Urology Services Inquiry

Oral Hearing

Day 18 – Tuesday, 24th January 2023 (Closed)

Being heard before: **Ms Christine Smith KC (Chair)**

Dr Sonia Swart (Panel Member)

Mr Damian Hanbury (Assessor)

Held at: **Bradford Court, Belfast**

Gwen Malone Stenography Services certify the following to be a verbatim transcript of their stenographic notes in the above-named action.

Gwen Malone Stenography Services

CHAIR: Good morning, everyone. Welcome back. I hope everyone had a pleasant break over Christmas and is ready for a long year.

Can I, first of all, thank [redacted] for coming along. Shortly I'm going to ask her to be sworn but first of all I think Ms. Treanor wants to say something to us. 10:07

MS. TREANOR: Yes. Good morning, Madam Chair, Dr. Swart, Mr. Hanbury. 10:07

This morning we have what will be our third set of closed patient hearings in this Inquiry. In terms of today's proceedings, you will hear from the families of two former patients of Mr. O'Brien. This morning you will hear from the daughter of Patient 82. Patient 82's care was the subject of a structured clinical record review, or SCRR, a process with which we are all by now familiar. 10:07

His case found his way into the SCRR process due to concerns about the prescription of Bicalutamide. Patient 82 was [redacted] years old when he was initially referred by his GP to Daisy Hill Hospital. Following further investigations, he was subsequently referred 10:08 onwards to Craigavon Area Hospital prostate assessment unit on the 13th January 2010. That referral was, inappropriately, in the language of the SCRR reviewer, triaged as routine by Mr. O'Brien. As a result,

Patient 82 was not seen until 10 May 2010 and, following further investigation, he was ultimately diagnosed with localised intermediate risk prostate cancer.

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Patient 82's case was discussed at MDM on 5th August 2010 prior to staging scans having taken place. The recollection of the MDT at that time was that suitable treatment would be watchful waiting. Those scans were then arranged, and Mr. O'Brien reviewed Patient 82 again on 4th February 2011, by which time his PSA had increased to 10.68. Mr. O'Brien did not refer Patient 82's case back to the MDM to discuss the options. Rather, Mr. O'Brien decided himself to commence the patient on low dose Bicalutamide 50mg once daily, and tamoxifen 10mg daily.

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On 2nd November 2021, some ten years later, Patient 82 was seen by Mr. Haynes, who identified the fact that Patient 82 had, by that stage, been on low dose Bicalutamide for ten years. After discussion, both Bicalutamide and tamoxifen were discontinued by Mr. Haynes, and Patient 82 and his family at that time advised Mr. Haynes that they could not recall having any conversation with Mr. O'Brien about alternative therapies.

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The SCRR reviewer indicates that Bicalutamide 50mg once daily is not registered as a treatment for localised prostate cancer, and concluded that Patient 82's

overall care was poor and not in keeping with good practice. The reviewer noted that any form of hormone ablation therapy represents additional risk in patients with significant cardiac co-morbidities, as was the case with Patient 82, and remarks that potential harm could have ensued from a long period of inappropriate hormone ablation therapy. In concluding, the reviewer suggests that Patient 82's quality of life may have been affected by the treatment he received.

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This afternoon, Chair, you will hear from the daughter of Patient 5. Patient 5's care was the subject of an SAI, and his case was one of the nine 2020 SAIs. Patient 5 is an Personal Informati year old man under the care of the urologists following a successful nephrectomy for cancer. Mr. O'Brien arranged a follow-up CT scan of the chest, abdomen and pelvis on 17th December 2019 and hoped to review the patient in January 2020. The scan report showing a possible sclerotic metastasis in the spine was available on 11th January 2020. Mr. O'Brien failed to action the result of that scan, with the consequence that Patient 5 was not called for discussion and further treatment until some eight months after the result was available.

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The Inquiry understands that there is an audit function on the PACS system which allows you to see when a scan has been accessed and by whom. That audit function appears to indicate seven months after they became

available, Mr. O'Brien accessed the results of the CT scan on 12th July 2020.

Madam Chair, Mr. O'Brien has prepared a written response to the SAI report in respect of Patient 5, wherein he seeks to explain the delay and action in the scan report. Mr. O'Brien indicates that his secretary transferred a copy of Patient 5's chart with the report of the CT scan, presumably in hard copy, to his office following receipt of the report. He explains that as the chart was not tracked, it has not been possible to determine the precise date on which it was left in his office. However, Mr. O'Brien suggests that it was probably during February 2020, and indicates that he did, in fact, review the scan report in either late February 2020 or early March 2020.

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He advises that, at that time, he did not arrange bone scan as he felt that doing so may expose Patient 5 to the risk of contracting COVID-19. Mr. O'Brien goes on to explain that he also later considered arranging for further CT scanning in April 2020 but again elected not to do so due to concerns around COVID-19.

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There is no record of Mr. O'Brien's review of the scan and nor has he suggested that he discussed the need for a further scan with anyone else. Mr. O'Brien states that having not been in his office at Craigavon Area Hospital since March 2020, he returned briefly on

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21st June 2020 to, in his own words, collect the clinical records of two patients regarding whom he intended to prepare reports during July 2020. It is unclear whether Patient 5's records were among those records collected by Mr. O'Brien in June 2020. In any event, no further action was taken in respect of the scan at that time. 10:12

Finally, Mr. O'Brien states that he had just begun to progress the administration of Patient 5's case on 2th July 2020 when he read the letter sent by Mr. Haynes in his role as Associate Medical Director the day before, which instructed Mr. O'Brien not to access or process patient information in light of the concerns which had emerged in June and July. For your note, Chair, that letter is available at AOB-02534, and the reference to the restriction on processing patient information appears at AOB-02535. 10:13 10:13

In seeking to explain the failure to action the CT scan, Mr. O'Brien states that had he not received this communication, he would have made arrangements for Patient 5's further assessment and management. Again, there is no suggestion that Mr. O'Brien alerted anyone to the need of further assessment and management in light of the scan report which was first available in January 2020. 10:13 10:13

Madam Chair, I should make clear that Mr. Haynes has

not had an opportunity to consider and respond to Mr. O'Brien's comments in his written response, but of course will have an opportunity to do so in due course.

A letter was then sent to Patient 5 on 29th July 2020 to advise of his CT result and to apologise for the delay. Mr. Haynes, the author of that letter, advised of a possible abnormality on the CT scan that required further investigation with a bone scan. The diagnosis of metastatic prostate cancer was confirmed by the bone scan, which took place on 6th August 2020. At a review on 12th August 2020, Mr. Haynes discussed treatment options with Patient 5 and commenced androgen deprivation therapy. Patient 5 was also made aware that a referral to oncology remained an option. 10:14

The SAI report into Patient 5's care concluded that the abnormal findings on the post-operative review scan should have been noted and acted upon by Mr. O'Brien. The review team observed that it would be unusual for a renal cell carcinoma to produce a sclerotic metastatic bone deposit, and other options should have been considered. 10:14

Madam Chair, I have previously addressed you on the purpose of these hearings and the relationship with the Inquiry's terms of reference, and you will be relieved to hear that I don't propose to repeat my remarks this morning, save to re-emphasise that it is not the role 10:15

of this Inquiry to make findings about clinician outcomes in individual cases. Rather, the main purpose of these hearings is to give effect to Part D of the Inquiry's terms of reference by affording patients and their families an opportunity to give direct evidence to the Inquiry about their experiences of urology services within the Southern Trust. 10:15

Madam Chair, as I indicated at the outset, this will be our third seat of patient-focused hearings. I should indicate that it is not intended that it should be the last. It is anticipated that the Inquiry will convene further patient hearings periodically as the need arises. 10:15

Those are my opening remarks.

CHAIR: Thank you very much, Ms. Treanor.

[redacted], I'm going to ask if you will take the oath or be affirmed now, please. 10:15

[redacted] HAVING BEEN SWORN, WAS QUESTIONED BY THE INQUIRY PANEL AS FOLLOWS:

CHAIR: [redacted], welcome. I'm Christine Smith, Chair of the Inquiry. To my left-hand side is Mr. Damian Hanbury, who is the consultant urologist and the assessor to the Inquiry. My co-panelist, Dr. Sonia Swart, is to my right. 10:16

I will be doing most of the talking, you'll be relieved to hear, probably. As with all of the other patient and family witnesses who come to speak to us, this is your opportunity to tell the Inquiry what you want us to know about your father, Patient 82. There are no right or wrong answers. We're going to ask you to tell us in your own words what you want us to know about his care. If you need to take a break at any time, just say so, we can arrange it. 10:16 10:17

Can I first of all express our condolences on behalf of the Inquiry on the loss of your father. I know it is a while ago but I'm sure you still feel it every day. 10:17

We have received a bundle of papers. Can I just assure you that the Inquiry has read all of those papers so we know what's in them. If you need to refer to anything that's in that bundle of papers, any particular page, can I ask you to use the number that is on the top right-hand corner of the page and we can pull it up on the screen so everyone can see it, if need be. 10:17

I also, as Ms. Treanor said, do need to remind you that the Inquiry can't make any decision about the care that your father received as an individual because we are looking at system issues and governance issues, but, obviously, we are also looking at the care in that 10:17

context. If I can ask you, just in your own words and in your own time, if you want to tell us what it is that you want us to know about what happened to Patient 82 and his care.

A. Well, I suppose initially I didn't think the Inquiry was relevant to me because it asked about a complaint in late '19 into '20. The only complaint ever I made to The Trust - and it wasn't as a complaint, it was more for the benefit of other people - was back in 2010 when Daddy's care was transferred out to 352. 10:18

CHAIR: Can I just pause there? We understand that that was the result of a waiting list initiative that the Trust engaged on to try to get patients seen more quickly than they might otherwise have been seen?

A. Yes. 10:18

CHAIR: So, they were then outsourced really to a private healthcare facility?

A. Yes, and we were informed of that just by letter. That letter come and there was errors in it in terms of advice, and just the shortness. Like, for instance, had Daddy needed an ANR blood test, there wasn't time from receiving the letter to the appointment for that to be done. There was difficulties with communication with 352. Indeed, I went back through the Trust as well, and it was difficult to get anybody there to take -- to give information. 10:19

But, anyway, Daddy went to 352. There was an incident where his blood pressure dropped and he had to be transferred out of the Downe Hospital to the Ulster

Hospital, and actually from there to the City Hospital. But the outcome was that Daddy had no long-term effects. But the biggest problem there was trying to find out what drugs Daddy had been given pre-operatively so that going forward, while he still needed the Botox, we would know not to give those drugs again. 10:20

When I went to Mr. O'Brien's clinic to see Daddy, he was oblivious to the fact of anything that had happened with 352 with Daddy. I asked at that time why did he allow Daddy's files to be transferred out, and he said that his files were all lifted and the patients that were allocated out were nothing to do with him; it was a management decision who went. So, they seemed to go to 352 without any preassessment for surgery. 10:20 10:20

Mr. O'Brien then tried to find out what drugs were used, and he wasn't able to find out. In fact, in one of his letters he wrote that he expected they would never find out, which causes me concern from the point of view that as commissioners of the service, I felt the Trust should have been able to find out, and expect to find out, what took place. Indeed, there was another letter from the Trust to me that said Daddy's notes would go to the private provider but they would remain belonging to the Trust and would be returned to the Trust. You know, I would have expected them to have got a full report. 10:21 10:21

On the back of the fact that Daddy was still having urology problems with urge continence, I mean we needed to know every toilet in the main street in [redacted] so he would be able to go out and do his business and yet be confident that we could get him to the toilet. He still needed this Botox, so we were pushing to get that information. The GP couldn't get the information either, apparently. At the last, between Mr. O'Brien and an anaesthetist in Craigavon, they decided that they would do a spinal anaesthetic to allow Daddy to have the Botox. 10:22 10:22

But it took -- I mean, I think there was about seven people in governance whose names were attached to the letters that I wrote. And when the letters -- when the conclusion come a year later, almost, from 352, it was 352 that wrote the explanation to my questions, which I don't really feel is right from the point of view, the Commissioner again go back. The overall responsibility I felt lay with 352. They subbed out the work to -- 10:22 10:23

CHAIR: You mean the Trust rather than with 352?

A. With the Trust, yes. The Trust, I felt, should have held overall responsibility. They should have been the ones that spoke to 352, got the answers and give me the answers. Initially I was told the answers would be there in 20 days, and that didn't materialise for various reasons. Then the next timeframe I was given 10:23

was 20 weeks, and that I would be invited to a meeting.
CHAIR: Did that happen?
A. No, you know. And as an employee of The Trust as well, as I say, it wasn't to make a complaint really, it was to say, look, you know, people need to be assessed before they go for surgery and there needs to be sharing of information, and if this isn't done, you know, it will be to the detriment of further patients. That was where I was trying to go. Thankfully, Daddy was okay from the event. You know, he didn't suffer.
CHAIR: Just so that I can be sure that I've got it clear, [redacted], your father's surgery was outsourced to 352 by the Trust. Our understanding is his notes and records didn't go with him, as it were, from the Trust?
A. No, no, no.
CHAIR: So 352 were in the dark, as it were, in terms of what treatment he had had?
A. Yes. I suppose even on that morning, when I arrived in Downpatrick Hospital, it was like a ghost town. There wasn't even a receptionist in the foyer. We went upstairs to the area where we were supposed to be and I observed, as I felt at the time, the anesthetist walking around and being shown round; she didn't know where she was, she was finding her way. Then a nurse came in and she started to take information from Daddy, and in the middle of that the anaethetist took over and really dismissed the nurse, from memory.

Then Mr. Thwani came in. At that point we did realise that there was no notes; he told us there was no notes. He did go into, in some details, all the complications about surgery. To the point then I started to get frightened and I says well, look, are you sure you're happy to proceed in the absence of notes. Bearing in mind I was standing with a [redacted]-year old man who had been fasting, who had been up from six o'clock in the morning, and really whose notion about medical staff was they knew best and not me. You know, we'd had an awful time with Daddy, as I say. We needed to know every toilet in the street for to get him out and about, to go shopping, to do anything he had to do. So I was busy thinking, well, we were on a waiting list for long enough and if I reneged today, where are we going to be on a waiting list again and, you know, this problem is a bother for Daddy, and he was highly embarrassed about it as well. You know, really is anything going to go on or is [redacted] over-dramatising the whole thing here? Mr. Thwani said that he had worked with Mr. O'Brien. He says, look, I have computer access and I have sufficient information to go ahead.

CHAIR: So he was able to access your dad's records, or he told you that?

A. Well, he did say he had computer access and he worked closely with Mr. O'Brien and he knew what needed to be done. Ten years ago, this is the recollection. So, we decided to proceed.

CHAIR: Unfortunately, your father would appear to have a reaction of the drug that he was given?

A. Yes. I had forgotten my glasses that day and I left to go and buy a pair. I got a call, it wouldn't have been half an hour, to come back, Daddy had deteriorated. 10:27
I was asked -- I got into the ward. They said he took a heart attack and I was asked to call the rest of the family. I called them, and then we just were in the corridor waiting to see what was going to happen.
Then, when we did get in to see Daddy, he was sitting 10:27
up quite bright and he said he was all right, but at that stage they decided he needed to go to the Ulster. I mean, he was in there for three/four days. He was on drips and he was on heart monitors, and he was moved
from there to the City to have an angiogram. Out of 10:28
that had come that, you know, his heart was okay, so they come to the conclusion that possibly he had got the anaesthetic too quick.

CHAIR: This was obviously a very upsetting and worrying time for you and your family, and you were 10:28
concerned to try to ensure that it didn't happen again to anything else, which is why you wrote then to the Trust?

A. Yes, that was why I wrote to the Trust.

CHAIR: And to 352. 10:28

A. Because once we got Daddy out of the hospital we realised he was okay and there wasn't going to be long-term harm, barring the fact that he didn't yet have his Botox injection and it was still needed. So,

there was an onus to try to find out what had happened so that it wouldn't happen again.

CHAIR: Yes. Now, you wrote, and we have seen the letters that you wrote and the response you got. You got a response from 352 which wasn't, perhaps, the best of explanations, if I can put it as neutrally as that. 10:29

A. No. Yes.

CHAIR: Then you received a letter also from the Trust, which we would describe as a holding letter.

A. Yes. 10:29

CHAIR: Saying that they were going to carry out investigations?

A. Yes.

CHAIR: The Inquiry wondered did you ever get that letter, because we couldn't see it in any papers, the result of the Trust investigations? 10:29

A. No, I never got that letter. That was the one that said -- well, there was a letter that said I would be invited to a meeting. It could take 20 weeks, and the conclusion of it was I would be invited to a meeting. 10:29

But no, I never got any explanation from the Trust. I wrote to 352 and complained and copied that letter to the Trust as well. Then 352 wrote back out to me again, and there was discrepancies in that explanation, 10:30 I felt, and I wrote back again to 352 and copied it to the Trust. Then 352 wrote again. You know, to me, their last letter was, well, this is the answers and, really, if you have any more. At that stage, well,

I was working and I was busy, you know. I had rang and I had tried to speak to people and they weren't available and they didn't ring back.

CHAIR: You basically just gave up?

A. Yeah, I gave up. You know, Daddy was annoyed because Daddy was going, "Sure, nothing happened to me, I'm all right". 10:30

CHAIR: So he didn't want you to pursue it either?

A. No.

CHAIR: Certainly, as far as the Inquiry is concerned, nine and a half years after you received a holding letter saying that the Trust was going to investigate, you received no further communication from them? 10:30

A. No. No.

CHAIR: You were saying your father, thankfully, had no adverse outcome as a result of what happened, as a result of the waiting list initiative incident. When did you discover that there was a further difficulty with the treatment that your father had received? 10:31

10:31

First of all, sorry, just to interrupt, I just want to make it clear that Mr. O'Brien also tried to find out information on behalf of you and the family; isn't that correct?

A. Yes, he did. Yes, Mr. O'Brien wrote to a lady, Corrigan, copied her into a letter that he had wrote, I think to Mr. Thwani, asking for information on what had happened. I don't think -- well, I certainly didn't get any reply or I don't think he 10:31

got a reply from Mr. Thwani about what had taken place. I thought that it was significant that the head of service and Mr. O'Brien didn't have discussions about what had taken place. He seemed to say in one of the letters, Mr. O'Brien, that he hadn't seen our complaint. In another paragraph, he was proceeding with the spinal because he didn't expect to get an answer. Well, you know, why would you not expect to get an answer?

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CHAIR: But you then discover that there is a further difficulty with the care that your father had received?

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A. Yes.

CHAIR: When did you discover that?

A. That sort of come to light -- well, I suppose the first bit that come to light was when we met Mr. Haynes in Craigavon. On reflection now when I think of it, I did feel "What's going on here", because normally we would have only met Mr. O'Brien at clinic. Nurses out and about but when we in for the consultations, it was Mr. O'Brien. But Sister O'Neill was there. When you're on the spot and asked to recall information, I couldn't think. And Mr. Haynes said to the effect that there was new research that Bicalutamide and tamoxifen were not effective and that their use increased the risk of heart attacks, heart problems, stroke, decrease in memory, decrease in energy, decrease in cognitive decline on a low dose, and the hormone treatment was not effective, and cure was the first course of action in early diagnosis. The plan

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was to stop the medication and do a baseline PSA, with a review of that in February 2021.

He said that a PSA below 10 would have no treatment. At this point, you know, I asked them, I started to think where are we going with this, so I says well, what happens if it's below 10, and he said there would be no treatment. I said, well, what about between 10 and 20, where do we go? He said we would have to see how quick that came back up again; increase and consider a large dose of a hormone injection intermittently would be the course of action. I said what happens if it goes above 20? They said, look, let's take one thing at a time, see how it progresses. But I was thinking, well, I have an [redacted]-year old man and what's he going to be able to cope with? They said a PSA above 20 would be query radiotherapy. I thought, well, that's going to be in Belfast and how is Daddy going to cope with all that when it looked like the Bicalutamide and tamoxifen was doing the job keeping a low PSA. He was told to stop intermittent catheratisation at that time, which he largely wasn't doing, although he was told he could do it if he felt he couldn't pass urine. A urine sample was to be obtained.

I also asked them that day, I says, well, if we're going to repeat this PSA, are we going to be in the middle of COVID in February and a lockdown here, and I can't get in to get the PSA done? They said that

there would be satellite clinics in Armagh, and it would be a drive-through for blood tests and you would get them. So, now we're going to take an [redacted]-year old man to Armagh.

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As it turned out, we were in lockdown. There never was a mention of a PSA. But by that stage, Daddy had had a fall and really there was marked deterioration in his overall demeanour. Bloods were being done to investigate that at Home. I knew it was coming up 10:36
to February and I asked the GP to repeat the PSA. At that time the PSA had rose for the first time in a long, long time to 0.28. Mr. Haynes did write out and say that it was within the normal limits and they weren't concerned, and it would be reviewed again. 10:36

There possibly was a mention too of x-ray or another scan, but Daddy at that stage wasn't fit to be going anywhere; he was all but off his feet.

CHAIR: This was as a result of the fall that he had 10:37
taken that he deteriorated? His health deteriorated generally; is that right?

A. Yes, and he did have a dementia diagnose. I would say he didn't know the harm of dementia, really. I mean, he knew us until the day he died, or a few days before 10:37
he died when he was unconscious more or less. But he knew where he was, he knew all of us, he didn't not ever not recognise any of us. Then he had COVID albeit he didn't die within the 28 days of COVID. He had

COVID on [redacted] and he didn't die until the [redacted]

But, you know, there again, I would ask the question. Mr. Haynes had said a hormone injection but there's a letter there from somebody to say that any hormone treatment would be detrimental to Daddy with his heart problems, so was even that right? I just don't know.

CHAIR: If I can just sum up. The first you were aware that there was an issue about -- just to be clear, your father was on Bicalutamide and tamoxifen for about ten years?

A. Yes.

CHAIR: The first you became aware that that was maybe not the appropriate treatment for your father is when you received communication from Mr. Haynes at a clinic that he took rather than Mr. O'Brien; is that right?

A. Yes.

CHAIR: And you haven't received any communication from the Trust other than what Mr. Haynes told you at the clinic?

A. No.

CHAIR: There was no letter came out saying, "We have reviewed the records" or anything like that?

A. I only knew that there even was a review taking place when I heard about it on UTV News, which again aggrieved me because I felt, you know, the Trust had responsibility for our care; there was an investigation taken into it. I know all about confidentiality but it

obviously was out there when it was in the news. I think the Trust should have took the opportunity when they had us to have said, look, there is a review also taking place here; we can't go into the ins and outs of it. I could have accepted that but at least I would have been informed, I wouldn't have had to hear it on UTV News.

You know, we talk about openness and transparency and keeping the patients informed. Certainly, I wasn't informed. 10:39

But it's funny, on reflection, I did sense the two people in the room that day had something more going on with them, which I think is a poor reflection of the Trust again. 10:39

CHAIR: You felt that they knew that there was -- that your father was part of this look-back exercise and weren't even tell you then?

A. Yes, on hindsight. When I went into that room that day, I thought "What's going on here"? I expected to see Mr. O'Brien. He wasn't there. I was told he had left and this was the new doctor and there was new research. But underpinning that all was a public inquiry, which I think the words could have been said - "There's a public inquiry taking place here, we can't discuss it but at the minute here's what we need to do with your daddy", and there would not have been any breach of public confidentiality, I don't feel. 10:40 10:40

CHAIR: Obviously there's the issue over the nine and a half years' lack of response from the Trust to your complaint, which you say was not designed to get anybody into trouble as such --

A. No.

CHAIR: -- but rather to help others.

A. Improve service.

CHAIR: So there's that issue about communication.

A. Yes.

CHAIR: But if I've heard what you're telling me correctly, you're saying that you were pretty dissatisfied with the level of communication generally from the Trust with patients and families; would that be fair?

A. Yes, yes. I find you write in a complaint and they write back to you what you wrote in. "I wish to complain"; "I see you want to complain", or "You have a complaint; I acknowledge your complaint". But they tell you nothing about the complaint, they don't answer the complaint.

CHAIR: Or give you answers as to maybe what happened in the individual circumstances?

A. Yes.

In terms of the Bicalutamide, you know, somebody has mentioned a -- just to I get all this terminology -- a pathway, a clinical -- a standard for clinical practice.

CHAIR: Sorry, you're reading from a document there,

[Patient 82's Daughter]?

A. No, it's my own words.

CHAIR: Sorry, your own notes.

A. It refers to standard clinical practice for Daddy's management, so I presume that's something that's written down that doctors are meant to follow. I would have expected Dr. Thwani and Mr. Tyson and Mr. O'Brien to have known that. Yet, Mr. Thwani and Mr. Tyson seen Daddy's medication and never queried why he was on a low dose of Bicalutamide. 10:42

CHAIR: There's some water there, if you need it, [Patient 82's Daughter].

A. Sorry.

CHAIR: You're okay, don't worry.

A. It looks like to me that there were two other doctors with knowledge of urology that should have questioned the use of Bicalutamide and tamoxifen in Daddy, and didn't. 10:43

Daddy took a dizzy spell one day in the main street in [Personal Information redacted by USI] and he was referred to a geriatrician. I understood that to be an expert in the care of the elderly and medicine suitable to that age group. He never questioned it. In fact, he actually reduced furosemide and clopidogrel at that review, and never questioned. 10:43 10:44

Daddy would have complained about hot flushes, and I could say on three occasions I have spoken to the GP

practices and been told, well, that's his cancer medication, you know, so we're not going to touch that. But nobody thought to ring or write to Mr. O'Brien and say is this still essential, is it appropriate to continue with this, he's having hot flushes? 11:31

CHAIR: Can I just ask, the hot flushes would be a side effect of the medication?

A. Dizziness.

CHAIR: Were you aware of any other side effects that he had in the ten years that he was on the drugs? 11:31

A. He would have had breast tissue, I would have felt. Fatigue. You know, there again he seen a cardiologist, Mr. Menown, and complained of fatigue, and there was no mention of it being down to Bicalutamide or tamoxifen, it wasn't questioned. From, I mean, a cardiologist -- 11:31 right, if hormone treatment is detrimental to somebody with Daddy's acknowledged cardiac condition, was the cardiologist not concerned that Daddy was being prescribed a drug from another practitioner and yet didn't consult with that practitioner to say, well, 11:31 look, you know, his heart condition is causing me concern, does he really need to be on this or can we do something different?

There didn't seem to be any of that correspondence 11:31 between either of those two people.

CHAIR: So, not only are you saying that the communication from the Trust to you as a family was less than satisfactory, but you're saying that the

interdisciplinary communication between the doctors was not satisfactory?

A. Well, it would seem that. You know, Mr. O'Brien did write to the cardiologist to ask about stopping the like of Plavix post-surgery, and they had to delay that for a time because Daddy was waiting to get stents in, so obviously his heart condition was taking priority over his cancer condition at that time. 11:31

The one thing that sticks in my mind that Mr. O'Brien did say to me was "Your Daddy's prostate cancer will never kill him, his heart condition will". So, you know, I took reassurance from that, to be honest. I mean, the PSA treatment, the Bicalutamide and tamoxifen, dropped the PSA. Well, it was the only thing that I can give a reason for dropping it. 11:31

I mean, Mr. O'Brien, in fairness, did ring after hours, after his working hours, and tell me if we had have gone to clinic and the PSA result wasn't available, he would have said "I'll get that and I'll ring it through to you". I would have got calls -- I did at least get a call at seven o'clock at night to say, look, the PSA is down. It was music to my ears, you know. 11:31

Again, on reflection, am I thinking now the Bicalutamide was taking care of the PSA, it was dropping within the normal limits, so the cancer was

stopped in its tracks as far as I was concerned. But when we go into clinic, what seems to be coming to the fore is the fact that Daddy had an irritable bladder and the management of that nearly seemed to supercede the cancer. That was a problem and there was various medications taken. Until the day Daddy passed away and that he was on his feet, he was up two to three times every night to the toilet. He still, in all his days, would have had the urge to get to the toilet. 11:31

I mean, no matter -- you know, like what did it mean for Daddy? Daddy stopped travelling distances where maybe he would have been in the car. He wouldn't have went to his home place in Personal Information redacted by USI because he couldn't have done the journey; he wouldn't have lasted unless we could have got him to a toilet. He curtailed activities in town to where he knew he would get to the toilet. There was actually one brother - my brother has reminded me there - wouldn't have taken him out because he just couldn't have coped with him being incontinent. 11:31

CHAIR: His quality of life was not what it might have been --

A. No.

CHAIR: -- in his later years -- 11:31

A. No.

CHAIR: -- because of his conditions?

A. Yeah.

CHAIR: I have no further questions that I want to ask

you, Patient 82's Daughter. I'm going to hand you over to, first of all, Dr. Swart, and also Mr. Hanbury in due course. Thank you.

DR. SWART: Let's go back to the complaint process. You wrote a letter to the Trust. Did anybody from The Trust ring you up and talk to you about what you wanted to achieve with the complaint? 11:31

A. No. I rang in several times to speak to people, and people were to ring me back but never phoned back, so then I put it in writing. Before I put it in writing, I made a phone call to say I wanted to speak to somebody. 11:31

DR. SWART: But did you get a phone call to say "We've received your written complaint. It would be helpful to discuss the main points of it so we can give you a good answer", or anything like that? 11:31

A. No, no, no. I sent them the letter telling them what my issues were and nobody from the Trust ever came back to discuss those.

DR. SWART: You worked in the hospital, you said? 11:31

A. I worked on community at the time.

DR. SWART: You worked for the Trust. What has this left you in terms of a feeling about complaint processes in general? If you could go to the Trust and say, look, you know, I would like you to consider a different way of doing it, what would your suggestions be? 11:31

A. Well, I think when a complaint comes in it, is all about self-preservation and protection of yourself. Or

themselves.
DR. SWART: What would it take to change that? What are some suggestions? If you were to go in a quiet room with someone and say look?
A. Well, it's hard to beat face-to-face. 11:31
DR. SWART: We have heard your story today and we can see the impact it has had.
A. It is hard to beat the face-to-face. You know, I think if you can't meet someone, a colleague, to discuss a complaint, it doesn't say much for the general public 11:31 trying to make a complaint.
DR. SWART: When we come on to the meeting with Mr. Haynes and the nurse where you had this kind of odd feeling, as you describe it --
A. Yes. 11:31
DR. SWART: -- were you given the opportunity to ring up and speak to them after? The nurse, in particular. Did they say just ring us if you have got anything?
A. In fairness to Sister O'Neill, she did give us her card. 11:31
DR. SWART: Did you ring her?
A. No, I didn't.
DR. SWART: How were you feeling at that point after you came out of that consultation? Can you remember how you felt? 11:31
A. Worried because I thought -- well, I mean, Health Service in crisis, can't get in to see doctors and what happens if this cancer takes off? Is it going to be monitored or are we not going to be getting the bloods

done? And, you know, the Bicalutamide was very simple to take; it didn't inconvenience Daddy in terms of having to travel for radiotherapy sessions. Yes, it had its side effects but radiotherapy would have its side effects. You know, even the injection, which I'm not sure now even was appropriate either. I mean -- 11:31

DR. SWART: From your perspective, you had confidence in something that was keeping the cancer under control and that confidence was then removed; is that what you are telling us? 11:31

A. Yes. Yes.

DR. SWART: How could that have been done differently, do you think?

A. How could that have been done differently?

DR. SWART: Yes. What would have made that easier for you, because it is quite easy to understand that that was hard. I mean, you have mentioned that you thought there was a lack of openness and transparency about things. 11:31

A. Well, if it had have been said it was the totally wrong medicine that he had been on for ten years, then I would have started to sit up and take notice, whereas I thought somebody else is coming in now and there's a bit of new research, you know. Well, as it was put to me when Daddy got the anaesthetic, the old head was better than the young. It was implied that the young anaesthetist had given the aesthetic too quick, whereas the older anaethetist that did do the eventual procedure said I would be going extremely very slow. 11:31

There is a notion of go low and go slow when medications are being introduced sometimes. I was thinking, well, we're not on the maximum dose so maybe it will be safer.

DR. SWART: In terms of the whole urology clinic setup and this thing going on over years and everything you now know, what advice would you give the Department now as a patient in terms of making things better for the future for patients and families? 11:32

A. Well, obviously there was some lack of governance in terms of -- well, was Mr. O'Brien operating solely on his own? I mean, that's not recommended. It is recommended that a multi-disciplinary team approach is taken. There is documentation and reference to a multi-disciplinary meeting which discusses watchful surveillance. I honestly can't recall that being discussed with us. 11:32

I think possibly surgery was mentioned but because of Daddy's heart, that was a big risk, and since this cancer wasn't going to kill him, why would you go down that route? Radiotherapy was mentioned. Again, I have to say I can't recall that conversation. But when I would have went to clinics at the last - when I got the letter to invite me - I would have maybe wrote the outcome of it. On the night of the 11th/12th, "no radiotherapy until bladder problem resolved". So radiotherapy obviously was discussed, in my thinking. 11:32

Then, did it take a back seat because the PSA was being managed by the Bicalutamide and it was dropping all the time? I don't think I ever remember going to clinic and Mr. O'Brien saying, well, it's up this time, it seemed to be dropping. I have to say that was reassuring. I just thought that's there, it's not going anywhere. 11:32

DR. SWART: I can understand that.

A. Yes, I knew there was side effects but did the side effects outweigh the risk of cancer? Yes, as far as -- I mean, I have a limited knowledge of the cancer treatments. 11:32

DR. SWART: Thank you very much. That's all from me.

CHAIR: Mr. Hanbury. 11:32

MR. HANBURY: Thanks very much for talking to us.

If I could just take you back to the first diagnosis away back in December 2009. Your father was seen actually very quickly at Daisy Hill initially. What were you or he told about the reason that he was referred to Craigavon at that point, because that took a few months, didn't it? Or maybe you can't remember. 11:32

A. Right. Well, honestly, I can't recall. But the fact he had a raised PSA, I would have had enough knowledge to know there was concerns that that could have been due to a cancer. 11:32

MR. HANBURY: That took about five months for that appointment to come up in May?

A. Yeah.

MR. HANBURY: Did that surprise you, that it didn't happen a bit more quickly since you had been seen very quickly for the first appointment?

A. Well, I can't honestly answer that but what I would say my knowledge of urology was, it was a very busy service and there was long waiting lists. That would have been sort of -- it was big clinics. 11:32

MR. HANBURY: Moving on. Then he was told the results, that there was some prostate cancer there. There were some scans arranged. Again, things took a while and it was nearly Christmas of that year, so about five months later, that he had the MRI scan. Again, did you think that was reasonable at the time? 11:32

A. No, there's probably nothing reasonable when you have a cancer diagnosis, but, I mean, the cancer diagnoses even today are not meeting their deadlines, you know. You're probably very grateful to be seen, even though you did have to wait. 11:32

Would I like to have been seen in two weeks? Yes, I would, but the reality of it is that the NHS doesn't see people in the time limits that are set. Clearly, that was back then too.

MR. HANBURY: Then he comes back to see Mr. O'Brien in February of the following year. You mention later you saw Sister O'Neill when you father met Mr. Haynes. Do you remember seeing Sister O'Neill or one of her colleagues at the time when you saw Mr. O'Brien in the 11:32

early days?
A. Oh, yes, yes. Sister O'Neill, well, she was there, I'm near sure, working from the early days. Yes, I think she was a longstanding member of staff.
MR. HANBURY: Would she have spoken to your father then and then offered to the family some support? 11:32
A. Well, not that stood out but, yes, I would have seen her face.
MR. HANBURY: But you remember her being there. Thank you. 11:32
A. Yes. Like, there was no deep, heavy discussions with her about anything.
MR. HANBURY: About the sort of options of, as you say, radiotherapy or surgery that you were -- you remember that was discussed. 11:32
A. No, it would be all with Mr. O'Brien.
MR. HANBURY: Would you have seen her separately, do you think, or all the conversations were with Mr. O'Brien?
A. No, no. The only nurse we would have seen separately at a nurse clinic would have been coronary care. Like, I never went to see the urology nurse like I would have seen the coronary care nurse? 11:32
MR. HANBURY: Independently.
A. Independently, no. She would have been there at the clinic. 11:32
MR. HANBURY: Going on then until the fateful surgery at 352, you said that the urologist had access to some notes?

A. Yes.

MR. HANBURY: Did the anaesthetist say the same? Did the anaesthetist have access to any information, cardiology notes?

A. I don't know if it was the personality/custom of the anaesthetist but she stood out as being abrupt and not knowing where she was going. I felt she was being shown around the environment. When we went in, the TV was on, doors were open, people were moving about the treatment -- or the waiting room that we were in. The nurse was in the middle of her assessment and the anaesthetist come in and I felt abruptly interrupted the nurse, dismissed her more or less. She came in with an A4 page and a pencil and that was all she had; an A4 page folded in half because I remember it. You know, it just didn't -- they say you should follow your gut. It just didn't feel right. 11:32 11:32 11:32

But then Mr. Thwani come in and he was more reassuring, a more confident person. The anaesthetist also had difficulty understanding Daddy and Daddy had difficulty understanding her, and it wasn't helped by the fact that the TV was going and the doors were all lying opened. I actually got up and closed the doors. 11:32

She didn't -- she stayed the least time in assessment. Then Mr. Thwani come out and he said that there was no notes.

There's a letter from Mr. Thwani that says Daddy was to have watchful surveillance. Had he have had them notes and seen his notes, his letter that he had sent at the time, he might have questioned why Daddy at this time was on the Bicalutamide and the tamoxifen, but he didn't have the notes at that point. He says, look, I've worked with Mr. O'Brien, I know what needs to be done, I've got some computer access here and I'm happy. But he give a big spiel about the risks of surgery and then I started, oh, he's a bit over the top. 11:32 11:32

I questioned him then and I said are you sure you can do this safely and he's going to be okay, and he says yes. I says, hmm, right. Faced with the option of going on a waiting list again against the possibility that something might not happen, we proceeded. 11:32

MR. HANBURY: We know that Mr. O'Brien, with the admission papers of the Trust, was very specific about the cardiac history and the stents.

A. Yes, he knew. He knew. 11:32

MR. HANBURY: It doesn't sound as though the anaesthetist had access to that.

A. When we came back to clinic, I said to Mr. O'Brien "Why would you have passed Daddy's file out of Craigavon Hospital; he should have stayed within the acute service because of his heart". Mr. O'Brien says my files were taken, it was nothing to do with me; the list was nothing to do with me. Which, you know, I thought, well, like who decided who was the 11:32

appropriate person to go forward to 352 and who should stay in the hospital?

Then 352, they decided -- as I said to them, did you operate just off a list? They had no notes either. They didn't write back to Craigavon Hospital to say we don't know the first thing about this man that you sent on a list. They didn't get the notes.

MR. HANBURY: Just to go back to your comment about all treatments have risks and the radiotherapy stirring up the bladder. Mr. O'Brien saw your father a lot over that 10 year period. Was there any time that that conversation about the Bicalutamide and the risk of heart disease was raised by Mr. O'Brien over that period? 11:32

A. Well, there never was a question of should we stop the Bicalutamide and the tamoxifen. If that was a discussion, the anxiety would have rose in me like it did the day Mr. Haynes asked to take it off. I was going, oh heavens, if they stop this, what will happen? 11:32 But I wouldn't have been adverse to having stopping it if it was explained why it should stop. I mean, I think all medication should be reviewed. But, I mean, there was a GP writing that prescription every month, did he not think about the standard clinical 11:32 practice and the long-term use of a hormone treatment? I mean, I definitely questioned Daddy's having fatigue and he's having dizziness and he's talking about hot flushes.

MR. HANBURY: So there were side effects, yes. That's all I have to ask. Thank you very much.
CHAIR: Ms. Treanor?

THE WITNESS WAS THEN QUESTIONED BY MS. TREANOR 11:32

MS. TREANOR: Just one thing I would like to clarify with you. In response to a question from the Chair, you said that your first knowledge of this review was when you heard it on UTV. Can I just clarify whether you are talking about this Inquiry or about the 11:32 look-back processes?

A. Well, the Inquiry, I think. It was the Inquiry, yes.

MS. TREANOR: I would like to take you to two letters, just for completeness, that were sent to you by the Trust to ask you to comment on them. If you could pull 11:32 up PAT-001628. This is a letter to you from Shane Devlin, who is the Chief Executive of the Southern Trust, dated 4th January 2022. If we scroll down to the bottom of 168, please.

11:32

This letter informs you that your father's care is going to be reviewed as part of a structured clinical record review - just go on to 1629 - a structured clinical record review, and includes a leaflet to advise you about that process in further detail. 11:32

If we just scroll down slightly again, please. Thank you. The letter says:

"The external independent consultant has determined that treatment plans Patient 82 was given in 2010 was potentially not appropriate and that it would be reviewed, and once that review is complete, that the Trust would write to you to inform you of the outcome." 11:32

Can I check whether you received that letter?

A. Right. Just bear with me.

The letter is dated 4/1/22?

MS. TREANOR: Yes. 11:32

A. I don't think I have received that letter. I have a letter to home the 31st January 2022. I don't have a letter dated 4/1/22.

MS. TREANOR: You can see the letter that I have up on the screen, which is dated 4th January. Is the letter 11:32 you have dated 31st January the same letter in substance?

A. Yes, yes. It says on 31 August '21 the Health Minister announced a public inquiry. But that date was wrong, it should have been 24/11/20. 11:32

MS. TREANOR: You can see just on the screen the date of the public inquiry is different on your letter?

A. Yes.

MS. TREANOR: Are there any other differences between your letter and the letter on the screen? 11:32

A. No, it largely seems to be the same.

MS. TREANOR: Okay. Did you understand when you received that letter that you were being told that your father's care was being reviewed as part of

that --

A. Yes.

MS. TREANOR: If we could just pull up a second letter then, PAT-001631. This is a letter, again to you, dated 20th June 2022. If we scroll down to the next page, we can see that that letter is from Dr. O'Kane, who has taken over as Chief Executive at that time. Could we just scroll go back to 1631. That letter sets out the detail of the outcome of the SCRR review. 11:32

A. Yes. 11:32

MS. TREANOR: You'll see about halfway down it sets out the history of your father's care and the issues around Bicalutamide.

A. Yes.

MS. TREANOR: At 1632 it offers you an opportunity to meet with Mr. Haynes in his capacity as a senior urology consultant and divisional medical director and a senior manager to discuss the situation further. Did you ever meet with anyone from the Trust? 11:32

A. Well, I never got that letter. 11:32

MS. TREANOR: You never received this letter?

A. No.

MS. TREANOR: How sure are you?

A. Well, like, I've all them letters. I mean, there was a number -- as I said to you, there was about 20 pages missing from my bundle. Of those 20 pages, I could replace them all, with the exception of that letter and the letter from Shane Devlin, which isn't the exact letter you're asking me for but it's a similar letter. 11:32

But I couldn't turn this up at home. So, did it not come? I don't know. I don't have it, that's all can I say to it.

MS. TREANOR: Just to clarify, I've taken you to a letter of 4th January. You've received essentially an identical letter dated 31st January 2022. 11:32

A. Yes.

MS. TREANOR: You are saying you haven't received the letter of 20th June 2022; is that correct?

A. No. No. 11:32

MS. TREANOR: If we could just scroll back up to 1631. Is that your address on that letter? That's the correct --

A. Yes, that he is my address. Correct, yes.

MS. TREANOR: Finally, [redacted], is it the case then that the first time you would have seen the detail of the SCRR outcome is when it was sent to you by this Inquiry? 11:32

A. The bundle. Yes.

MS. TREANOR: Thank you. I have nothing further. 11:32

CHAIR: [redacted], thank you very much indeed for coming along and speaking to us today. We really do appreciate family members coming along, the patients themselves coming along and explaining what it is that they want us to hear. We do appreciate the time you've taken to come along. 11:32

A. Thank you for having us.

CHAIR: Just before you leave, is there anything you want the Inquiry to know or anything that you feel

we haven't covered, either in the papers that you received from the Inquiry or in anything that we have asked you today?

A. I don't know. It's very disappointing, like, you know. I just thought he was being well looked after and it turns out he hasn't, and I sort of feel I should have been smarter myself. Awful, so it is, you know. But the Health Service is under a lot of pressure and this is what happens when it isn't managed correctly. 11:32

CHAIR: We'll certainly be paying attention to all that you have told us and we'll be bearing it in mind as we look through other evidence. Thank you very much indeed. 11:32

A. Just there's files and files of paper and, really, how much of it really is read when people are reviewing, you know, clinics and that. 11:32

CHAIR: Certainly anything that is coming through our door is being looked at and being analysed. If you do need assurance that the Inquiry is looking at it in detail, we are. 11:32

A. But it is the Trust that need to be looking in detail, you know. Like, why did the other urologists not question it? Why did the GP not question it? You know, like, I'm told as a nurse if a doctor writes a medicine and a dose and I don't think it's right or it isn't right, that I'm asked to speak to the doctor, "Is this what you want the patient to have". If I still think it is not what should be given, I'm not supposed to give it. To me, there was a lot of 11:32

well-qualified people, better than myself, that could have queried that Bicalutamide or tamoxifen.

CHAIR: Certainly those are questions that we will be asking.

A. So it is. I think the Trust is in a very bad light over the 352 business. I think it is just about clearing a waiting list and they didn't do their assessments properly, and they didn't... It's terrible when you are putting out a helping hand and that helping hand is not taken. That's what I feel. Thank you. 11:32 11:32

CHAIR: Well, thank you again, [redacted]. We appreciate you coming along.

(The witness withdrew) 11:32

CHAIR: We will reconvene at two o'clock this afternoon then.

THE INQUIRY ADJOURNED UNTIL 2.00 P.M. 11:32

CHAIR: Good afternoon, everyone. Good afternoon, [redacted].

14:09

Just before we continue with this afternoon's session, can I ask the lawyers present to remain for a little while after [redacted] concludes her evidence. You will recall, I think it was 27th September, we had

a witness who gave his evidence unsworn and we are bringing him back remotely just to rectify that omission. So, if you wouldn't mind staying for about 15 or 20 minutes so we can do that, please.

14:09

Can I now ask that Patient 5's Daughter be sworn, please.

Patient 5's Daughter, HAVING BEEN SWORN, WAS EXAMINED BY THE INQUIRY PANEL AS FOLLOWS:

14:10

CHAIR: Patient 5's Daughter, thank you very much for coming along to speak to us. I know it is difficult. We do appreciate you coming along to speak to us about your father. If you feel you need a break at any stage, we can take that at any time. Please don't feel you have to sit here and get through it all if you need a break. 14:10

A. Okay, thank you.

CHAIR: My name is Christine Smith, I am chairing this Inquiry. To my right is Dr. Sonia Swart, who is my co-panelist. And Mr. Damian Hanbury, who is the consultant assessor on the team. 14:10

You have received a bundle of papers from the Inquiry. We have the same bundle and can I assure you that we have read the material, so you don't need to refer to any of the papers in it. If you wish to do so, can I ask that you refer to the number on the top right-hand corner and that way we all know which document we're all looking at. 14:10

I just remind you that we can't make any decision about the individual care that your father received and we are looking at issues wider than that, but it is very important that we hear from people like yourself about what happened either to themselves personally or to their loved one. Can I, on behalf of the Inquiry, express our condolences on the loss of your father. I know it is [redacted] and I know you must still be missing him. 14:11

A. Thank you very much.

CHAIR: Having said all that, [redacted], can I ask you just to tell us in your own words what it is that you want the Inquiry to know about the care that your father received in the Southern Health and Social Care Trust. If you want to start in your own words. I can have a conversation with you as we go along. 14:11

A. I'm very nervous. It is a story of two halves for Daddy, for my father. I would describe the care that he received in terms of his kidney cancer, the nephrectomy was excellent. Mr. O'Brien was so supportive of us a family. He presented as a very intelligent, articulate, knowledgeable man. He seemed to have a genuineness, a genuine interest in Daddy. He, you know, had a great sense of engagement and was able to build up a rapport with Daddy and us as a family. We trusted him and we valued that support, and we are... you know, Daddy was very clear that he was very grateful to Mr. O'Brien. He felt that he had 14:12 14:12

exemplary care in terms of his kidney. You know, we felt at that juncture Daddy's life had been saved as a result of the nephrectomy. So, I could not fault the care around Daddy's kidney and the nephrectomy.

CHAIR: Your father had other health issues at the time of the kidney removal? 14:13

A. Yes.

CHAIR: And the risks were fully explained by Mr. O'Brien at that time?

A. The risks were fully explained to Daddy. Daddy was an intelligent, articulate man. He understood the risks. The risks were reiterated again by the anaesthetist during the assessment -- or by the anaesthetist who undertook the assessment. We read around the risks; they were very, very clear. But Daddy was a very determined man and he made the choice that he would prefer to undertake the operation knowing about the risk, because my understanding is that it was a 14/15 centimetre tumour; it was very large on his kidney; it was near a major vein, vena cava. We supported Daddy in making that decision. It was his right, it was his choice, and he was very clear about that. 14:13 14:13

CHAIR: And that went well?

A. That went well, yes. It was a success. You know, we had a follow-up meeting with Mr. O'Brien. At that point in time, you know, we were feeling very positive. We have under no illusion that there could be microscopic spread and that it could come back again and it was very close to the vena cava vein, but 14:14

we certainly had no expectation or understanding that Daddy who have had a secondary primary cancer that had not been excluded at that time.

So yes, everything was explained to us openly, transparently and in detail, and Daddy had a clear understanding of his circumstances, the risks associated with the operation and, you know, he made his decision. 14:14

CHAIR: The first half, as you described it, everything had gone well in the first half? 14:14

A. Yes.

CHAIR: When did you discover that there was an issue in the second, as it were?

A. Daddy had his first follow-up scan in June '19. No sign of disease, very positive. Throughout that time, Daddy was very, very tired. You know, he was just so exhausted. When you imagine an [redacted]-year old man, that's not Daddy; he was an active, independent man. He looked about 70. He had a very positive attitude to disability. He was very capable. We just felt he wasn't recovering sufficiently in terms of what we would have expected. That may have been high expectations, but we just felt he was under par. 14:15 14:15

My sister took him to the doctor and he had an appointment with a locum, who then suggested that he be seen by a cardiologist. He, you know, was seen by -- we arranged a private appointment, saw the

cardiologist. He had a short stay in hospital. His medication, I think, was realigned, he was rehydrated, etcetera. I don't know the detail but obviously it would be there. We thought, okay, that's okay.

14:16

Daddy had his scan, follow-up scan, in December '19 and it was available from 11th January. Daddy was clear at that point in time that he -- in the previous instance, my sister had phoned up for the result of the scan and then it had been followed up by a letter. Daddy was 14:16
clear at that point in time that he didn't want us to call, ring up about the scan. He had complete trust in Mr. O'Brien and felt that if there were any concerns, that Mr. O'Brien would be in touch. That was his view and we had to respect that. 14:16

We did not know anything about the result of the scan until we were contacted by Mr. Haynes, which I think was towards the end of July. He phoned my sister, who then said you need to speak to our Patient 5's Daughter. I suppose 14:17
the background that I come from, you know, speak to me. He explained to me that there was a suspicion, something suspicious on Daddy's scan. From memory, I was very distressed, very upset, very angry. You know, Mark Haynes was the ultimate gentlemen and calmed 14:17
me down and talked me through everything and the ramifications. My first thought was had there been microscopic spread and had Daddy's kidney cancer spread. Mr. Haynes explained that that was unlikely,

that it was potentially a prostate cancer. I was completely shocked. I guess I had a naive approach, thinking if Daddy had been scanned before and he has been in hospital, you know, why was this not discovered, number 1, before; and, number 2, why has the scan not been followed up in a seven to eight-month period.

I guess with my background, I read a lot. I started to do some generic reading around radiological investigations in Northern Ireland and prostate cancer, you know, diagnosis. I emerged myself in the world of PSA tests, the gold standard being a PSA test and an MRI; the pros and cons of the false negatives and the false positives. But also I read the RQIA previous investigations into review of radiological investigations in Northern Ireland, where the issues seemed to be the delay in investigations were at the juncture from the Radiology Department to the clinician, not from the juncture of the clinician once it had been delivered virtually. So, I had assumed that that potentially was what had happened.

CHAIR: Just to interrupt you, if you don't mind, Patient 5's [redacted], just to check when was this? When were you first made aware? This was in July '20?

A. July '20, yes.

CHAIR: The scan had been in December or January?

A. December. Yeah, the date is there. The scan was --

CHAIR: That's right, it is December the 17th.

A. December the 19th was the scan. The scan was available from 11th January '20. We were not informed until Mr. Haynes got in touch, I think from memory, towards the end of July 2020, so it was some seven/eight months later. 14:19

CHAIR: Although your father had been under the care of Mr. O'Brien and Mr. O'Brien had been treating him right up until that scan that was resulted in January '20, he didn't hear anything more from Mr. O'Brien then?

A. No. 14:19

CHAIR: If I can put it in a colloquial term, it was a case of no news was good news as far as the family was concerned?

A. That would have been Daddy's view, no news is good new. He put his trust in Mr. O'Brien. If there was anything 14:19 that -- anything to worry about, Mr. O'Brien would be in touch.

CHAIR: So, Mr. Haynes contacts the family. Were you told at that stage that this incident was going to be resulting -- 14:20

A. Yes, in SAI.

CHAIR: You were told that at the end of July in 2020?

A. Yes.

CHAIR: Did you know what an SAI was or was it explained to you? 14:20

A. It was explained to me, and then I went and did what I do and read up on the SAI; on the different levels, the categories, the process. Yes.

CHAIR: At that meeting with Mr. Haynes, it was

explained that this would be looked at in terms of a Serious Adverse Incident?

A. Yes. It was a telephone conversation, yes.

CHAIR: Then if you can just maybe -- I'm sorry I interrupted you. If you can continue on with what happened next, as it were. 14:20

A. Then Daddy went for - was it a bone scan - for a scan. You know, we were absolutely terrified. You know, Daddy was completely shocked, distressed and anxious when we heard about a potential prostate cancer. The fact it had metastasised in his bones, we knew this was extremely serious. He was worried sick and we were worried sick that it would have spread in the interim because of the delay. That was just our human view rather than based on any clinical information. 14:21 14:21

Daddy went for his scan. You know, it indicated further spread. We had a follow-up meeting with Mr. Haynes, who explained, you know, the next -- the way forward for Daddy. Daddy was trying to be positive, to look at treatment options. You know, he didn't have -- you know, I don't know how he dealt with it mentally or emotionally because it was so traumatic, but he was focused on what are my options now moving forward, what is my treatment going to be, and what do I have to deal with. 14:21 14:22

Then treatment started for Daddy, and we were in the trauma of regular PSA tests. You were just waiting all

the time for the result to ensure that things, you know, were reducing; the numbers reduced over a period of time. We were thinking, right, okay, this is working. Then, the numbers started to rise. In a scan in February '21, Daddy was diagnosed as having a third cancer, a bowel cancer, a tumour in his caecum, which I believe was between the large and the small intestine. That was absolutely devastating. 14:22

Then, throughout last year, Daddy's PSA started to rise. We were given advice in terms of treatment. I think one treatment was withdrawn. He was monitored closely; his PSAs were taken regularly. He had a virtual consultation with an oncologist, and then we had a meeting with an oncologist in November last year where we were told clearly that, you know, there was no additional evidence of any further spread on the scan, that the PSA test was going up and that, you know, we would continue to monitor the situation. 14:22 14:23

Daddy wasn't exhibiting any symptoms of prostate cancer at that time in terms of pain. I will say he went through a horrific time in terms of chronic fatigue, in terms of hot flushes. The fatigue and the hot flushes were very, very difficult for him. They affected his life 24/7. We did everything. You know, we tried everything. I read up about it. We chilled pillows, we had air conditioners, we tried sage, aromatherapy. We tried everything we could to try to alleviate the 14:23

symptoms.

I will say, reflecting back on our experience of not having a clinical nurse specialist when Daddy had his kidney cancer, compared to having two clinical nurse specialists when Daddy had his prostate cancer and his bowel cancer, there was no comparison. We were able to ring the nurses and ask them for advice and support. It was an absolutely amazing service. I don't feel -- I think it was alluded to in the SAI report that the scans may have been followed up quicker. I think the role of a clinical nurse specialist is so much more than that. It is about holistic assessment of your needs; it is about having a port of call, someone to advise, someone to support. Having been able to compare and contrast the two experiences, they were absolutely phenomenal, and I cannot thank them enough for the support that they gave us and Daddy. 14:24 14:24 14:24

CHAIR: That was one of the things that the Inquiry just wanted to be clear. When your father underwent the nephrectomy for the kidney cancer, there was no clinical nurse specialist assigned to him at that point? 14:25

A. No.

CHAIR: And that differed from when the prostate cancer was actually diagnosed? 14:25

A. Yes.

CHAIR: I assume that you would have had discussions with the clinical nurse specialists. The SAI report is

clear that had there been one, there may have been someone to chase up the scan and make sure that it was resulted, or that the results were looked at, I should say.

A. Yes. I think that is one aspect of it, in tandem with the support services that we were provided. Having someone to call, you know, you are not feeling as if you're a ship without a rudder, you have someone you can speak to. Even about minor issues such as, you know, is sage useful for hot flushes. You know, Daddy is feeling a bit under the weather, there's some nausea. Having that port of call when are you going through this horrific journey was of great benefit to us. 14:25 14:25

CHAIR: Sorry I keep interrupting you, Patient 5's Daughter. 14:26

Just in terms of the SAI, Mr. Haynes told you that your father's case was going to be looked at in an SAI.

A. Yes.

CHAIR: Whenever that happened, what level of contact was there between yourselves and the Trust during the SAI process? Were you kept informed? 14:26

A. Yes. So we were -- we were contacted initially, I think, on 26th October. Patricia Kingsnorth phoned me. At that point Daddy had given his permission for me to be involved -- Personal Information redacted by USI to be involved in the SAI. She rang and explained the process and said that she would like to meet. I think it was followed up with a letter from Melanie McClements on 14:26

28th October outlining the purpose of the SAI. They would be keen to meet and for Daddy to sign a consent form. At that juncture, Daddy changed his mind. He was weary, he was tired, he had so much going on. He said I just want to leave it for now, which I respected. 14:27

He subsequently then reflected on it and changed his mind, primarily because he felt it was important to find out what went wrong, and to prevent this from happening to other patients in the future was his motivation and that was our motivation. 14:27

So I contacted Mrs. Kingsnorth on, I think around 3rd January. We met with her -- Personal Information redacted by USI met with her and Dr. Hughes on 11th January '21. 14:27

CHAIR: We have seen the notes of that meeting with him but it certainly seemed from my reading of it - and I'm interested to know your view - it certainly seemed a frank discussion that you had with both of them where you were able to put the family's views and ask the questions that you wanted answers to? 14:28

A. Absolutely. I mean, it was a difficult situation. You know, COVID was under way. We went over to the Trust for a face-to-face. You are sitting across a large room with face masks on. You can't pick up on nonverbal cues or reassuring smiles. You know, I cried a lot throughout it. I'm the crier in the family. I found it very, very difficult and very, very 14:28

distressing, and very difficult to control my emotions, but at the same time [redacted] had answers that we felt needed to be answered to protect -- to find out what had happened to Daddy but also to protect patients in the future, I suppose, are the two reasons for that. 14:28

We were able to be open and honest in terms of our feelings. We could not have felt more supported. You know, Dr. Hughes and Patricia Kingsnorth could not have been more empathic. They gave us time, they did not 14:29 rush us, they did not take over the meeting. Everything was explained carefully to us and it was as positive as it could have been.

CHAIR: Just in terms of once they had done their work and the SAI was reported, what level of communication 14:29 was there at that point in time with the Trust?

A. After our first meeting, we put together a family timeline because it felt to me that there were some gaps. I didn't know what level of research had been done into Daddy's case at that juncture, so we decided 14:29 to consolidate our thinking in terms of questions that we would like to be answered, which we annotated, which I'm sure you have seen.

CHAIR: Yes, we have that as well.

A. At the second meeting, all of our questions were 14:29 answered and commented on in depth. I think there were several versions of the SAI form. I think we went back and suggested some amendments, and then there was an issue that required clarification around a metastic

incident or a comment that Mr. Gilbert had made in terms of Daddy's circumstances. We asked for that to be clarified because we were unclear what that meant. It will be in the papers, it was due to a research paper that indicated that there may have been, you know, a resultant paralysis or some type of impact on Daddy as a result of the delay in the treatment. Sorry, I'm not a medic so I don't know. The general thing was that an event could have occurred within that timeframe and it was lucky that it didn't. 14:30

So, it was very -- we appreciated that clarity. Then I think we made a further change about we felt it was important for the MDM non-quorate issues to be included in the report. 14:31

I cannot fault the contact from the Trust and the support that we experienced throughout the SAI process. I don't think there's anything. You know, COVID got in the way. Having two virtual consultations is always very difficult as well. Dr. Hughes and Patricia had face masks on during the virtual meeting, so it is more difficult and it is more stressful but they made it as easy as possible for us, and they did everything they could to clarify circumstances for us, took on board our feedback and acted accordingly. So, I was very impressed by the process. 14:31 14:31

CHAIR: In terms of the impact on you and your father, how did you as a family, how did you feel when all this

came to light?

A. I'm not going to get upset; I promised that I wouldn't. I think we're appreciative of all the apologies that have been given in the hearings to date, and the language used is "anxiety and distress". For me, it doesn't cut it. For me it was harrowing, it was horrific, it was traumatic, it was distressing, it was long term, it was an emotional roller coaster, it was devastating, it was shocking. It was all of those emotions. It was difficult for us to deal with as a family. Daddy was our life; our life revolved around him. He reared us as a single parent. So, you know, he was part of our lives 24/7. 14:32 14:32

Coming from the background that I come from, I just could not understand how it could have happened. I had a lot of questions and was reading and reading and reading to try to make sense of protocols and safeguards that were in place and yet this happened, and why. Our biggest concern was for Daddy. Daddy went into lockdown in March '20. In lockdown, no physical contact with his family, apart from my sister going in just to leave his food literally at the kitchen door. He was in lockdown; he was isolated. You know, we were protecting him. And in tandem with that, he had undiagnosed cancers on top of his recovery from his nephrectomy. That is horrific in itself. I don't know how Daddy had the strength to deal with what he did but he was resilient. Coming here today to 14:32 14:33 14:33

speak to the Panel is nothing compared to what he went through. It was the most traumatic and horrific experience of our lives as a family, I think.

CHAIR: I know that you were deeply concerned about the governance issues. 14:34

A. Yes.

CHAIR: I mean, you expressed that to the Trust through the Zoom meetings that you had and through the timeline you put together, and asked for those concerns to be addressed. 14:34

A. Yes.

CHAIR: You actually went a stage further and became involved in the -- I think it is called the Task and Finish Group.

A. Task and Finish, a service user group, yes. 14:34

CHAIR: I know that you are happy to talk about that in general terms without going into the details of what the group is doing.

A. Yes, yes.

CHAIR: Would you like to tell the Inquiry a little bit about that? 14:34

A. I mean, the motivation for becoming involved in the group was my background in [redacted] for many years, but also that sense of responsibility and duty, and Daddy saying put your education to good use, go and take part in this group, do as much as you can to ensure this does not happen to other patients and their families in the future, you know? 14:34

The group, I have never met such a more open, warm and welcoming group of professionals. I felt I wasn't there as a silent partner. I felt very much listened to. You will know from looking at the minutes that I wasn't shy in terms of putting my personal opinions forward in terms of governance, in terms of issues, in terms of the action plan generally. I think they are a very, very committed group who really want to make a difference and ensure that the correct governance, policies and procedures are in place; that the action plan is clearly mapped to current policy and procedure expectations, benchmarks and standards; and also - which I think is particularly important - that there is a clear evidence base on which to measure the success of the action plan and the enhancements in situ. 14:35 14:35 14:35

Sarah Ward was my contact for the group, and Mr. Ronan Carroll chaired the group. I feel that I was there as a layperson, in effect, as a daughter of a patient, and I think I would defer to the clinical and governance experts to give an overview of the progress to date. There was regular updating, and I know there were regular reports to the overarching urology quality assurance group. I would not suggest anything different in terms of how I was treated, welcomed in terms of the conduct of the group and in terms of their embracing me working as a partner within that group. 14:36 14:36

I had great support from the family liaison officers, from the PPI staff. You know, it was a very, very positive experience but it was a difficult experience because this affected us and our family and our story. 14:37
But that made me more motivated to ask questions and to probe and to make suggestions.
CHAIR: It's good to hear that it has been such a positive experience for you on a personal level.
A. Yes. 14:37
CHAIR: Can I ask you maybe what your reflection might be on the involvement generally of service users of patients and families in issues of governance and the involvement in the SAI process? Your experience certainly seems to have been a positive one; would you 14:37
like to see that for all patients and families?
A. Absolutely. I think, you know, there are guidelines in terms of approaches to service user involvement in SAIs and groups. I think it is really, really important that -- I hate the term "service user" and I hate the 14:37
term "lessons to be learned." I think they dehumanise the situation. We are people, we are real families and we need a voice. I think, moving forward, I know that the urology group had suggested disbanding the Task and Finish Group after 12 months at the last meeting. At 14:38
the last meeting I said I didn't feel that was appropriate. I felt that service users' families needed to continue to be involved in the action plan and involved, you know, in the progress to date and to

continue to be updated, that it shouldn't just stop at that juncture. So, it was agreed that the group would meet again at regular intervals, which I was really pleased about.

14:38

I think, moving forward, families need a voice at the table, whatever table that is. That is reviewing, monitoring and critiquing the effectiveness of the action plan moving forward, and also identifying any further enhancements and changes that need to be raised 14:38 or changed as a result of the evidence base moving forward. I think we have a unique voice in that we have experienced it. I think we have the opportunity to raise issues as non-employees of the Trust and to give that kind of objective viewpoint which I think is 14:39 really, really important.

CHAIR: [redacted], thank you. I'm not going to ask you anything more at the moment. I'm going to hand over to my two colleagues here in a moment and they will have some questions for you. I am aware that at 14:39 the end of that, there is something you would wish to read to the Inquiry. Just so you know we are aware of that.

Dr. Swart. 14:39

DR. SWART: Thank you very much. I agree it is very important to hear from people as individual people, patients, so much more than a service user.

You describe a harrowing experience, being shocked, and we have all the papers in front of us. What, of all of this, shocked you the most? What was the biggest moment where you were pulled up short and thought I can't believe this has been allowed to happen? 14:40

A. Where Daddy's scan was not acted upon over a seven to eight-month period, and the subsequent diagnosis of prostate cancer.

DR. SWART: Going back to that, you had a look and you looked at the RQIA report which is a similar thing. You will be aware this is not an unusual series incident in the UK actually, not just in Northern Ireland. What is your reflection on -- why is it that you think those reports and the recommendations from them haven't got traction and these things still happen? Do you have any observations for us? 14:40

A. Yes. I mean, this morning I was reading over the second RQIA report and thinking that one of the recommendations articulates really clearly that scans or whatever should be followed up and disseminated quickly; that the Trusts should have systems and processes in place for the effective tracking and monitoring of those scans but, more importantly, clinician follow-up. For me, that is a concern for me. When the NIPACS system came into fruition in Northern Ireland, I think in 2010, you know, one of the aspects that were heralded was that instantaneous ability to click a mouse and you would be able to see a scan to 14:40 14:41

prevent any delay in follow-up, not relying on paper and hard copies. That was supposed to be a system which was foolproof and which would enhance the governance and, I suppose, the timely dissemination of scans and results moving forward. For me, the Department of Health spent an awful lot of money on that. I read in one digital health article, it was £50 million for the new phase, perhaps between 100 and 132 million for a five-year contract. If you are spending that amount of money - which I know it was BSO who commissioned it, I know there's a leading NIPACS coordinator within BSO and one within the Trust - if you are spending that amount of money on the system, I would like to think - and I don't know anything about its functionality - but you would like to think that there would be some way of monitoring clinician follow-up. 14:41 14:42 14:42

I think reflecting on the evidence to date within the Inquiry, the DARO system, I don't understand why there's a separate system. It sounds as though the systems within the Trust are not talking to each other. I'm not an IT expert but, for me, I still have concerns about the ineffectiveness of the follow-up and tracking mechanisms in terms of clinicians looking at a scan, because the DARO process for me seems to rely on human intervention, whereas I feel with the technology that we have available to us now, why was there not an escalating opportunity where, if a scan had not been 14:42 14:42

looked at, that that would have been escalated to another level within the Trust immediately and the issue would have been addressed. So there's a system issue for me as well.

DR. SWART: It is hard to understand, I agree with you. 14:43

Do you think it has just been lost in lots of important things and nobody has given it the priority --

A. No.

DR. SWART: -- or do you think that people haven't 14:43 tried hard enough? How does that strike you?

A. Sorry, could you repeat the question?

DR. SWART: Do you think it has been lost because there are so many competing priorities, or do you think people have not tried hard enough to make that system 14:43 foolproof? What sense have you got from it?

A. Looking at it as a layperson, there's an imaging board for Northern Ireland, there's an imaging strategy for Northern Ireland. There's so much importance out there about the importance of CT scans, imaging standards, 14:44 expectations, key issues around protecting and safeguarding service users. You know, it is clear: If a scan is not followed up quickly, that is a risk to the patient. It is not an administrative issue, it is a risk to a patient. 14:44

I personally feel that more could have been done to drill down to the actual processes and systems and whether they were fit for purpose, would be my personal view.

DR. SWART: Keeping on that theme because I think it is a very important theme, in your service user group following up the actions from the SAI, did you have the opportunity to keep talking about this?

A. Yes. 14:44

DR. SWART: Is it your view that, as a result of your involvement in that group, the right things were in place to make that happen now?

A. I think I would talk about it generically that work is being done by the Trust, but I think it would be up to 14:45 the chair of the meeting to give that --

DR. SWART: You haven't had assurance in that group that this is now fixed?

A. I think what I do know is that extensive work has been undertaken and it is still in process. I think it is 14:45 more than a Trust issue, I think this is a regional issue, I think it is a systems issue. You know, I think it's an issue in terms of, you know, why do we have NIPACS but then we have DARO. I think it is an infrastructural issue that needs to be -- it is 14:45 a bigger conversation because it affects thousands and thousands of patients. I know the Trust have invested, and now it is moving on to pathology results, isn't it, NIPACS? I'm not an IT expert but I do think that the IT systems and the monitoring systems do need a bigger 14:45 look at external to the Trust. I think that's something that the Department of Health should do as that overarching agency. I think that's a core responsibility of theirs.

DR. SWART: As a patient and as a family member, you have been able to highlight that in the action group. In that group, what have you personally learned about the way the Trust works and the pressures people are under in the Trust? What revelations have you had as part of that group? 14:46

A. I think we all know that there are resourcing issues within the Trust. You know, I think this doesn't necessarily come from the group. I think around the general reading I have done, we know there is a shortage of urologists and oncologists. My personal view is that there needs to be a specific recruitment campaign. A two-pronged approach, really, I think maybe for international recruitment of urologists and oncologists, but I think we can also start at that pretraining level perhaps, where there are bursaries and incentives put in place for the new doctors of the future that would incentivise them to work within a urology discipline. I think much more could be done in terms of that. 14:46 14:47

DR. SWART: Did you learn anything surprising about the way the hospital works or doesn't work as a result of your involvement in that group? Was there anything that struck you as something you never would have thought of? 14:47

A. I suppose I didn't have an understanding, really, of the infrastructure within governance within an organisation. I didn't know how huge it was; I didn't know how many policies, procedures and standards. It

is a massive, massive arena and I think it is one that should be resourced effectively. I would say that all Trusts could do with as many resources as possible to track and to ensure that there are effective governance arrangements in place. That would be in terms of 14:47
people having time to do that; it would be time to reflect and critique and measure against standards. It would also be the structures around the supporting technology and the supporting administration. I think it is a whole arena within itself and it is much vaster 14:48
than I thought it was.

DR. SWART: Thank you very much. That's all from me. That's really helpful.

CHAIR: Mr. Hanbury.

MR. HANBURY: Thank you very much. I would just like 14:48
to ask you a couple of things on a similar theme. Your father got through a really very high-risk nephrectomy, and I'm sure the family were really relieved at that point. Just to go back to the follow-up arrangements, which is where a lot of this 14:48
hangs.

Mr. O'Brien arranged a follow-up CT in June after the initial one in March and then, I think, to see your father after that? 14:48

A. Sorry?

MR. HANBURY: Then to see your father after that, with the results.

A. Yes.

MR. HANBURY: From what you've said, we heard the importance of good news from the scan as well as worrisome news. But then nothing happened in terms of outpatient appointment?

A. There was no appointment, no. No follow-up appointment. 14:49

MR. HANBURY: What happened then? I think you said your sister phoned in but that wasn't until November. Did you make any --

A. No. My sister phoned in for the results of the June scan and then that was followed up by a letter. Then Daddy received a letter inviting him to attend for the scan in December. I think Mr. O'Brien had hoped to review him in January with the results of the scan, but that didn't happen. 14:49

MR. HANBURY: In the notes we have, that letter was November. It was a while after the June scan, that letter which clarified the ... So, there has been a bit of a delay.

A. I can't recall the date of the letter, yes. 14:49

MR. HANBURY: I suppose what I'm hinting at is you hadn't heard for a while --

A. Yeah.

MR. HANBURY: -- about the June scan.

A. No, my sister -- I think my sister phoned up. 14:50

MR. HANBURY: Yes, but that wasn't until a couple of months later.

A. Right, okay. Sorry, I have got confused about that.

MR. HANBURY: Who did she ring, do you recall? Was it

Mr. O'Brien's secretary?
A. She spoke to Mr. O'Brien's secretary, yes.
MR. HANBURY: It was a result of that that he rang the family or your sister?
A. If it's in the records that he rang her, then yes. 14:50
MR. HANBURY: This is all around November time. So that is the three...
A. Yes.
MR. HANBURY: There had already been a bit of a wobble; would you agree? 14:50
A. A wobble in terms of not hearing about the scan results, yes.
MR. HANBURY: Communicating, exactly. Then the December thing happened.
A. Yes. 14:50
MR. HANBURY: So the no news is good news, I suppose, was almost emphasised by that experience from your point of view; is that correct?
A. Yes, yes. That was Daddy's point of view, that the previous scan was positive and, you know, he felt that 14:51 no news was good news and that Mr. O'Brien would be in touch if there was anything of concern.
MR. HANBURY: Yes. I think one of the problems in hospital systems is often the abnormal CTs are alerted, but what you've emphasised is that normal or 14:51 satisfactory ones are equally important to know about, although probably slightly less so.
Also, in light of you saying about the role of the cancer nurse specialists, that may well have helped

that communication?
A. Absolutely, because you would have been -- you know, we may have decided to ring the nurse to see what the current set of circumstances were. Yes. That would have been available to us to do. 14:51
MR. HANBURY: Were you given any explanation for why the outpatient appointment wasn't forthcoming?
A. No, not that I'm aware of.
MR. HANBURY: Thank you. 14:52
The next thing was about your private -- you went to the GP when your father wasn't doing well around about October and saw the cardiologist?
A. Yes.
MR. HANBURY: There were a couple of things there. He was picked up as being anaemic at that time; do you remember? 14:52
A. Yes.
MR. HANBURY: Was there any explanation given to you for that, the anaemia? 14:52
A. I can't recall. I do know that Mr. O'Brien contacted my sister after Daddy had been in hospital and I think recommended folate for Daddy.
MR. HANBURY: But that particular thing wasn't picked up by the physicians? 14:52
A. I remember having a conversation with a doctor on Daddy's discharge but I can't recall the detail.
MR. HANBURY: Right, okay. I think that's all I have.
CHAIR: If I might come back to one point about the

cancer nurse specialists.

A. Yes.

CHAIR: Whenever your father was treated for his kidney cancer, was there ever any suggestion or -- how did you know that there was a difference? I am not being very clear on this, but you weren't given a cancer nurse specialist when he was diagnosed with the kidney cancer yet you were when he was diagnosed with prostate cancer. I know you had two, but was that cancer nurse specialist present at the meeting with Mr. Haynes the first time? 14:53

A. Yes.

CHAIR: Were you aware of the existence of cancer nurse specialists before that?

A. No, at that juncture I wasn't aware. You'd think that I would know that in terms of my background but no, I wasn't aware of the existence of clinical nurse specialists or their role and function and how important it was until it was mentioned at the SAI meeting, and then I read up on the role and function and recognised that, you know -- I think, you know, people say why did you not complain. If you don't know what the baseline expectations are in terms of what you're entitled to, then you don't complain. If we had known that, if it had have been indicated to us that your dad should have a clinical nurse specialist allocated to him, if that hadn't been done, we would have followed that up but that was not indicated to us at any juncture. But certainly the two nurses, the 14:53 14:53 14:54

urology nurse and the colorectal nurse, were both allocated promptly and were present at the meetings to support us throughout Daddy's journey.

CHAIR: [redacted], thank you very much. Ms. Treanor, do you have any questions? 14:54

THE WITNESS WAS QUESTIONED BY MS. TREANOR AS FOLLOWS:

MS. TREANOR: [redacted], I just wanted to ask you about an answer that you gave to Dr. Swart. You said 14:54 that one of the things that you were most shocked by was the failure to act on the CT scan and your father's diagnosis of prostate cancer. I just want to take you very briefly to one of the pages in the bundle. It is from your second meeting with the SAI review team. It 14:55 is at PAT-001972.

A. Yes.

MS. TREANOR: If you just look at the second paragraph for me. We can see there I think this was you had challenged the review team to explain whether there had 14:55 been disease progression and whether earlier action may have prevented the spread of the cancer. Dr. Hughes, in response to you, said he would get oncology and Mr. Gilbert to advise. I just want to ask you, do you feel the SAI answered that question for you? 14:55

A. I have no memory of an oncologist being consulted or feedback from an oncologist. My memory is Mr. Gilbert commented on the impact on prognosis. I do know, having listened to the previous hearings, that there

was not an oncologist on the review team, but I have no memory of feedback coming from an oncologist. It was from Mr. Gilbert, who made the comment in the SAI in terms of impact on prognosis.

MS. TREANOR: Just one more issue so perhaps you can help me clarify this. If I can take you to PAT-001933. This is the cover page of what is the final version of the SAI relating to your father's care as it is held by the Department of Health and as it was submitted to the Health and Social Care Board. If we could just scroll down to internal page 5, which I believe is at 1937. There are eight bullet points on this page; I think there are nine paragraphs. If I could just take you then, to cross-reference that, to PAT-002388. This is a copy of the same SAI report which was disclosed to the Inquiry, with the title "Final Draft Patient Copy." The cover sheet essentially looks the same. If we could scroll to internal page 5 again. 14:56 14:56 14:57

A. Sorry, I am just trying to find. My eyesight is really bad. 14:57

MS. TREANOR: It should be on the screen in front of you, if you are able to see it. This is the Final Draft Patient Copy. If I could take you to page 5.

A. Sorry, my eyesight is terrible. 2238. Let me just find it here. 14:57

MS. TREANOR: If you could look at 2242 for me.

A. Yes.

MS. TREANOR: You will just see about halfway down, I think it is the sixth bullet point, which says that the

MDM was quorate 11% 2017, 22%, and so on. That paragraph seems to have been added into this copy.

A. Yes.

MS. TREANOR: I just wanted to check with you which version was sent to you as the final version, if you can recall. 14:58

A. That version. I think we may have -- I think there was a letter received from Mrs. McClements identifying that the final version of the report was sent to us with the change made on page 5. I felt it was important to note that the multi-disciplinary team, the attendance and the quorate levels was of great concern to me. 14:58

I cannot remember if we suggested that that be added into the report or not, I cannot remember. But that was the final version we were sent. 14:58

Thank you very much. I believe you have something further.

A. Thank you very much.

I have written a statement that I would like to read out and hope that I don't get upset and weepy. I think it is really important that, you know, we are able to put forward our views today and I really appreciate the Panel giving me the opportunity, and everyone here in the room for taking the time to give me the opportunity today to reflect on Daddy's circumstances and to reflect on the poor care that he did receive with regard to the follow-up and action of the scan. 14:59 14:59

Chair and Panel members and everyone present here today, thank you for giving me the opportunity to tell my father's story and the impact that these events had on my father and my family. I would therefore like to read out the statement pertaining to the failings on my father Patient 5 's cancer journey, who sadly passed away on Personal Information redacted by USI

14:59

I feel that my father, Patient 5 , was failed by Mr. O'Brien, the Department of Health, and the Southern Health and Social Care Trust. Initially as a family we were indeed aware that after my father's kidney removal, there was no guarantee there had been no microscopic spread from his tumour which could become evident at a future date. Fortunately, a June 19th CT scan revealed no sign of disease. At this time we were all unaware that my father also had an undiagnosed prostate cancer.

14:59

15:00

Whilst we appreciate the extensive evidence presented in this Inquiry and the detailed response by Mr. O'Brien, we still don't have an answer to our main concern: Did the lack of prompt action and follow-up with my father's CT scan on 17 December '19 affect his prognosis? My father's cancer metastasised further in intervening months. We are not talking seven to eight weeks, nor seven to eight days, we are talking seven to eight months.

15:00

Mr. O'Brien, in his statement, which I received yesterday, described how this delay came about, detailing his administrative processes and his rationale. He suggested he reviewed the scan results in late February or early March 2020. However, at a very minimum the results of the scan should have been communicated to my father once the scan had been reviewed. Surely he had a right to know at that juncture rather than not being informed until late July 2020. 15:01 15:01

My father should have been allowed to make an informed choice on whether to attend for an additional scan. We appreciate that COVID-19 measures also came into effect. 15:01

When I reflect on my father's circumstances, he was neither protected nor safeguarded and was not reviewed post-CT scan, even though there were clear governance policies and procedures. These serious governance issues and failings need to be addressed by the Department of Health, and the Trust. An arm's length approach to governance does not seem to be working when I reflect on my father's circumstances. More rigorous oversight by the Department of Health of governance in the Trust is required, in my opinion. 15:01

In addition, if unannounced inspections do not

currently take place across Trusts with regard to governance, doing so would provide a realtime snapshot of practice.

The longevity of the concerns with regards to the lack of prompt follow-up of scans is worrying, harrowing and upsetting. Had they been addressed or resolved, we perhaps might not be where we are today, in the middle of another public inquiry. It was the first noticed almost ten years ago that scans were not being followed up promptly, yet it has happened to my father again. In my opinion, and based on the hearings to date, there appears to be ineffective leadership in the Trust at different levels where risk factors were not sufficiently addressed, escalated, and dealt with appropriately. Chief executives should have taken ownership and responsibility of addressing serious concerns in order to maintain public confidence in the Trust. 15:02

In terms of Trust culture, work needs to be done in changing the Trust culture to ensure the staff are not afraid to raise professional practice issues and feel supported to do so. The systems tracking patient scans and monitoring the follow-up scans by clinicians is not fit for purpose, in my opinion, and should be reviewed. Remember, patients and their families are not just a number, a statistic on a PowerPoint reflecting lessons to be learned. Instead of lessons to be 15:02

learned, it should be mandatory changes and enhancements required, closely monitored by the Department of Health and its associated arm's length organisations to safeguard patients.

We no longer have my father in our lives. We continue to grieve and mourn him every day. The public inquiry, although necessary, is difficult and distressing for us as a family. We hope that eventually it will provide closure and will make a difference and safeguard patients in the future, which was [redacted]'s wish. 15:03

CHAIR: [redacted], thank you very much. We do appreciate how difficult it has been for you to come and speak to us and I know that from the correspondence that you directed to me a year ago. We do really appreciate you coming along to speak to us. 15:03

What we hope to be able to do at the end of our work is to make recommendations that will make a difference to patient safety overall. So, thank you again. 15:04

A. Thank you very much. Thank you.

(The witness withdrew)

CHAIR: Ladies and gentlemen, we're going to take a break now until 3.30 when I hope that we will able to deal with the one remaining issue on the patient list today. 15:04

THE INQUIRY PANEL ADJOURNED

CHAIR: Good afternoon again, everyone. Good afternoon, Patient 35's Son. So long as you can see and hear us, that's the important thing. 15:30

Thank you very much for coming back this afternoon. I'm going to ask you now to take an oath or affirm, whichever is your choice. I don't know if you can see our Inquiry Secretary, Mr. MacInnes. Can you see him 15:30 okay?

A. I can, yes.

Patient 35's Son, HAVING BEEN SWORN, WAS QUESTIONED BY THE INQUIRY PANEL AS FOLLOWS: 15:30

CHAIR: Thank you very much, Patient 35's Son.

Patient 35's Son, you gave evidence before us on 27th September of last year, that's 2022. 15:31

A. Okay.

CHAIR: Can I just ask you to confirm that you want the Inquiry to adopt that as your sworn testimony before the Inquiry?

A. Yes, please. I do. 15:31

CHAIR: Thank you very much. That's all we need from you, Patient 35's Son. I apologise that we had to bring you back for our omission to have you sworn on the first day but thank you.

A. No problem. No problem at all. Thank you very much.

(The witness withdrew)

CHAIR: Thank you very much for staying behind, ladies and gentlemen. I just felt it was important that we do things formally and make sure there's no issue. 15:31

THE INQUIRY ROSE AT 3.31 P.M.