

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

3
4 CHAIR: Good morning everyone. Welcome back. I hope
5 everyone had a restful summer's break. Just to say 10:09
6 that you have probably noticed that there have been
7 some changes to the chamber in your absence. These are
8 in readiness for our hearings in November which will be
9 live-streamed and we will be trialing out the systems
10 this week. If there are any difficulties, then please 10:09
11 let the Inquiry Secretariat know. We are about to
12 start our second session of private patient family
13 hearings and at the end of the evidence on Thursday,
14 I'll say a little more about what you can expect in
15 November and how we will be time-tabling the Inquiry 10:10
16 from then on.

17
18 If I can just introduce, basically for the benefit of
19 our witness and family who are here today, I'm Chair of
20 the Inquiry, I'm Christine Smith KC, Senior Counsel at 10:10
21 the Bar of Northern Ireland. I have Dr. Sonia Swart
22 who is my co-panelist to my right, and to my left is
23 Mr. Damian Hanbury, who is a urology assessor. We will
24 be doing most of the talking today and asking you
25 questions, Patient 15's son, but before that, can I 10:10
26 also introduce some of the other people who are present
27 in the room. You have probably met Ms. Marshall, our
28 Inquiry Secretary, and we have Ms. Leah Treanor, who is
29 one of the Junior Counsel to the Inquiry, and

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

10:11

8
9 OPENING REMARKS: MS. TREANOR BL

10
11 MS. TREANOR: Yes, Good morning Madam Chair. If I may,
12 I'd like to briefly introduce what will be the
13 second set of patient-focused hearings in this Inquiry,
14 in continuation of the patient hearings which commenced
15 earlier this year in June.

10:11

16
17 Madam Chair, in opening the patient hearings in June,
18 Mr Wolfe KC eloquently set out the relationship between
19 these hearings and the Inquiry's Terms of Reference
20 and, whilst I don't propose to rehearse that, I do
21 think it is important at the outset to call to mind
22 again the wording of paragraph (d) of the Inquiry's
23 Terms of Reference, which asks the Inquiry:

24
25 To afford those patients affected, and/or their
26 immediate families an opportunity to report their
27 experiences to the Inquiry.

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

8
9 To that end, Chair, this week you will hear from the
10 families of 3 patients, who each have valuable evidence
11 to give the Inquiry about their loved ones' experiences
12 of accessing the Southern Trust's Urology Service. By
13 way of overview, before we begin:

14
15 This morning, you will hear from Patient 15's son, the
16 son of Patient 15, sadly deceased. I understand
17 Patient 15's son will be accompanied this morning by
18 his mother, Patient 15's wife. Patient 15 was referred
19 to Urology by his GP on 30 August 2015 for assessment
20 and advice in respect of elevated PSA and that referral
21 was marked ROUTINE. The referral was not triaged upon
22 receipt by the Trust and, at the relevant time, that
23 triage exercise should have been done by Mr. O'Brien.
24 Patient 15's GP then referred him for a second time, on
25 29 January 2016. That second referral was marked RED
26 FLAG, meaning suspected cancer. Following the second
27 referral, Patient 15 was seen in clinic by another
28 Consultant Urologist, Mr. O'Donoghue, and, following
29 further investigations, he was ultimately diagnosed

1 with prostate cancer on 29 February 2016. Patient 15's
2 case was the subject of an SAI review by the Trust,
3 which concluded that the failure to triage had resulted
4 in a 6 month delay in obtaining a diagnosis of prostate
5 cancer (PAT-001101). Whilst Patient 15's treatment for
6 this cancer was ultimately successful in June 2017
7 (PAT-001155), in the questionnaire they have submitted
8 to the Inquiry, Patient 15's family describe the impact
9 of, in their words, 'an additional six months of
10 unnecessary stress' on Patient 15. (PAT-001155)
11
12

13 This afternoon you will hear from the son of Patient
14 35. Patient 35's case was the subject of Structured
15 Clinical Record Review (SCRR), which called into
16 question the appropriateness of his treatment and
17 concluded that he did not receive standard care for
18 localized prostate cancer (PAT-000818). Patient 35 was
19 first referred to Mr. O'Brien in September 2008. On 7
20 December 2009, Patient 35 was diagnosed with prostate
21 cancer. Between December 2009 and March 2013, Patient
22 35 was reviewed a number of times by Mr. O'Brien and,
23 further, his case was discussed at Multi-disciplinary
24 Meetings (MDMs) on 11 November 2010 (PAT-000880) and 20
25 December 2012 (PAT-000895). Throughout that time,
26 Patient 35 was managed by way of 'active surveillance'
27 of his PSA levels. There is no evidence to suggest that
28 Patient 35 was offered any active treatment options,
29 such as radical prostatectomy or radical radiotherapy

1 in that time and this was one of the criticisms of his
2 care raised by the SCRR, which concluded that 'active
3 surveillance would not be standard recommendation for
4 Gleason 7 prostate cancer in a fit man' (PAT-000807). On
5 8 March 2013, Mr. O'Brien commenced Patient 35 on
6 Bicalutamide 50mg and Tamoxifen (PAT-000903). The SCRR
7 outcome suggests that Bicalutamide monotherapy was
8 inappropriate and that low-dose Bicalutamide is not
9 licensed for treatment of patients with localized
10 prostate cancer (PAT-000807). Patient 35 was finally
11 referred for radiotherapy on 5 August 2014
12 (PAT-000915), and began his treatment in November 2014.
13 At (PAT-000807) the SCRR reviewer opines that Patient
14 35 could have been offered radiotherapy as early as
15 2009. Sadly, Patient 35 died with metastatic prostate
16 cancer in December 2019. The SCRR reviewer indicates
17 that 'although radical treatment in 2009 may not have
18 been curative, earlier treatment would likely have
19 improved prognosis. It is very difficult to quantify
20 the extent to which his overall survival was
21 compromised' (PAT-000818). In the minutes of a meeting
22 with the Trust, Patient 35's wife describes her
23 'devastation' at losing her husband then receiving the
24 news that there were issues with his care (PAT-000968).

25
26
27 Finally, Madam Chair, on Thursday morning you will hear
28 from the family of Patient 1. Patient 1 was diagnosed
29 with a Gleason 4 + 3 prostate cancer on 28 August 2019.

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

24
25
26 The care of all 3 of these patients has been subject to
27 either the SAI or SCRR process and, therefore,
28 paragraph (c) of the Inquiry's Terms of Reference is
29 also engaged. Paragraph (c) requires the Inquiry:

1
2 “To examine the clinical aspect of the cases identified
3 by the date of commencement of the Inquiry as meeting
4 the threshold for a Serious Adverse Incident and any
5 further cases which the Inquiry considers appropriate,
6 in order to provide a comprehensive report of findings
7 related to the governance of patient care and after
8 within the Trust's urology specialty.”
9

10
11 In concluding, Chair, it would be remiss of me not to
12 re-emphasise at this point that the focus of paragraph
13 (c) of the Terms of Reference is firmly upon examining
14 the clinical aspects of cases for the dominant purpose
15 of making comprehensive findings relating to governance
16 and patient care and safety.
17

18 As such, whilst the Inquiry is keen to hear from
19 patients and their families about their experiences of
20 urology in the Southern Trust, and will inevitably ask
21 questions about alleged clinical shortcomings in
22 discharging its duty under Term of Reference (c), it is
23 not the role of this Inquiry to make findings about
24 clinical outcomes in individual cases.
25

26 Thank you, Chair, those are my opening remarks.

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

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

5
6 Can I also say that I'm very grateful for you coming to
7 speak to us and tell us about his care in the Southern
8 Trust and I will be asking you and the other witnesses
9 who come to speak to us this week some questions which
10 we hope you'll find easy to answer but if you're unsure 10:19
11 of what I'm asking, please do say so. Please, if you
12 want to take a break, don't be afraid to say that you
13 need a break, we can take whatever breaks you need.

14 This is your opportunity to tell us how and your family
15 feel about the care that your father received and also 10:20
16 about anything you can tell us about how he felt about
17 his treatment. You have received a bundle of papers
18 and that includes the completed questionnaire that you
19 sent to the Inquiry. Can I assure you that myself and
20 my co-panelists here have read all of those papers but 10:20
21 if you do want to refer to any of them, if you could
22 use the number in the top right-hand corner and that
23 way, we can ensure that everyone is looking at the same
24 page and it would also then be possible for us to pull
25 this document up on the screens if you give us the full 10:20
26 number.

27
28 As Ms. Treanor has reminded you, that the Inquiry
29 cannot make any decision about the care that your

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

12 THE WITNESS: Yes, sure.

13
14 PATIENT 15'S SON, HAVING BEEN SWORN, GAVE HIS EVIDENCE
15 TO THE INQUIRY AS FOLLOWS: 10:21

16
17 1 Q. CHAIR: Thank you. Now, Patient 15's son, as we've
18 already heard from Ms. Treanor, your father was
19 referred by his GP in August 2015 and then having heard
20 nothing, he then went back to the GP and got the GP to 10:22
21 contact the Trust again, isn't that correct?

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

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

3 2 Q. would I be right in thinking that that is the main
4 thing that you and the family are concerned about?

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

19 3 Q. So there really was -- that six-month delay did have an
20 impact on you and your father and your family? 10:23

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

25 4 Q. We know that he was then referred back and this time, 10:24
26 the designation on the referral letter was one of red
27 flag and he was seen then and treated by Mr. O'Donoghue
28 in the Trust?

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

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

8 5 Q. One of the things that we noted in the papers was that
9 when he was assigned to Mr. O'Donoghue for treatment,
10 he was also assigned a cancer nurse specialist, is that 10:24
11 correct?

12 A. I believe so, yeah.

13 6 Q. And did the family find that -- did your father, first
14 of all, and did the family find that helpful?

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

16 7 Q. In any event, he received treatment that was in fact
17 successful?

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

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

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

1 time went on, and the delay went on, the treatment went
2 on, the treatment was hard on him. He was a fairly
3 elderly man and the treatment, did it need to be so
4 severe eventually when it came? You know, he was up
5 and down to Belfast every day on the train early in the 10:26
6 morning. It had an impact on him, and my mother as
7 well. But there's such a change in his character. Dad
8 was the life and soul, that's how I would describe him.

9 Q. The diagnosis itself had an affect?

10 A. The diagnosis itself but, again, what I think was 10:26
11 difficult for him was, as time went on, haven't heard
12 anything, we're into another year, and everybody knows
13 the whole thing; the earlier you catch these things,
14 the more successful treatment generally is and he was
15 fully aware of that and I believe, just the silence of 10:27
16 that first six months was very difficult for him, for
17 everybody, waiting, what's going to happen? And I know
18 that he spoke to me whenever the diagnosis came through
19 in January, or February, that he spoke to me basically
20 going, we need to make arrangements now for what 10:27
21 happens next, because this is it.

22 10 Q. He was expecting the worst?

23 A. He absolutely expected the worst. As I said in
24 submissions, whenever the all clear eventually did come
25 through, back to normal, it was like years being lifted 10:27
26 off people, that's exactly what it was. So I remember
27 that well, the day that he came back with the good news
28 and the big grin.

29 11 Q. And as you said, treatment was successful?

1 A. Yeah.

2 12 Q. And he was in reasonable health then for a while?

3 A. Yeah.

4 13 Q. Before, sadly, he died from something unrelated to the
5 cancer? 10:28

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

16 14 Q. Can I come on, Patient 15's son, to ask you a little
17 bit about when you first became aware that there was an
18 issue about how the referral was handled within the
19 Trust?

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

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

11 15 Q. Is that PAT-001132.

12 A. PAT-001132.

13 16 Q. Do you want to maybe call that document up? Perhaps if
14 we can make that a little bit bigger. Sorry, I think
15 that's the wrong number, isn't it? It's PAT-001132. 10:30

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

18
19 "19/05/21 I can confirm that Mr. Haynes has telephoned
20 Patient 15's wife this morning and advised that her 10:30
21 husband was part of the original SIA."
22

23
24 17 Q. If I can just pause you there, Patient 15's son. We're
25 having a little technological difficulty. This is 10:31
26 what this week is designed to iron out so I hope you
27 will bear with us. I'm not quite sure what has
28 happened. There we go, thank you.

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

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

5 18 Q. Can I pause you there? 10:31

6 A. Yeah, sure.

7 19 Q. Was that the first time -- were you told that? Do you
8 recall were you told that at that time?

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

27
28 If SAI was mentioned, it may have been, I don't
29 honestly remember, neither of us can remember those

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

13
14 Then the other thing, still in PAT-001132:

15
16 "26/5/21: Mr. Haynes spoke with family. CLOSE." 10:33
17

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

24 20 Q. That's something that we can ask the Trust about that
25 and ask for clarity around that, Patient 15's son. Can 10:34
26 I just ask, though, it does say that he advised your
27 mother that the review looked at two aspects; what can
28 be done about the process and the Consultant and what
29 impact the delay in referral letters had on the

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

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

8 21 Q. There are a series of letters in the bundle of
9 papers --

10 A. There are. 10:34

11 22 Q. -- that you have received and you might just...

12 A. Starting at PAT-001136, I think.

13 23 Q. Can you just call that up, 1136. Again it's addressed
14 to your father at that stage and it seems to be dated
15 19th February 2018? 10:35

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

22 24 Q. On the screen at the moment, you'll see the e-mails but
23 the first letter is signed by Mrs. Esther Gishkori.
24 Can I ask did your father ever receive that letter, to
25 the best of your knowledge? 10:35

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

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

13 25 Q. Then if I can just move on to the next one, which is
14 PAT-001137?

15 A. Yeah. Again that's an identical letter and it's dated 10:36
16 1st November 2018. This is where the question of
17 confusing comes in because again, if we go become to
18 PAT-001216.

19 26 Q. This is an e-mail, an internal e-mail chain within the
20 Southern Trust? 10:37

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

23 27 Q. If you just scroll down, please, and you'll see that
24 there are a number of patients referred to.

25 A. Yeah. 10:37

26 28 Q. And then we have highlighted your father's name there.

27 A. Yeah. It clearly states:
28
29 "This is the only urology patient that hasn't been

1 advised of the SAI."

2

3 And this is 2018.

4 29 Q. That's the 2nd November 2018?

5 A. Yeah. So that PAT-001137 is dated 1st November so we're 10:37

6 assuming that that's the letter that was sent for your

7 approval, as is mentioned in PAT-001217 there.

8 30 Q. Can I just ask you, though, did your mother or did any

9 of you ever remember that letter being received?

10 A. No. 10:38

11 31 Q. And again, it wasn't filed by your father?

12 A. No, and it's two identical letters, one is signed, one

13 is not. I don't know whether the fact that there's no

14 reference number on them, if that's relevant or if

15 that's normal, but we're not aware of that letter. 10:38

16 Even in my notes, I have red dots on these four letters

17 here.

18 32 Q. Then I think there's another draft, certainly a draft

19 letter at PAT-001138?

20 A. Yes. And again this one talks about a lookback 10:38

21 exercise, which presumably is different to an SAI, but

22 again, we're not aware of this letter. Now that letter

23 was dated the day before my father died. So whether

24 something arrived and it was missed in the few weeks

25 after my father's death, I don't know. 10:38

26 33 Q. Certainly, what we have been given is not signed by

27 anyone, which would suggest that it's a draft, and

28 again there's no reference on it.

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

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

5 34 Q. Mm-hmm.

10:39

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

10
11 "Firstly, I want to apologise if the phone call you
12 received from the Trust caused you some distress or
13 confusion. That was not my intention."

10:39

14
15 How did he know? Where did he get this information
16 from? We were only spoke to by Mr. Haynes once. We
17 didn't speak to anybody else to let them know that it
18 had caused distress. Mainly, whenever the Irish news
19 published the article, my mother wasn't in great shape
20 for a couple of weeks after that but.....

10:39

21 35 Q. But you hadn't actually contacted the Trust after that
22 Irish News?

10:40

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

10:40

1 the background to it, where the information that
2 Mr. O'Donoghue is working from there is coming from and
3 an offer to discuss. As my mother said to me, if for a
4 second she thought at this stage, you know, she could
5 have talked to somebody or we could have talked to 10:41
6 somebody, the offer would have been accepted,
7 definitely.

8 36 Q. So you don't believe that letter was ever received?
9 A. No. A hundred percent, that's addressed to my mother
10 I'm a hundred percent that that letter was never 10:41
11 received.

12 37 Q. Is it fair to say that most of the communication and
13 documentation that you received came, in fact, from the
14 Inquiry to the family?

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

19 38 Q. Thank you very much, Patient 15's son. Is there
20 anything else that you would wish to say at this stage 10:41
21 or wish the Inquiry to know, either about your father
22 or about his care?

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

1 the evidence and you read the media articles, which
2 seem to be reasonably accurate, you're going; 'It's not
3 a mistake and we can't ignore it.' The fact that, you
4 know, we don't see any one individual, there is
5 certainly plenty of individuals who have caused 10:42
6 problems but we don't -- we see it as a collective, if
7 there's a failure to triage and then there's a failure
8 to address the failure to triage and it goes back 25
9 years, I mean, if you or I, we were talking about,
10 anybody in a normal profession was in that position 10:42
11 where they were challenged multiple times, something
12 would be done. But even excluding individuals, the
13 Trust has a duty of care, everyone knows that, the
14 Trust has a duty of care and the Trust needs to be
15 grown up and deal with its problems and it hasn't done 10:43
16 that. And we're just obviously one of many and God
17 knows how far back it goes. We understand, too, that
18 you know, the medical profession, and I'm sure it's a
19 thankless task at times, and there are many people
20 doing wonderful jobs every day, you know, certainly 10:43
21 with my father, the same, you know, very thankful, but,
22 again, it's kind of like football, you're only as good
23 as your last win and whenever you see, you know, if a
24 thousand patients are successfully cured and then a
25 handful are missed because of any sort of action or 10:43
26 whatever way you want to describe it, it's not
27 acceptable. I understand there's pressures on every
28 part of the NHS at the minute, financially and all
29 that, but we still need to find ways to do the

1 important things, unfortunately. So...

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

4 39 Q. DR. SWART: Thank you very much for sharing your story,
5 it is so important that we hear about how it has made 10:44
6 you feel and your family feel and your father feel.
7 I think you have described quite well the impact of the
8 six-month delay and the anxiety that caused. Clearly,
9 there's been some communication, significant
10 communication issues around the Serious Adverse 10:44
11 Incident.

12 A. Yeah.

13 40 Q. If you'd had the offer, would you have been happy as a
14 family to come in and contribute to the Terms of
15 Reference of such an investigation? Did you know about 10:44
16 serious incidents about this or did anybody ask you
17 what you'd like it to find out, for example?

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

19 41 Q. Yeah.

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

23 42 Q. And how did you feel about the fact that nobody
24 explained that to you and the sort of confusion around
25 it? 10:45

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

28 43 Q. Mm-hmm.

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

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

10:45

7 44 Q. If you had the opportunity to talk to the Trust Board
8 today and they said, you know: "Patient 15's son, can
9 you give us one piece of advice about the serious
10 incident process in relation to families?", what would
11 that advice be?

10:46

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

10:46

10:46

10:47

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

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

4 CHAIR: Mr. Hanbury.

5 45 Q. MR. HANBURY: Thank you very much for your compelling 10:47
6 evidence. There's just a couple of things I'd quite
7 like to sort of dig a bit deeper. When your father
8 went to see the GP with his symptoms and this high PSA,
9 was your recollection that the GP told him why he was
10 worried and why he was referring? 10:47

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

14 46 Q. Yeah. But did the GP sort of vocalise the possible 10:48
15 significance of that?

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

17 47 Q. Correct, yeah.

18 A. Yes, I believe so.

19 48 Q. Yes. Which obviously made that six months that much
20 more...(interjection) 10:48

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

24 49 Q. And then there was no communication at all in that
25 six-month period? 10:48

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

28 50 Q. Thank you. And just to pick up on Ms. Smith's comment
29 about when you met Mr. O'Donoghue and got the bad news,

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

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

6 CHAIR: Of course.

7 PATIENT 15'S WIFE: Yes, everything was helpful. We
8 didn't want to contact the cancer nurse because Patient
9 15 wanted to leave it but the treatment that he got
10 from Mr. O'Donoghue we were very happy with, and with 10:49
11 the cancer centre in Belfast.

12 51 Q. MR. HANBURY: Okay. So that's very helpful to hear the
13 offer was there. Thank you. The Inquiry is quite
14 interested in the role of hormone treatment, we have
15 not heard a lot about it, but the hormone injections 10:49
16 that your father was on for that, for about three
17 years, I think, wasn't it?

18 A. Yeah.

19 52 Q. Did he complain of any particular side effects? Was
20 that a thing or -- again, this has not come through in 10:49
21 the....

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

25 53 Q. Did he have sort of backup for that? I guess that 10:50
26 might have been a role for cancer nurses but he just
27 bottled it, did he?

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

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

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

6 54 Q. But in terms of organising the injections and things,
7 that all happened automatically?

8 A. Yeah.

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

11 55 Q. Okay.

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

13 56 Q. With the general practitioner?

14 PATIENT 15' S WIFE: Yes.

15 57 Q. Okay. Thank you. There's just one last thing. In 10:51
16 fact, when he went through surgery and then the
17 radiotherapy and then in that, you elegantly say a
18 weight was listed off his shoulders. You saw a
19 difference in his personality once the PSA went down
20 and this kind of thing? 10:51

21 A. Yes.

22 58 Q. Just tell us a bit more about his mood?

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

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

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

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

11 59 Q. The point I am making is that we see from some of the
12 oncology letters his PSA went right down, it is hardly
13 recordable, this is 2020, just a few months before he
14 passed away. In that last year or so, I think he was
15 off hormones? Do you remember that? 10:52

16 PATIENT 15' S WIFE: Yes, he was.

17 60 Q. And did you see an improvement to his?

18 PATIENT 15' S WIFE: Yes.

19 61 Q. That was --

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

21 62 Q. It was obviously very helpful to get him off the
22 hormones then.

23 PATIENT 15' S WIFE: Yeah.

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

26 CHAIR: Ms. Treanor, do you have anything?

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

29 THE WITNESS: Sure.

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

- 63 Q. MS. TREANOR: If I have understood your evidence today 10:53
correctly, you said that the only contact you had from
the Trust was the telephone call of the 19th May 2021,
is that right?
- A. That's correct.
- 64 Q. And that telephone call was from Mr. Haynes, is that 10:53
right?
- A. That's right, yes.
- 65 Q. In answer to the Chair, you had said that the phone 10:53
call wasn't particularly long, that it was short. Do
you recall how long it was?
- 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 10:54
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

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

6 67 Q. Okay. So you had no further contact from the Trust
7 after that call?

8 A. No.

9 68 Q. And were you ever invited to a meeting?

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

12 69 Q. Okay. And my last question: Have you ever, to date,
13 been provided with that SAI report by the Trust?

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

16 70 Q. So that was first provided to you by this?

17 A. Yes, by the Inquiry.

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

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

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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.

1 THE INQUIRY RESUMED AS FOLLOWS:

2
3 PATIENT 35'S SON GAVE HIS EVIDENCE TO THE INQUIRY AS
4 FOLLOWS:

5
6 CHAIR: Good afternoon, everyone. This afternoon's
7 witness, as you can all probably see, is coming to us
8 remotely, which is a big test of our remote system.
9 I think we've lost him. Oh, there he is again! Hello,
10 Patient 35's son, how are you? 13:45

11 THE WITNESS: Hello there. Pleased to meet you. 14:02

12 CHAIR: Can you hear everything okay?

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

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

19 THE WITNESS: Yeah. Thank you very much.

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

28
29 This is the opportunity to tell us what you want the

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

13
14 I also just wanted to remind you that the Inquiry is
15 not in a position to make any decision about the 14:03
16 standard of clinical care that your father received,
17 that is whether that treatment was appropriate or
18 otherwise, that is really for others to look at, both
19 in the Trust and in the GMC who are looking at the
20 standard of care received by patients in the trust. 14:03
21 Then when I have asked you some questions, I will hand
22 over to my colleagues, Dr. Swart, who is my co-panelist
23 here to my right-hand side, or Mr. Hanbury, who is to
24 my left-hand side. I'm not sure if you're able to see
25 them on your screen at the moment but you will see them 14:04
26 in due course. Then I will also ask Ms. Treanor, who
27 I believe you have met virtually, if she has anything
28 to ask at the end.

29 THE WITNESS: okay, that's clear.

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

7 A. Yeah.

8 71 Q. And he was then treated between 2009 and 2013 by
9 Mr. O'Brien?

10 A. Mm-hmm. 14:05

11 72 Q. And the treatment that he received during that time was
12 one of what we now come to know is called active
13 surveillance?

14 A. Yes.

15 73 Q. So basically keeping an eye on things during that time, 14:05
16 and then ultimately in 2014 he received radiotherapy?

17 A. Correct.

18 74 Q. And then, sadly, he died in 2019.

19 A. Yes, that's right.

20 75 Q. Now can you just tell us about the treatment that your 14:05
21 father received during those years and the effect that
22 it had on him?

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

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

12
13 I think, you know, that's debatable whether that was
14 the right thing to do then but certainly that didn't
15 alleviate the pain and, in fact, it magnified the pain 14:07
16 for Dad, really, from that point forward. Really,
17 like, by an order of magnitude that the pain was
18 increased immediately after that operation and,
19 you know, there was various theories as to what was
20 causing it, nerve damage or whatever, that happened in 14:07
21 there. But that really, like, slowed him down
22 significantly then from that point forward and,
23 you know, he spent, like, really from that point until
24 he died, you know, in pain trying to
25 manage that with whatever, all sorts of medication and 14:08
26 different types of painkillers and, you know, he was
27 always in and out of pain clinics and so on.

28
29 So that was kind of like, you know, one issue that came

1 out of that, that operation, and obviously the other
2 output from that was that, like, the diagnosis on the
3 cancer, so it was established then at that point that
4 he had prostate cancer. And, yeah, I mean, you're
5 right, like, nothing really happened then, you know. 14:08
6 Like, I spoke to my mom and it was sort of explained at
7 the time that this is non-aggressive and that we have,
8 we don't really need to do anything immediate here with
9 this, this cancer. And so, you know, "we'll keep an
10 eye on it", basically and, sort of like, you know, once 14:09
11 you're reading all this back now, maybe it's like a
12 moment where I wish that you could go back in time and
13 sort of, like, you know, sort of -- but I suppose
14 throughout this entire process like, you know, there
15 was no reason for us -- there was complete trust on the 14:09
16 part of my Dad and the rest of us that, do you know
17 everything, the advice, everything he was getting was
18 -- well, there was no reason to doubt it. And actually
19 at that time as well, you know, really, the pain that
20 he was now experiencing in his side was actually the 14:09
21 thing that was most prominent and the thing then, it
22 was almost taking his primary focus, if you know what I
23 mean, you know. He was told that the cancer piece,
24 "you don't need to worry about that, we'll keep an eye
25 on things, it's fine." But it was the pain that was 14:09
26 causing him such trouble day in day out that, you
27 know, that kind of distracted, I suppose, as well, him
28 and my Mum's attention away from that other piece.
29 76 Q. He received radiotherapy in 2014, that was some five

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

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

13
14 Even then, I'm not quite sure why, but it took until,
15 like -- so this was 2013 when these things were 14:11
16 observed and then it was, like, he finished the
17 radiotherapy treatment on Christmas Eve 2014, it still
18 took another almost two years for that to work its way
19 through, you know, the process and for him to receive
20 that treatment. 14:11

21 77 Q. You subsequently discovered that your father's cancer
22 was terminal. Can you recall what the circumstances of
23 finding that out were?

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

1 significantly then and it was sort of springtime of
2 2019. So he had to go and get various sort of tests
3 and scans and whatever done then and I think it was
4 like around about August 2019, him and my Mum went to
5 Craigavon to meet Mr. O'Brien and it was then when he 14:12
6 told them that, you know, he sort of put it like:
7 "There's good news and bad news. The bad news is that
8 the cancer has returned and it's spread to the bone and
9 the lung, but the good news is that the tablet, the
10 treatment that we've been putting you on for the last 14:13
11 two months or so has significantly reduced the PSA
12 values down." And so whilst my Mum, or as soon as she
13 heard, like, you know, that it was in the bone, you
14 know, she kind of almost had a breakdown there and then
15 in the hospital room or whatever but it wasn't, you 14:13
16 know -- I don't believe they left that meeting with --
17 well, they didn't leave that meeting with the
18 understanding that it was like this was a terminal
19 condition, that it was now just a matter of how long.
20 It was explained that had it not have been for this PSA 14:14
21 coming down, he would have needed chemotherapy
22 immediately and we could be looking at one-and-a-half
23 years of life expectancy. However, because of this
24 positive reaction that we don't need to look at chemo
25 immediately and there's nothing really to be that 14:14
26 worried about in terms of immediate, you know, urgency
27 and they were advised to go on holiday, they were
28 booked to go for a month on holiday. He received
29 another hormone, analogue treatment there and then in

1 the hospital, it was delivered, like, through an
2 injection, and that didn't really react very well with
3 him and by the time they came home from hospital, he
4 was in pretty bad shape, actually, because I went back
5 to visit them then and I was very shocked by kind of 14:15
6 what I was walking into because, like, I had seen him
7 maybe two or three months previous to that, and the
8 change in that space of time was really quite
9 significant. So, like, do you know it wasn't really --
10 I know there's a balance to be had between optimism and 14:15
11 sort of doom and gloom, you know, you can't just tell
12 somebody that game's over here, but I don't think that
13 the full severity of the situation was properly
14 explained there and, you know, not that it would have
15 changed anything but it might have -- it would have 14:15
16 changed how those last few months were spent, you know,
17 and they didn't really talk about the fact that he
18 wasn't going to be here, he was trying to stay positive
19 and saying "I can beat this", but, like, in hindsight,
20 even reading all the material that's there, it was 14:16
21 fairly obvious he had no chance of beating this. It
22 was like, it was very sort of ominous, as the text put
23 it in some of those letters.

24 78 Q. When did you actually discover then, or did your family
25 discover, or your father, that the cancer was terminal 14:16
26 and that he wasn't going to beat it, as you say? How
27 did that come about?

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

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

20 79 Q. How did you and your Mum and your father feel when you 14:18
21 discovered this?

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

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

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

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

1 came through and in the last few moments when there
2 was, you know, the findings of the investigation that
3 these issues had been presented where, you know, it
4 sort of appears that had different things been done at
5 different times then, you know, we could have had a 14:21
6 very different outcome and that's really just in the
7 last few months we've become aware of that.

8 81 Q. And finding that out, how did you actually find out?
9 What was the method of communication?

10 A. So there were letters sent throughout the lookback 14:21
11 process and I suppose they start with a, like, you
12 know: 'Because your Dad has been in the care of the
13 Trust and Mr. O'Brien in this period, then he's been
14 selected for review.' Then was it in, like, January,
15 December/January of last, like around last Christmas, 14:21
16 there was a letter sent to say, well, that the initial
17 filtering process has found some issues and that was a
18 letter with not so much detail but just that it is
19 significant enough to warrant it going to the next
20 stage. So that's when you start to think; 'Oh, okay, 14:21
21 what's going on here? And then sort of in the summer
22 time then we got a phone call, there was a phone call
23 or letter to say that, you know, there has been, you
24 know, the review, the findings from the independent
25 urologist have come back and, you know, we can -- so in 14:22
26 the end we chose to have a letter sent, first of all,
27 which sort of summarised the findings and then we had a
28 meeting with them and we did it remotely, my Mum was
29 actually with me and we both, like, had a Zoom meeting

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

3 82 Q. I think, if I have got this right, it was Dr. O'Kane
4 who wrote to you and set out the findings of the SCRR
5 in her letter? 14:23

6 A. Yeah.

7 83 Q. And then you had, as you describe it, the virtual
8 meeting, can you recall who that meeting was with?

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

12 84 Q. Margaret O'Hagan, what that would be right?

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

16 85 Q. At that meeting, can you recall what you were told?

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

29

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

3 86 Q. Bicalutamide?

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

23 87 Q. There was some discussion, was there not, though, about
24 when MDMs became operational in the Trust and the Trust
25 undertook to tell you when the MDM team was set up and 14:26
26 the meetings happened?

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

1 88 Q. You haven't had any communication since that meeting.
2 That meeting, I think, was in August of this year so it
3 wasn't that long ago.

4 A. Correct.

5 89 Q. But you haven't as yet had any update from the Trust 14:26
6 about that?

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

12 90 Q. And the other thing that they said at that meeting that
13 they would come back to you on is to explain to you
14 what improvements the Trust had made to MDM meetings
15 since all of this came to light, isn't that correct? 14:27

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

21 91 Q. Can I just ask you, I mean, because this has all come
22 to light as a result of the lookback review and it is
23 fairly recent information for you and your family, how
24 have you felt to learn that there is an issue with the
25 care that your father received? 14:27

26 A. Yeah, I mean it's been, you know, I suppose, like,
27 it's -- well, obviously it's difficult to lose someone.
28 You know, for me and my Mum it was a hard time back in
29 2019. They were very, very close and so it was very

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

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

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

24
25 So, yeah. So, I don't know, it's almost like, you 14:34
26 know, there wasn't any sort of culture of looking at
27 what had been done and what they can learn from it and
28 instead it was like, you know, this must be the
29 cleverest cancer ever if it has outwitted us.

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

6 THE WITNESS: Thank you.

7 92 Q. DR. SWART: Thank you. Before I ask you anything,
8 I just want to thank you for reminding us about two
9 really important things; one is the guilt that patients
10 and their families often feel with cancer. It's quite 14:35
11 a complicated thing, but it does underlie this and
12 thank you for reminding us about that. And the other
13 is the need for humility on the part of the medical
14 profession. Patients usually teach us that and it's
15 very, very important because without it, we don't 14:35
16 learn. So thank you.

17

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

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

27 93 Q. Okay. In the later phases when you describe your
28 father deteriorating and the difficult encounter with
29 the oncologist at Daisy Hill Hospital, were you given

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

14:36

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

9 94 Q. Then just one last thing about the letter. The letter
10 you got from Maria O'Kane telling you about the results
11 of the review I should imagine was quite a shocking
12 letter to read because it lays out quite clearly what
13 the decision was about what had gone wrong. What do
14 you think could be done to make the communications of
15 those findings a little bit easier for families? Is
16 there anything that you would suggest?

14:36

14:37

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

14:37

14:38

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

4 95 Q. Did you feel the need to ring the Patient/Client
5 Council or did you have enough support, do you think, 14:38
6 in dealing with the contents of that letter?

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

26 96 Q. And were you a bit shocked about the fact that the MDT
27 decisions weren't particularly tracked and things of
28 that nature? Did that strike you as odd or...?

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

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

19 97 Q. The meeting with Mr. Haynes, though, you were
20 reassured, I think, that the Trust was trying to 14:41
21 improve matters and had indeed already made
22 improvements; is that the case?

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

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

8 98 Q. I mean, those are exactly the right questions and
9 observations, you know, in this situation and I'm
10 hopeful, you know, that all the comments we have from 14:42
11 the patients and families and so on will be fed back.
12 So it's really useful to hear your perspective, having
13 come to it quite fresh, if you like. We are all used
14 to these terms. So thank you very much. That's all
15 from me. 14:43

16 A. Okay.

17 CHAIR: Mr. Hanbury?

18 99 Q. MR. HANBURY: Thank you very much, Patient 35's son,
19 it's very striking evidence and a few of my questions
20 have already been answered so thank you for that. 14:43

21
22 I'd just like to run over a couple of events in a
23 little bit more detail. Obviously, I appreciate
24 there's a lot history of flank pain. Many clinicians,
25 apart from the urologists, struggle to diagnose that. 14:43
26 But when your father came back and had seen Mr. O'Brien
27 after the big kidney operation and had the positive
28 prostate cancer biopsy, I'm not sure if you were with
29 him at the time or did your father recollect having any

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

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

24 100 Q. Thank you. So just running forward until, I think your
25 father had some "waterworks" trouble that was getting 14:45
26 worse at the time which sort of complicated the issue
27 and had a second set of biopsies in 2012. Do you
28 remember how the results were presented to your father
29 then? Was there an opinion whether things were worse

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

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

3 101 Q. Okay.

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

6 102 Q. Right. And the same question about other treatment
7 options at the time, I guess that didn't come up, from
8 your recollection?

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

11 103 Q. Okay. Just also at that time, so then I think he
12 started on this Bicalutamide hormone treatment?

13 A. Mmm.

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

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

29 105 Q. I suppose it's the more general communication issue and

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

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

10 106 Q. Thank you, that's interesting. I think again moving 14:48
11 forward with the communication issues when, five years
12 later, obviously, there's a few things when things, on
13 paper at least, are relatively well controlled between
14 2015 and 2018. But then things go wrong that summer
15 and Mr. O'Brien sort of gives your father the bad news, 14:48
16 the family bad news then about it having spread.
17 I mean, apart from Mr. O'Brien, was there anyone else
18 there to support? Because that really would have been
19 the time that another person in the room might have
20 helped, professionally. 14:49

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

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

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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.