. However, the ward was obviously not adapted for paediatric use, and we had to put things in place to prevent people from walking through the ward. We had no day care facilities, which had to be co-located on the ward, which meant there were fewer inpatient rooms as we used the top end of the ward for day care. That meant that we lost five or six potential patient bedrooms.

200. We also lost a big day room at the end of the ward which had fabulous views over the city. That was used for day care. Day care didn't have office space, they were having to operate in the corridor, so they weren't the best facilities. There were games there and if somebody got sick in day care, there were already staff on site on the ward, so that was positive but, overall, it wasn't ideal.

201. With regard to the decants, it takes a lot of time and a lot of people to do a move, so there were risks but none that were insurmountable or deemed too risky. For our patients, it created a challenge because we were then operating over two wards. We had patients going through transplant down in 4B and patients both pre- and post-transplant up in 6A, so one team was looking after patients in two sites. We needed more nursing staff because we needed to have nursing staff down with transplant patients at all times with enough staff to cover breaks also. If we had a very sick transplant patient, then we needed a medic down there all the time as well, so we might have a medic sitting down there for one patient, whereas upstairs we had four or five patients, so it did stretch the staffing resources somewhat. I can't recall if we actually got more staff. Either way, we just mucked in and did what we needed to do.

202. When we moved up to 6A, there were no HEPA filters installed, so we had lots of mobile HEPA filter units throughout the ward. They were in place when we moved and they seemed to be everywhere. I'm sure I asked a question about how they worked. I'm not sure who I asked but I was assured that they were effective in making the air safe for transplant patients and I accepted that assurance.

203. I know there was investigation of the ventilation in 6A but I don't know any of the details as I wasn't involved in any of it. During 2019 - the period after we moved back into 6A and before we moved back to 2A - we were still uncertain as to whether or not we'd addressed any cause of infection. I think there was still a worry about whether or not our new environment was safe, possibly because we still didn't have clarity on whether or not we had a problem with

the water supply in 2A or what the cause was. We were still wondering if there was a problem and how widespread it might be. Emelia Crighton, who took over the IMTs from Dr Inkster, was trying to persuade us there wasn't a problem and that what we were seeing was a natural fluctuation in the pattern of infection, but I know that individuals in Infection Control and Microbiology were still of the view that there was a problem, so there was continued uncertainty about whether we had found a safer environment.

204. The staff accommodation was miniscule and there were limited operational areas. We ended up taking over a room that would have been a useful room to have difficult conversations in, but it wasn't purpose built and you could tell it wasn't purpose built. It wasn't particularly child friendly, so we had to make it so, for example, putting up suitable artwork. There weren't any purpose-built playrooms or communal areas for patients or families and there was no kitchen for the parents. A useful innovation was that they then allowed families to be fed off the trolley, so we started providing parents with food and drink, which I think was a great thing.

205. Where we were before, a lot of families would be a support for each other. They had children on the same journey so they would compare notes, but there was no longer the space for this to happen, for families to mix as they would have done previously.

206. I did actually prefer the shape of the ward though. There were two straight lines, so you could put your head round one side and see people. There was also a lot of natural daylight there.

207. Another additional challenge there included our anxiety about patients who were deteriorating, because PICU was much further away. There was the physical distance, but also the fact that we had to use service lifts. It took time having to get to the service lift and then to get in it. Someone timed it as taking at least five minutes, even when the lifts came on time. We did some transfers to PICU while we were there and you had to rely on people being able to access the service lifts and hold them for you.

208. When it came to us taking a patient to PICU, I don't recall a plan as such, we just knew what the route was and went. I recall for a while we had an additional advanced nurse practitioner on the ward, who was doing overnight shifts to address the fact that the "hospital at night" team might have a longer response time for our patients. For a while we were deploying people to do additional shifts just until things settled down and we got more of a feel for it.

209. On 6A, specialist reviews took place later in the day, and we saw less of some colleagues than we would have before on 2A. My feeling is that the geography contributed to this and that they were less inclined to pop by and discuss difficult cases face to face, or review patients, because we were six floors up in another building, rather than being next door.

210. With regard to inpatient admissions, the patient pathway would be that they would come in through A&E, be seen in CDU (Clinical Decision Unit), get their immediate care there and then be transferred up to 6A if there was a bed available there. That all got more complicated when COVID happened, because then you had to be COVID negative. A lot of families hated that they were in CDU or other medical wards in the children's hospital when we had no beds available, so that was a contentious time for families.

211. For facilities on 4B, we had two rooms. We did have access to three transplant rooms but sometimes it went down to two. In the corridor, there was a space where we had a desk on which we could put all our paperwork and other stuff. There were a couple of chairs round that desk and there was also a desktop computer, and that was all. Two members of the nursing staff were sitting essentially in the corridor. I know families used to complain that they could hear the nurses talking, because the nurses would be sitting so close to the patient's room.

212. There were obviously phones ringing quite a bit too, so that was hard on the staff, to be in a corridor when we were seeing patients or having discussions

with families about patients, with the phones ringing at the same time. The adult nursing staff on 4B were very welcoming and any time we asked for help, they gave it. We did always feel a bit isolated if there was an emergency though, you could be there on your own waiting a while for assistance.

213. The rooms on Ward 4B had positive pressure. They were single doored rooms which were HEPA filtered and there were portable HEPA filters in the corridor when we moved there. It was not a purpose-built transplant ward. The adult transplant ward didn't have anterooms or the room that we had available for transplant patients in the children's hospital.

214. I wasn't unduly concerned when we moved to 4B because it was delivering an effective transplant programme for adults and they didn't appear to have a gram-negative infection issue. I didn't have any concerns about the air quality or ventilation, although I did wonder how the HEPA filters in the corridor, being only waist high, were actually effective. Again, I can't recall who I asked but I was told they were fine and I had no cause to doubt that.

215. Some of the infection prevention and control (IPC) measures we were taking were carried over to Wards 6A and 4B. All the taps were filtered, and there was a programme of chilled beam cleaning. I've never asked anyone to explain to me what a chilled beam does. Periodically rooms would be shut off while there was HPV cleaning of the rooms or there would be people with equipment doing the chilled beam cleaning, so rooms would occasionally be out of bounds and patients would have to be moved rooms.

216. There were some concerns about 6A when we were first shown round, such as the urine smell in the wet rooms, and we were told there would be remediation before the move. We were told it would all be sorted and, in fairness, it was. When we moved in, there was one room that had a persistent smell in it, and I think they sorted this by replacing the floor.

217. In terms of storage and bed linen etc, those things didn't really affect me. The hospital did convert a large bathroom and toilet facility into a staff kitchen,

which was really nice because we were quite a long way from things. During COVID, they also made a patient bedroom into a staff room.

218. There was also a communal room off the ward that was a staff room and it was adapted for our department, so the nurses used to go there for breaks. They put keypads on the toilets and that made it a bit more restricted.

COMMUNICATION ABOUT THESE MATTERS

219. In terms of communication, it was often the case the Comms team would issue some kind of communication following an IMT. This was often a press release or some form of statement. I was not involved in drafting any statements. I cannot remember any specific details of any communications. There was usually a 6pm deadline for this, but often the deadline was missed, as I understand they sometimes struggled to find a suitable form of words. These statements influenced what we told families because it was important that what we said was consistent with these, and so it was difficult when there was a delay in the Comms team issuing the statement, because we had to leave the IMTs and go straight back to the wards.

220. Communication about these issues with families was very difficult because we did not have the answers. We always tried to be reassuring by proactively telling families about the measures that were being put in place, but understandably that led to an assumption that, if steps were being taken to address a problem, there must be proof of a problem. As that was not something we could confirm or deny, it resulted in a lot of uncertainty and speculation.

221. There was a Facebook group and families were told about it. I don't have a Facebook account and wasn't involved with it so I don't know how it was maintained or moderated. Occasionally we would be sent a screenshot of what was on Facebook, and I know Prof Gibson also contributed statements to the Facebook page to try to inform parents about what was happening.

222. I know that there was a parent Facebook page moderated by a parent of a patient. I understand that this was not open beyond the parents, so I am not aware of its contents. I think that the "official" GGC Facebook group for parents may have been created because there were concerns that the parents' Facebook group might not always be accurate, but I couldn't be sure of this.

223. There were also posters displayed in the hospital saying how people could keep up to date with what was happening regarding Wards 6A and 4B. Examples are those shown to me to me at pages 78 and 79 of the bundle (**A38097072 – Flyer about the Closed Facebook Page for Ward 6A and 4B dated 20 January 2021 – Bundle 5 – Page 445** and **A38097080 – Poster about the Closed Facebook page for Ward 6A and 4B dated 20 January 2021 – Bundle 5 - Page 446**).

224. It is possible that some families may not have heard about the closure of Wards 2A and 2B from the media we were using. There are families who would not be interacting with us regularly, who might only be seeing us as outpatients and might only need to come in very, very occasionally, and I would assume some people were missed off the list of communication.

225. In terms of communication about the move from 6A to CDU and back again, I know a lot of people were angry about the communication, but I don't recall any details.

226. I have been shown the document at page 37 of the bundle which is a GGC Media Statement from 29 March 2018 about bacteria concerns (**A39123914 – Media Statement titled "NHS Greater Glasgow and Clyde Update on Bacteria Concerns" dated 29 March 2018 – Bundle 5 - Page 138**). I am sure I would have read the statement at the time but cannot recall it or comment on its contents.

227. I have been shown the document at page 38 of the bundle which is an Update Ward 2A/2B dated 7 June 2018 (**A39123885 – Update for Parents on Ward 2A/B regarding cleaning, Hydrogen Peroxide Vapour (HPV) and Antibiotics dated 7 June 2018 – Bundle 5 – Page 142**). I am not familiar with the document but it looks like the type of briefing aimed at parents. I cannot say how such materials were disseminated but the contents of that note would have been the subject of routine discussion with staff and families. The nurses in charge did a lot of the heavy lifting with that kind of communication. I would imagine that the antibiotic prophylaxis mentioned in that update is the Ciprofloxacin that was being used at the time.

228. I have been shown the document at page 39 of the bundle (**A39123918 – Poster for Wash Hand basins – Bundle 5 – Page 143**) which is a poster telling people not to pour anything down the basin. Those kind of posters were everywhere I think, including all the rooms. They wanted to prevent people from putting foodstuffs and down a cubicle sink because of the concern that it would interfere with the efficiency of the flow of water along that pipe. If you pour things like milk and sugary drinks in there, it potentially creates a favourable environment for bacteria to grow.

229. I have been shown the document at page 40 of the bundle (**A38662234 – Update for Parents regarding cleaning in Ward 2A dated 13 June 2018 – Bundle 5 – Page 144**) which is an information sheet for parents regarding cleaning in Ward 2A. This relates to the HPV cleaning I mentioned earlier. Parents' questions about this would have gone to the nursing staff so I cannot comment on the communication.

230. I have been shown the documents at pages 52, 53 and 54 of the bundle (**A39123907 – Briefing for Parents and Carers regarding the measures taken to enhance the Ward dated 16 August 2019 – Bundle 5 – page 338**, **A39123898 – Briefing for Parents and Carers regarding the Work that has Taken Place to the Ward dated 6 September 2019 – Bundle 5 – Page 345** and **A39123912 – Letter to parents Regarding Ongoing Concerns**

about the Lack of Facilities in the Ward and the Creation of a Parents' Kitchen dated 23 October 2019 – Bundle 5 Page 381) which are further updates to parents in August and September 2018. Again, I was not involved with these but I would guess that the notes were intended to provide further reassurance and more information about the various precautions that were ongoing. With regard to the NHS England expert mentioned, I do not know who this was or what they did.

231. I have been shown the document at page 70 of the bundle (**A41519618 – Letter for parents dated 9 September 2019 – Bundle 5 – Page 365**) which is a Ward 6A Family Information Q&A. I can't recall seeing it or how it was communicated but the contents would have been helpful in supporting the staff's discussions with families. I guess that the document stemmed from an IMT and would have involved a number of people contributing to the content, but I cannot recall it.

232. I have been shown the document at page 55 of the bundle (**A39123903 on original AME Bundle – but listed as A41501454 Letter from Kevin Hill, Director, Women and Childrens Directorate to parents and carers of patients on Wards 6A and 4B regarding update on investigations and infections in Ward 6A dated 12 November 2019 – Bundle 5 – Page 382**) which is a letter from Kevin Hill to Ward 6A and 4B parents dated 12 November 2019. I am not aware of what prompted the letter but, again, it seems to be an update about the infections and measures that were being taken in the decant wards.

233. I have been shown the document at page 56 of the bundle (**A39123903 – Letter from Jane Grant, Chief Executive NHS Greater Glasgow and Clyde regarding meeting to discuss concerns about the situation in the paediatric oncology unit dated 14 November 2019 – Bundle 5 – Page 383**), which is Jane Grant's letter of 14 November 2019. I'm guessing that this letter went to parents who attended the town hall type meeting I described earlier. There was a lot of criticism of communications, and I mentioned the

challenge of competing with all the information and opinion on social media, so I would imagine that this is what prompted the Chief Executive's letter.

234. I have been shown the documents at pages 6 and 7 of the bundle (**A38845623 – Core Brief prepared by NHS Greater Glasgow and Clyde Health Board dated 11 July 2017 – Bundle 5 – Page 67** and **A38845660 – Core Brief prepared by NHS Glasgow and Clyde Health Board 10 August 2017 – Bundle 5 – Page 73**) which are Core Briefs. These are common methods of communication and look familiar, although how much time staff get to read them is possibly another matter. I am a recipient of these and not involved with contributing to them.

235. I have been shown the document at page 13 of the bundle **(A38845769 – Cladding briefing prepared by NHS Greater Glasgow and Clyde Health Board for Paediatric haemato-oncology inpatients dated 7 September 2018 – Bundle 5 – Page 103**), which is a note to parents dated September 2018 about alternative access to the QEUH while building work was going on. I know that there were concerns about fungal spores while cladding was removed, and this note gives related information. Again, I was not involved in its production, but I'd have thought that Infection Control colleagues and clinicians would have been consulted regarding the reference to antifungal drugs as a precaution. It didn't really apply to transplant patients as they would have been on antifungals anyway.

236. There was a lot of media coverage of the infections in the hospital in 2018. I found this very upsetting and demoralising. I recall being in a shop and seeing all the tabloid headlines and being upset by this. I don't remember all the details of the media coverage because, for a time, I stopped reading the newspapers and watching the news. This was because I had seen the word "murder" being used and I had to stop reading this in order to cope.

THE REFURBISHED SCHIEHALLION WARD

237. Since we returned to the new ward in 2022, some things have changed. There are the two repurposed rooms behind the nurses' station, which are the pharmacy and the so called 'Tweenies' room. There is a new treatment room and there is a new room for the nurses to make up and prepare drugs, so those are definite improvements.

238. There is also better accommodation for the junior medical staff on the ward, and that's definitely welcome. Since we've moved back, the patient or parent kitchen hasn't really been operational, but that's because of COVID and infection control reasons.

239. We can only have one child at a time in the playroom, which is a bit sad. I don't know if that's going to be a long-term thing. In terms of the building there's the double door rooms, double doored entrances and exits and the ventilation specs have increased and improved. The trough sinks have been removed. Everything is new and clean and painted and nice. Overall, I would say it's an improvement.

240. I understand the rationale for the removal of the trough sinks from the transplant anterooms was that the more drains you have in a unit, the more likelihood you have of build-up of water in drains, because you don't have a constant volume of water running through them. If you have a room lying idle for a couple of days, there is an increased risk of a build-up of bacteria in the pipes and drains.

241. Since our most recent move back into Ward 2A there have been one or two relatively minor problems, like blocked toilets, which made us wonder if there would be further issues, but these were rectified fairly quickly and were more of an inconvenience rather than anything that impacted patient safety. It just gave us that dreadful sense of déjà vu, but happily things have been fine since then. I am an optimist and I think the new environment is going to be good. I'm certainly hoping it will be.

242. You have to proceed on the basis that everything has been fixed because there's been a lot of time and money spent on improving facilities. I have to believe that it's top notch because I couldn't in all conscience take consent for a transplant if I had any suspicion that it wasn't safe for patients. I've been to other transplant units, and I know they're not perfect and I know that there are always going to be compromises but I believe that the new unit is an honest attempt at producing a very good environment.

243. I'd say that it's all in nice order at the moment, including the ventilation. While it can be noisy at times, and a bit cooler than I might personally want, the engineers have assured us that the ventilation is excellent. I understand that it would be way above the ventilation requirements for transplant, or the ventilation spec of any other unit in the country.

INFECTIONS

244. Our concern about infections was not about the absolute numbers of infections. We had fewer central line infections than we'd had at Yorkhill, so it wasn't the number that caused concern. It was more because central line infections are normally from gram-positive bacteria, that is, bacteria that live on the surface of the skin. These don't tend to make you as unwell as gram-negative bacteria. You might have to lose your central line because you can't get rid of the infection, but as a rule gram-positive infections don't cause you to get very sick. Without wishing to trivialise them, they're more annoying than dangerous, although they can become dangerous if they infect your heart valves.

245. Gram-negative bacteria on the other hand can produce endotoxins that can make you very, very sick. If you have an endotoxin producing gram-negative, you can drop your blood pressure catastrophically and have a cardiac arrest. Whilst this is thankfully uncommon, they tend to make you quite suddenly unwell, and much more severely unwell than infection with a gram-positive bug.

246. If gram-negative bacteria get into a central venous line, they can often be quite difficult to eradicate because some of them can produce slime that makes them very adherent to the line. Once they're stuck in that line, even though you're pushing antibiotics into it, the slime protects them from the antibiotic, so they're very good at occupying a space and building defences against antibiotics. The solution is often to remove the line, because that's where they're sticking. Intravenous antibiotics are good at circulating around the body, but they can be ineffective if the bacteria produce this protective slime or biofilm.

247. There are risks associated with continuing to use a line which has gram-negative bacteria in it. When you flush the line, you might be flushing bacteria through the patient's body.

248. We were seeing a much wider variety of gram-negatives. If you take the whole group of central line infections, gram-negatives were disproportionately dominant in a space usually occupied by gram-positives. Proportionately we were seeing more gram-negatives and we were seeing a greater variety of gram-negatives and organisms that we didn't recognise as having seen before.

249. We tell all the patients that there are upsides and downsides of having a central venous line. Sometimes, in the face of infection, we may have to take the line out. The Microbiologist will tell you what the bug is and they'll tell you if it's gram-positive or gram-negative and then they'll tell you if you're likely to be able to treat it with antibiotics. They'll give you a heads up that things may not be salvageable; then it would be advisable to remove the central line.

250. As a consequence of the concerns expressed about the gram-negative infections, we had quite a lot of meetings. I can't remember if it was 2016 or 2017, but we had a Health Improvement project running, looking at how to identify sick patients early, and also looking at how we responded to the various indicators of deterioration of patients. There were a number of

innovations which followed on from this, such as a new paediatric observation chart, with Paediatric Early Warning Scoring (PEWS) and SBAR (Situation Background Assessment Recommendation) documentation, identifying vulnerable patients for priority discussion at the twice daily handover meetings.

251. SBAR reporting is completed for a patient you have identified as at risk of deterioration. The SBAR report will be filed in the notes, and if somebody comes to review the patient, they can see the background, the expectation in terms of treatment escalation, and who to contact if escalation measures do not result in improvement.

252. We also introduced the term “watcher” to identify patients in the ward who are likely to be unstable for a variety of reasons. When you have identified a “watcher”, you alert the “hospital at night” team, and in the morning the senior nursing team prioritises discussion of these patients so that the daytime team can review those patients first.

253. I don’t think this was introduced in response to gram-negative infections. The project was spearheaded by a senior nursing colleague who worked in the operating theatres. They set about identifying patient factors which could be predictive of the development of complications, to ensure timely intervention to prevent deterioration. They audited their activities and proved during the project that fewer patients suffered post-operative complications. We were very keen to adopt this approach of being proactive in spotting patients who might deteriorate, and institute early intervention.

254. We were aiming to identify patients early enough to be able to make an intervention that prevented them needing maximum support. This was a patient safety initiative in 2017 and we were pushing ahead with that. With the type of patients in our ward, gram-negative infections are always going to be a major cause of the patients deteriorating. Within the group of patients I look

after, gram-negative infections mostly come from the bowel flora. Your bowel is full of them and that's where they should stay.

255. Chemotherapy hits cells that have a high turnover rate, so the renewal of your gut lining is impacted by chemotherapy and that's why you get vomiting, diarrhoea and often feel terrible. In addition to this, you are also not renewing the lining efficiently, so you can get ulceration in the gut, and that can lead to sometimes bloody diarrhoea or loss of specialised cells in the gut because it's not had time to repair. Crucially, pathogenic or potentially pathogenic bacteria which have been living in your gut flora can get into your bloodstream because the protective lining has been breached.

256. You can see ulceration in the mouths of patients to whom we give chemotherapy; they'll be unable to swallow saliva because the back of their throat is ulcerated. If that's occurred all the way through the gut, our patients can get gram-negative bloodstream infections.

257. If you've got a bit of plastic sitting in your veins (by way of a central line), the bacteria can go there and stick together. That's the rationale for giving neutropenic patients Ciprofloxacin: you can maybe modify the pathogenic nature of the bacteria in the gut.

258. The thinking behind giving non-transplant patients Ciprofloxacin was to reduce the risk of environmentally acquired gram negative infections,

259. I was aware of ongoing investigations to find a source for the perceived increase in a variety of gram-negative infections. People were swabbing drains and my understanding of swabbing drains is that you would expect to see gram-negative bacteria in drains. I don't have enough knowledge of the microbiology of drains to comment further. I was willing to take the advice of those who knew better in that area. I think it was Estates who were carrying out the swabbing. I do not know whether any patients became infected from a germ in their room, from a shower or sink, for example. I am not qualified to

say whether this happened or not, but I understand that making a direct link is extremely difficult.

260. Fungal infections or mould infections can be environmental, but I don't know if it possible to create an environment where there is no risk of such infection. Even in HEPA filtered air, there are going to be pathogens. They could come off somebody who walks into the room.

261. During the period 2017/18 and at the point we were decanted, I don't recall if we were given any additional advice around management of infection or infection risk. However, when there were gram-negative infections, or when we saw positive blood cultures, we followed the febrile neutropenia policy initially, and discussed them with the Microbiology team at the then daily lunchtime meetings.

262. A number of new members of the Microbiology team came on board when we moved hospital, and there was a shift in practice from giving 7 days of antibiotics to giving 10 days, then to giving 14 days. Essentially, we follow their advice. It must have increased our bed occupancy. Sometimes the microbiologists would advise us to remove the line in response to us telling them of a patient with a specific bug.

263. However, you might have a patient like the one I mentioned earlier who had multiple infections. You can get to a stage with a patient, especially an infant or a child under two, where you have inserted and removed so many lines that you no longer have a venous access. If you keep going into the same vein it will develop clots, and not be usable.

264. You have two veins on each side of the neck that you can use for central venous access, and you can use a vein more than once, but not if it has a clot in it. We got to the stage with a child where if we took the line out, we wouldn't be able to perform the transplant because we would have no other central

venous access, and there's no way you would be able to transplant without central venous access.

265. Sometimes we need to make a clinical judgement. Microbiology might tell us to take a line out, but that might compromise future treatment to such a degree that we have to make a judgement to keep going with antibiotics and try to clear the infection. Removal of a line was always understood to be a clinical decision, taken in the context of how many lines that patient has had in the past and what future treatment we plan.

266. For certain patients, when removing the line risked not being able to deliver life-saving treatment, we did not follow advice to remove lines. We would sometimes give the antibiotic the bug was sensitive to, and then we would challenge the line. By 'challenging' a line I mean re-accessing a line that has previously been colonised with a bug and observing if it causes fever when it is flushed. If the challenge is unsuccessful, we would ask the surgeons to take the line out. Sometimes line challenges resulted in the line coming out and other times it resulted in the line being successfully salvaged, and the patient avoiding 2 anaesthetics.

267. After the Case Note Review, one of the recommendations was that if the microbiologist tells you take the line out, you should take the line out. That's quite a powerful recommendation to make when you could be facing a patient who has no other venous access.

268. Nobody would lightly override the advice to remove an infected central line, but there might be times where you might have to say to the family, 'There are no other options for placing a central line". In that situation, if you were to give the information to the parent to make that decision, and they are fully informed based on all the information available to you, they could consent to the continuing use of the central line.

269. In response to the Case Note Review, we did a survey of the rest of the UK and asked what everyone else did in those circumstances. Some centres said

they don't re-challenge the line, but others said, 'Of course we do.' There isn't therefore a right or a wrong answer here, there's a judgement call to be made. This judgement was previously a clinical one but following the Case Note Review it is now directed by Microbiology colleagues who may never see the patient. They can make a recommendation for action that may jeopardise future treatment. In my opinion, the adoption of this particular Case Note Review recommendation, could be potentially harmful as it takes away a level of clinical discretion.

INFECTION MONITORING, REPORTING AND INFECTION PREVENTION CONTROL

270. My understanding of how infection is monitored in the hospital is that if we discover infection by swabbing or sending tissue for culture, that's reported by Microbiology. We interact every day with the microbiologists about positive cultures and often that's to do with getting advice about the best choice of antibiotics, the duration of antibiotics and whether or not the central line is likely to remain in-situ at the end of this episode.

271. The microbiology team is fully informed of infections that are in circulation amongst the hospital population and hence has good oversight. We discuss on a day-to-day basis with the microbiologists, but we also bring it up again at the Friday meeting where we go through the details of each patient on the ward and discuss any infections. The microbiology team are therefore aware of what's happening in our unit and have oversight of trends in infection. In my view, Microbiology and Infection Control are from the same department.

272. When dealing with infections, we report to or share information with Microbiology. If I phone them to discuss a particular patient who has an infection, then they look on their computer system, ask me the name and the date of birth of the patient, and then confirm which bug they have and which antibiotic it is sensitive to. If I say that the patient is continuing to have fevers or that I've added in this antibiotic but need advice on what to do next if the

fever doesn't settle, they might tell me to add this or that antibiotic and call them with an update in the morning. Microbiology will record that electronically on their lab system. It's not something I can necessarily see, but they always ask us the patient's name and date of birth and they will be able to call up the advice that was given the day before.

273. I know that that system of recording was very useful to the Case Note Review team. That's something a lot of the laboratory specialists would get access to, but it's not something that I would necessarily see day to day.

274. With regard to my interaction with the Infection Control team, I always felt well supported by Dr Teresa Inkster. I thought she spoke up very well and voiced her concerns when necessary. I thought she was persistent and logical and kept her concerns foremost at meetings. She followed through. I was more than happy with her representing our concerns.

275. The IMTs became a forum where infections and their causes were discussed. I was involved in some of the IMTs shortly after the decant, around the October/November 2018 period. The anxieties at those were related to the gram-negative infections. I know I was at the IMT where somebody described what was found when they explored the drains. They explained that the drains were set in the concrete floor and just replacing them was not going to be an easy job.

276. After the move to 6A the incidence of infection was definitely lower. After 2A, I'm sure every gram-negative infection was investigated. I think the trigger before then had been two gram-negatives but now awareness was heightened.

277. As regards gram negative infections, I was aware of the concerns that the infections had come from the environment, but I am not aware of any firm evidence that the environment was the source of the infections. People would talk about water or pigeons but to the best of my knowledge no links were proven. I do not believe that this has been established categorically even to

date. If somebody comes in from home with a gram-negative infection, I would not call it a hospital acquired infection necessarily unless they'd been up at the hospital that day and had the line accessed. In Wards 2A we do a root cause analysis of each candidate infection. We examine when certain patients got a fever, what organism they grew, and so on.

278. The root cause analysis is usually carried out by the Infection control nurse in conjunction with the treating clinician, going through all the notes and taking into account everything that happened in the time preceding the presentation with infection. I was never involved in a root cause analysis that concluded that an infection had been picked up because of the hospital environment.

279. Professor Gibson tended to go to the IMTs if she was available, but I sometimes went and I definitely spoke at more than one, but I don't seem to have been referenced. There were many people at the IMTs. A lot of time was spent with people introducing themselves and explaining their roles.

PROPHYLACTICS

280. There's always a debate to be had about the utility of prophylactic antibiotics and the potential damage they can do. Drugs have side effects; they can interact with other drugs and make management of the patient more complicated. You have to justify their use. It did reach a stage where there was such concern that the environment was a threat that we decided to prescribe many patients Ciprofloxacin and Posaconazole. Groups were set up to try and examine the situation, the timescales and what sort of exposure we were going to have.

281. Ciprofloxacin is an antibiotic routinely used in the adult haematology practice. It is given to reduce the risk of Gram-negative infections. We also use it in transplant routinely to cover periods of neutropenia. If you give somebody ciprofloxacin, you alter their bowel flora. Bowels are full of lots of bacteria so the drug will reduce the Gram-negative population of bacteria in your bowel.

However, as your bowel flora is in balance, if you wipe out one set of bacteria, you may be replacing it with something that's resistant to ciprofloxacin, so there's always a risk in doing that.

282. Ciprofloxacin is not routinely prescribed in children for leukaemia or in children treated for solid cancers. It is more routinely given to transplant patients. We extended its use to cover patients we wouldn't normally give it to. The rationale was that we were worried about gram-negative infections, and we thought this might be a way of reducing the burden of these infections. I suspect Microbiology colleagues recommended it but can't remember exactly.

283. Ciprofloxacin wouldn't be your "go to" antibiotic in very small children as it can interfere with bone development and can inflame tendons. It interacts with other drugs. If you give somebody an antibiotic, you alter their gut flora and you can cause other problems. There are good reasons why Ciprofloxacin is not routine outside of transplant. All our children are on a lot of other drugs and Ciprofloxacin is a drug that can cause complications, so for that reason we don't reach for it as a first option.

284. I can't recall how long the patients were prescribed these drugs for, but I think it was for a fairly prolonged period, probably months. I'm sure we were giving it at the time when we were in Ward 6A. There were a group of doctors who sat with Microbiology to work out how long this should be for and that was in light of evidence they were seeing. We did stop its use and only the transplants patients are on it now.

285. The parents were told about the additional drug. We were up front about concerns about the environment and we knew that it was all over Facebook and WhatsApp, so people knew anyway. Families interact on social media to a greater or lesser extent. Some families wanted more information than others or rightly challenged the advice, so it was useful to have a communique and an agreed line.

COMMUNICATION

286. After IMTs there was always somebody making sure Communications would put something out that night or the next day. Meanwhile social media was running ahead, with people asking what was happening and it was sometimes not great having to wait for the official version, the agreed version, which came from Comms and the Board.

287. There were certain parents who were convinced that their child had suffered because of the environment. I tried to reassure them. Some had had gram-positive infections which had most likely come from the skin or the mouth. I think some parents were convinced that we were covering something up.

288. This put us in an invidious situation, as if we had put them in harm's way and now we were covering up that they had suffered harm. All we could do was present them with the details and facts, as best we could. There were some parents who were convinced, even in the face of evidence, that their child had suffered and that we were not giving them the full story.

289. I'm not sure if anything more could have been done in terms of communication. Sometimes I felt communication just got people's hackles up. The Scottish Government appointed Professor Craig White, who we never met, to be an interface with families. I understand that he was appointed as a sort of 'contact me' person and I used to wonder what he was saying to families because he's not a microbiologist or a clinician, as far as I know.

290. We were hearing feedback that families were not happy. As a group of doctors and nurses, we felt that some families lost trust in us. I'm not sure what could have been done to rebuild that trust and confidence, but I know there was a lot of uncertainty for both families and staff. I did understand parent's concerns but often was not in a position to either confirm or refute whether the environment was to blame.

291. We talked to families in terms of risk of infection. We did not nuance it to discuss all the environmental issues, but it did come up with some families. One family from outside of Glasgow were very concerned that they might be putting their child in harm's way by coming to a unit that was now transplanting in an adult hospital and that family explored going elsewhere. That's a very sensible thing for somebody to suggest. To be fair, hospital management was very supportive of them taking that option. We talked it through and the family made the decision to be transplanted in our unit. However, you did sometimes worry that the discussion has shifted away from what transplant meant for this child and their family, to this whole other issue, maybe distracting people from the central issues that they were being asked to consider.

292. I went along to a town hall style meeting at one point, in the lab building. I can't remember exactly when it was, but it was an evening in the winter. Professor Gibson and, I think, Jamie Redfern were there. Prof Gibson was speaking to families whose children were receiving treatment as outpatients at the time. Inpatients had very frequent access to hospital management and senior nursing and medical staff. However, she was worried there was a constituency that maybe only come to clinic but could end up admitted and might find themselves in a strange environment. She explained the situation and the new approach with antimicrobials to try to reassure everyone.

293. The meeting got a bit difficult, but there were parents who sat in the front row and said, 'We're here to support you, we trust you.' I was relieved by that. They had come out on a winter's night to sit there whilst there were some other dissenting voices who felt that there was a cover up going on. These people who didn't have any complaints came along to say, 'No, that's not our experience, we don't feel that, we don't agree with that.' That was heartening to hear. It was a difficult night and not the exchange we were expecting.

294. It is a challenge to communicate effectively with staff because of the way people work. Many of the nursing staff will be on nightshift, there are days off and there's a continuous churn of junior medics, so reaching everybody at the

same time is impossible. I think there was a deluge of meetings and that's challenging because you've still got your clinical workload going on and you're trying to fit extra meetings in alongside your clinical workload.

295. There were a lot of meetings, and it's difficult for everybody to get to all the meetings. Information was often trickling or being filtered through certain people that were going to most of the meetings, and they were doing their level best to communicate but I'm not sure what the solution to that is.

296. In addition to those meetings, there were emails, although they tended to be over wordy, and things like the GGC newsletters, although I haven't retained any copies of these.

297. I'm full of admiration for Professor Gibson, Jamie Redfern and Jen Rodgers. They came in and they spoke to families, but I suppose that was only families that were present on the ward at the time. They were conscious that there was a constituency there who were relying on social media or were outpatients who were probably very anxious, whom they couldn't easily reach. It's a delicate balance as constant communication risks increasing anxieties, making stressful situations even more stressful.

298. I think it is important to highlight that during this period we were continuing to treat patients with leukaemia and continuing to do transplants. We had to explain to them that they had to have chemotherapy because their disease would be fatal without it, but that chemotherapy can lead to infection. These families were often aware of the concerns about the environment and the associated risk of infection, so this was a very difficult situation, and these were very difficult conversations. I felt very sorry for families who were asking very sensible questions about what the risk was.

299. It was difficult to reassure patients, when we ourselves carried so much uncertainty about what was happening. We did not know whether this could be a cluster of infections that might happen by chance or whether we had a

problem. If we had a problem, we did not know whether it was being addressed appropriately. We did not know whether our patients were at greater risk being treated at the RHC than they would be being treated elsewhere. We knew that these infections were occurring in other hospitals, because we went to meetings, and we heard about them. We didn't have any of the answers to these questions.

300. I think that when uncertainty is the overriding anxiety, no communication is going to make that any less anxious for people. Families did not like the uncertainty and the kind of stages we all had to go through to try and get to somewhere better. I think communication has improved and I think it's a bit slicker and that's probably appreciated by a lot of people, but I don't really think it changes the content of the information. I think it just changes the angst around it.

301. Communication is now quicker. There's less delay in getting information out there. We're a bit more agile in our ability to meet and discuss things that arise.

302. In terms of communications with staff, across GGC matters appear in the Core Brief, which is a document that appears in your GGC inbox fairly frequently. It's often printed off and posted on notice boards and the like. As regards information for QEUH and RHC, information from the Board might be disseminated from the General Manager (formerly Jamie Redfern), or it might come from the Medical Director or the Clinical Director, who would use email or might be present at a unit meeting to provide information that's relevant to our department. There are other hospital-wide situations where you might get a cascaded email providing information.

303. We have ward huddles every day, and senior nurses will disseminate information from the RHC huddle. I'm assuming there are clinicians there, but it tends to be senior nurses who let you know what's happening. There are lots of huddles round the hospitals. Basically, the key ingredient to them is that they're supposed to be safety-minded, so essential information that

needs to be known is discussed. For example, there's a surgical huddle every day where, if you have a patient on an emergency list, you go and speak to all the teams involved and you advocate for your patient. It's an opportunity for you to be seen and for you to listen and see the context of what you're expecting somebody else to do.

304. The Board have communicated through the common channels like Core Briefs, but we've also had visits from Chairmen, Chairmen's deputies and people in management positions who have come and spoken to our unit. This has happened on a couple of occasions when they have spoken to perhaps a dozen of us. They've also come and visited the ward and not spoken specifically to me, but maybe spoken to colleagues. Overall, it's been a combination of written communication and titles like the Core Brief.

305. People can become overwhelmed at the amount of information. There is a need to filter what's relevant. Sometimes you rely on colleagues to draw your attention to important stuff.

DUTY OF CANDOUR

306. With regard to our duty to communicate when something has gone wrong, we always have to tell families when something has happened. That is the case whether or not it's something that is predictable, such as a side effect of treatment, and whether or not it's ground we've covered before. Sometimes we're in a position of explaining to a family that something has happened but not being able to explain the reason why, due to the very complex nature of the conditions that we treat.

307. We do try to sit families down and explain situations to them, setting out why we think they've arisen, what we're going to investigate, and what we're going to do to treat it. Those are often quite difficult conversations. It's not possible to cover every conceivable side effect in every situation, so you're occasionally involved in discussions that are new territory. However, it is

absolutely our responsibility to tell families the facts. We have to provide explanations in understandable language because this is complicated. You have to provide the information, and also provide an explanation of what it means, as it would be easy for someone to make incorrect assumptions. That can cause distrust. You have to be mindful that you're often imparting technical information to somebody who maybe doesn't have background or technical knowledge.

308. I think we expect an awful lot of our families. We give them these complex diagnoses and possible treatment regimes, and we expect them to understand it and consent for treatment within 24 hours. If your child has leukaemia, then that treatment has to start tomorrow. We're using a whole new lexicon of words and concepts, whilst the family have just had devastating news, as far the diagnosis goes. Then you're saying, 'Apply your rational brain to reading this protocol and tell us whether or not you consent.' We're often in that situation of having to deconstruct very complicated issues and allow parents space and time to ask questions and to understand what you're requiring of them.

309. I think being able to do this comes with experience. At the start, you sit in on conversations and you learn yourself, you observe. You observe how families take in information. With time you learn to ask, 'Should we pause, have you heard enough, is there something you want me to go over?' It's often good to bring somebody with you and reflect on it afterwards and ask, 'How do you think that went?', 'Did you understand what I said?', and so on. We often bring a trainee so you can get a perspective. You get somebody in the room who can think critically about how the conversation went. You'll often be surprised that whereas you thought you laboured something, a family might say a couple of days later that you never told us about it. So you say, 'Okay'. What not to do is to say, 'Yes I did, you signed it.'

310. It can be very overwhelming. Sometimes I think we should record these conversations and say to families, 'Please listen again,' because this is a lot of information, this is really important information. I know that you can cover all

the details in a difficult consultation and later find that half of it has not filtered through to the family, because there's so much anxiety surrounding the discussion.

311. Duty of candour as far as I'm concerned is my duty to inform parents or patients of events that have occurred that have impacted them adversely or maybe even in a neutral sense if it's a significant event. There's a time limit on when you need to impart that information. That can be a challenge if you are not working on the ward immediately afterwards, but there is a duty to tell families information as soon as you reasonably can. I think one of the ways we try to facilitate that duty of candour is by encouraging families to come to us with any questions they might have. I think sometimes they're reluctant to, because they think we're so busy, but I always encourage them to ask.

INCIDENT MANAGEMENT TEAM MEETINGS

312. IMT meetings were called if there were concerns about the environment. They were multidisciplinary meetings, with attendees from Scottish Government, Estates, Public Health and Microbiology, as well as the clinicians.

313. The meetings were quite formally constituted and they were scheduled to last around an hour but it felt that you spent about 20 minutes with people introducing themselves and explaining their roles. At the meetings I attended, I think most of the talking was done by Estates and Public Health.

314. In terms of the effectiveness of the IMT process, I felt it was useful to see the structures and the personnel responsible for managing these issues. I'm not sure the process was sufficiently responsive to our anxieties as clinicians. There were very long and detailed discussions about matters in which I had little interests from a clinical point of view, e.g. drains. Discussions could get quite technical and very "Estates-focused". I wanted to bring the focus back to the patient and address the risk to the patient and what we were going to do.

315. To be fair to the Board, there were always actions and preventative measures taken forward. I suppose we were probing at possible causes, and we needed to get to the cause because if we could identify this, we might have been able to prevent the infections recurring.

316. Disentangling the cause and effect and impact of control measures is a very complex thing to decode. I don't know that the IMT was the best forum to do this, but it was the only forum we had, and I think it was convened in good faith to be open and to allow people to say their bit. Teresa Inkster was a very good advocate in it from the clinicians' point of view. I was reassured that Teresa was on the case.

317. There was an IMT meeting after we moved to Ward 6A where gram-negatives infections were discussed. There was a theory put forward that perhaps we didn't have a problem with more unusual gram-negatives; what we were seeing was a taxonomy (a classification of organisms) issue. Microbiologists sometimes change the names of bugs, so something we knew of as pseudomonas aeruginosa is now called something different. I remember it was suggested that we had seen the bugs before, they were just called something different. I think this theory was put forward by a representative from Public Health, but I don't think it was agreed.

318. We did get support from management. Jamie Redfern, Jen Rodgers and Susie Dodds were frequent visitors to the unit; they were very approachable and very available to speak to families.

319. I know there was doubt cast on, for example, people washing their hands properly. There was a big hand washing audit, and another to do with the way we were handling central lines. They started putting green caps on the lines, which had not been used previously. This was to protect central lines, so if they did get in contact with water, it would stop any bugs getting into them.

320. There were several control measures taken on the wards which were noted in the IMTs. We told families not to drink the tap water and this applied to the

staff too. I also think children had to bath with bottled water for a limited period.

321. I have been shown the document at pages 32 and 33 of the bundle, which is an email from Angela Johnson dated 28 March 2018 about control measures introduced around water use by immunocompromised patients. I can see that I was not on the distribution list, and I do not recall seeing the email before, but I recognise the kind of measures being described.

322. My understanding from that time was that there was a concern there was contamination of the water, because I know there were samples being taken from all the water tanks and there were diagrams showing where the water that goes into Children's Hospital comes from. It was thought the water coming out of the tap was potentially a source of infection. As time moved on and problems started to emerge with slime in the sink drains, a theory grew that the drains were the problem and what was happening was that water was splashing up from the drains when people were washing their hands in the sink, and their hands were becoming contaminated with organisms from the drains which were then being passed to patients.

323. Whilst we weren't entirely certain if there was a problem with the water and the drains, I recall that the drains were investigated, and they found that slime could be seen in the drains. I remember being told that when they'd been fitted, the pipes in the drains had been joined with tape and other temporising measures. The pipe joins were not smooth, and the disruption to the interior of the pipe made it more likely that bacteria would build up. I think it was discussed at IMTs and my impression was that Estates would be doing whatever needed to be done to address this.

324. I don't think there was increased use of source isolation. There are certain criteria you need to meet to source isolate patients, for example, patients with diarrhoea, with vomiting, or with obvious respiratory infections. Staff don’t do that lightly. If a patient develops diarrhoea, even if you think it’s mucositis and

it's the side effect of drugs, you isolate them until you've proven that the stool doesn't have norovirus or arbovirus or something infectious. They will only be in source isolation until it is proven that they don't need it.

325. There was a period in Ward 2A when rooms were closed for HPV, which was hydrogen peroxide treatment. I remember the smell of it. Rooms were closed when there were plumbing issues too. I know there were intermittently issues with sinks blocking and drains blocking and issues like that.

326. HPV is a sterilising, vapourised treatment that can treat whole external surfaces. I suppose it was a decontaminant measure, but they also put stuff in the water supply. I believe they conducted the HPV cleaning in cycles, doing perhaps two rooms at a time, so we didn't shut the full ward. This did impact on bed availability and reduced the number of patient beds available at times, so it might have led to patients being admitted to other wards.

327. Other remedial measures that were taken in Ward 2A included work on the drains. I recollect that we were told that when they started using chlorine in the water, it was corroding the chrome drain elements. The corrosion was then creating a sticky surface for bacteria to cling to, so they had to replace those.

328. I think they realised that these drains shouldn't actually have chrome in them, and the spec of the fitments wasn't appropriate because of the risk of corrosion. I believe that was rectified when we decanted. We haven't had any concerns regarding the water supply since we returned to Ward 2A.

OVERSIGHT BOARD / INDEPENDENT REVIEW / CNR / PUBLIC INQUIRY

329. I was not directly involved in the Case Note Review. I was part of the group that was consulted about its remit and progress. I made some suggestions and contributions along with colleagues. We did not anticipate that it would result in clinical recommendations. It seemed that the remit got wider as time went on. They didn't consult us about their conclusions. They gave the results

back to the families. They had confidential meetings with the families that didn't include us as the care providers, so it felt as if our care was being evaluated without us being offered an opportunity to contribute.

330. The CNR report said that it was not a response to criticism of clinical care and not a critique of clinical care, but it did actually make recommendations about clinical care. I think we also felt it used metrics that weren't validated or justifiable. It used a paediatric trigger tool which had not been validated for the purpose it was used for.

331. I think there was some context missing by not having our proper input. The Review team did not have local knowledge, and we could have provided helpful information about the processes in the RCH. It was also done virtually, relying on material scanned from case notes, which I think is very difficult because it's often not chronological or can sometimes be put in the wrong folder. If you don't know the patient, you don't know the story, and don't necessarily know where to look for the information. I think it is inevitable that there would have been a lot of gaps that clinicians might have been able to fill, had we been given the opportunity.

332. I'm not sure what the purpose of the CNR was. It only covered a specific patient group. I believe that some families refused to cooperate with the process, as they were grieving the death of their child. We only saw some parts of the summary and we did not see the individual responses from families. We were not given the opportunity to learn from this critique. I accept that everyone should be open to external scrutiny, but this seemed like a very unusual approach, and I feel that there should have been more opportunity for us to contribute to and learn from the Review. We were disappointed in the CNR. I am not sure who benefitted from it.

THE INDEPENDENT REVIEW

333. There was also the Independent Review. I wasn't involved.

THE OVERSIGHT BOARD

334. I know there was an Oversight Board and I know Professor Craig White was involved, but I don't know what they did.

IMPACT OF MEDIA COVERAGE

335. There has been coverage of these issues in the media and some families do bring it up. You have to tell them the truth. I think for me the truth is that I don't know if there's been a final finding here. Concerns were raised, investigations happened, control measures and remediation have taken place and we now have quite a low level of bloodstream infections amongst our patient group. We're very vigilant about it. I know there's been a lot of anxiety in the minds of families, and I think that's been really tough for them. I'm not surprised there's distrust of professionals because of that.

336. I do feel that because of this situation, clinicians have been put in a difficult position. That is because you can't discuss what's in the press, nor should you, but that's what families want to discuss. All you can do is give them the facts and give them time to make a decision.

PERSONAL IMPACTS

337. As a clinician working through the various decants and issues, there has been a professional impact on me. It's been very stressful, and it has created a new part of my job that's now all about this subject. Previously, you had inpatient ward rounds, outpatient clinics, administrative and planning work, educational work, and quality management, but in addition I had to deal with all the IMTs, all the meetings about the IMTs, and cooperating with and contributing to several different reviews and investigations, including all the preparation for the Public Inquiry. I think one of the real regrets I have is that we've been in

the hospital for seven years now and we haven't grown our service because we have not had the time to do this.

338. We should be moving forward, we should be innovating and adopting new treatments, but that has been impeded. Service development has absolutely stalled. Adding COVID into everything has also led to a lot of missed opportunities.

339. I think it'll take a lot of energy to get the initiative back to grow something good, which is a regret. It has felt like a bottomless pit of stress. We've been firefighting instead of trying to grow the service and that's been very harmful.

340. In terms of personal impact on me, there was a whole period where every Sunday there was a headline in the newspapers. We have stopped buying Sunday papers. People would ask me about it; I couldn't avoid it as a topic of conversation.

341. People say things off the back of a headline that can be quite hurtful, and you can't say anything in response, so it did impact. I would avoid telling people where I worked because they would then ask if that was the hospital with all the infections.

342. I see my work as a vocation. It's a hard job to do, but it's extremely worthwhile and that's the upside of it. You can make a very profound impact on somebody's life, in a good way, by doing your job well, and that's what we all aspire to do. There's a great team of people in Glasgow, Edinburgh, round the country and the rest of the UK that support that, and that's really good to be part of.

343. The perception that you would knowingly willingly put people in harm's way and cover it up or in any way assist other people in covering it up is very damaging, it is hard to take. I think that affects morale in the unit, which is a real shame, because there are lots of fantastic doctors and nurses there. I feel

that they have been beaten down with all the harsh scrutiny they have had to endure.

CONCLUDING COMMENTS

344. In conclusion, I think it is good that we are in a shared campus with the adult hospital because I think we should work in collaboration with our adult colleagues who are providing the same treatment. I think it's a great opportunity. I like the possibilities that exist from being part of a bigger centre. I think we can influence each other in positive ways from that point of view.

345. There are a lot of good things about the hospital now. There are some ongoing minor issues, but I think these are fixable and I am hopeful this will settle down and we'll move on from all the bad publicity. I suppose I would like some clarity about what has happened, as I still don't know, and I don't think anyone really knows.

346. It is difficult not having the answer to the question of whether or not we had an environmental cause of these infections. We do not know whether the cause has been addressed, and how best to eradicate the risks.

347. If the answer is that "this was a cluster that cannot be explained but the environment was not at fault", then that doesn't lessen the suffering of the patients who suffered from infections. However, it maybe shows us that we have to be in a state of preparedness for it happening sporadically in the future and accepting that it's a potential risk. Either way, in my view, we should strive the achieve the safest environment for patients by maintaining practices which have helped achieve and maintain our current very low rate of gram-negative infections.

348. I believe that the facts stated in this witness statement are true. I understand that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.