Urology Services Inquiry

Oral Hearing

Day 4 – Tuesday 27 September 2022 (Closed)

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

Dr Sonia Swart (Panel Member)

Mr Damian Hanbury (Assessor)

Held at: **Bradford Court, Belfast**

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THE HEARING COMMENCED ON TUESDAY, 27TH SEPTEMBER 2022 AS FOLLOWS:

CHAIR: Good morning everyone. Welcome back. I hope everyone had a restful summer's break. Just to say that you have probably noticed that there have been some changes to the chamber in your absence. These are in readiness for our hearings in November which will be live-streamed and we will be trialing out the systems this week. If there are any difficulties, then please let the Inquiry Secretariat know. We are about to start our second session of private patient family hearings and at the end of the evidence on Thursday, I'll say a little more about what you can expect in November and how we will be time-tabling the Inquiry from then on. 10:09 10:09 10:10

If I can just introduce, basically for the benefit of our witness and family who are here today, I'm Chair of the Inquiry, I'm Christine Smith KC, Senior Counsel at the Bar of Northern Ireland. I have Dr. Sonia Swart who is my co-panelist to my right, and to my left is Mr. Damian Hanbury, who is a urology assessor. We will be doing most of the talking today and asking you questions, Patient 15's son, but before that, can I also introduce some of the other people who are present in the room. You have probably met Ms. Marshall, our Inquiry Secretary, and we have Ms. Leah Treanor, who is one of the Junior Counsel to the Inquiry, and 10:10 10:10

Ms. Shauna Benson is one of the solicitors to the Inquiry. And then are representatives of the core participants before the Inquiry present. I am going to then ask Ms. Treanor if she would outline something about what evidence we're going to hear this week so you can just relax for a moment, Patient 15's son, while Ms. Treanor does some talking

10:11

OPENING REMARKS: MS. TREANOR BL

10:11

MS. TREANOR: Yes, Good morning Madam Chair. If I may, I'd like to briefly introduce what will be the second set of patient-focused hearings in this Inquiry, in continuation of the patient hearings which commenced earlier this year in June.

Madam Chair, in opening the patient hearings in June, Mr Wolfe KC eloquently set out the relationship between these hearings and the Inquiry's Terms of Reference and, whilst I don't propose to rehearse that, I do think it is important at the outset to call to mind again the wording of paragraph (d) of the Inquiry's Terms of Reference, which asks the Inquiry:

To afford those patients affected, and/or their immediate families an opportunity to report their experiences to the Inquiry.

The purpose of these hearings, therefore, as with the previous hearings in June and any future patient hearings, is to give effect to this aspect of the Inquiry's Terms of Reference by affording patients and their families an opportunity to give direct evidence to the Inquiry about their experiences of Urology Services within the Southern Trust.

To that end, Chair, this week you will hear from the families of 3 patients, who each have valuable evidence to give the Inquiry about their loved ones' experiences of accessing the Southern Trust's Urology Service. By way of overview, before we begin:

This morning, you will hear from Patient 15's son, the son of Patient 15, sadly deceased. I understand Patient 15's son will be accompanied this morning by his mother, Patient 15's wife. Patient 15 was referred to Urology by his GP on 30 August 2015 for assessment and advice in respect of elevated PSA and that referral was marked ROUTINE. The referral was not triaged upon receipt by the Trust and, at the relevant time, that triage exercise should have been done by Mr. O'Brien. Patient 15's GP then referred him for a second time, on 29 January 2016. That second referral was marked RED FLAG, meaning suspected cancer. Following the second referral, Patient 15 was seen in clinic by another Consultant Urologist, Mr. O'Donoghue, and, following further investigations, he was ultimately diagnosed

with prostate cancer on 29 February 2016. Patient 15's case was the subject of an SAI review by the Trust, which concluded that the failure to triage had resulted in a 6 month delay in obtaining a diagnosis of prostate cancer (PAT-001101). Whilst Patient 15's treatment for this cancer was ultimately successful in June 2017 (PAT-001155), in the questionnaire they have submitted to the Inquiry, Patient 15's family describe the impact of, in their words, 'an additional six months of unnecessary stress' on Patient 15. (PAT-001155)

This afternoon you will hear from the son of Patient 35. Patient 35's case was the subject of Structured Clinical Record Review (SCRR), which called into question the appropriateness of his treatment and concluded that he did not receive standard care for localized prostate cancer (PAT-000818). Patient 35 was first referred to Mr. O'Brien in September 2008. On 7 December 2009, Patient 35 was diagnosed with prostate cancer. Between December 2009 and March 2013, Patient 35 was reviewed a number of times by Mr. O'Brien and, further, his case was discussed at Multi-disciplinary Meetings (MDMs) on 11 November 2010 (PAT-000880) and 20 December 2012 (PAT-000895). Throughout that time, Patient 35 was managed by way of 'active surveillance' of his PSA levels. There is no evidence to suggest that Patient 35 was offered any active treatment options, such as radical prostatectomy or radical radiotherapy

in that time and this was one of the criticisms of his care raised by the SCRR, which concluded that 'active surveillance would not be standard recommendation for Gleason 7 prostate cancer in a fit man' (PAT-000807).On 8 March 2013, Mr. O'Brien commenced Patient 35 on Bicalutamide 50mg and Tamoxifen (PAT-000903). The SCRR outcome suggests that Bicalutamide monotherapy was inappropriate and that low-dose Bicalutamide is not licensed for treatment of patients with localized prostate cancer (PAT-000807). Patient 35 was finally referred for radiotherapy on 5 August 2014 (PAT-000915), and began his treatment in November 2014. At (PAT-000807) the SCRR reviewer opines that Patient 35 could have been offered radiotherapy as early as 2009. Sadly, Patient 35 died with metastatic prostate cancer in December 2019. The SCRR reviewer indicates that 'although radical treatment in 2009 may not have been curative, earlier treatment would likely have improved prognosis. It is very difficult to quantify the extent to which his overall survival was compromised' (PAT-000818). In the minutes of a meeting with the Trust, Patient 35's wife describes her 'devastation' at losing her husband then receiving the news that there were issues with his care (PAT-000968).

Finally, Madam Chair, on Thursday morning you will hear from the family of Patient 1. Patient 1 was diagnosed with a Gleason 4 + 3 prostate cancer on 28 August 2019.

His case was discussed at MDM on 31 October 2019, at which time the recommendation of the MDM was to commence LHRH analog therapy and to refer Patient 1 for an opinion from a clinical oncologist regarding External Beam Radiation Therapy (EBRT). Rather than implement the recommendation of the MDM, Patient 1 was continued on low-dose Bicalutamide 50mg daily, a regime he had been on from in or about mid October 2019. Patient 1 was finally commenced on LHRHa on 1 June 2020 and was referred to Oncology on 22 June 2020. His disease progressed and he sadly died on 18 August 2020. Patient 1's care was the subject of an SAI review, which found, at (PAT-001309), that the prescription of Bicalutamide did not conform to the relevant Northern Ireland Cancer Network (NICAN) Guidelines, and at (PAT-001310), that Patient 1 'developed metastases whilst being inadequately treated for high-risk prostate cancer. The opportunity to offer him radical treatment was lost.' In the questionnaire submitted to the Inquiry, Patient 1's family describe the impact of this on Patient 1, explaining that he 'felt that he had been “thrown under a bus” by the health care system' (PAT-001353).

The care of all 3 of these patients has been subject to either the SAI or SCRR process and, therefore, paragraph (c) of the Inquiry's Terms of Reference is also engaged. Paragraph (c) requires the Inquiry:

"To examine the clinical aspect of the cases identified by the date of commencement of the Inquiry as meeting the threshold for a Serious Adverse Incident and any further cases which the Inquiry considers appropriate, in order to provide a comprehensive report of findings related to the governance of patient care and after within the Trust's urology specialty."

In concluding, Chair, it would be remiss of me not to re-emphasise at this point that the focus of paragraph (c) of the Terms of Reference is firmly upon examining the clinical aspects of cases for the dominant purpose of making comprehensive findings relating to governance and patient care and safety.

As such, whilst the Inquiry is keen to hear from patients and their families about their experiences of Urology in the Southern Trust, and will inevitably ask questions about alleged clinical shortcomings in discharging its duty under Term of Reference (c), it is not the role of this Inquiry to make findings about clinical outcomes in individual cases.

Thank you, Chair, those are my opening remarks.

CHAIR: Thank you very much, Ms. Treanor. If I can turn then to address Patient 15's family. First of all, may I, on behalf of the Inquiry, express

condolences on the loss of your husband and father. We recognise that his death is not as a direct result of his cancer. Nonetheless, I'm sure you feel his loss keenly to this day.

10:19

Can I also say that I'm very grateful for you coming to speak to us and tell us about his care in the Southern Trust and I will be asking you and the other witnesses who come to speak to us this week some questions which we hope you'll find easy to answer but if you're unsure 10:19
of what I'm asking, please do say so. Please, if you want to take a break, don't be afraid to say that you need a break, we can take whatever breaks you need. This is your opportunity to tell us how and your family feel about the care that your father received and also 10:20
about anything you can tell us about how he felt about his treatment. You have received a bundle of papers and that includes the completed questionnaire that you sent to the Inquiry. Can I assure you that myself and my co-panelists here have read all of those papers but 10:20
if you do want to refer to any of them, if you could use the number in the top right-hand corner and that way, we can ensure that everyone is looking at the same page and it would also then be possible for us to pull this document up on the screens if you give us the full 10:20
number.

As Ms. Treanor has reminded you, that the Inquiry cannot make any decision about the care that your

father received, whether that was the appropriate treatment for him or not. Others both in the Trust and in the General Medical Council have been looking at the care of patients and after I have asked you some questions then, Dr. Swart may have some questions, Mr. Hanbury may have some and I will hand over again to Ms. Treanor in case there is anything she wants to ask you. But I will try to cover all the matters that we need to ask you about and in the meantime, I'm now going to ask you, Patient 15's son, if you wouldn't mind taking the oath. 10:21 10:21

THE WITNESS: Yes, sure.

PATIENT 15'S SON, HAVING BEEN SWORN, GAVE HIS EVIDENCE TO THE INQUIRY AS FOLLOWS: 10:21

1 Q. CHAIR: Thank you. Now, Patient 15's son, as we've already heard from Ms. Treanor, your father was referred by his GP in August 2015 and then having heard nothing, he then went back to the GP and got the GP to contact the Trust again, isn't that correct? 10:22

A. That's correct. So there was the initial referral because of the elevated PSA levels and then, in a way, my father was one of those people who didn't complain, so whenever there was a delay it was just this is the way things were. But eventually the worry of it brought him back to the GP and it was a worry for him, for my mother, for myself and my sister, and that's at the point that things started to move, I suppose. But 10:22

that initial six-month delay was the main thing, you know.

2 Q. Would I be right in thinking that that is the main thing that you and the family are concerned about?

A. Concerned about not only the delay but the impact. I know you say that this isn't looking at, you know, outcomes and things from a medical point of view, but we believe it impacted his health. We certainly know that the PSA levels were increased six months down the line, things like that. So we do believe it had an impact on his life. And I notice one of the phrases used, not only for my father but for other patients, was things weren't clinically significant. But I believe I noted "clinical significance" defined as a real genuine, palpable effect on daily life. So it was certainly was clinically significant from a mental health point of view, from stress levels and the impact on my mother and sister, so. 10:22 10:23 10:23

3 Q. So there really was -- that six-month delay did have an impact on you and your father and your family? 10:23

A. It really did. Again, as I said in my submission in the questionnaire, I mean, it seems to be a very unnecessary additional six months of worry and stress but it didn't need to be. It shouldn't have been.

4 Q. We know that he was then referred back and this time, the designation on the referral letter was one of red flag and he was seen then and treated by Mr. O'Donoghue in the Trust? 10:24

A. Yes, my father spoke very highly of him, and my mother

also speaks very highly of Mr. O'Donoghue. But again, from what I understand from the evidence as well, if it weren't for that second referral, he would have been missed for who knows how long. So, you know, no triage in six months but for the second referral, who knows when he would have been triaged and actually when treatment would have been instigated, you know. 10:24

5 Q. One of the things that we noted in the papers was that when he was assigned to Mr. O'Donoghue for treatment, he was also assigned a cancer nurse specialist, is that correct? 10:24

A. I believe so, yeah.

6 Q. And did the family find that -- did your father, first of all, and did the family find that helpful?

A. I would need to check on my mother on that one. 10:25

7 Q. In any event, he received treatment that was in fact successful?

A. Successful, yeah. Ultimately successful and this was the thing, as the whole process began from the initial referral, because he fully understood, you know, what the raised PSA levels potentially point to. Nobody wants to hear the word "cancer" and then the amount of time that went by from that initial August referral, he was depressed. 10:25

8 Q. Just take your time, Patient 15's son. I appreciate this is difficult and if you do want to take a break, please just say. 10:25

A. So, he believed, like anybody, he was convinced it was a death sentence, essentially, because "cancer" and as

time went on, and the delay went on, the treatment went on, the treatment was hard on him. He was a fairly elderly man and the treatment, did it need to be so severe eventually when it came? You know, he was up and down to Belfast every day on the train early in the morning. It had an impact on him, and my mother as well. But there's such a change in his character. Dad was the life and soul, that's how I would describe him.

9 Q. The diagnosis itself had an affect?

A. The diagnosis itself but, again, what I think was difficult for him was, as time went on, haven't heard anything, we're into another year, and everybody knows the whole thing; the earlier you catch these things, the more successful treatment generally is and he was fully aware of that and I believe, just the silence of that first six months was very difficult for him, for everybody, waiting, what's going to happen? And I know that he spoke to me whenever the diagnosis came through in January, or February, that he spoke to me basically going, we need to make arrangements now for what happens next, because this is it.

10 Q. He was expecting the worst?

A. He absolutely expected the worst. As I said in submissions, whenever the all clear eventually did come through, back to normal, it was like years being lifted off people, that's exactly what it was. So I remember that well, the day that he came back with the good news and the big grin.

11 Q. And as you said, treatment was successful?

A. Yeah.

12 Q. And he was in reasonable health then for a while?

A. Yeah.

13 Q. Before, sadly, he died from something unrelated to the cancer? 10:28

A. We wonder how much of an impact it took on his health, those couple of years in total, whether if it was not directly related to the cancer, certainly, but a man of that age and we know that towards the end, part of the reason for his death was stomach ulcers and things like 10:28 that, and they're things that are connected to stress. So whether a connection can be made, and I know it's outside of the scope of the Inquiry, it can't have helped his health in the long run. It can't have, and we don't believe it did. 10:28

14 Q. Can I come on, Patient 15's son, to ask you a little bit about when you first became aware that there was an issue about how the referral was handled within the Trust?

A. The only thing we, as a family, knew about any of this, 10:28 we never heard of SAI or we had never had of any review, we never heard of any details, was in May of last year whenever my mother received a phone call from the Trust, I presume the hospital, Craigavon, saying: "I believe you have made a complaint about the 10:29 treatment of your husband", and this was confusing. No complaint was made. We didn't know that there was a reason at this time for a complaint to be raised. And then a phone call was arranged for Mr. Haynes to call

back to my mother to speak to her. So that happened later in the week, and during that phone call was the first time any indication that there was any sort of delay, any sort of abnormality or reason for concern in the treatment or triage or anything like that, but for 10:29
the fact that it was going to -- it seems to us but for the fact it was going to be in the media, we wouldn't have received that phone call, and that phone call, despite what some of the evidence there says, if I could point you to PAT-1132. 10:30

15 Q. Is that PAT-001132.

A. PAT-001132.

16 Q. Do you want to maybe call that document up? Perhaps if we can make that a little bit bigger. Sorry, I think that's the wrong number, isn't it? It's PAT-001132. 10:30

A. PAT-001132, yeah. You know, that middle paragraph there:

"19/05/21 I can confirm that Mr. Haynes has telephoned Patient 15's wife this morning and advised that her 10:30
husband was part of the original SIA."

17 Q. If I can just pause you there, Patient 15's son. We're having a little technological difficulty. This is what 10:31
this week is designed to hang out so I hope you will bear with us. I'm not quite sure what has happened. There we go, thank you.

A. So because my mother was notified that that call was

going to happen, she asked me to sort of be there and listen in, and the fact that that mentions or advises that her husband was part of the original SAI in urology services,that's not what we came away with.

18 Q. Can I pause you there? 10:31

A. Yeah, sure.

19 Q. Was that the first time -- were you told that? Do you recall were you told that at that time?

A. We discussed this and neither of us recall SAI or Serious Adverse Incident or anything like that, we 10:31 don't recall the term but it may have been mentioned but it wasn't what the call started for. The call started to let us know that there is going to be a report in the Irish news that there was some attempt by whoever going to be made to block it but that this was 10:31 shining a light on somebody and practices within the Trust. And again, for us not to worry, it didn't affect the treatment or the outcome for my father. I queried that point again, what was said there, any delay did have an impact, both for my father and the 10:32 family. But the impression we were left, after the call, was this was purely a spin exercise. This seemed to be going -- 'There is going to be media attention, just ignore it, don't worry about that, everything is fine. Patient 15 survived.' That seemed to be the 10:32 thing.

If SAI was mentioned, it may have been, I don't honestly remember, neither of us can remember those

terms being used. There was mention of a delay and this was the first time we'd had any indication that there'd been any sort of delay or problem with the treatment. It was the very first instance and the only instance until the Inquiry. So there was mention -- he did offer to meet, in fairness, but at the time, Covid was rampant and nobody wanted to go to a hospital in the middle of that, but he said he would follow up and that never happened. That is the only information we had and it seems to be purely the only reason we got it was because there was going to be something in the press. 10:33 10:33

Then the other thing, still in PAT-001132:

10:33

"26/5/21: Mr. Haynes spoke with family. CLOSE."

We're confused by that. He didn't speak to us on the 26th, maybe it refers to the 19th, but why "close" in capital letters? Does he think that's them dealt with, the family doesn't need anything more. We don't need to share anything more? That's something possibly for yourself. 10:33

20 Q. That's something that we can ask the Trust about that and ask for clarity around that, Patient 15's son. Can I just ask, though, it does say that he advised your mother that the review looked at two aspects; what can be done about the process and the Consultant and what impact the delay in referral letters had on the 10:34

patient's overall care. Do you remember any discussion about letters?

A. No, and there are several letters. In that phone call there was no talk about, you know, looking into these things, you know, to correct them, you know, I don't remember that. It wasn't a particularly long phone call, you know, it was fairly short. 10:34

21 Q. There are a series of letters in the bundle of papers --

A. There are. 10:34

22 Q. -- that you have received and you might just...

A. Starting at PAT-001136, I think.

23 Q. Can you just call that up, 1136. Again it's addressed to your father at that stage and it seems to be dated 19th February 2018? 10:35

A. Yeah. This PAT-001136 and PAT-001137 seem to come about from reading the bundle as a result of the e-mails in PAT-001216 so the dates tie up there. The first letter, PAT-001136, appears to be the one the Trust is saying was sent and PAT-001137 seems to be possibly the one that was sent for review. 10:35

24 Q. On the screen at the moment, you'll see the e-mails but the first letter is signed by Mrs. Esther Gishkori. Can I ask did your father ever receive that letter, to the best of your knowledge? 10:35

A. To the best of our knowledge, no, and the reason we say that we can't honestly say definitely/definitely not, but there's an "in" joke within the family about my father filed everything, and I mean everything. If he

went out and a bought a pencil, the receipt would be put into the filing cabinet. There's receipts going back to the sixties for rent, you, know. It's incredible. And not only that but my mother and my father worked as a team. There was nothing hidden. It would have been incredibly out of character if my father had received a letter and not shared it and not filed it. And on top of that, my sister, after my father died, my sister was going through various things like this and this is the sort of thing that stands out and she doesn't recall ever seeing it. So we're not aware of it, is the way I'd phrase it. 10:36 10:36

25 Q. Then if I can just move on to the next one, which is PAT-001137?

A. Yeah. Again that's an identical letter and it's dated 1st November 2018. This is where the question of confusing comes in because again, if we go become to PAT-001216. 10:36

26 Q. This is an e-mail, an internal e-mail chain within the Southern Trust? 10:37

A. And towards the end of that, where my father's name is mentioned.

27 Q. If you just scroll down, please, and you'll see that there are a number of patients referred to.

A. Yeah. 10:37

28 Q. And then we have highlighted your father's name there.

A. Yeah. It clearly states:

"This is the only urology patient that hasn't been

advised of the SAI."

And this is 2018.

29 Q. That's the 2nd November 2018?

A. Yeah. So that PAT-001137 is dated 1st November so we're assuming that that's the letter that was sent for your approval, as is mentioned in PAT-001217 there. 10:37

30 Q. Can I just ask you, though, did your mother or did any of you ever remember that letter being received?

A. No. 10:38

31 Q. And again, it wasn't filed by your father?

A. No, and it's two identical letters, one is signed, one is not. I don't know whether the fact that there's no reference number on them, if that's relevant or if that's normal, but we're not aware of that letter. 10:38 Even in my notes, I have red dots on these four letters here.

32 Q. Then I think there's another draft, certainly a draft letter at PAT-001138?

A. Yes. And again this one talks about a lookback exercise, which presumably is different to an SAI, but again, we're not aware of this letter. Now that letter was dated the day before my father died. So whether something arrived and it was missed in the few weeks after my father's death, I don't know. 10:38 10:38

33 Q. Certainly, what we have been given is not signed by anyone, which would suggest that it's a draft, and again there's no reference on it.

A. Again, no reference, no signature and if that had come

through, you'd think we'd be going "what's going on here", as a family, and say is there something we need to know about? But we don't believe we have ever seen that. And PAT-001139...

34 Q. Mm-hmm. 10:39

A. ....is very confusing. Again no reference, no signature, no date. And from Mr. O'Donoghue. It seems to be a very well intentioned letter but what has got us baffled is:

10:39

"Firstly, I want to apologise if the phone call you received from the Trust caused you some distress or confusion. That was not my intention."

How did he know? Where did he get this information 10:39
from? We were only spoke to by Mr. Haynes once. We didn't speak to anybody else to let them know that it had caused distress. Mainly, whenever the Irish news published the article, my mother wasn't in great shape for a couple of weeks after that but..... 10:40

35 Q. But you hadn't actually contacted the Trust after that Irish News?

A. No. We were, between ourselves, debating what should we do next and then we found out Mr. Swann had announced that there'd be an Inquiry. So, you know, 10:40
knowing well that these things need to run their course, I suppose, there's no point in us challenging things now if the Inquiry is going to take over. But this letter, why it's confusing, we don't understand

the background to it, where the information that Mr. O'Donoghue is working from there is coming from and an offer to discuss. As my mother said to me, if for a second she thought at this stage, you know, she could have talked to somebody or we could have talked to somebody, the offer would have been accepted, definitely.

36 Q. So you don't believe that letter was ever received?

A. No. A hundred percent, that's addressed to my mother I'm a hundred percent that that letter was never received. 10:41

37 Q. Is it fair to say that most of the communication and documentation that you received came, in fact, from the Inquiry to the family?

A. Apart from Mr. Haynes' phone call about the press article and that admission that there was a delay, all of our information has come from the Inquiry. All of it. Everything. 10:41

38 Q. Thank you very much, Patient 15's son. Is there anything else that you would wish to say at this stage or wish the Inquiry to know, either about your father or about his care? 10:41

A. Again, just I'm not very good at conveying just how big an impact it did have on him but what is very frustrating for the family, I think, and I don't know if "anger" is the right word because you're at a stage where you are frustrated and everybody, I think, when it comes to this sort of thing, initially you go; 'Well, maybe it was a mistake', but then when you see 10:41

the evidence and you read the media articles, which seem to be reasonably accurate, you're going; 'It's not a mistake and we can't ignore it.' The fact that, you know, we don't see any one individual, there is certainly plenty of individuals who have caused problems but we don't -- we see it as a collective, if there's a failure to triage and then there's a failure to address the failure to triage and it goes back 25 years, I mean, if you or I, we were talking about, anybody in a normal profession was in that position where they were challenged multiple times, something would be done. But even excluding individuals, the Trust has a duty of care, everyone knows that, the Trust has a duty of care and the Trust needs to be grown up and deal with its problems and it hasn't done that. And we're just obviously one of many and God knows how far back it goes. We understand, too, that you know, the medical profession, and I'm sure it's a thankless task at times, and there are many people doing wonderful jobs every day, you know, certainly with my father, the same, you know, very thankful, but, again, it's kind of like football, you're only as good as your last win and whenever you see, you know, if a thousand patients are successfully cured and then a handful are missed because of any sort of action or whatever way you want to describe it, it's not acceptable. I understand there's pressures on every part of the NHS at the minute, financially and all that, but we still need to find ways to do the

10:42

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10:43

important things, unfortunately. So...

CHAIR: Thank you, Patient 15's son. Dr. Swart is there anything else you would like to ask?

39 Q. DR. SWART: Thank you very much for sharing your story, it is so important that we hear about how it has made you feel and your family feel and your father feel. I think you have described quite well the impact of the six-month delay and the anxiety that caused. Clearly, there's been some communication, significant communication issues around the Serious Adverse Incident. 10:44 10:44

A. Yeah.

40 Q. If you'd had the offer, would you have been happy as a family to come in and contribute to the Terms of Reference of such an investigation? Did you know about serious incidents about this or did anybody ask you what you'd like it to find out, for example? 10:44

A. You mean, if it had happened back then?

41 Q. Yeah.

A. We would certainly would have taken any offer, if we'd known or if we had been contacted, absolutely we would have engaged with them. 10:44

42 Q. And how did you feel about the fact that nobody explained that to you and the sort of confusion around it? 10:45

A. The frustration, mostly, I'd like to say anger is the wrong word.

43 Q. Mm-hmm.

A. It's that sort of frustration of why, you know? Is it

somebody trying to hide something? Is somebody trying to avoid culpability? Why were we excluded? Why was the information not shared? It's frustrating and it makes you worry about if this has happened to us, what else is happening? You know, you lose faith in the systems which are there, which shouldn't be the case.

44 Q. If you had the opportunity to talk to the Trust Board today and they said, you know: "Patient 15's son, can you give us one piece of advice about the serious incident process in relation to families?", what would that advice be?

A. I think that there needs to be better procedures which you see in the recommendations. There's a start there, but there needs to be better procedures in place to catch things like this. It seems that there is no auditing in the past of these procedures to catch any sort of failure or anything or anybody that would be missed and there is no escalation process. So that is the thing I guess I would say to the Trust; improve your procedures to make it so that this can't be happen, you know. I work in IT so we've got procedures and we've got risk assessments and we go, you know, "Can you do this?", blah, blah, blah, and there's always an escalation made and there's also a way to audit and check everything's done right and, you know, those can be annoying and complex, but at least I'm only dealing with computers, you know, not life. So, you know, it's a very different matter. So the fact that those weren't in place is kind of flabbergasting

and hopefully you'll put something in place that is a workable annotation.

DR. SWART: Thank you, that's all from me.

CHAIR: Mr. Hanbury.

45 Q. MR. HANBURY: Thank you very much for your compelling evidence. There's just a couple of things I'd quite like to sort of dig a bit deeper. When your father went to see the GP with his symptoms and this high PSA, was your recollection that the GP told him why he was worried and why he was referring? 10:47

A. There was blood tests going on and that pointed out the elevated PSA and I think that the referral was as a result of that.

46 Q. Yeah. But did the GP sort of vocalise the possible significance of that? 10:48

A. Do you mean that it would point to cancer?

47 Q. Correct, yeah.

A. Yes, I believe so.

48 Q. Yes. Which obviously made that six months that much more...(interjection) 10:48

A. He did that, and my father was well aware of what a PSA test was looking for, checking for, that it could point to an elevation as an indication of cancer.

49 Q. And then there was no communication at all in that six-month period? 10:48

A. Nothing in the six months until the second referral, that's when things started moving.

50 Q. Thank you. And just to pick up on Ms. Smith's comment about when you met Mr. O'Donoghue and got the bad news,

that's always a tough day, and he met the specialist cancer nurses, did you find that that was useful backup? Was that helpful? Did the family or your father avail yourself of --

A. Is it okay if I... 10:49

CHAIR: Of course.

PATIENT 15'S WIFE: Yes, everything was helpful. We didn't want to contact the cancer nurse because Patient 15 wanted to leave it but the treatment that he got from Mr. O'Donoghue we were very happy with, and with 10:49 the cancer centre in Belfast.

51 Q. MR. HANBURY: Okay. So that's very helpful to hear the offer was there. Thank you. The Inquiry is quite interested in the role of hormone treatment, we have not heard a lot about it, but the hormone injections 10:49 that your father was on for that, for about three years, I think, wasn't it?

A. Yeah.

52 Q. Did he complain of any particular side effects? Was that a thing or -- again, this has not come through in 10:49 the....

PATIENT 15'S WIFE: Yes, he did have a lot of side affects, a lot of side effects, tiredness and things like that, but other things as well.

53 Q. Did he have sort of backup for that? I guess that 10:50 might have been a role for cancer nurses but he just bottled it, did he?

PATIENT 15'S WIFE: He kept it to myself.

A. PATIENT 15'S SON: Again, as I said earlier, I would

describe my father as "old school", you know, you don't complain, you don't go too far in sharing your problems you don't worry other people where you don't have to. So that was his attitude in life, I think, and it probably wasn't helpful in this instance, you know. 10:50

54 Q. But in terms of organising the injections and things, that all happened automatically?

A. Yeah.

PATIENT 15'S WIFE: That didn't happen automatically, I arranged that. I had to make those appointments. 10:50

55 Q. Okay.

A. PATIENT 15'S WIFE: Every 12 weeks.

56 Q. With the general practitioner?

PATIENT 15'S WIFE: Yes.

57 Q. Okay. Thank you. There's just one last thing. In fact, when he went through surgery and then the radiotherapy and then in that, you elegantly say a weight was listed off his shoulders. You saw a difference in his personality once the PSA went down and this kind of thing? 10:51

A. Yes.

58 Q. Just tell us a bit more about his mood?

A. He came back from the "all clear" meeting, where it was all clear. Was it Mr. O'Donoghue where he got the all clear? 10:51

PATIENT 15'S WIFE: No, it was Belfast, Mr. Jain, I think his name was.

A. PATIENT 15'S SON: I remember my father had a great sense of humour and when he came back he said -- one of

the things he'd said during the all clear meeting, he told me was he said: "So it's not going to kill me?", to the Dr. Jain or Mr. Jain, whoever it was and he said "no". My father says: "It's not going to kill me, I'm going to live to 100?" And he said: "The cancer won't kill you but we can't say you'll live to 100." After that, he was dancing on air, he really was, you know. I mean, you could see it in the way he stood, his smile, the colour in his skin, eventually everything. We saw our dad back. 10:52

59 Q. The point I am making is that we see from some of the oncology letters his PSA went right down, it is hardly recordable, this is 2020, just a few months before he passed away. In that last year or so, I think he was off hormones? Do you remember that? 10:52

PATIENT 15'S WIFE: Yes, he was.

60 Q. And did you see an improvement to his?

PATIENT 15'S WIFE: Yes.

61 Q. That was --

PATIENT 15'S WIFE: Yes. Those symptoms went. 10:52

62 Q. It was obviously very helpful to get him off the hormones then.

PATIENT 15'S WIFE: Yeah.

MR. HANBURY: Okay. So that's all I've got. Thank you very much. 10:53

CHAIR: Ms. Treanor, do you have anything?

MS. TREANOR: Just a couple of questions, if I may, Patient 15's son.

THE WITNESS: Sure.

PATIENT 15'S SON WAS QUESTIONED BY MS. TREANOR AS FOLLOWS:

63 Q. MS. TREANOR: If I have understood your evidence today correctly, you said that the only contact you had from the Trust was the telephone call of the 19th May 2021, is that right? 10:53

A. That's correct.

64 Q. And that telephone call was from Mr. Haynes, is that right? 10:53

A. That's right, yes.

65 Q. In answer to the Chair, you had said that the phone call wasn't particularly long, that it was short. Do you recall how long it was? 10:53

A. Minutes. It would have been -- the phone call would have been five minutes, would it?

PATIENT 15'S WIFE: Well, it might have been five.

PATIENT 15'S SON: Approximately five minutes.

PATIENT 15'S WIFE: Not much more. 10:53

66 Q. Okay. And you say in that phone call that neither you nor your mother recall hearing the term "SAI" or the word Serious Adverse Incident?

A. PATIENT 15'S SON: We don't, and whether that's a result of that being sort of an unusual phrase that it wouldn't have registered or it wasn't said, I honestly don't remember, neither of us can recall if it was mentioned, but we didn't come away from the call thinking that there was some sort of inquiry or review 10:54

going on, we just thought that there's media attention and it had no impact on my father's case, don't worry about it. That was what we left with. Not that there was something ongoing. He did say that he would get back to us, but he didn't. 10:54

67 Q. Okay. So you had no further contact from the Trust after that call?

A. No.

68 Q. And were you ever invited to a meeting?

A. No, the only invites were what are in those letters that we don't believe we received. 10:54

69 Q. Okay. And my last question: Have you ever, to date, been provided with that SAI report by the Trust?

A. No. The only thing, literally the only paperwork we've got is from the Inquiry. 10:54

70 Q. So that was first provided to you by this?

A. Yes, by the Inquiry.

MS. TREANOR: Okay. Thank you, Patient 15's son. Nothing further.

CHAIR: Patient 15's son, Patient 15's wife, thank you both very much for coming along, and your daughter also. We really do appreciate you coming along and speaking to the Inquiry. As we have said, it is very important that we hear first-hand from patients and families who have been affected by the service that was offered to them in the Trust. So we really do appreciate you taking the time out of what I'm sure is a busy IT life, particularly, to come along and speak to us. 10:55 10:55

THE WITNESS: Unfortunately, too busy!

CHAIR: Thank you.

THE WITNESS: No, thank you all very much for what you're doing here, and everybody involved. Thanks.

CHAIR: Okay then. I think we're back at two o'clock this afternoon, ladies and gentlemen. 10:55

THE HEARING THEN ADJOURNED TO 2 P.M.

THE INQUIRY RESUMED AS FOLLOWS:

PATIENT 35'S SON GAVE HIS EVIDENCE TO THE INQUIRY AS FOLLOWS:

13:45

CHAIR: Good afternoon, everyone. This afternoon's witness, as you can all probably see, is coming to us remotely, which is a big test of our remote system. I think we've lost him. Oh, there he is again! Hello, Patient 35's son, how are you? 14:02

THE WITNESS: Hello there. Pleased to meet you.

CHAIR: Can you hear everything okay?

THE WITNESS: I can, yes. Can you hear me?

CHAIR: We can indeed, yes. So first of all, can I, on behalf of the Inquiry, express our condolences on the 14:02 loss of your father? I know it's a while ago but, nonetheless, I'm sure you and your family still feel his loss.

THE WITNESS: Yeah. Thank you very much.

CHAIR: Can I also say that, like the other witnesses 14:02 who have come to speak to us in person, I will be asking you questions but if, at any stage, you don't understand, please stop me and ask. I'm getting some feedback from our system here. If you're unsure what I'm asking, don't be afraid to ask me or if you feel 14:02 you need a break at any time, just let us know and we'll all ensure that you get a break.

This is the opportunity to tell us what you want the

Inquiry to know about the care that your father received and about the impact that it had both on him and on the family. So you can take your time and tell us anything that you want us to know. I will ask some questions which will hopefully prompt you to give us your evidence and I have also -- you should have received a bundle of papers I think in electronic form in any case, but if you want to refer to any of those, if you could use the number on the top right-hand corner then we can maybe draw up the document on our screen or at least people will have the reference number, if nothing else. 14:03 14:03

I also just wanted to remind you that the Inquiry is not in a position to make any decision about the standard of clinical care that your father received, that is whether that treatment was appropriate or otherwise, that is really for others to look at, both in the Trust and in the GMC who are looking at the standard of care received by patients in the trust. Then when I have asked you some questions, I will hand over to my colleagues, Dr. Swart, who is my co-panelist here to my right-hand side, or Mr. Hanbury, who is to my left-hand side. I'm not sure if you're able to see them on your screen at the moment but you will see them in due course. Then I will also ask Ms. Treanor, who I believe you have met virtually, if she has anything to ask at the end. 14:03 14:03 14:04

THE WITNESS: Okay, that's clear.

CHAIR: Just to set some background. Your father was referred to the Southern Trust back in 2008 and I understand that at that time he was complaining of pain in his side, effectively, and he was operated on by Mr. O'Brien at that time and it was Mr. O'Brien who diagnosed in 2009 that he also had prostate cancer. 14:04

A. Yeah.

71 Q. And he was then treated between 2009 and 2013 by Mr. O'Brien?

A. Mm-hmm. 14:05

72 Q. And the treatment that he received during that time was one of what we now come to know is called active surveillance?

A. Yes.

73 Q. So basically keeping an eye on things during that time, and then ultimately in 2014 he received radiotherapy? 14:05

A. Correct.

74 Q. And then, sadly, he died in 2019.

A. Yes, that's right.

75 Q. Now can you just tell us about the treatment that your father received during those years and the effect that it had on him? 14:05

A. Yeah, certainly. So I think if you go back to the start then in 2008, you're right, he had issues of pain in his left side and there was then various tests and scans performed and it was, you know, spotted that there was, like, a lesion of some sort that was on his kidney and whilst I believe that it was not thought that this was in itself cancerous or whatever, 14:05

I suppose it was like a hypotheses that this could have been the root cause of the pain. I believe in 2008 then, it was also observed that his PSA was at high levels but it wasn't until then 2009 that I'm pretty sure that the decision then was made to actually do something about this. And so what happened then was there was an operation performed, I guess, to remove the lesion in the hope that it would then alleviate the pain and while in there doing that, like, a biopsy was to be taken to establish whether, you know, there was prostate cancer. 14:06 14:07

I think, you know, that's debatable whether that was the right thing to do then but certainly that didn't alleviate the pain and, in fact, it magnified the pain for Dad, really, from that point forward. Really, like, by an order of magnitude that the pain was increased immediately after that operation and, you know, there was various theories as to what was causing it, nerve damage or whatever, that happened in there. But that really, like, slowed him down significantly then from that point forward and, you know, he spent, like, really from that point until he died, you know, in pain trying to manage that with whatever, all sorts of medication and different types of painkillers and, you know, he was always in and out of pain clinics and so on. 14:07 14:07 14:08

So that was kind of like, you know, one issue that came

out of that, that operation, and obviously the other output from that was that, like, the diagnosis on the cancer, so it was established then at that point that he had prostate cancer. And, yeah, I mean, you're right, like, nothing really happened then, you know. 14:08
Like, I spoke to my mom and it was sort of explained at the time that this is non-aggressive and that we have, we don't really need to do anything immediate here with this, this cancer. And so, you know, "we'll keep an eye on it", basically and, sort of like, you know, once 14:09
you're reading all this back now, maybe it's like a moment where I wish that you could go back in time and sort of, like, you know, sort of -- but I suppose throughout this entire process like, you know, there was no reason for us -- there was complete trust on the 14:09
part of my Dad and the rest of us that, do you know everything, the advice, everything he was getting was -- well, there was no reason to doubt it. And actually at that time as well, you know, really, the pain that he was now experiencing in his side was actually the 14:09
thing that was most prominent and the thing then, it was almost taking his primary focus, if you know what I mean, you know. He was told that the cancer piece, "you don't need to worry about that, we'll keep an eye on things, it's fine." But it was the pain that was 14:09
causing him such trouble day in day day out that, you know, that kind of distracted, I suppose, as well, him and my Mum's attention away from that other piece.

76 Q. He received radiotherapy in 2014, that was some five

years after he'd been diagnosed with the prostate cancer.

A. That's right, yeah. So he -- like, to be honest, I don't know the full, I mean, I've read back the same information that you had access to and I've sort of spoken to my Mum on this. But effectively, yes, in or around 2013, I believe, there were, like, observations on his PSA again that sort of prompted action. He went on to a hormone therapy tablets which, again the lookback has established was not correct, I believe, in terms of dosage and using that as a way of treating this particular disease. 14:10 14:11

Even then, I'm not quite sure why, but it took until, like -- so this was 2013 when these things were observed and then it was, like, he finished the radiotherapy treatment on Christmas Eve 2014, it still took another almost two years for that to work its way through, you know, the process and for him to receive that treatment. 14:11 14:11

77 Q. You subsequently discovered that your father's cancer was terminal. Can you recall what the circumstances of finding that out were?

A. So after 2014 he was then, you know, he was again monitored every maybe -- he got a PSA test taken every three months or so and for the most part there was -- at least if you were to look at that as a metric of whether he was healthy or sick, those scores were good until 2019 when, you know, it shot up quite 14:12

significantly then and it was sort of springtime of 2019. So he had to go and get various sort of tests and scans and whatever done then and I think it was like around about August 2019, him and my Mum went to Craigavon to meet Mr. O'Brien and it was then when he told them that, you know, he sort of put it like: "There's good news and bad news. The bad news is that the cancer has returned and it's spread to the bone and the lung, but the good news is that the tablet, the treatment that we've been putting you on for the last two months or so has significantly reduced the PSA values down." And so whilst my Mum, or as soon as she heard, like, you know, that it was in the bone, you know, she kind of almost had a breakdown there and then in the hospital room or whatever but it wasn't, you know -- I don't believe they left that meeting with -- well, they didn't leave that meeting with the understanding that it was like this was a terminal condition, that it was now just a matter of how long. It was explained that had it not have been for this PSA coming down, he would have needed chemotherapy immediately and we could be looking at one-and-a-half years of life expectancy. However, because of this positive reaction that we don't need to look at chemo immediately and there's nothing really to be that worried about in terms of immediate, you know, urgency and they were advised to go on holiday, they were booked to go for a month on holiday. He received another hormone, analogue treatment there and then in

14:12 14:13 14:13 14:14 14:14

the hospital, it was delivered, like, through an injection, and that didn't really react very well with him and by the time they came home from hospital, he was in pretty bad shape, actually, because I went back to visit them then and I was very shocked by kind of what I was walking into because, like, I had seen him maybe two or three months previous to that, and the change in that space of time was really quite significant. So, like, do you know it wasn't really -- I know there's a balance to be had between optimism and sort of doom and gloom, you know, you can't just tell somebody that game's over here, but I don't think that the full severity of the situation was properly explained there and, you know, not that it would have changed anything but it might have -- it would have changed how those last few months were spent, you know, and they didn't really talk about the fact that he wasn't going to be here, he was trying to stay positive and saying "I can beat this", but, like, in hindsight, even reading all the material that's there, it was fairly obvious he had no chance of beating this. It was like, it was very sort of ominous, as the text put it in some of those letters.

14:15
14:15
14:15
14:16

78 Q. When did you actually discover then, or did your family discover, or your father, that the cancer was terminal and that he wasn't going to beat it, as you say? How did that come about?

14:16

A. Well, I kind of pieced it together when -- he was checked into Daisy Hill Hospital one time I was at home

and the night before I went back, he just was in really bad shape and we got an ambulance and so he went to Daisy Hill that night and was taken into a ward and the next day, a Consultant Oncologist was there and was able to see him and look at the same data, I presume, 14:17
that was available, you know, from the previous meetings and it was kind of his tone, the language he was using and, you know, "we just got to get your Dad comfortable." He used the word "palliative", which was the first time I heard that. I actually had to Google 14:17
it to make sure my interpretation of what it meant was correct, and even he didn't -- it was almost like he kind of assumed that we knew. You know, it wasn't like he said, you know, your Dad, I am sure, is only -- he never talked about a timeline or "terminal" or anything 14:17
but it was almost like he would have assumed that this was known to me and my Mum, that this is just something we have to manage now; it's not something that you're going to win, to beat.

79 Q. How did you and your Mum and your father feel when you 14:18
discovered this?

A. Well, I mean, to be honest I didn't -- like, I kind of figured it out a little bit but it was almost like because my Dad was still so... I kind of knew in my heart, let's say, but he was still -- because no-one 14:18
had actually told him that, I didn't want to -- I wasn't going to be the person to sort of say, do you know -- like, he was still being as positive as he could. So it wasn't really spoken about, to be honest.

And, you know, it was kind of like always this: "Well, we're seeing this consultant in a week, we're seeing this person then." You know, it was kind of like a week by week sort of a process and, like, in the end it all happened very quickly. But there wasn't really ever a conversation about, like, this is now, this is kind of, you know, that "terminal" thing, which is strange when you sort of say it out loud now but it wasn't. Like I said, it was kind of like, maybe it's something that -- like, I mean, I didn't feel comfortable in bringing that up to him just based on this sort of inference that I had heard from this, if you know what I mean, from this particular doctor. 14:19 14:19

80 Q. Yeah. Well, when were you first told that there was an issue regarding the treatment that your father had received? 14:19

A. It was really as a result of this whole process and the lookback review, you know, throughout -- with the exception of that moment in the Daisy Hill Hospital where I was like why, you know, why is this guy saying one thing and Mr. O'Brien hadn't really spelled this out? There wasn't really any moment along this entire, like, that ten-year span that there was any reason for us to have anything other than complete trust in the care that he was receiving, you know, everything surrounding that. And even after he died, you know, it was -- you kind of just were: 'Well, he was unlucky, you know, and there was nothing that could be done', and whatever, and it was only really when this process 14:20 14:20

came through and in the last few moments when there was, you know, the findings of the investigation that these issues had been presented where, you know, it sort of appears that had different things been done at different times then, you know, we could have had a very different outcome and that's really just in the last few months we've become aware of that.

81 Q. And finding that out, how did you actually find out? What was the method of communication?

A. So there were letters sent throughout the lookback process and I suppose they start with a, like, you know: 'Because your Dad has been in the care of the Trust and Mr. O'Brien in this period, then he's been selected for review.' Then was it in, like, January, December/January of last, like around last Christmas, there was a letter sent to say, well, that the initial filtering process has found some issues and that was a letter with not so much detail but just that it is significant enough to warrant it going to the next stage. So that's when you start to think; 'Oh, okay, what's going on here? And then sort of in the summer time then we got a phone call, there was a phone call or letter to say that, you know, there has been, you know, the review, the findings from the independent urologist have come back and, you know, we can -- so in the end we chose to have a letter sent, first of all, which sort of summarised the findings and then we had a meeting with them and we did it remotely, my Mum was actually with me and we both, like, had a Zoom meeting

with the Trust and explained then the findings in a bit more detail and allowed us to ask questions about it.

82 Q. I think, if I have got this right, it was Dr. O'Kane who wrote to you and set out the findings of the SCRR in her letter? 14:23

A. Yeah.

83 Q. And then you had, as you describe it, the virtual meeting, can you recall who that meeting was with?

A. Yes, it was... well, it was Mr. Haynes, the medical expert, there was Sarah Ward who was our liaison on the 14:23 Trust and then there was a Margaret....

84 Q. Margaret O'Hagan, what that would be right?

A. Yeah, I think. And that was the one and only time I spoke with Margaret so I believe that's who it was, yes. 14:23

85 Q. At that meeting, can you recall what you were told?

A. Yeah. I mean, Mr. Haynes was doing most of the talking and explaining -- so we dived quite deep into the findings from that lookback review in terms of, you know, he explained, you know, like, what in 2009 the 14:23 NICE guidelines were, really, having established it as prostate cancer, really my Dad should have been offered radical treatment, either in the form of radiation therapy or the prostate removal surgery altogether rather than active surveillance. So, you know, we 14:24 spoke a lot about that and, you know, how that really was already in the guidelines and that really should have been what was offered at that time.

He also then spoke about, you know, that, I can't pronounce -- Bical....

86 Q. Bicalutamide?

A. Yes. That that treatment wasn't really appropriate at that time either in 2013, it was the wrong dose and that even then, you know, I think there was, like, you know, there was this thing where, well, we need to get the PSA down under 1 before we can do radiotherapy and that type of thing, which again he didn't agree with things like that. So it was a very informative meeting, I suppose, to ask a lot of questions and to hear I suppose more on the medical side. Margaret did apologise upfront, you know, on behalf of the Trust in terms of, like, you know, for the below standard of care that my Dad received and we didn't, I suppose, dive into too much of, like, the governance around, like, why these decisions, like who was making the decisions, why were they not again these MDM meetings going on and checks and measures and stuff like that. It was more the sort of looking at the lookback review and the findings and giving us a chance to ask some questions around that. 14:24 14:25 14:25 14:26

87 Q. There was some discussion, was there not, though, about when MDMs became operational in the Trust and the Trust undertook to tell you when the MDM team was set up and the meetings happened? 14:26

A. Yeah, we're still waiting to hear on that, when it was. I think Leah might have found out something separately but I haven't been told.

88 Q. You haven't had any communication since that meeting. That meeting, I think, was in August of this year so it wasn't that long ago.

A. Correct.

89 Q. But you haven't as yet had any update from the Trust about that? 14:26

A. We have exchanged a few e-mails on the notes, the notes have been sent over and we have reviewed them. There's one or two little updates to be made and then I also asked today, actually, I asked about the MDM meetings. 14:26 So they're still to come back on that one.

90 Q. And the other thing that they said at that meeting that they would come back to you on is to explain to you what improvements the Trust had made to MDM meetings since all of this came to light, isn't that correct? 14:27

A. Yeah. Funny, yeah, I haven't heard on that either. Maybe was I supposed to follow that? Was I to supposed to ask them that one? I'm not sure. But either way, there hasn't been any sharing of that information either. 14:27

91 Q. Can I just ask you, I mean, because this has all come to light as a result of the lookback review and it is fairly recent information for you and your family, how have you felt to learn that there is an issue with the care that your father received? 14:27

A. Yeah, I mean it's been, you know, I suppose, like, it's -- well, obviously it's difficult to lose someone. You know, for me and my Mum it was a hard time back in 2019. They were very, very close and so it was very

tough for her, you know, even more so. So you're starting to just come to terms with this loss and then it is quite distressing, very distressing whenever this news comes out again and I suppose there's all this information is starting to get dug up and, you know, 14:28
memories are evoked again and wounds that maybe are starting to heal are opened. So it has been a very emotional and distressing time, for my Mum in particular. And then whenever you find out that, like, you know, whenever you read what the findings are and 14:29
you sort of hear how critical they have been and I suppose there's, like, a sense of it could have been avoided and, like, all the pain, especially at the end, the pain that he was in and endured, like, you know, to feel that that could have been prevented, maybe he 14:29
could still be with us today had, you know, just the right checks and measures been in place. That's heart breaking and it's really tough to come to terms with that and, you know, if you dwell too much on it, you would sort of like, you know -- well, you can't dwell 14:29
too much on it because it is, it's so sort of sad. And, you know, I suppose, like, on the back of that, at times you maybe feel angry. You want to sort of maybe -- like, I'm keen to know what went wrong, how did these things happen ,what's been done to make sure 14:30
it doesn't happen again? Was it like a cultural thing or what? Because, like, I mean, even for me, like reading that, you know, last week, one night last week I sat and read all of the pack that you sent, you know,

from start to finish and there was a lot of letters in it back and forth and, like, that was, you know, quite emotional, it's almost like reading a book where you, you know, your Dad is like the main character in it and you kind of -- you know how it ends and you sort of 14:30
just put yourself in his shoes as you go through that. And, like, you know, so that's difficult and it sort of just brings it all back. To me, you know, I didn't know the half of it, I suppose, of what he was going through because he kept so much of it to himself. 14:31
But, like, you sort of -- yeah, so it's tough like that. I mean, at times you kind of feel like a little bit -- like I say, there was so much trust put in it. You sort of read, like, you know, he had this prostate cancer diagnosis and, like, we sort of just took it at 14:31
face value that yeah, well, you don't need to do anything. So you kind of feel a little bit almost like a little bit of guilt and regret as well that you didn't sort of poke him and, you know, sort of question my Dad and sort of, you know, give him a harder time 14:31
about: "Are you sure, like? Should we not research this ourselves or go and ask somebody for another opinion or whatever?" We kind of went along with it. So there's an element of guilt in there as well. And, yeah, I suppose it's just not nice, obviously, I'm 14:32
sure, for anyone in this position. But I think one other thing when I read through that was, like, for me, I would like to know why because, you know, on each of these letters back and forth to various consultants

along the way, it was almost like a summary at the top of each of these letters of what his history was, the key points, and when the cancer returned, it was almost like this amazement of how could this -- shock, how could this clever cancer have come back? You know. 14:33
And there was some conversations my Mum and Dad had with various consultants that they would have talked to, with this sort of language that made them feel quite, I don't know, sort of belittling almost that, you know, these clever consultants have done everything 14:33
they possibly could and yet this thing had outwitted them and it's unlucky, sort of thing. When in fact surely they all knew that by looking, you know, that they themselves were partly culpable here and had they -- you know, there was never a mention of, like, 14:33
maybe we could have done something different or, you know, self-reflection or anything. It was, you know, there was one or two moments towards the end where I would say the lowest points were coming, having met some consultants who kind of spoke to them with that 14:34
sort of language which kind of to this day my Mum still talks about having, you know, left a very sort of negative impression.

So, yeah. So, I don't know, it's almost like, you 14:34
know, there wasn't any sort of culture of looking at what had been done and what they can learn from it and instead it was like, you know, this must be the cleverest cancer ever if it has outwitted us.

CHAIR: Thank you, Patient 35's son. I really appreciate you taking the time to come up and speak to us. I'm going to ask Dr. Swart if she has anything that she would like to ask you, but we do appreciate all that you've told us. 14:34

THE WITNESS: Thank you.

92 Q. DR. SWART: Thank you. Before I ask you anything, I just want to thank you for reminding us about two really important things; one is the guilt that patients and their families often feel with cancer. It's quite 14:35 a complicated thing, but it does underlie this and thank you for reminding us about that. And the other is the need for humility on the part of the medical profession. Patients usual teach us that and it's very, very important because without it, we don't 14:35 learn. So thank you.

I wanted to ask you, there's a big role in cancer treatment in multidisciplinary meetings which you will now be aware of, having read your book. How aware of 14:35 that was the family during your father's treatment? Did people explain the role of that to you?

A. No. The first we became aware of these meetings would have been just through this process when the findings were made. Like, that meeting was with the Trust 14:36 basically in the summer just a couple of months ago.

93 Q. Okay. In the later phases when you describe your father deteriorating and the difficult encounter with the Oncologist at Daisy Hill Hospital, were you given

access to other people to talk to about the course of events other than your actual consultations? Were you put in contact with cancer nurses? I don't mean palliative care but the cancer nurses from the Department and so on?

A. I don't believe so, and when I asked my Mum, she had no recollection of this either. So no-one stands out as somebody who would have sort of fit that description.

94 Q. Then just one last thing about the letter. The letter you got from Maria O'Kane telling you about the results of the review I should imagine was quite a shocking letter to read because it lays out quite clearly what the decision was about what had gone wrong. What do you think could be done to make the communications of those findings a little bit easier for families? Is there anything that you would suggest?

A. Yeah. Well, look, I mean there's no easy way of divulging that information. To be honest, I felt that that piece of it went okay, like, the Trust through Sarah, Sarah had arranged to e-mail or send me through secure mail a copy of this. So I received it before, like, my Mum received it. So, yeah, it was shocking to me but at least then I was kind of able to sort of, like, prepare her for what was going to land on her doorstep in an actual letter. And, indeed, I think she might have been with me by the time it actually arrived. So that bit of it worked out okay. We chose to receive a letter rather than go and walk in sort of to a meeting. Like, you know, I think that way, at

least we had some time in our own sort of environment to process that information and think about what questions we wanted to answer and everything.

95 Q. Did you feel the need to ring the Patient/Client Council or did you have enough support, do you think, in dealing with the contents of that letter? 14:38

A. Yeah, I didn't personally, we didn't ring -- that option was made. We were made aware of that. We didn't feel we needed to, so I can't really comment on that. You know, I think it was helpful that the two of us were together at that time so that we could kind of talk about it and not -- you know, we were still able to sort of say: "Look, you know, we've got this meeting and there's no point in worrying about it until ... Let's just go and have the meeting." And in fairness, in the meeting, I got the feeling that, you know, that the individuals there were not trying to hide or, like, offer any excuses or anything. They were being brutally honest. They gave their own opinion on matters where we asked it. They were critical and, you know, agreed with the findings that were found. They weren't trying to sort of, like, wriggle out of anything, or anything like that. So I don't really have any major issues with how that whole communication side of things has been managed here. 14:39 14:39 14:40

96 Q. And were you a bit shocked about the fact that the MDT decisions weren't particularly tracked and things of that nature? Did that strike you as odd or...?

A. Yeah, I suppose you kind of, like, I don't know, it's

not something I've really thought about before as to how these decisions are made and, you know, it is disappointing now to hear that, like, well, you know, was it the Wild West or was it just like, you know, when the most senior person in the room just gets to make a decision and no-one... There isn't like a culture where people can challenge or have a debate or whatever and I know that's what those meetings were there for; to drive that sort of quality and make sure the right decisions were being made. Obviously, like, they weren't happening for whatever reason -- or either they weren't happening or didn't happen in the case of my Dad at that time. And, you know, I don't think that's a healthy environment where just there's too much responsibility if it's just on one person to make these decisions, it should be experts from different viewpoints are considered. But, like, yeah, I mean that's... 14:40 14:41 14:41

97 Q. The meeting with Mr. Haynes, though, you were reassured, I think, that the Trust was trying to improve matters and had indeed already made improvements; is that the case? 14:41

A. Yeah, well, it sounds as if these meetings are happening now, which is good, or happened even soon after 2009. I guess, you know, the one question I still have is how are they being run effectively and I mean, I have no insight so I don't know. But, yeah, it sounded as if measures had been taken but it's certainly a learning there. Even if the meetings are 14:41

happening, you know, are all the right people there and do they have -- is there an environment where they feel its safe for them to speak their opinion and, you know, challenge a decision or an opinion even if it's that of -- it all boils down to culture, ultimately, and I guess so many people inside of that environment would be able to answer that. 14:42

98 Q. I mean, those are exactly the right questions and observations, you know, in this situation and I'm hopeful, you know, that all the comments we have from the patients and families and so on will be fed back. So it's really useful to hear your perspective, having come to it quite fresh, if you like. We are all used to these terms. So thank you very much. That's all from me. 14:42 14:43

A. Okay.

CHAIR: Mr. Hanbury?

99 Q. MR. HANBURY: Thank you very much, Patient 35's son, it's very striking evidence and a few of my questions have already been answered so thank you for that. 14:43

I'd just like to run over a couple of events in a little bit more detail. Obviously, I appreciate there's a lot history of flank pain. Many clinicians, apart from the urologists, struggle to diagnose that. But when your father came back and had seen Mr. O'Brien after the big kidney operation and had the positive prostate cancer biopsy, I'm not sure if you were with him at the time or did your father recollect having any 14:43

other treatment options given to him apart from just having kept an eye on him? Do you remember that?

A. No, there's certainly not to my knowledge and it wasn't like he came home and spoke about having radiotherapy or having the prostate taken out and, like, I don't think he would have, like, not mentioned that. I mean when it was then mentioned later, five years later, he took it. It wasn't that, you know, if somebody was to tell him there's no need to worry about this or whatever, you know, he would have totally believed them and taken that easy way out, in a sense. But if they had have told him, well, we need to do something and there's these two options, then I believe he would have acted on those. So not to my knowledge was there any talk of any other treatment options at that time. And, indeed, I mean, my Mum spoke to Mr. O'Brien on the phone back there before when she was concerned, like, you know: "Is it okay for us to go on holidays, like a two-week holiday?" And he said: "Yes, not at all, this is not an aggressive cancer. If we did nothing for another year, it'll be fine, nothing to worry about." It was another four or five years before anything of note happened. 14:44 14:44 14:44 14:45

100 Q. Thank you. So just running forward until, I think your father had some "waterworks" trouble that was getting worse at the time which sort of complicated the issue and had a second set of biopsies in 2012. Do you remember how the results were presented to your father then? Was there an opinion whether things were worse 14:45

or better or just the same? Can you remember that?

A. I don't have that information, I'm afraid.

101 Q. Okay.

A. Like from my sort of second-hand, third-hand information, I couldn't say one way or another. 14:46

102 Q. Right. And the same question about other treatment options at the time, I guess that didn't come up, from your recollection?

A. No, not in that timeframe, I would be unable to comment on that, unfortunately. 14:46

103 Q. Okay. Just also at that time, so then I think he started on this Bicalutamide hormone treatment?

A. Mmm.

104 Q. Did he talk to you about that and he was given how it worked, how long it would work and advice about it? 14:46 What information do you recall that he had?

A. Yeah. Honestly, again, I don't really know. He wasn't the type of person -- he wouldn't have spoke to me about these things. He kind of didn't like speaking about himself and these things. You know, I'm sure he 14:47 spoke to my Mum but even she had to, like, really extract the information out of him, sort of a bit "old school" in that sense, typical sort of man and wouldn't sort of speak openly a lot about his own health issues. So I'm sorry, I know what you're getting at; was it 14:47 sort of explained and was there other or what the purpose of this was, even, but I couldn't comment probably accurately on that at the minute.

105 Q. I suppose it's the more general communication issue and

whether I think from our reading, the cancer nurses weren't seemingly involved at that time but he may not have been someone who would have engaged with them or would you have thought otherwise?

A. I think he would have. I mean, yeah, I think if it had have been offered, he would have because, like, he was seeing lots of different doctors and nurses. So, yeah, I mean, if there had have been a person available, I'm sure he would have availed of that. 14:48

106 Q. Thank you, that's interesting. I think again moving forward with the communication issues when, five years later, obviously, there's a few things when things, on paper at least, are relatively well controlled between 2015 and 2018. But then things go wrong that summer and Mr. O'Brien sort of gives your father the bad news, the family bad news then about it having spread. 14:48

I mean, apart from Mr. O'Brien, was there anyone else there to support? Because that really would have been the time that another person in the room might have helped, professionally. 14:49

A. Yeah. Well, I don't think so. My Mum was with him that time. I mean, again I wasn't there so I can't say. I don't believe there was anybody else in the room but, I mean, I could be wrong. But I don't -- like, I spoke to my Mum about this and I don't know. As far as I'm aware, there wasn't. That's not much of answer, sorry. 14:49

MR. HANBURY: You've done brilliantly. Thank you very much.

THE WITNESS: No worries.
CHAIR: Have you any questions, Ms. Treanor?
MS. TREANOR: No, Madam Chair, all the questions have been covered, thank you.
CHAIR: Patient 35's son, thank you very much. We really do appreciate you coming to speak to us today virtually and as I say, we will be taking account of all that you and the other patients and families have told us when it comes to the end of our work and hopefully you will see some of that reflected in what we write in the report. So thank you again. 14:49 14:50
THE WITNESS: Thank you. Thanks for hearing me.
CHAIR: Okay. Ladies and gentlemen, then, our next sitting will be on Thursday when we will be starting at 11:00 a.m. rather than 10:00 a.m. on Thursday morning and we'll hear from one other patient family. Thank you. 14:50

THE HEARING WAS THEN ADJOURNED TO THURSDAY 29TH SEPTEMBER 2022 AT 11:00 A.M.