



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

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

4
5 Can I, first of all, thank Patient 82's Daughter for coming 10:07
6 along. Shortly I'm going to ask her to be sworn but
7 first of all I think Ms. Treanor wants to say something
8 to us.

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

11
12 This morning we have what will be our third set of
13 closed patient hearings in this Inquiry. In terms of
14 today's proceedings, you will hear from the families of
15 two former patients of Mr. O'Brien. This morning you 10:07
16 will hear from the daughter of Patient 82. Patient
17 82's care was the subject of a structured clinical
18 record review, or SCRR, a process with which we are all
19 by now familiar.

20 10:07
21 His case found his way into the SCRR process due to
22 concerns about the prescription of Bicalutamide.
23 Patient 82 was Perso years old when he was initially
24 referred by his GP to Daisy Hill Hospital. Following
25 further investigations, he was subsequently referred 10:08
26 onwards to Craigavon Area Hospital prostate assessment
27 unit on the 13th January 2010. That referral was,
28 inappropriately, in the language of the SCRR reviewer,
29 triaged as routine by Mr. O'Brien. As a result,

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

5
6 Patient 82's case was discussed at MDM on 5th August
7 2010 prior to staging scans having taken place. The
8 recollection of the MDT at that time was that suitable
9 treatment would be watchful waiting. Those scans were
10 then arranged, and Mr. O'Brien reviewed Patient 82
11 again on 4th February 2011, by which time his PSA had
12 increased to 10.68. Mr. O'Brien did not refer Patient
13 82's case back to the MDM to discuss the options.

14 Rather, Mr. O'Brien decided himself to commence the
15 patient on low dose Bicalutamide 50mg once daily, and
16 tamoxifen 10mg daily.

17
18 On 2nd November 2021, some ten years later, Patient 82
19 was seen by Mr. Haynes, who identified the fact that
20 Patient 82 had, by that stage, been on low dose
21 Bicalutamide for ten years. After discussion, both
22 Bicalutamide and tamoxifen were discontinued by
23 Mr. Haynes, and Patient 82 and his family at that time
24 advised Mr. Haynes that they could not recall having
25 any conversation with Mr. O'Brien about alternative
26 therapies.

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

1 overall care was poor and not in keeping with good
2 practice. The reviewer noted that any form of hormone
3 ablation therapy represents additional risk in patients
4 with significant cardiac co-morbidities, as was the
5 case with Patient 82, and remarks that potential harm 10:10
6 could have ensued from a long period of inappropriate
7 hormone ablation therapy. In concluding, the reviewer
8 suggests that Patient 82's quality of life may have
9 been affected by the treatment he received.

10
11 This afternoon, Chair, you will hear from the daughter 10:10
12 of Patient 5. Patient 5's care was the subject of an
13 SAI, and his case was one of the nine 2020 SAIs.
14 Patient 5 is an Personal
Informati year old man under the care of the
15 urologists following a successful nephrectomy for 10:10
16 cancer. Mr. O'Brien arranged a follow-up CT scan of
17 the chest, abdomen and pelvis on 17th December 2019 and
18 hoped to review the patient in January 2020. The scan
19 report showing a possible sclerotic metastasis in the
20 spine was available on 11th January 2020. Mr. O'Brien 10:10
21 failed to action the result of that scan, with the
22 consequence that Patient 5 was not called for
23 discussion and further treatment until some eight
24 months after the result was available.

25
26 The Inquiry understands that there is an audit function 10:11
27 on the PACS system which allows you to see when a scan
28 has been accessed and by whom. That audit function
29 appears to indicate seven months after they became

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

3
4 Madam Chair, Mr. O'Brien has prepared a written
5 response to the SAI report in respect of Patient 5, 10:11
6 wherein he seeks to explain the delay and action in the
7 scan report. Mr. O'Brien indicates that his secretary
8 transferred a copy of Patient 5's chart with the report
9 of the CT scan, presumably in hard copy, to his office
10 following receipt of the report. He explains that as 10:11
11 the chart was not tracked, it has not been possible to
12 determine the precise date on which it was left in his
13 office. However, Mr. O'Brien suggests that it was
14 probably during February 2020, and indicates that he
15 did, in fact, review the scan report in either 10:11
16 late February 2020 or early March 2020.

17
18 He advises that, at that time, he did not arrange bone
19 scan as he felt that doing so may expose Patient 5 to
20 the risk of contracting COVID-19. Mr. O'Brien goes on 10:12
21 to explain that he also later considered arranging for
22 further CT scanning in April 2020 but again elected not
23 to do so due to concerns around COVID-19.

24
25 There is no record of Mr. O'Brien's review of the scan 10:12
26 and nor has he suggested that he discussed the need for
27 a further scan with anyone else. Mr. O'Brien states
28 that having not been in his office at Craigavon Area
29 Hospital since March 2020, he returned briefly on

1 21st June 2020 to, in his own words, collect the
2 clinical records of two patients regarding whom he
3 intended to prepare reports during July 2020. It is
4 unclear whether Patient 5's records were among those
5 records collected by Mr. O'Brien in June 2020. In any 10:12
6 event, no further action was taken in respect of the
7 scan at that time.

8
9 Finally, Mr. O'Brien states that he had just begun to
10 progress the administration of Patient 5's case on 2th 10:13
11 July 2020 when he read the letter sent by Mr. Haynes in
12 his role as Associate Medical Director the day before,
13 which instructed Mr. O'Brien not to access or process
14 patient information in light of the concerns which had
15 emerged in June and July. For your note, Chair, that 10:13
16 letter is available at AOB-02534, and the reference to
17 the restriction on processing patient information
18 appears at AOB-02535.

19
20 In seeking to explain the failure to action the CT 10:13
21 scan, Mr. O'Brien states that had he not received this
22 communication, he would have made arrangements for
23 Patient 5's further assessment and management. Again,
24 there is no suggestion that Mr. O'Brien alerted anyone
25 to the need of further assessment and management in 10:13
26 light of the scan report which was first available in
27 January 2020.

28
29 Madam Chair, I should make clear that Mr. Haynes has

1 not had an opportunity to consider and respond to
2 Mr. O'Brien's comments in his written response, but of
3 course will have an opportunity to do so in due course.
4

5 A letter was then sent to Patient 5 on 29th July 2020 10:14
6 to advise of his CT result and to apologise for the
7 delay. Mr. Haynes, the author of that letter, advised
8 of a possible abnormality on the CT scan that required
9 further investigation with a bone scan. The diagnosis
10 of metastatic prostate cancer was confirmed by the bone 10:14
11 scan, which took place on 6th August 2020. At a review
12 on 12th August 2020, Mr. Haynes discussed treatment
13 options with Patient 5 and commenced androgen
14 deprivation therapy. Patient 5 was also made aware
15 that a referral to oncology remained an option. 10:14
16

17 The SAI report into Patient 5's care concluded that the
18 abnormal findings on the post-operative review scan
19 should have been noted and acted upon by Mr. O'Brien.
20 The review team observed that it would be unusual for 10:14
21 a renal cell carcinoma to produce a sclerotic
22 metastatic bone deposit, and other options should have
23 been considered.
24

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

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

8
9 Madam Chair, as I indicated at the outset, this will be
10 our third set of patient-focused hearings. I should 10:15
11 indicate that it is not intended that it should be the
12 last. It is anticipated that the Inquiry will convene
13 further patient hearings periodically as the need
14 arises.

15
16 Those are my opening remarks. 10:15

17 CHAIR: Thank you very much, Ms. Treanor.

18
19 Patient 82's Daughter, I'm going to ask if you will take the
20 oath or be affirmed now, please. 10:15

21
22 Patient 82's Daughter HAVING BEEN SWORN, WAS QUESTIONED
23 BY THE INQUIRY PANEL AS FOLLOWS:

24
25 CHAIR: Patient 82's Daughter, welcome. I'm Christine Smith, 10:16
26 Chair of the Inquiry. To my left-hand side is
27 Mr. Damian Hanbury, who is the consultant urologist and
28 the assessor to the Inquiry. My co-panelist, Dr. Sonia
29 Swart, is to my right.

1
2 I will be doing most of the talking, you'll be relieved
3 to hear, probably. As with all of the other patient
4 and family witnesses who come to speak to us, this is
5 your opportunity to tell the Inquiry what you want us 10:16
6 to know about your father, Patient 62. There are no right or
7 wrong answers. We're going to ask you to tell us in
8 your own words what you want us to know about his care.
9 If you need to take a break at any time, just say so,
10 we can arrange it. 10:17

11
12 Can I first of all express our condolences on behalf of
13 the Inquiry on the loss of your father. I know it is
14 a while ago but I'm sure you still feel it every day.
15 10:17

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

24
25 I also, as Ms. Treanor said, do need to remind you that 10:17
26 the Inquiry can't make any decision about the care that
27 your father received as an individual because we are
28 looking at system issues and governance issues, but,
29 obviously, we are also looking at the care in that

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

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

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

15 A. Yes. 10:18

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

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

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

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

8
9 When I went to Mr. O'Brien's clinic to see Daddy, he
10 was oblivious to the fact of anything that had happened 10:20
11 with 352 with Daddy. I asked at that time why did he
12 allow Daddy's files to be transferred out, and he said
13 that his files were all lifted and the patients that
14 were allocated out were nothing to do with him; it was
15 a management decision who went. So, they seemed to go 10:20
16 to 352 without any preassessment for surgery.

17
18 Mr. O'Brien then tried to find out what drugs were
19 used, and he wasn't able to find out. In fact, in one
20 of his letters he wrote that he expected they would 10:21
21 never find out, which causes me concern from the point
22 of view that as commissioners of the service, I felt
23 the Trust should have been able to find out, and expect
24 to find out, what took place. Indeed, there was
25 another letter from the Trust to me that said Daddy's 10:21
26 notes would go to the private provider but they would
27 remain belonging to the Trust and would be returned to
28 the Trust. You know, I would have expected them to
29 have got a full report.

1
 2 On the back of the fact that Daddy was still having
 3 urology problems with urge continence, I mean we needed
 4 to know every toilet in the main street in Personal Information redacted by USI so
 5 he would be able to go out and do his business and yet 10:22
 6 be confident that we could get him to the toilet. He
 7 still needed this Botox, so we were pushing to get that
 8 information. The GP couldn't get the information
 9 either, apparently. At the last, between Mr. O'Brien
 10 and an anaesthetist in Craigavon, they decided that 10:22
 11 they would do a spinal anaesthetic to allow Daddy to
 12 have the Botox.

13
 14 But it took -- I mean, I think there was about seven
 15 people in governance whose names were attached to the 10:22
 16 letters that I wrote. And when the letters -- when the
 17 conclusion come a year later, almost, from 352, it was
 18 352 that wrote the explanation to my questions, which
 19 I don't really feel is right from the point of view,
 20 the Commissioner again go back. The overall 10:23
 21 responsibility I felt lay with 352. They subbed out
 22 the work to --

23 CHAIR: You mean the Trust rather than with 352?

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

1 was 20 weeks, and that I would be invited to a meeting.

2 CHAIR: Did that happen?

3 A. No, you know. And as an employee of The Trust as well,
4 as I say, it wasn't to make a complaint really, it was
5 to say, look, you know, people need to be assessed 10:23
6 before they go for surgery and there needs to be
7 sharing of information, and if this isn't done, you
8 know, it will be to the detriment of further patients.
9 That was where I was trying to go. Thankfully, Daddy
10 was okay from the event. You know, he didn't suffer. 10:24

11 CHAIR: Just so that I can be sure that I've got it
12 clear, Patient 82's Daughter, your father's surgery was
13 outsourced to 352 by the Trust. Our understanding is
14 his notes and records didn't go with him, as it were,
15 from the Trust? 10:24

16 A. No, no, no.

17 CHAIR: So 352 were in the dark, as it were, in terms
18 of what treatment he had had?

19 A. Yes. I suppose even on that morning, when I arrived in
20 Downpatrick Hospital, it was like a ghost town. There 10:24
21 wasn't even a receptionist in the foyer. We went
22 upstairs to the area where we were supposed to be and
23 I observed, as I felt at the time, the anaesthetist
24 walking around and being shown round; she didn't know
25 where she was, she was finding her way. Then a nurse 10:25
26 came in and she started to take information from Daddy,
27 and in the middle of that the anaesthetist took over and
28 really dismissed the nurse, from memory.

29

1 Then Mr. Taiwany came in. At that point we did realise
2 that there was no notes; he told us there was no notes.
3 He did go into, in some details, all the complications
4 about surgery. To the point then I started to get
5 frightened and I says well, look, are you sure you're 10:25
6 happy to proceed in the absence of notes. Bearing in
7 mind I was standing with a **Personal**-year old man who had been
8 fasting, who had been up from six o'clock in the
9 morning, and really whose notion about medical staff
10 was they knew best and not me. You know, we'd had an 10:26
11 awful time with Daddy, as I say. We needed to know
12 every toilet in the street for to get him out and
13 about, to go shopping, to do anything he had to do. So
14 I was busy thinking, well, we were on a waiting list
15 for long enough and if I reneged today, where are 10:26
16 we going to be on a waiting list again and, you know,
17 this problem is a bother for Daddy, and he was highly
18 embarrassed about it as well. You know, really is
19 anything going to go on or is **Patient 82's
Daughter** over-dramatising
20 the whole thing here? Mr. Taiwany said that he had 10:26
21 worked with Mr. O'Brien. He says, look, I have
22 computer access and I have sufficient information to go
23 ahead.
24 CHAIR: so he was able to access your dad's records, or
25 he told you that? 10:27
26 A. well, he did say he had computer access and he worked
27 closely with Mr. O'Brien and he knew what needed to be
28 done. Ten years ago, this is the recollection. So,
29 we decided to proceed.

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

3 A. Yes. I had forgotten my glasses that day and I left to
4 go and buy a pair. I got a call, it wouldn't have been
5 half an hour, to come back, Daddy had deteriorated. 10:27
6 I was asked -- I got into the ward. They said he took
7 a heart attack and I was asked to call the rest of the
8 family. I called them, and then we just were in the
9 corridor waiting to see what was going to happen.

10 Then, when we did get in to see Daddy, he was sitting 10:27
11 up quite bright and he said he was all right, but at
12 that stage they decided he needed to go to the Ulster.
13 I mean, he was in there for three/four days. He was on
14 drips and he was on heart monitors, and he was moved
15 from there to the City to have an angiogram. Out of 10:28
16 that had come that, you know, his heart was okay, so
17 they come to the conclusion that possibly he had got
18 the anaesthetic too quick.

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

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

25 CHAIR: And to 352. 10:28

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

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

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

7 A. No. Yes.

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

10 A. Yes. 10:29

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

13 A. Yes.

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

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

21
22 But no, I never got any explanation from the Trust.
23 I wrote to 352 and complained and copied that letter to
24 the Trust as well. Then 352 wrote back out to me
25 again, and there was discrepancies in that explanation, 10:30
26 I felt, and I wrote back again to 352 and copied it to
27 the Trust. Then 352 wrote again. You know, to me,
28 their last letter was, well, this is the answers and,
29 really, if you have any more. At that stage, well,

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

4 CHAIR: You basically just gave up?

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

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

9 A. No.

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

14 A. No. No.

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

20 10:31

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

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

1 got a reply from Mr. Taiwany about what had taken
2 place. I thought that it was significant that the head
3 of service and Mr. O'Brien didn't have discussions
4 about what had taken place. He seemed to say in one of
5 the letters, Mr. O'Brien, that he hadn't seen our 10:32
6 complaint. In another paragraph, he was proceeding
7 with the spinal because he didn't expect to get an
8 answer. Well, you know, why would you not expect to
9 get an answer?

10 CHAIR: But you then discover that there is a further 10:32
11 difficulty with the care that your father had received?

12 A. Yes.

13 CHAIR: When did you discover that?

14 A. That sort of come to light -- well, I suppose the first
15 bit that come to light was when we met Mr. Haynes in 10:32
16 Craigavon. On reflection now when I think of it, I did
17 feel "what's going on here", because normally we would
18 have only met Mr. O'Brien at clinic. Nurses out and
19 about but when we in for the consultations, it was
20 Mr. O'Brien. But Sister O'Neill was there. When 10:33
21 you're on the spot and asked to recall information,
22 I couldn't think. And Mr. Haynes said to the effect
23 that there was new research that Bicalutamide and
24 tamoxifen were not effective and that their use
25 increased the risk of heart attacks, heart problems, 10:33
26 stroke, decrease in memory, decrease in energy,
27 decrease in cognitive decline on a low dose, and the
28 hormone treatment was not effective, and cure was the
29 first course of action in early diagnosis. The plan

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

3
4 He said that a PSA below 10 would have no treatment.
5 At this point, you know, I asked them, I started to 10:34
6 think where are we going with this, so I says well,
7 what happens if it's below 10, and he said there would
8 be no treatment. I said, well, what about between 10
9 and 20, where do we go? He said we would have to see
10 how quick that came back up again; increase and 10:34
11 consider a large dose of a hormone injection
12 intermittently would be the course of action. I said
13 what happens if it goes above 20? They said, look,
14 let's take one thing at a time, see how it progresses.
15 But I was thinking, well, I have an Person
al
Informa-year old man and 10:35
16 what's he going to be able to cope with? They said
17 a PSA above 20 would be query radiotherapy. I thought,
18 well, that's going to be in Belfast and how is Daddy
19 going to cope with all that when it looked like the
20 Bicalutamide and tamoxifen was doing the job keeping a 10:35
21 low PSA. He was told to stop intermittent
22 catheratisation at that time, which he largely wasn't
23 doing, although he was told he could do it if he felt
24 he couldn't pass urine. A urine sample was to be
25 obtained. 10:35

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

1 there would be satellite clinics in Armagh, and it
2 would be a drive-through for blood tests and you would
3 get them. So, now we're going to take an Personal
Information-year old
4 man to Armagh.

5
6 As it turned out, we were in lockdown. There never was
7 a mention of a PSA. But by that stage, Daddy had had
8 a fall and really there was marked deterioration in his
9 overall demeanour. Bloods were being done to
10 investigate that at Home. I knew it was coming up
11 to February and I asked the GP to repeat the PSA. At
12 that time the PSA had rose for the first time in
13 a long, long time to 0.28. Mr. Haynes did write out
14 and say that it was within the normal limits and they
15 weren't concerned, and it would be reviewed again.

16
17 There possibly was a mention too of x-ray or another
18 scan, but Daddy at that stage wasn't fit to be going
19 anywhere; he was all but off his feet.

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

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

1 COVID on Personal Information redacted by USI and he didn't die until the

2 Personal Information

3
4 But, you know, there again, I would ask the question.
5 Mr. Haynes had said a hormone injection but there's 10:38
6 a letter there from somebody to say that any hormone
7 treatment would be detrimental to Daddy with his heart
8 problems, so was even that right? I just don't know.

9 CHAIR: If I can just sum up. The first you were aware
10 that there was an issue about -- just to be clear, your 10:38
11 fare was on Bicalutamide and tamoxifen for about ten
12 years?

13 A. Yes.

14 CHAIR: The first you became aware that that was maybe
15 not the appropriate treatment for your father is when 10:38
16 you received communication from Mr. Haynes at a clinic
17 that he took rather than Mr. O'Brien; is that right?

18 A. Yes.

19 CHAIR: And you haven't received any communication from
20 the Trust other than what Mr. Haynes told you at the 10:38
21 clinic?

22 A. No.

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

25 A. I only knew that there even was a review taking place 10:38
26 when I heard about it on UTV News, which again
27 aggrieved me because I felt, you know, the Trust had
28 responsibility for our care; there was an investigation
29 taken into it. I know all about confidentiality but it

1 obviously was out there when it was in the news.
2 I think the Trust should have took the opportunity when
3 they had us to have said, look, there is a review also
4 taking place here; we can't go into the ins and outs of
5 it. I could have accepted that but at least I would 10:39
6 have been informed, I wouldn't have had to hear it on
7 UTV News.

8
9 You know, we talk about openness and transparency and
10 keeping the patients informed. Certainly, I wasn't 10:39
11 informed.

12
13 But it's funny, on reflection, I did sense the two
14 people in the room that day had something more going on
15 with them, which I think is a poor reflection of 10:39
16 the Trust again.

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

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

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

5 A. No. 10:41

6 CHAIR: -- but rather to help others.

7 A. Improve service.

8 CHAIR: So there's that issue about communication.

9 A. Yes.

10 CHAIR: But if I've heard what you're telling me 10:41
11 correctly, you're saying that you were pretty
12 dissatisfied with the level of communication generally
13 from the Trust with patients and families; would that
14 be fair?

15 A. Yes, yes. I find you write in a complaint and they 10:41
16 write back to you what you wrote in. "I wish to
17 complain"; "I see you want to complain", or "You have
18 a complaint; I acknowledge your complaint". But they
19 tell you nothing about the complaint, they don't answer
20 the complaint. 10:41

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

23 A. Yes.

24
25 In terms of the Bicalutamide, you know, somebody has 10:41
26 mentioned a -- just to I get all this terminology --
27 a pathway, a clinical -- a standard for clinical
28 practice.

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

1 [REDACTED] Patient 82's Daughter ?

2 A. No, it's my own words.

3 CHAIR: Sorry, your own notes.

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

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

13 A. Sorry.

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

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

19

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

28

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

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

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

8 A. Dizziness.

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

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

24
25 There didn't seem to be any of that correspondence 11:31
26 between either of those two people.

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

1 interdisciplinary communication between the doctors was
2 not satisfactory?

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

9
10 The one thing that sticks in my mind that Mr. O'Brien 11:31
11 did say to me was "Your Daddy's prostate cancer will
12 never kill him, his heart condition will". So, you
13 know, I took reassurance from that, to be honest.
14 I mean, the PSA treatment, the Bicalutamide and
15 tamoxifen, dropped the PSA. Well, it was the only 11:31
16 thing that I can give a reason for dropping it.

17
18 I mean, Mr. O'Brien, in fairness, did ring after hours,
19 after his working hours, and tell me if we had have
20 gone to clinic and the PSA result wasn't available, 11:31
21 he would have said "I'll get that and I'll ring it
22 through to you". I would have got calls -- I did at
23 least get a call at seven o'clock at night to say,
24 look, the PSA is down. It was music to my ears, you
25 know. 11:31

26
27 Again, on reflection, am I thinking now the
28 Bicalutamide was taking care of the PSA, it was
29 dropping within the normal limits, so the cancer was

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

10
11 I mean, no matter -- you know, like what did it mean 11:31
12 for Daddy? Daddy stopped travelling distances where
13 maybe he would have been in the car. He wouldn't have
14 went to his home place in Personal Information
redacted by USI because he couldn't
15 have done the journey; he wouldn't have lasted unless 11:31
16 we could have got him to a toilet. He curtailed
17 activities in town to where he knew he would get to the
18 toilet. There was actually one brother - my brother
19 has reminded me there - wouldn't have taken him out
20 because he just couldn't have coped with him being 11:31
21 incontinent.

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

24 A. No.

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

26 A. No.

27 CHAIR: -- because of his conditions?

28 A. Yeah.

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

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

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

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

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

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

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

21 A. I worked on community at the time.

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

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

1 themselves.

2 DR. SWART: what would it take to change that? what
3 are some suggestions? If you were to go in a quiet
4 room with someone and say look?

5 A. Well, it's hard to beat face-to-face. 11:31

6 DR. SWART: we have heard your story today and we can
7 see the impact it has had.

8 A. It is hard to beat the face-to-face. You know, I think
9 if you can't meet someone, a colleague, to discuss
10 a complaint, it doesn't say much for the general public 11:31
11 trying to make a complaint.

12 DR. SWART: when we come on to the meeting with
13 Mr. Haynes and the nurse where you had this kind of odd
14 feeling, as you describe it --

15 A. Yes. 11:31

16 DR. SWART: -- were you given the opportunity to ring
17 up and speak to them after? The nurse, in particular.
18 Did they say just ring us if you have got anything?

19 A. In fairness to Sister O'Neill, she did give us her
20 card. 11:31

21 DR. SWART: Did you ring her?

22 A. No, I didn't.

23 DR. SWART: How were you feeling at that point after
24 you came out of that consultation? Can you remember
25 how you felt? 11:31

26 A. Worried because I thought -- well, I mean, Health
27 Service in crisis, can't get in to see doctors and what
28 happens if this cancer takes off? Is it going to be
29 monitored or are we not going to be getting the bloods

1 done? And, you know, the Bicalutamide was very simple
2 to take; it didn't inconvenience Daddy in terms of
3 having to travel for radiotherapy sessions. Yes, it
4 had its side effects but radiotherapy would have its
5 side effects. You know, even the injection, which I'm 11:31
6 not sure now even was appropriate either. I mean --
7 DR. SWART: From your perspective, you had confidence
8 in something that was keeping the cancer under control
9 and that confidence was then removed; is that what you
10 are telling us? 11:31

11 A. Yes. Yes.

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

14 A. How could that have been done differently?

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

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

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

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

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

18
19 I think possibly surgery was mentioned but because of
20 Daddy's heart, that was a big risk, and since this 11:32
21 cancer wasn't going to kill him, why would you go down
22 that route? Radiotherapy was mentioned. Again, I have
23 to say I can't recall that conversation. But when
24 I would have went to clinics at the last - when I got
25 the letter to invite me - I would have maybe wrote the 11:32
26 outcome of it. On the night of the 11th/12th, "no
27 radiotherapy until bladder problem resolved". So
28 radiotherapy obviously was discussed, in my thinking.

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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?

1 A. Yeah.

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

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

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

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

20 11:32
21 would I like to have been seen in two weeks? Yes,
22 I would, but the reality of it is that the NHS doesn't
23 see people in the time limits that are set. Clearly,
24 that was back then too.

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

1 early days?

2 A. Oh, yes, yes. Sister O'Neill, well, she was there, I'm
3 near sure, working from the early days. Yes, I think
4 she was a longstanding member of staff.

5 MR. HANBURY: would she have spoken to your father then 11:32
6 and then offered to the family some support?

7 A. well, not that stood out but, yes, I would have seen
8 her face.

9 MR. HANBURY: But you remember her being there. Thank
10 you. 11:32

11 A. Yes. Like, there was no deep, heavy discussions with
12 her about anything.

13 MR. HANBURY: About the sort of options of, as you say,
14 radiotherapy or surgery that you were -- you remember
15 that was discussed. 11:32

16 A. No, it would be all with Mr. O'Brien.

17 MR. HANBURY: would you have seen her separately, do
18 you think, or all the conversations were with
19 Mr. O'Brien?

20 A. No, no. The only nurse we would have seen separately 11:32
21 at a nurse clinic would have been coronary care. Like,
22 I never went to see the urology nurse like I would have
23 seen the coronary care nurse?

24 MR. HANBURY: Independently.

25 A. Independently, no. She would have been there at the 11:32
26 clinic.

27 MR. HANBURY: Going on then until the fateful surgery
28 at 352, you said that the urologist had access to some
29 notes?

1 A. Yes.

2 MR. HANBURY: Did the anaesthetist say the same? Did

3 the anaesthetist have access to any information,

4 cardiology notes?

5 A. I don't know if it was the personality/custom of the 11:32

6 anaesthetist but she stood out as being abrupt and not

7 knowing where she was going. I felt she was being

8 shown around the environment. When we went in, the TV

9 was on, doors were open, people were moving about the

10 treatment -- or the waiting room that we were in. The 11:32

11 nurse was in the middle of her assessment and the

12 anaesthetist come in and I felt abruptly interrupted

13 the nurse, dismissed her more or less. She came in

14 with an A4 page and a pencil and that was all she had;

15 an A4 page folded in half because I remember it. You 11:32

16 know, it just didn't -- they say you should follow your

17 gut. It just didn't feel right.

18

19 But then Mr. Taiwany come in and he was more

20 reassuring, a more confident person. The anaesthetist 11:32

21 also had difficulty understanding Daddy and Daddy had

22 difficulty understanding her, and it wasn't helped by

23 the fact that the TV was going and the doors were all

24 lying opened. I actually got up and closed the doors.

25

26 She didn't -- she stayed the least time in assessment.

27 Then Mr. Taiwany come out and he said that there was no

28 notes.

29

1
2 There's a letter from Mr. Taiwany that says Daddy was
3 to have watchful surveillance. Had he have had them
4 notes and seen his notes, his letter that he had sent
5 at the time, he might have questioned why Daddy at this 11:32
6 time was on the Bicalutamide and the tamoxifen, but
7 he didn't have the notes at that point. He says, look,
8 I've worked with Mr. O'Brien, I know what needs to be
9 done, I've got some computer access here and I'm happy.
10 But he give a big spiel about the risks of surgery and 11:32
11 then I started, oh, he's a bit over the top.
12 I questioned him then and I said are you sure you can
13 do this safely and he's going to be okay, and he says
14 yes. I says, hmm, right. Faced with the option of
15 going on a waiting list again against the possibility 11:32
16 that something might not happen, we proceeded.
17 MR. HANBURY: we know that Mr. O'Brien, with the
18 admission papers of the Trust, was very specific about
19 the cardiac history and the stents.
20 A. Yes, he knew. He knew. 11:32
21 MR. HANBURY: It doesn't sound as though the
22 anaesthetist had access to that.
23 A. When we came back to clinic, I said to Mr. O'Brien "why
24 would you have passed Daddy's file out of Craigavon
25 Hospital; he should have stayed within the acute 11:32
26 service because of his heart". Mr. O'Brien says my
27 files were taken, it was nothing to do with me; the
28 list was nothing to do with me. which, you know,
29 I thought, well, like who decided who was the

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

3
4 Then 352, they decided -- as I said to them, did you
5 operate just off a list? They had no notes either. 11:32
6 They didn't write back to Craigavon Hospital to say
7 we don't know the first thing about this man that you
8 sent on a list. They didn't get the notes.

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

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

1 MR. HANBURY: So there were side effects, yes.
2 That's all I have to ask. Thank you very much.

3 CHAIR: Ms. Treanor?
4

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

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

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

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

20 11:32

21 This letter informs you that your father's care is
22 going to be reviewed as part of a structured clinical
23 record review - just go on to 1629 - a structured
24 clinical record review, and includes a leaflet to
25 advise you about that process in further detail. 11:32
26

27 If we just scroll down slightly again, please. Thank
28 you. The letter says:
29

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

6

7 Can I check whether you received that letter?

8 A. Right. Just bear with me.

9 The letter is dated 4/1/22?

10 MS. TREANOR: Yes. 11:32

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

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

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

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

23 A. Yes.

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

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

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

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

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

7 A. Yes.

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

10 A. No. No. 11:32

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

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

15 MS. TREANOR: Finally, Patient 82's Daughter, is it the case 11:32
16 then that the first time you would have seen the detail
17 of the SCRR outcome is when it was sent to you by this
18 Inquiry?

19 A. The bundle. Yes.

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

21 CHAIR: Patient 82's Daughter, thank you very much indeed for
22 coming along and speaking to us today. We really do
23 appreciate family members coming along, the patients
24 themselves coming along and explaining what it is that
25 they want us to hear. We do appreciate the time you've 11:32
26 taken to come along.

27 A. Thank you for having us.

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

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

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

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

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

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

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

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

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

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

12 CHAIR: well, thank you again, Patient 82's Daughter
13 We appreciate you coming along.

14
15 (The witness withdrew) 11:32

16
17 CHAIR: we will reconvene at two o'clock this afternoon
18 then.

19
20 THE INQUIRY ADJOURNED UNTIL 2.00 P.M. 11:32

21
22
23 CHAIR: Good afternoon, everyone. Good afternoon,
24 Patient 5's Daughter .

25 14:09
26 Just before we continue with this afternoon's session,
27 can I ask the lawyers present to remain for a little
28 while after Patient 5's Daughter concludes her evidence. You
29 will recall, I think it was 27th September, we had

1 a witness who gave his evidence unsworn and we are
2 bringing him back remotely just to rectify that
3 omission. So, if you wouldn't mind staying for about
4 15 or 20 minutes so we can do that, please.

14:09

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

7
8 Patient 5's Daughter, HAVING BEEN SWORN, WAS EXAMINED BY THE
9 INQUIRY PANEL AS FOLLOWS:

14:10

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

14:10

17 A. Okay, thank you.

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

14:10

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

14:10

1
 2 I just remind you that we can't make any decision about
 3 the individual care that your father received and we
 4 are looking at issues wider than that, but it is very
 5 important that we hear from people like yourself about 14:11
 6 what happened either to themselves personally or to
 7 their loved one. Can I, on behalf of the Inquiry,
 8 express our condolences on the loss of your father.
 9 I know it is Personal Information redacted by USI and I know you must still
 10 be missing him. 14:11

11 A. Thank you very much.

12 CHAIR: Having said all that, Patient 5's Daughter, can I ask you
 13 just to tell us in your own words what it is that you
 14 want the Inquiry to know about the care that your
 15 father received in the Southern Health and Social 14:11
 16 Care Trust. If you want to start in your own words.
 17 I can have a conversation with you as we go along.

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

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

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

7 A. Yes.

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

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

23 CHAIR: And that went well?

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

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

4
5 So yes, everything was explained to us openly, 14:14
6 transparently and in detail, and Daddy had a clear
7 understanding of his circumstances, the risks
8 associated with the operation and, you know, he made
9 his decision.

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

12 A. Yes.

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

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

25 14:15
26 My sister took him to the doctor and he had an
27 appointment with a locum, who then suggested that he be
28 seen by a cardiologist. He, you know, was seen by --
29 we arranged a private appointment, saw the

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

5
6 Daddy had his scan, follow-up scan, in December '19 and
7 it was available from 11th January. Daddy was clear at
8 that point in time that he -- in the previous instance,
9 my sister had phoned up for the result of the scan and
10 then it had been followed up by a letter. Daddy was
11 clear at that point in time that he didn't want us to
12 call, ring up about the scan. He had complete trust in
13 Mr. O'Brien and felt that if there were any concerns,
14 that Mr. O'Brien would be in touch. That was his view
15 and we had to respect that.

16
17 We did not know anything about the result of the scan
18 until we were contacted by Mr. Haynes, which I think
19 was towards the end of July. He phoned my sister, who
20 then said you need to speak to our Patient 5's Daughter. I suppose
21 the background that I come from, you know, speak to me.
22 He explained to me that there was a suspicion,
23 something suspicious on Daddy's scan. From memory,
24 I was very distressed, very upset, very angry. You
25 know, Mark Haynes was the ultimate gentlemen and calmed
26 me down and talked me through everything and the
27 ramifications. My first thought was had there been
28 microscopic spread and had Daddy's kidney cancer
29 spread. Mr. Haynes explained that that was unlikely,

1 that it was potentially a prostate cancer. I was
 2 completely shocked. I guess I had a naive approach,
 3 thinking if Daddy had been scanned before and he has
 4 been in hospital, you know, why was this not
 5 discovered, number 1, before; and, number 2, why has 14:17
 6 the scan not been followed up in a seven to eight-month
 7 peered.

8
 9 I guess with my background, I read a lot. I started to
 10 do some generic reading around radiological 14:18
 11 investigations in Northern Ireland and prostate cancer,
 12 you know, diagnosis. I emerged myself in the world of
 13 PSA tests, the gold standard being a PSA test and an
 14 MRI; the pros and cons of the false negatives and the
 15 false positives. But also I read the RQIA previous 14:18
 16 investigations into review of radiological
 17 investigations in Northern Ireland, where the issues
 18 seemed to be the delay in investigations were at the
 19 juncture from the Radiology Department to the
 20 clinician, not from the juncture of the clinician once 14:18
 21 it had been delivered virtually. So, I had assumed
 22 that that potentially was what had happened.

23 CHAIR: Just to interrupt you, if you don't mind, Patient
 24 [REDACTED], just to check when was this? when were you
 25 first made aware? This was in July '20? 14:19

26 A. July '20, yes.

27 CHAIR: The scan had been in December or January?

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

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

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

14:19

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

10 A. No.

14:19

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

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

14:19

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

14:20

21 A. Yes, in SAI.

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

23 A. Yes.

24 CHAIR: Did you know what an SAI was or was it
25 explained to you?

14:20

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

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

1 explained that this would be looked at in terms of
2 a serious Adverse Incident?

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

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

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

16
17 Daddy went for his scan. You know, it indicated
18 further spread. We had a follow-up meeting with
19 Mr. Haynes, who explained, you know, the next -- the
20 way forward for Daddy. Daddy was trying to be 14:21
21 positive, to look at treatment options. You know,
22 he didn't have -- you know, I don't know how he dealt
23 with it mentally or emotionally because it was so
24 traumatic, but he was focused on what are my options
25 now moving forward, what is my treatment going to be, 14:22
26 and what do I have to deal with.

27
28 Then treatment started for Daddy, and we were in the
29 trauma of regular PSA tests. You were just waiting all

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

9
10 Then, throughout last year, Daddy's PSA started to 14:22
11 rise. We were given advice in terms of treatment.
12 I think one treatment was withdrawn. He was monitored
13 closely; his PSAs were taken regularly. He had
14 a virtual consultation with an oncologist, and then
15 we had a meeting with an oncologist in November last 14:23
16 year where we were told clearly that, you know, there
17 was no additional evidence of any further spread on the
18 scan, that the PSA test was going up and that, you
19 know, we would continue to monitor the situation.

20 14:23
21 Daddy wasn't exhibiting any symptoms of prostate cancer
22 at that time in terms of pain. I will say he went
23 through a horrific time in terms of chronic fatigue, in
24 terms of hot flushes. The fatigue and the hot flushes
25 were very, very difficult for him. They affected his 14:23
26 life 24/7. We did everything. You know, we tried
27 everything. I read up about it. We chilled pillows,
28 we had air conditioners, we tried sage, aromatherapy.
29 We tried everything we could to try to alleviate the

1 symptoms.

2

3 I will say, reflecting back on our experience of not
4 having a clinical nurse specialist when Daddy had his
5 kidney cancer, compared to having two clinical nurse 14:24
6 specialists when Daddy had his prostate cancer and his
7 bowel cancer, there was no comparison. We were able to

8 ring the nurses and ask them for advice and support.
9 It was an absolutely amazing service. I don't feel --
10 I think it was alluded to in the SAI report that the 14:24
11 scans may have been followed up quicker. I think the
12 role of a clinical nurse specialist is so much more
13 than that. It is about holistic assessment of your
14 needs; it is about having a port of call, someone to

15 advise, someone to support. Having been able to 14:24
16 compare and contrast the two experiences, they were
17 absolutely phenomenal, and I cannot thank them enough
18 for the support that they gave us and Daddy.

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

24 A. No.

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

27 A. Yes.

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

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

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

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

16
17 Just in terms of the SAI, Mr. Haynes told you that your
18 father's case was going to be looked at in an SAI.

19 A. Yes.

20 CHAIR: whenever that happened, what level of contact 14:26
21 was there between yourselves and the Trust during the
22 SAI process? were you kept informed?

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

1 28th October outlining the purpose of the SAI. They
2 would be keen to meet and for Daddy to sign a consent
3 form. At that juncture, Daddy changed his mind. He
4 was weary, he was tired, he had so much going on. He
5 said I just want to leave it for now, which 14:27
6 I respected.

7
8 He subsequently then reflected on it and changed his
9 mind, primarily because he felt it was important to
10 find out what went wrong, and to prevent this from 14:27
11 happening to other patients in the future was his
12 motivation and that was our motivation.

13
14 So I contacted Mrs. Kingsnorth on, I think around 3rd
15 January. We met with her -- Personal Information redacted by USI met with 14:27
16 her and Dr. Hughes on 11th January '21.

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

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

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

6
7 we were able to be open and honest in terms of our
8 feelings. We could not have felt more supported. You
9 know, Dr. Hughes and Patricia Kingsnorth could not have
10 been more empathic. They gave us time, they did not 14:28
11 rush us, they did not take over the meeting.
12 Everything was explained carefully to us and it was as
13 positive as it could have been.

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

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

24 CHAIR: Yes, we have that as well.

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

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

11
12 So, it was very -- we appreciated that clarity. Then
13 I think we made a further change about we felt it was
14 important for the MDM non-quorate issues to be included
15 in the report. 14:31

16
17 I cannot fault the contact from the Trust and the
18 support that we experienced throughout the SAI process.
19 I don't think there's anything. You know, COVID got in
20 the way. Having two virtual consultations is always 14:31
21 very difficult as well. Dr. Hughes and Patricia had
22 face masks on during the virtual meeting, so it is more
23 difficult and it is more stressful but they made it as
24 easy as possible for us, and they did everything they
25 could to clarify circumstances for us, took on board 14:31
26 our feedback and acted accordingly. So, I was very
27 impressed by the process.

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

1 came to light?

2 A. I'm not going to get upset; I promised that I wouldn't.

3 I think we're appreciative of all the apologies that

4 have been given in the hearings to date, and the

5 language used is "anxiety and distress". For me, it 14:32

6 doesn't cut it. For me it was harrowing, it was

7 horrific, it was traumatic, it was distressing, it was

8 long term, it was an emotional roller coaster, it was

9 devastating, it was shocking. It was all of those

10 emotions. It was difficult for us to deal with as 14:32

11 a family. Daddy was our life; our life revolved around

12 him. He reared us as a single parent. So, you know,

13 he was part of our lives 24/7.

14

15 Coming from the background that I come from, I just 14:32

16 could not understand how it could have happened. I had

17 a lot of questions and was reading and reading and

18 reading to try to make sense of protocols and

19 safeguards that were in place and yet this happened,

20 and why. Our biggest concern was for Daddy. 14:33

21 Daddy went into lockdown in March '20. In lockdown, no

22 physical contact with his family, apart from my sister

23 going in just to leave his food literally at the

24 kitchen door. He was in lockdown; he was isolated.

25 You know, we were protecting him. And in tandem with 14:33

26 that, he had undiagnosed cancers on top of his recovery

27 from his nephrectomy. That is horrific in itself.

28 I don't know how Daddy had the strength to deal with

29 what he did but he was resilient. Coming here today to

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

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

6 A. Yes.

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

11 A. Yes.

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

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

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

19 A. Yes, yes.

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

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

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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 like to see that for all patients and families? 14:37

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 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 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 14:38

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

5
6 I think, moving forward, families need a voice at the
7 table, whatever table that is. That is reviewing,
8 monitoring and critiquing the effectiveness of the
9 action plan moving forward, and also identifying any
10 further enhancements and changes that need to be raised 14:38
11 or changed as a result of the evidence base moving
12 forward. I think we have a unique voice in that we
13 have experienced it. I think we have the opportunity
14 to raise issues as non-employees of the Trust and to
15 give that kind of objective viewpoint which I think is 14:39
16 really, really important.

17 CHAIR: Patient 5's Daughter, thank you. I'm not going to ask
18 you anything more at the moment. I'm going to hand
19 over to my two colleagues here in a moment and they
20 will have some questions for you. I am aware that at 14:39
21 the end of that, there is something you would wish to
22 read to the Inquiry. Just so you know we are aware of
23 that.

24
25 Dr. Swart. 14:39

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

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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

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

1 prevent any delay in follow-up, not relying on paper
2 and hard copies. That was supposed to be a system
3 which was foolproof and which would enhance the
4 governance and, I suppose, the timely dissemination of
5 scans and results moving forward. For me, the 14:41
6 Department of Health spent an awful lot of money on
7 that. I read in one digital health article, it was
8 £50 million for the new phase, perhaps between 100 and
9 132 million for a five-year contract. If you are
10 spending that amount of money - which I know it was BSO 14:42
11 who commissioned it, I know there's a leading NIPACS
12 coordinator within BSO and one within the Trust - if
13 you are spending that amount of money on the system,
14 I would like to think - and I don't know anything about
15 its functionality - but you would like to think that 14:42
16 there would be some way of monitoring clinician
17 follow-up.

18
19 I think reflecting on the evidence to date within the
20 Inquiry, the DARO system, I don't understand why 14:42
21 there's a separate system. It sounds as though the
22 systems within the Trust are not talking to each other.
23 I'm not an IT expert but, for me, I still have concerns
24 about the ineffectiveness of the follow-up and tracking
25 mechanisms in terms of clinicians looking at a scan, 14:42
26 because the DARO process for me seems to rely on human
27 intervention, whereas I feel with the technology that
28 we have available to us now, why was there not an
29 escalating opportunity where, if a scan had not been

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

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

6

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

9 A. No.

10 DR. SWART: -- or do you think that people haven't 14:43

11 tried hard enough? How does that strike you?

12 A. Sorry, could you repeat the question?

13 DR. SWART: Do you think it has been lost because there 14:43

14 are so many competing priorities, or do you think

15 people have not tried hard enough to make that system 14:43

16 foolproof? What sense have you got from it?

17 A. Looking at it as a layperson, there's an imaging board 14:44

18 for Northern Ireland, there's an imaging strategy for

19 Northern Ireland. There's so much importance out there

20 about the importance of CT scans, imaging standards, 14:44

21 expectations, key issues around protecting and

22 safeguarding service users. You know, it is clear: If

23 a scan is not followed up quickly, that is a risk to

24 the patient. It is not an administrative issue, it is

25 a risk to a patient. 14:44

26 I personally feel that more could have been done to

27 drill down to the actual processes and systems and

28 whether they were fit for purpose, would be my personal

29 view.

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

5 A. Yes. 14:44

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

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

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

14 A. I think what I do know is that extensive work has been
15 undertaken and it is still in process. I think it is 14:45
16 more than a Trust issue, I think this is a regional

17 issue, I think it is a systems issue. You know,
18 I think it's an issue in terms of, you know, why do we
19 have NIPACS but then we have DARO. I think it is
20 an infrastructural issue that needs to be -- it is 14:45

21 a bigger conversation because it affects thousands and
22 thousands of patients. I know the Trust have invested,
23 and now it is moving on to pathology results, isn't it,
24 NIPACS? I'm not an IT expert but I do think that the
25 IT systems and the monitoring systems do need a bigger 14:45

26 look at external to the Trust. I think that's
27 something that the Department of Health should do as
28 that overarching agency. I think that's a core
29 responsibility of theirs.

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

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

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

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

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

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

14 CHAIR: Mr. Hanbury.

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

22
23 Mr. O'Brien arranged a follow-up CT in June after the
24 initial one in March and then, I think, to see your
25 father after that? 14:48

26 A. Sorry?

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

29 A. Yes.

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

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

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

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

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

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

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

23 A. Yeah.

24 MR. HANBURY: -- about the June scan.

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

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

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

29 MR. HANBURY: who did she ring, do you recall? was it

1 Mr. O'Brien's secretary?

2 A. She spoke to Mr. O'Brien's secretary, yes.

3 MR. HANBURY: It was a result of that that he rang the

4 family or your sister?

5 A. If it's in the records that he rang her, then yes. 14:50

6 MR. HANBURY: This is all around November time. So

7 that is the three...

8 A. Yes.

9 MR. HANBURY: There had already been a bit of a wobble;

10 would you agree? 14:50

11 A. A wobble in terms of not hearing about the scan

12 results, yes.

13 MR. HANBURY: Communicating, exactly. Then the

14 December thing happened.

15 A. Yes. 14:50

16 MR. HANBURY: So the no news is good news, I suppose,

17 was almost emphasised by that experience from your

18 point of view; is that correct?

19 A. Yes, yes. That was Daddy's point of view, that the

20 previous scan was positive and, you know, he felt that 14:51

21 no news was good news and that Mr. O'Brien would be in

22 touch if there was anything of concern.

23 MR. HANBURY: Yes. I think one of the problems in

24 hospital systems is often the abnormal CTs are alerted,

25 but what you've emphasised is that normal or 14:51

26 satisfactory ones are equally important to know about,

27 although probably slightly less so.

28 Also, in light of you saying about the role of the

29 cancer nurse specialists, that may well have helped

1 that communication?

2 A. Absolutely, because you would have been -- you know,
3 we may have decided to ring the nurse to see what the
4 current set of circumstances were. Yes. That would
5 have been available to us to do.

14:51

6 MR. HANBURY: were you given any explanation for why
7 the outpatient appointment wasn't forthcoming?

8 A. No, not that I'm aware of.

9 MR. HANBURY: Thank you.

10

14:52

11 The next thing was about your private -- you went to
12 the GP when your father wasn't doing well around
13 about October and saw the cardiologist?

14 A. Yes.

15 MR. HANBURY: There were a couple of things there. He
16 was picked up as being anaemic at that time; do you
17 remember?

14:52

18 A. Yes.

19 MR. HANBURY: was there any explanation given to you
20 for that, the anaemia?

14:52

21 A. I can't recall. I do know that Mr. O'Brien contacted
22 my sister after Daddy had been in hospital and I think
23 recommended folate for Daddy.

24 MR. HANBURY: But that particular thing wasn't picked
25 up by the physicians?

14:52

26 A. I remember having a conversation with a doctor on
27 Daddy's discharge but I can't recall the detail.

28 MR. HANBURY: Right, okay. I think that's all I have.

29 CHAIR: If I might come back to one point about the

1 cancer nurse specialists.

2 A. Yes.

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

12 A. Yes.

13 CHAIR: were you aware of the existence of cancer nurse
14 specialists before that?

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

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

4 CHAIR: [Patient 5's Daughter], thank you very much. Ms. Treanor,
5 do you have any questions? 14:54

6
7 THE WITNESS WAS QUESTIONED BY MS. TREANOR AS FOLLOWS:

8
9 MS. TREANOR: [Patient 5's Daughter], I just wanted to ask you
10 about an answer that you gave to Dr. Swart. You said 14:54
11 that one of the things that you were most shocked by
12 was the failure to act on the CT scan and your father's
13 diagnosis of prostate cancer. I just want to take you
14 very briefly to one of the pages in the bundle. It is
15 from your second meeting with the SAI review team. It 14:55
16 is at PAT-001972.

17 A. Yes.

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

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

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

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

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

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

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

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

27 A. Yes.

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

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

3 A. Yes.

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

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

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

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

18 A. Thank you very much.

19
20 I have written a statement that I would like to read 14:59
21 out and hope that I don't get upset and weepy. I think
22 it is really important that, you know, we are able to
23 put forward our views today and I really appreciate the
24 Panel giving me the opportunity, and everyone here in
25 the room for taking the time to give me the opportunity 14:59
26 today to reflect on Daddy's circumstances and to
27 reflect on the poor care that he did receive with
28 regard to the follow-up and action of the scan.
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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

14:59

Personal Information redacted by USI

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

15:00

1
2 Mr. O'Brien, in his statement, which I received
3 yesterday, described how this delay came about,
4 detailing his administrative processes and his
5 rationale. He suggested he reviewed the scan results 15:01
6 in late February or early March 2020. However, at
7 a very minimum the results of the scan should have been
8 communicated to my father once the scan had been
9 reviewed. Surely he had a right to know at that
10 juncture rather than not being informed until 15:01
11 late July 2020.

12
13 My father should have been allowed to make an informed
14 choice on whether to attend for an additional scan.
15 We appreciate that COVID-19 measures also came into 15:01
16 effect.

17
18 When I reflect on my father's circumstances, he was
19 neither protected nor safeguarded and was not reviewed
20 post-CT scan, even though there were clear governance 15:01
21 policies and procedures. These serious governance
22 issues and failings need to be addressed by the
23 Department of Health, and the Trust. An arm's length
24 approach to governance does not seem to be working when
25 I reflect on my father's circumstances. More rigorous 15:01
26 oversight by the Department of Health of governance in
27 the Trust is required, in my opinion.

28
29 In addition, if unannounced inspections do not

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

4
5 The longevity of the concerns with regards to the lack 15:02
6 of prompt follow-up of scans is worrying, harrowing and
7 upsetting. Had they been addressed or resolved, we
8 perhaps might not be where we are today, in the middle
9 of another public inquiry. It was the first noticed
10 almost ten years ago that scans were not being followed 15:02
11 up promptly, yet it has happened to my father again.
12 In my opinion, and based on the hearings to date, there
13 appears to be ineffective leadership in the Trust at
14 different levels where risk factors were not
15 sufficiently addressed, escalated, and dealt with 15:02
16 appropriately. Chief executives should have taken
17 ownership and responsibility of addressing serious
18 concerns in order to maintain public confidence in the
19 Trust.

20 15:02
21 In terms of Trust culture, work needs to be done in
22 changing the Trust culture to ensure the staff are not
23 afraid to raise professional practice issues and feel
24 supported to do so. The systems tracking patient scans
25 and monitoring the follow-up scans by clinicians is not 15:02
26 fit for purpose, in my opinion, and should be reviewed.
27 Remember, patients and their families are not just
28 a number, a statistic on a PowerPoint reflecting
29 lessons to be learned. Instead of lessons to be

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

5
6 We no longer have my father in our lives. We continue
7 to grieve and mourn him every day. The public inquiry,
8 although necessary, is difficult and distressing for us
9 as a family. We hope that eventually it will provide
10 closure and will make a difference and safeguard
11 patients in the future, which was Patient 5's wish.

12 CHAIR: Patient 5's Daughter, thank you very much. We do
13 appreciate how difficult it has been for you to come
14 and speak to us and I know that from the correspondence
15 that you directed to me a year ago. We do really
16 appreciate you coming along to speak to us.

17
18 what we hope to be able to do at the end of our work is
19 to make recommendations that will make a difference to
20 patient safety overall. So, thank you again.

21 A. Thank you very much. Thank you.

22
23 (The witness withdrew)

24
25 CHAIR: Ladies and gentlemen, we're going to take
26 a break now until 3.30 when I hope that we will be able to
27 deal with the one remaining issue on the patient list
28 today.

1 THE INQUIRY PANEL ADJOURNED

2
3 CHAIR: Good afternoon again, everyone. Good
4 afternoon, Patient 35's Son. So long as you can see and
5 hear us, that's the important thing. 15:30

6
7 Thank you very much for coming back this afternoon.
8 I'm going to ask you now to take an oath or affirm,
9 whichever is your choice. I don't know if you can see
10 our Inquiry Secretary, Mr. MacInnes. Can you see him 15:30
11 okay?

12 A. I can, yes.

13
14 Patient 35's Son, HAVING BEEN SWORN, WAS QUESTIONED BY
15 THE INQUIRY PANEL AS FOLLOWS: 15:30

16
17 CHAIR: Thank you very much, Patient 35's Son.

18
19 Patient 35's Son, you gave evidence before us on
20 27th September of last year, that's 2022. 15:31

21 A. Okay.

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

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

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

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

2

3

(The witness withdrew)

4

5

CHAIR: Thank you very much for staying behind, ladies 15:31

6

and gentlemen. I just felt it was important that we do

7

things formally and make sure there's no issue.

8

9

THE INQUIRY ROSE AT 3.31 P.M.

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