

Thursday, 10 June 2021

(10.00 am)

SIR BRIAN LANGSTAFF: Now I think you may have been saying something there, Simon.

MR HAMILTON: Good morning, Sir Brian.

SIR BRIAN LANGSTAFF: Good morning.

MR HAMILTON: Yes, I was just having a chat with the technician.

SIR BRIAN LANGSTAFF: So you're at home, are you?

MR HAMILTON: I'm not, no, I'm out in our business office.

The company very kindly gave me access here to our boardroom because we have a particularly good signal and I didn't want to risk the quality of what we were going to be doing by working from home, as it were, because I live quite rurally and we have an agricultural connection in terms of our technology.

SIR BRIAN LANGSTAFF: Understood.

MR HAMILTON: Thank you.

SIR BRIAN LANGSTAFF: You're joined this morning by Lynne Kelly and Bill Wright, if you'd come forward please.

Now you need no introduction to each other, I think. But let me just tell you, Simon, you're talking to what is for us a full house. I'd say for us, in the present circumstances.

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circumstances of a panel. If you find that you don't agree and want to say something, this is the forum to say it. We do want to understand the differences between the different constituent parts of the United Kingdom insofar as they are important to us.

Questions by MS FRASER BUTLIN

MS FRASER BUTLIN: Simon, before I start, can I make sure you can see and hear me?

MR HAMILTON: I can, yes, thank you.

MS FRASER BUTLIN: I'm not sure when I look at you whether you feel I am looking at you or not because of the way my screens are set up but please don't think I'm being rude if it looks like I'm looking away from you.

MR HAMILTON: No, no, I totally accept that, thank you.

MS FRASER BUTLIN: Before we start with the evidence, sir, I do need to highlight that it's inevitable that some criticisms are likely to be made by these witnesses of various individuals and organisations. As we said yesterday, through no fault of their own, several of those people may not have had the opportunity to respond to those criticisms, as yet. But as and when responses are received, they will be published on the website. In some circumstances we do have a response, and I'll note those as we go, but no inferences should be drawn from a lack of response.

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MR HAMILTON: Yes.

SIR BRIAN LANGSTAFF: But beyond this room there will be quite a lot of the people watching today. We are expecting 200 or 300 at least from the various constituent parts of the United Kingdom.

MR HAMILTON: Yes.

SIR BRIAN LANGSTAFF: So that's who you're talking to.

MR HAMILTON: Thank you.

SIR BRIAN LANGSTAFF: Now we'll take the -- administer the oath. You first, Simon. Mary will administer that in a moment. Mary, please.

SIMON HAMILTON, affirmed

LYNNE KELLY, sworn

WILLIAM WRIGHT, affirmed

SIR BRIAN LANGSTAFF: Let me just check that you have a screen in front of you. Can you see Simon in that screen? You can. Good. Then that part of it is working. Can I just mention now, for later, that you are a panel. If you are to have discussions between yourselves, they should be in public, so the usual -- today, that is. Afterwards, you can talk as much as you wish in private. So during breaks if you please, don't talk about the evidence that you've been giving and that which you might be asked to give.

It's the usual rule for everyone adjusted for

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SIR BRIAN LANGSTAFF: Thank you.

MS FRASER BUTLIN: Simon, if I can start with you. You've been the chair of Haemophilia Northern Ireland since it was founded in December 2017.

MR HAMILTON: Yes, that's correct.

MS FRASER BUTLIN: There was previously a Northern Irish group of The Haemophilia Society.

MR HAMILTON: Yes.

MS FRASER BUTLIN: Can you tell us why Haemophilia Northern Ireland was formed?

MR HAMILTON: Yes. As far as I understand there has always been a local branch of the UK Society. Due to a period of inactivity and, therefore, a sense that there was a lack of representation, it was felt that, in light of the model, if you like, that was in Scotland and Wales, that it was perhaps time that a local charity in its own standing would be formed, replicating what was being carried out elsewhere. And the desire to better advocate for people in Northern Ireland who were suffering from blood issues, we felt that it would be useful to form a society because there had been a period of inactivity, fundamentally, and, as a consequence of that, we felt that representation could best be served by a local group, a local group setting itself up as a recognised

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1 charity, a Northern Ireland Haemophilia Society.
 2 **MS FRASER BUTLIN:** Can you tell us what the aims and
 3 objectives of Haemophilia Northern Ireland are?
 4 **MR HAMILTON:** Yes, fundamentally we see ourselves as
 5 advocates and supporters of all haemophiliacs,
 6 bleeding sufferers, von Willebrand's sufferers,
 7 et cetera. We set ourselves up regardless of the
 8 issues relating to the public Inquiry. That wasn't
 9 a driver for us setting ourselves up. Fundamentally
 10 we set ourselves up in order to provide support and
 11 a talking shop somewhere, where counselling guidance,
 12 as it were, signposting could be provided and the
 13 normal charitable activities to support different
 14 groups relating to the bleeding disorders. So young
 15 parents, families, children, young adults, older men,
 16 von Willebrand's sufferers and -- issues relating to
 17 women's bleeding disorders and, in general, to be
 18 a voice in Northern Ireland, because we observed in
 19 other regions that there was an effective voice when
 20 individuals took up, if you like, an indigenous
 21 charitable role, and ran with those objectives.

22 And those were fundamentally our objectives: to
 23 provide support and advocacy for families and
 24 sufferers, the infected and affected, the affected
 25 with this -- with the blood disorder.

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1 a moment but just to confirm that you were certainly
 2 involved prior to the formation?
 3 **MR HAMILTON:** Certainly, I was. Yes, that's correct.
 4 **MS FRASER BUTLIN:** Bill, you've been an active campaigner
 5 in Scotland over a number of years. I know you're not
 6 a fan of the word "campaigner", but if we can use that
 7 term in terms of -- you've had an active involvement
 8 in a lot of the issues in Scotland, starting off in
 9 about 1997, 1998?
 10 **MR WRIGHT:** Yes.
 11 **MS FRASER BUTLIN:** And that was as a member of the
 12 Scottish Haemophilia Groups Forum?
 13 **MR WRIGHT:** Yes, both individually, in terms of writing to
 14 politicians and ministers, but also a bit of a guy in
 15 the background within the Scottish Haemophilia Groups
 16 Forum.
 17 **MS FRASER BUTLIN:** In terms of the Scottish Haemophilia
 18 Groups Forum, that drew on representatives from The
 19 Haemophilia Society local groups in Scotland?
 20 **MR WRIGHT:** That's correct.
 21 **MS FRASER BUTLIN:** Can you tell us in 2010 how the
 22 Scottish management committee of the Scottish
 23 Haemophilia Society came to be established?
 24 **MR WRIGHT:** Well, at that time, the Society had appointed
 25 a very dynamic Scottish officer. Can I name her?

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1 However, because of the timing, we also felt
 2 that it was important to represent issues relating to
 3 the public Inquiry and the infected blood scandal, and
 4 because some of us were obviously in the category of
 5 being recipient -- scheme recipients, we were already
 6 recognised sufferers from the infected blood and
 7 therefore we formed part of that victim group. And
 8 under those circumstances it made total sense that we
 9 would provide a voice for people in Northern Ireland
 10 who wanted us to -- who wanted to channel their views
 11 through us. And as a consequence, then, another
 12 stream of what we try -- have tried to do was to
 13 provide representation and to be an active voice,
 14 advocating for the needs of people who fall under the
 15 infected blood scandal.
 16 **MS FRASER BUTLIN:** You gave evidence when we were in --
 17 when the Inquiry was in Belfast, so your personal
 18 story has been provided to the Inquiry.
 19 **MR HAMILTON:** Yes.
 20 **MS FRASER BUTLIN:** But it's right, isn't it, that you were
 21 involved in campaigning around some of the issues on
 22 financial recompense prior to the formation of
 23 Haemophilia Northern Ireland?
 24 **MR HAMILTON:** Yes, my involvement in --
 25 **MS FRASER BUTLIN:** We'll come to the detail of that in

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1 **MS FRASER BUTLIN:** I believe so. I don't believe she's
 2 anonymised.
 3 **MR WRIGHT:** Susan, who brought a great deal of expertise
 4 and energy to Scotland -- *[Redacted]*
 5 **MS FRASER BUTLIN:** Could we pause the transmission?
 6 **SIR BRIAN LANGSTAFF:** Yes, you might have mentioned this,
 7 actually.
 8 **MS FRASER BUTLIN:** Can I take a moment?
 9 **SIR BRIAN LANGSTAFF:** I think leave those details, leave
 10 those personal details out. Can we just redact that
 11 for a moment, sorry.
 12 **MR WRIGHT:** Sorry, sir.
 13 **SIR BRIAN LANGSTAFF:** It's just protecting -- it's fine to
 14 mention her name.
 15 **MR WRIGHT:** Yeah, okay. Um, Susan was a very dynamic,
 16 very bright, intelligent -- brought a lot of energy.
 17 **MS FRASER BUTLIN:** Just pause a minute. I just want to
 18 make sure that the transmission.
 19 **SIR BRIAN LANGSTAFF:** I think it's on again. We're okay.
 20 Yes.
 21 **MR WRIGHT:** She had experience of bleeding disorders. She
 22 was very bright, energetic, and renewed a lot of the
 23 energy within Scotland, and she kind of got me hooked
 24 in to all of this. I physically had a collapse
 25 following my fourth attempt at interferon treatment in

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1 2007, and my wife was reluctant for me to get involved
 2 at all. However, Susan dragged me along to a couple
 3 of meetings, and that led to a very -- a renewed
 4 involvement in the whole affair.

5 **MS FRASER BUTLIN:** There was a governance review by the UK
 6 Haemophilia Society which resulted in the Scottish
 7 Management Committee being established?

8 **MR WRIGHT:** Yes.

9 **MS FRASER BUTLIN:** In about 2010?

10 **MR WRIGHT:** Yes.

11 **MS FRASER BUTLIN:** And in 2011 you became chair of that
 12 committee, is that right?

13 **MR WRIGHT:** Yes, the committee had struggled because
 14 frankly a lot of people became ill, and I was
 15 approached by the then chair of the UK society to form
 16 a Scottish committee, completely undemocratic, but
 17 I went about that task. Between us, Susan and
 18 I recruited a few people to join that committee. It
 19 was our intention that we -- we made ourselves
 20 democratic. And initially our focus was very much on
 21 the issues that Simon's talking about, about people
 22 with bleeding disorders, families, and so on and so
 23 forth, who -- we actually wanted to highlight the
 24 understanding of bleeding disorders in haemophilia in
 25 Scotland, and we ran some events in the Scottish

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1 the society but just very broadly, can you tell us how
 2 Haemophilia Scotland came to be established?

3 **MR WRIGHT:** Well, in many senses it was the Penrose
 4 Inquiry that led to that, because we reached a point
 5 where, as Lynne might cover, I think you might have
 6 been a trustee at the time in 2012, there were very
 7 understandable calls for a UK inquiry, and we found
 8 ourselves in a position where we were amid a very big
 9 inquiry, one of the biggest inquiries that's taken
 10 place in Scotland, and so our view was that we simply
 11 couldn't engage in that process at that point. And so
 12 we also looked at the terms of the 2005 Inquiries Act,
 13 which I think section 24 talks about, devolved
 14 governments' involvement in UK inquiries, and we took
 15 some advice about this because, politically, we
 16 thought it would be nigh on impossible.

17 Scottish Government was spending £12 million on
 18 its own Inquiry, and we really couldn't see how it
 19 would engage in the way that it needed to, in the way
 20 that it's now engaged in this Inquiry, and actually
 21 act on the recommendations of this Inquiry, when there
 22 may be conflicting recommendations came from
 23 Lord Penrose's Inquiry.

24 So that was really one of the main reasons. But
 25 I've presented a document that -- it was presented

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1 Parliament to that fact.

2 So I -- there was already a sort of steering
 3 group, briefing group for Thompsons Solicitors, who
 4 had been drawn from campaigners across Scotland, and
 5 therefore at that point we weren't particularly
 6 involved in the Penrose Inquiry. I, in an individual
 7 capacity, was a Core Participant of that Inquiry quite
 8 actively, but I didn't at that point -- I was --
 9 I thought it was important to allow the steering group
 10 to be the main people briefing the -- Thompsons
 11 Solicitors.

12 **MS FRASER BUTLIN:** We're going to come back to lots of
 13 that detail.

14 **MR WRIGHT:** Of course.

15 **MS FRASER BUTLIN:** If we could just map out your
 16 involvement.

17 **MR WRIGHT:** Yes.

18 **MS FRASER BUTLIN:** 2011, you were chair of the management
 19 committee. And then, in 2012, the -- Haemophilia
 20 Scotland was established as an entirely separate
 21 entity.

22 **MR WRIGHT:** That's correct.

23 **MS FRASER BUTLIN:** My understanding is that, for a long
 24 time, the Scottish part of The Haemophilia Society
 25 had, in reality, been quite separate to the rest of

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1 actually at a meeting of the Scottish Haemophilia
 2 Groups Forum in my own front room in our house, where,
 3 when devolution took place in 1999 in Scotland, one of
 4 the members of that committee at that point said we
 5 need an independent charity in Scotland. And it took
 6 us, in effect, 12, 13 years to go through that process
 7 and finally do it. And, I have to say, when we made
 8 that decision to effectively break away, my wife was
 9 not a happy woman, because we had no money, we had no
 10 staff, we had no constitution, we had no charitable
 11 status. All we had was a hell of a lot of goodwill
 12 from people in Scotland. Bruce gave us his goodwill.
 13 We had the goodwill of the Haemophilia Centres in
 14 Scotland as well and the Scottish Government,
 15 ministers, in effect, welcomed the step we were
 16 taking.

17 So I cannot emphasise enough the importance of
 18 devolution in this whole story, as I hope I'm able to
 19 illustrate as the day goes on, but that -- those
 20 moments when we broke away, we got nothing other than
 21 goodwill and hard work and, later, we hopefully were
 22 able to make an impact.

23 **MS FRASER BUTLIN:** Can you just outline for us the aims
 24 and objectives of Haemophilia Scotland?

25 **MR WRIGHT:** Yes, they're set out in our constitution, in

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1 our governance documents, which are registered with
 2 the office of Scottish Charities Regulator, OSCR. In
 3 summary, they are very similar to Simon's. They
 4 involve providing information, they involve support
 5 for people with bleeding disorders, and they involve
 6 advocacy.

7 **MS FRASER BUTLIN:** I will try and use the term "advocacy"
 8 rather than "campaigning" for you, Bill.

9 Lynne, as I've indicated we've heard evidence
 10 from both Bill and Simon in previous hearings about
 11 their own personal story. Can you tell us a little of
 12 how you came to be involved in campaigning in Wales?

13 **MS KELLY:** Okay. So my involvement started when my first
 14 son was born with haemophilia in 1989. My grandfather
 15 was a haemophiliac and there were three generations of
 16 haemophilia in my family, so I already had four
 17 cousins with haemophilia. I wasn't involved with the
 18 early campaign at that point, but I was involved with
 19 the South Wales Haemophilia Group, and I did mainly
 20 the activities with children, supporting children's
 21 activities and family's needs and mother's meetings
 22 and raising money.

23 But my campaigning started with regard to
 24 recombinant Factor VIII and that was the first time
 25 that I'd contacted MPs and that was when I met Julie

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1 Morgan, who was my MP at the time, at Westminster,
 2 along with other mothers in her constituency and we
 3 were basically looking for non-plasma derived
 4 Factor VIII.

5 So we met Julie and she lobbied on our behalf
 6 and we managed to get recombinant Factor VIII by the
 7 time my third son was born with haemophilia in
 8 1997/98. So that was the start of my campaigning.
 9 But then when devolution came in -- sorry, do you want
 10 me to carry on?

11 **MS FRASER BUTLIN:** Do, yes.

12 **MS KELLY:** When devolution came along in 1999, there had
 13 always been a difficult relationship with The
 14 Haemophilia Society and the South Wales Haemophilia
 15 Group because obviously, as a group, we felt we were
 16 raising money and the money was going up to London but
 17 we weren't seeing any benefit from that money. So
 18 there were various issues regarding fundraising and
 19 around the campaigning, which members of the South
 20 Wales Haemophilia Group, the main campaigners, who
 21 I think I can name as Paul Jenkins, and the Lewis
 22 brothers, but [redacted] but I won't mention anybody
 23 else.

24 **MS FRASER BUTLIN:** Can we pause the transmission?
 25 [Transmission paused]

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1 **MS FRASER BUTLIN:** The final name there needs to be
 2 redacted.

3 **MS KELLY:** Oh, I'm sorry.

4 **MS FRASER BUTLIN:** Are we live, again, sir?

5 **SIR BRIAN LANGSTAFF:** We are.

6 **MS FRASER BUTLIN:** Thank you. You were just saying there
 7 were some difficulties in relation to fundraising and
 8 around the campaigning.

9 **MS KELLY:** Yes. So basically we felt that in Wales we
 10 would do better to start lobbying the Welsh Assembly,
 11 which was established then in 1999, and we held the
 12 first Cross Party Group there in 2001, and that was
 13 led by Plaid Cymru, so we felt from an early start,
 14 then, we had a good relationship with the Welsh
 15 Assembly and many of the Welsh politicians, they got
 16 to know us. So obviously, things carried on with the
 17 campaign, very much from a Welsh perspective, and then
 18 Haemophilia Wales was established as a charity in
 19 2003, and --

20 **MS FRASER BUTLIN:** After 2003, it was subsequently wound
 21 down --

22 **MS KELLY:** Yes.

23 **MS FRASER BUTLIN:** -- because people were unwell and
 24 unable to maintain it?

25 **MS KELLY:** Yes.

15

1 **MS FRASER BUTLIN:** Then I think it's right, isn't it, that
 2 you re-established the group in 2014?

3 **MS KELLY:** Yes, so by 2010, six of our committee members
 4 had died and as a mother with three boys with
 5 haemophilia I felt that I could bridge the gap between
 6 the needs of the newly diagnosed families and the
 7 needs of the infected blood community. But I decided
 8 that it would all be down to me, basically, to do all
 9 of that. So I thought it would be better to apply to
 10 be a trustee of The Haemophilia Society, which I did,
 11 and I was elected. So I joined The Haemophilia
 12 Society in 2011. But I did tender my resignation in
 13 2014, because I just felt completely disillusioned
 14 with the way they were -- they weren't actively
 15 engaging in the campaign and there just was no urgency
 16 to address the very real issues in our community,
 17 particularly in Wales but across the wider UK.

18 **MS FRASER BUTLIN:** Out of that, the Haemophilia Wales was
 19 established?

20 **MS KELLY:** Yes.

21 **MS FRASER BUTLIN:** I should say at that point, sir, we've
 22 had a response from Bernard Manson in relation to some
 23 of the criticisms raised in Lynne's statement about
 24 The Haemophilia Society and it will be on the website
 25 and published in due course.

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1 **SIR BRIAN LANGSTAFF:** Thank you.

2 **MS FRASER BUTLIN:** You've been the chair of Haemophilia

3 Wales since 2014. Can you tell us also what the aims

4 and objectives of Haemophilia Wales are?

5 **MS KELLY:** Okay. So we provide information, support and

6 advocacy to people of all ages with inherited bleeding

7 disorders in Wales, and to some outside of Wales as

8 well. We also campaign and represent transfusion

9 victims, and that has mainly come from our work with

10 the Cross Party Group at the Welsh Assembly, because

11 obviously there were Assembly members in the Welsh

12 Parliament who had constituents who had been affected

13 by contaminated blood but they weren't haemophiliacs.

14 And our meetings at the Welsh Assembly were always

15 quite large and people would come to meetings and

16 basically when all the people got into room together

17 and they started networking, we could see that the

18 issues were the same.

19 So our group just grew and grew, and basically

20 we have a united voice and we represent both

21 haemophiliacs infected with contaminated blood but

22 also transfusion victims, families and bereaved

23 families.

24 **MS FRASER BUTLIN:** You've also been heavily involved in

25 the Cross Party Group on haemophilia and contaminated

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1 anybody can speak out, and they can say -- they can

2 talk about the issues that they would like to be

3 raised, and they feel that it's a safe environment to

4 do that.

5 **MS FRASER BUTLIN:** I want to go back in time to May 1999,

6 Bill, with you, when the Scottish Parliament was

7 formed, and the advocacy work that was done at that

8 stage. One of the first things that was done was that

9 the Scottish Infected Blood Forum submitted a formal

10 petition, PE45.

11 Could we have that on the screen, please,

12 Soumik. It's WITN2287022. Next page, please.

13 We can see there that it's a petition to the

14 Scottish Parliament calling on the Scottish Parliament

15 to:

16 "... hold an independent inquiry into

17 hepatitis C and other infections of people with

18 haemophilia contracted from contaminated blood

19 products in Scotland and to consider providing

20 financial assistance for people with haemophilia

21 affected by HCV similar to that already provided with

22 people with haemophilia infected with HIV."

23 Bill, how did this petition come to be

24 submitted?

25 **MR WRIGHT:** Well, I was heavily involved in this. In my

19

1 blood since 2011.

2 **MS KELLY:** Yes.

3 **MS FRASER BUTLIN:** Who makes up that group?

4 **MS KELLY:** So initially Julie Morgan, who was my MP at

5 Westminster, she became an Assembly member or, as they

6 are now known, members of the Senedd in the Welsh

7 Parliament, in 2010. And, obviously, I met with Julie

8 and -- well, she actually thought it would be a good

9 idea if we had a Cross Party Group and because she

10 knew there was a lot of cross party support for our

11 issues. She understood the concerns, she knew lots of

12 the families anyway.

13 So the Cross Party Group was established. Julie

14 is no longer chair because she was promoted to Deputy

15 Health Minister in 2019. So the chair was Mick

16 Antoniw, but we've just had another election and we're

17 in the process of electing another chair for the

18 group. But basically, heavily involved in that, and

19 our meetings are open to anybody who has been, you

20 know, affected or infected with contaminated blood or,

21 indeed, if they have any issues relating to

22 haemophilia and those issues aren't being resolved

23 through our All-Wales Advisory Group on Inherited

24 Bleeding Disorders, they can bring those issues to our

25 meetings as well. And our meetings are very large,

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1 working life, I worked in the third sector. I worked

2 for an environmental charity that was campaigning for

3 the -- campaigning for the Cairngorms to become

4 a National Park. And within that, I was very involved

5 with an umbrella body called Scottish Environment

6 Link. In fact, a lot of the thinking that went into

7 the whole idea of having a petitions committee within

8 the new Parliament had been -- had come up via the

9 Scottish Civic Forum, which was the body that designed

10 the Scottish Parliament, and Link had been feeding

11 into that idea and seeing what needed to happen.

12 So I was very aware of the opportunity that the

13 petitions committee presented. We'd had complete

14 intransigence within Westminster. We were getting

15 nowhere in London. Philip Dolan, who was -- the late

16 Philip Dolan, who was incredibly energetic, for a man

17 of some age, was travelling up and down to London,

18 something, I have to say, until this Inquiry I have

19 avoided, but he was trying very hard to get some

20 movement. We were writing to MPs and our voice was

21 not being heard.

22 So this petition in many ways was absolutely

23 pivotal to what happened next in Scotland, because

24 there were discussions about what had happened to us.

25 People were dying at that point, already dying. And

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1 people were in very ill health, we were starting to
2 learn that the damage that hepatitis C was causing,
3 and the Scottish Haemophilia Groups Forum at that
4 point -- again, I think it might have been a meeting
5 in my front room -- said, "We need to go there", and
6 you'll see it's PE45. That's one of the earliest
7 petitions to be submitted within the Parliament.

8 I had experience because I was also presenting
9 petitions about the Cairngorms. So we went down this
10 line. It was a real opportunity, the proposal went to
11 the petitions committee. The only real condition on
12 getting that in front of the Petitions Committee, was
13 that we'd already spoken to Scottish Government about
14 the idea of an inquiry. Susan Deacon was then the
15 Health Minister and she was saying no, an absolute no.

16 And so we thought well, we're not giving up on
17 this. Let's take this to the Parliament, and we were
18 welcomed with open arms by that Petitions Committee
19 who then quite correctly passed on the proposal to the
20 Scottish Parliament's Health Committee, and that was
21 extremely significant because we gave evidence to that
22 committee in Parliament, and there were some very
23 significant figures at that time on the Health
24 Committee.

25 **MS FRASER BUTLIN:** We're going to come to the Health

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1 **MS FRASER BUTLIN:** We've got a letter you wrote and if we
2 could put that up on the screen, WITN2287024, page
3 2 -- I'm sorry, it's the next page, Soumik. We can
4 see in the third paragraph that this is your letter to
5 Susan Deacon. You said:

6 "Simply to undertake to publish the findings of
7 a departmental enquiry doesn't give rise to confidence
8 in open government when a departmental enquiry may
9 well involve officials who have in the past been
10 involved in either 'advising' on matters they
11 themselves are being asked to investigate. They are
12 potentially being asked to either criticise themselves
13 or other public servants whom they have worked closely
14 with."

15 Then the bottom of the letter:

16 "Given the potential controversy brewing over
17 this affair, I urge you not to leave this matter in
18 the hands of your department or the Scottish National
19 Blood Transfusion Service to deal with, but to take
20 a hands on approach to ensuring that an investigation
21 is wide ranging, open and thorough."

22 They were your concerns about the internal
23 departmental inquiry?

24 **MR WRIGHT:** That's correct.

25 **MS FRASER BUTLIN:** In her reply, she simply said that

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1 Committee in just a moment, Bill, but just in terms of
2 this petition, this was submitted, a separate petition
3 was submitted by someone else calling for
4 a compensation scheme for those who'd contracted
5 hepatitis C from blood transfusions and the two
6 petitions went forward together, didn't they?

7 **MR WRIGHT:** That's correct.

8 **MS FRASER BUTLIN:** You mentioned a moment ago your
9 interactions with Susan Deacon and whether there
10 should be an independent inquiry. Just prior to these
11 petitions, there had been discussions, hadn't there,
12 between The Haemophilia Society and Susan Deacon about
13 a departmental inquiry?

14 **MR WRIGHT:** Indeed. Can I just point out, you used the
15 word "your". I have never met Susan Deacon, even
16 though I wrote to her asking to meet her. She refused
17 me.

18 **MS FRASER BUTLIN:** These petitions were held while the
19 internal departmental inquiry took place, weren't
20 they?

21 **MR WRIGHT:** Yes.

22 **MS FRASER BUTLIN:** But you had quite considerable concerns
23 about that departmental inquiry, didn't you?

24 **MR WRIGHT:** Well, it was civil servants looking at
25 themselves, marking their own homework.

22

1 those points would be considered, didn't she?

2 **MR WRIGHT:** Yes. I think it's worth bearing in mind that
3 when the Scottish Parliament was formed, and therefore
4 a Scottish Government, there were two dynamics
5 happening. First of all, we had got a fresh new
6 Parliament. The majority of MSPs had never been
7 Parliamentarians before. They were new, enthusiastic,
8 they wanted to get stuck in and, as we'll see in terms
9 of the opposition MSPs at that point, they really got
10 stuck in. But you don't just magic the other part of
11 government, the Civil Service, out of nowhere.
12 Effectively, we still had the same behemoth that was
13 the Scottish Office civil servant who got -- all got
14 similar positions within the new -- it was actually
15 called the Scottish Executive at the time. And that's
16 what I think particularly alarmed us at that time.

17 **MS FRASER BUTLIN:** In the interests of fairness, the
18 response from the Scottish Executive was that they had
19 made clear to you that they would be open to scrutiny
20 conducted in an impartial manner but, from your
21 response, you were not convinced that that would be --

22 **MR WRIGHT:** I contest that.

23 **MS FRASER BUTLIN:** The report of the departmental inquiry
24 was published in October 2000 and we've got a copy of
25 the full report but what I want to take you to is the

24

1 letter that you were sent, which copies across the
2 conclusions and makes some other points that we want
3 to look at as well. It's WITN2287025, please, Soumik.
4 If we pick up at page 3.

5 No, sorry, back one page. Thank you.

6 We can see there the heading "Findings" and
7 these are copied across from the report of the
8 inquiry, the departmental inquiry. The findings were:

9 "the Scottish National Blood Transfusion Service
10 were around 18 months behind the Bio Products
11 Laboratory in England in producing a heat-treated
12 product which was subsequently found to have
13 eliminated the hepatitis C virus;

14 "there were understandable technical reasons why
15 this was the case:

16 "there was no test to identify the presence of
17 the virus, so scientists could not be sure that any
18 particular heat treatment had actually worked until
19 they reviewed the effects of the resultant products on
20 patients;

21 "the heating process could easily render blood
22 products unusable, and different types of heating and
23 freeze-drying processes and equipment had to be tried
24 in order to obtain a usable product;

25 "once SNBTS had managed to develop a suitable

25

1 products, as indeed to all people who have suffered
2 inadvertent harm through medical treatment.

3 "She also notes that the exercise failed to find
4 evidence of any policy by Haemophilia Centre Directors
5 deliberately to mislead patients about the risks of
6 hepatitis. She cannot deal with individual cases
7 where a patient believes he or she was nevertheless
8 misled, although she sympathises with any patient who
9 was unable for whatever reason to appreciate the risks
10 of their treatment."

11 Again, what was your reaction to that part of
12 her letter?

13 **MR WRIGHT:** Oh, god! Can we go back to the previous
14 paragraph, please.

15 **MS FRASER BUTLIN:** The bottom of page 1.

16 **MR WRIGHT:** "... repeat her expressions of sympathy ..."
17 She was bloody patronising.

18 **SIR BRIAN LANGSTAFF:** Take a moment.

19 **MR WRIGHT:** I later found out just what was going on
20 there. She wanted to take us to the courts.

21 Can we go to the next paragraph, please?

22 She didn't want to meet the requests of either
23 PE45 or PE185.

24 Can we deal with this "deliberately" element?
25 I'm here, sir, under oath to speak the truth, but also

27

1 heat-treated product, they were quickly able to
2 produce sufficient for domestic demand;

3 "no evidence of any policy by Haemophilia Centre
4 Directors deliberately to mislead patients about the
5 risks of hepatitis."

6 Bill, what was your reaction to this report?

7 **MR WRIGHT:** Well, I'd had one of these -- these products.

8 As I've given evidence personally, from a single dose,
9 in 1986, I was infected with hepatitis C, leading to
10 four attempts at interferon treatment. It was
11 a pretty pathetic attempt at getting to the truth and
12 certainly the subsequent evidence that's come about
13 through this Inquiry so far, and indeed the Penrose
14 Inquiry, actually shows how wrong they were.

15 **MS FRASER BUTLIN:** Soumik, could we have the letter that
16 went to Bill, WITN2287026.

17 We can see there the bullet points that I've
18 just read from the report, and then the last paragraph
19 on the first page:

20 "The Minister considers it an important general
21 principle that the NHS should not pay compensation for
22 non-negligent harm; she acknowledges that medical
23 treatment often necessarily involves a balance of
24 risks. She would like to repeat her expressions of
25 sympathy to haemophiliacs infected through blood

26

1 the whole truth. Now, in terms of the whole truth
2 that's coming to light during this Inquiry, I'll give
3 an example of what happened to me personally.

4 Christopher Ludlam, who was my consultant --
5 you, sir, are in a better position than I to judge
6 intent, so I don't know about the word "deliberately",
7 however, what I will say is he did not tell me the
8 whole story, when I was infected. It took me until
9 the late 1990s to find out that there'd been an
10 investigation into my infection. He didn't tell me
11 that. So whether it was deliberate or not, he simply
12 didn't -- she uses the term "deliberately". She
13 didn't -- the doctors were not telling us the whole
14 story at that time. She also says:

15 "She cannot deal with individual cases where
16 a patient believes he or she was nevertheless
17 misled ..."

18 No, because she wanted -- as will hopefully come
19 out in evidence, from 15 years later, she wanted to
20 point us at the courts, and fight us there.

21 **MS FRASER BUTLIN:** Let's pick that straight up.

22 If we can have WITN2287029.

23 If we go to page 3, this is a news article that
24 you've exhibited to your statement which is headlined
25 "Records reveal minister unease over blood scandal

28

1 payouts", published in January 2017.

2 And if we go over the page, we can see that the
3 article says this:

4 "The newly-declassified papers from 2001 show
5 the then Scottish Executive feared paying out to
6 £20m to people affected by the scandal."

7 A little further down:

8 "The documents released by the National Records
9 of Scotland under the 15-year rule show ministers
10 feared making payouts to 400 patients who received
11 contaminated blood between the 1970s and 1991 because
12 they thought it would create a precedent for
13 compensation and lead to 'immense future
14 difficulties'.

15 "Susan Deacon, health minister at the time, said
16 defending the claims would mean the Executive would
17 look 'unsympathetic' but said her 'inclination' was
18 for court action because of the wider implications."

19 Bill, that's obviously something that you read
20 about later than the letter from her.

21 **MR WRIGHT:** Yes.

22 **MS FRASER BUTLIN:** But can you tell us at this point:
23 after this October 2000 letter from Susan Deacon, what
24 was the stance taken by the Scottish Executive --

25 **MR WRIGHT:** Sorry, October 2000 and?

29

1 I presented an analysis of that --

2 **MS FRASER BUTLIN:** We're going to come to that.

3 **MR WRIGHT:** Okay. But Malcolm Chisholm -- and it appears
4 that this is really what led to the establishing or
5 was a big influence in the establishment of the
6 Skipton Fund. What we struggled with was what was
7 going on between Westminster and Edinburgh. John Reid
8 was the minister at the time within the UK Government,
9 and I've never really got to the bottom of why
10 Lord Ross's recommendations were not implemented. And
11 in fact, in terms of the Skipton Fund, the amounts
12 were much less, and they were made UK-wide.

13 It's important, I think, that -- my
14 understanding is that the money went to the -- in
15 effect, the Skipton Fund acted as the administrative
16 body for the payments from Scottish Government to
17 those of us who'd been infected in Scotland.

18 So that was a significant factor but
19 nevertheless I've never got to the bottom of what was
20 going on between John Reid and Malcolm Chisholm,
21 between the respective governments at that point.
22 There is some evidence that takes us in that
23 direction, but this Inquiry -- I would really welcome
24 this Inquiry taking us to places I've never been able
25 to get to in terms of Government documentation in that

31

1 **MS FRASER BUTLIN:** October 2000 is the letter from
2 Susan Deacon. From that point until -- for the next
3 few years after that, what was the stance taken by the
4 Scottish Executive towards your requests for an
5 inquiry and recompense?

6 **MR WRIGHT:** Well, between 1999 and a pretty radical change
7 in the political scene in Scotland in 2007, in terms
8 of a different colour of administration, there were
9 three ministers: Susan Deacon, Malcolm Chisholm and
10 Andrew Kerr.

11 We have to acknowledge that Malcolm Chisholm,
12 when he became minister, he did actually try and act
13 on these petitions, and the process that was taking
14 part in the Parliament, by ordering the investigation
15 that was led by Lord Ross, and on which the late
16 Frank Maguire of Thompsons Solicitors and the late
17 Philip Dolan sat on, along with anonymous witness
18 I think it was AA or X or whatever who had been
19 infected. And he reported -- and there was -- we felt
20 there was some really useful stuff in that. And
21 subsequently, ten years later, when I was chair of
22 Haemophilia Scotland, I talked to Dan Farthing, our
23 chief executive -- we had got staff by then -- and
24 said, "Look, it's ten years, this is a good punch
25 point at which to look at what Lord Ross said", and

30

1 respect.

2 **MS FRASER BUTLIN:** Before we get to Malcolm Chisholm's
3 role, just staying with Susan Deacon, you had the
4 letter saying there was not going to be any
5 consideration of financial recompense. You also, in
6 your statement, have recalled observing a debate from
7 the public gallery at some point in 1999 and 2000, and
8 I think this also ties in to your evidence about the
9 issues with the civil service element of Scotland.

10 What do you recall -- what can you tell us about that?

11 **MR WRIGHT:** Well, we're introducing a key figure in
12 Scotland into the story.

13 Can I name them?

14 **MS FRASER BUTLIN:** I don't believe she's --

15 **SIR BRIAN LANGSTAFF:** Are they a public figure?

16 **MR WRIGHT:** A senior civil servant.

17 **MS FRASER BUTLIN:** I don't believe it's been redacted,
18 sir. I'm just going to quadruple check.

19 It's not been redacted.

20 **SIR BRIAN LANGSTAFF:** Yes, you can.

21 **MR WRIGHT:** Dr Aileen Keel, who was the Deputy Chief
22 Medical Officer of Scotland, had been heavily involved
23 in this whole story. She'd been Deputy Chief Medical
24 Officer prior to devolution, she remained Deputy Chief
25 Medical Officer immediately after. I've had

32

1 a conversation with Bruce, and he has a similar
2 recollection, that in the very, very early days of
3 Parliament she somehow appeared at the front bench
4 passing a piece of paper to the Health Minister, which
5 I thought was a really weird thing to do.

6 I may not -- I may have misidentified her,
7 however, she was involved in several meetings that
8 I've presented in submissions, where she clearly had
9 an involvement. She was involved in the meeting
10 between the directors and the Scottish Government in
11 February 2000 that we may come on to. She was
12 involved in advice to ministers. If you look at the
13 look-back exercise, she was -- that's discussed, she
14 was the point of contact.

15 **MS FRASER BUTLIN:** We'll pick up her role later on.

16 **MR WRIGHT:** Okay.

17 **MS FRASER BUTLIN:** But just in terms of that time frame,
18 of 1999 to 2000, your recollection of seeing her pass
19 a note to -- or you think it was her passing a note to
20 Susan Deacon during a debate, and you've said in your
21 statement that that gave you some realisation of the
22 impact of devolution and the difficulties that
23 might -- you might be facing.

24 Can you tell us a little bit more about what you
25 were thinking there.

33

1 Minister if my recollection serves me correct.

2 So I'd really like the Inquiry to get to the
3 bottom of -- we were a bit naive, I think, at times
4 where the Scottish -- in terms of the importance of
5 the Scottish Office in this whole story.

6 **MS FRASER BUTLIN:** After the departmental report, the
7 Inquiry report was published, as you said, you then
8 gave evidence to the Health Committee in March 2001?

9 **MR WRIGHT:** That's correct.

10 **MS FRASER BUTLIN:** And we've got the conclusions of the
11 committee, if we can look at that.

12 WITN2287028, please. And I think it's page 20
13 that we want. Sorry, it's page 21. Thank you.

14 We can see the heading "Conclusions", and I want
15 to pick it up in paragraphs 97 and 98:

16 "We are not persuaded of the case for a further,
17 independent inquiry into all the concerns raised by
18 the Haemophilia Society and others, if that were to
19 focus mainly on exploring questions of alleged fault.
20 The evidence we have so far considered does not
21 suggest that this is likely to be a fruitful line of
22 Inquiry. We are also concerned that further
23 investigating issues of fault would only delay
24 consideration of whether and how financial and
25 practical assistance could be provided to sufferers.

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1 **MR WRIGHT:** I think I -- that was the moment that it hit
2 home that it was not just the elected Government that
3 was in control here. There was a great deal of
4 experience of the story, good and bad, within
5 Scottish Government in terms of what used to be the
6 Scottish Office. And one of the things that has
7 intrigued me and concerned me throughout the story is
8 actually prior to what's called devolution, my
9 understanding was that there was already
10 a considerable degree of devolution within the British
11 Government to the Scottish Office.

12 And while there were very different colours
13 politically north and south of the border -- in fact
14 we had a moment where I think they were struggling to
15 find a minister of the correct colour within the
16 Scottish Office -- there was -- decisions were allowed
17 to be made. We had a different legal system.
18 Whenever you passed an act of Parliament, you had to
19 have the Scotland Act. And so there was a Health
20 Minister in the Scottish Office, Sam Galbraith, prior
21 to 1999. He then became, in the new Scottish -- he
22 was one of the guys, in a sense, who was the baggage
23 from pre-devolution as a politician, the late
24 Sam Galbraith, who was a surgeon by profession, but he
25 then took a cabinet post post-devolution, as Education

34

1 A review of the adequacy of clinical advice on risks
2 arising from blood and blood products would, however,
3 be welcome."

4 Then paragraph 98:

5 "We have come to the view that financial and
6 other practical assistance, awarded on a no-fault
7 basis, is the clearest solution to the issues raised
8 in these petitions. We believe as a matter of
9 fairness that individuals who have suffered serious,
10 long-term harm as a result of NHS treatment should
11 receive some practical assistance. We also believe
12 that this solution is required for reasons of
13 consistency, in recognition of the fact that HIV
14 sufferers already receive assistance under clearly
15 analogous circumstances, via the Macfarlane Trust."

16 That report resulted in an expert group on
17 financial and other support chaired by Lord Ross.

18 **MR WRIGHT:** Yes.

19 **MS FRASER BUTLIN:** You -- am I right, you weren't a member
20 of that group but Philip Dolan was?

21 **MR WRIGHT:** Yes.

22 **MS FRASER BUTLIN:** When the Ross Committee was
23 established, what expectations did you and the rest of
24 the infected and affected community have for that
25 committee?

36

1 **MR WRIGHT:** Well, I think I may have fed into the thinking
 2 on the terms of reference at the time. But actually
 3 we'd taken some messages to both Government and
 4 Lord Ross about -- that this wasn't just about money.
 5 For example, one of the findings of the Ross committee
 6 is about palliative care. And that's because the
 7 experiences of people of end of life with hepatitis C
 8 had been particularly traumatic -- and continue to be
 9 so, I'm afraid, in terms of some of the experiences.
 10 And a lot of the thinking that was fed in, not just by
 11 Philip and Frank and anonymous member AA, came from
 12 us. And -- I mean, I'm reluctant to in any way
 13 pre-determine the findings of this Inquiry, but
 14 I think Lord Ross had a lot of answers that, if they'd
 15 been implemented at the time -- which is why, frankly,
 16 sir, we came up with this ten years later in terms of
 17 our analysis.

18 **MS FRASER BUTLIN:** In just one moment, Bill, we're going
 19 to get there.

20 **MR WRIGHT:** Okay.

21 **MS FRASER BUTLIN:** But in terms of expectations of you and
 22 the community, were you expecting that the
 23 recommendations would go somewhere?

24 **MR WRIGHT:** Yes.

25 **MS FRASER BUTLIN:** Would be implemented?

37

1 then "compensation to be calculated under principles
 2 of common law damages", et cetera.

3 Then, on the right-hand side, you've marked in
 4 red where nothing has been implemented, and in yellow,
 5 those that are in the process of being implemented.

6 If we -- so we can see what Lord Ross
 7 recommended in terms of financial help. As you have
 8 said already in your evidence, Bill, on 29 August
 9 2003, it was announced that there would be the Skipton
 10 Fund as a UK-wide scheme. Were you expecting that
 11 announcement?

12 **MR WRIGHT:** No.

13 **MS FRASER BUTLIN:** What was your feeling when that
 14 announcement was made, having just had the Lord Ross
 15 Report?

16 **MR WRIGHT:** This was taking us back to London. This was
 17 taking us back to pre-devolution position.

18 **MS FRASER BUTLIN:** And I'm sure it's obvious to you, Bill,
 19 but why was that so problematic?

20 **MR WRIGHT:** Well, one of the huge benefits of Scottish
 21 Parliament is that we were able to nail them. We were
 22 able to -- I hate the expression, but hold feet to
 23 fire.

24 And actually, in the case of some MSPs -- and
 25 we'll see the difference there was in culture compared

39

1 **MR WRIGHT:** Of course.

2 **MS FRASER BUTLIN:** So we then have the document that you
 3 wanted us to have up, WITN2287031.

4 I should say that obviously the Inquiry has
 5 already looked at the Ross Report in other hearings,
 6 so if we look at this document we can pick up some of
 7 the points you raise, Bill.

8 It's a document that Haemophilia Scotland
 9 produced ten years from the Ross report.

10 If we could go to the next page, please, Soumik.

11 Bill, tell us what this is and what it shows.

12 **MR WRIGHT:** Well, Dan and I, our chief executive,
 13 commissioned a -- I don't know if I can name her. We
 14 commissioned someone, we paid them, who was very well
 15 acquitted to actually look at what -- Lord Ross's
 16 recommendations and then investigate what had actually
 17 happened. That was what was behind this document. It
 18 was a bit of a lobbying document in 2013/14.

19 **MS FRASER BUTLIN:** And if we just look at the first page
 20 that the table -- Soumik, just little bit further
 21 down -- we can see that the financial help elements
 22 that Lord Ross recommended is on the left-hand side of
 23 the screen: an initial lump sum of £10,000, an
 24 additional lump sum of £40,000 for those who develop
 25 chronic hepatitis C, to cover pain and suffering, and

38

1 to the Susan Deacon party whip period from 1999 to
 2 2000 to those opposition MSPs during that period, who
 3 later became very senior ministers, in terms of their
 4 attitude and approach to the whole matter, that -- the
 5 contrast between that Susan Deacon-type approach and
 6 what was said on 26th March 2015 couldn't be more
 7 stark.

8 And, I mean, I -- the Scottish Parliament has
 9 been everything to us. And it -- there's different
 10 experiences. I know that Simon's had different
 11 experiences in Northern Ireland and Lynne's had
 12 different experiences in Wales, but any progress we've
 13 made in Scotland has been due to the existence of the
 14 Scottish Parliament.

15 **MS FRASER BUTLIN:** Have you been able to glean any insight
 16 into why the recommendations of the Ross Report
 17 weren't followed by those setting up the Skipton Fund?

18 **MR WRIGHT:** No.

19 **MS FRASER BUTLIN:** At the time that Skipton was being set
 20 up, there were suggestions that waivers would have to
 21 be signed.

22 **MR WRIGHT:** [Laughs]

23 **MS FRASER BUTLIN:** And you wrote to The Herald about this.
 24 If we can have ILIT0000660, please.
 25 Sorry, it's a slightly strange copy because it's

40

1 taken from the website, but we can see at the
 2 bottom -- could we take that down, please.
 3 **MR WRIGHT:** I wasn't buying a pair of sandals, sir.
 4 **SIR BRIAN LANGSTAFF:** No, I think it was something else
 5 that was causing it to be taken down.
 6 **MS FRASER BUTLIN:** There was a difficulty. What I'll do,
 7 sir, is I'll simply read the letter that Bill wrote to
 8 the newspaper:
 9 "The latest revelations on hepatitis C show that
 10 the Scottish Executive has sunk to a new low in how
 11 it's dealing with this vexed affair. On the one hand,
 12 it's making a derisory financial offer to
 13 haemophiliacs, which does not admit to any legal
 14 responsibility for their being contaminated through
 15 NHS blood products with this sometimes fatal virus.
 16 On the other hand, it seeks to deny haemophiliacs
 17 their future legal rights, should it be found that
 18 they collectively or individually have a case against
 19 the Executive. The only logical conclusion,
 20 therefore, is that the Executive is aware that
 21 haemophiliacs might have a legal case against it.
 22 Otherwise, if it's so certain of its innocent position
 23 why build in the clause that signs haemophiliacs'
 24 rights away? The Executive has of course also denied
 25 legal aid to those affected.

41

1 **MR WRIGHT:** Well, we got a reaction in their actions, in
 2 that they backed down. I've not suggested that one
 3 letter to The Scotsman from me achieved that, but
 4 yeah, they backed down.
 5 **MS FRASER BUTLIN:** During this time, post the Ross Report,
 6 you were advocating in Scotland and seeking to build
 7 support across the political spectrum.
 8 **MR WRIGHT:** Yes.
 9 **MS FRASER BUTLIN:** You have already noted you had
 10 particular support from some MSPs, I think you were
 11 referring to Nicola Sturgeon and Shona Robison. At
 12 this point in time, when they were in opposition, can
 13 you tell us briefly what they did to support your
 14 work?
 15 **MR WRIGHT:** Well, you simply need to look at the minutes
 16 of the Health Committee during those periods in that
 17 they were terrier-like in not accepting that this
 18 needed to be pushed to the courts, or in -- they
 19 effectively were in support at various different
 20 times, of both the petitions. And I think, initially,
 21 there was reference there that the Health Committee in
 22 the early -- the first Health Committee wasn't
 23 supportive of an inquiry. A subsequent Health
 24 Committee prior to 2007 when Andrew Kerr was Health
 25 Minister were in support of an inquiry, and you'll see

43

1 "Most living haemophiliacs could have received
 2 at least £50,000 under the recommendations of the
 3 ministerial appointed expert working group chaired by
 4 Lord Ross. They will now have to decide whether they
 5 not only settle for the Westminster controlled offer
 6 from the Health Minister, Malcolm Chisholm, which for
 7 many is less than half of what Lord Ross recommended,
 8 but also sign their life away."

9 That was the letter you wrote to The Herald.
 10 Were they the views of the wider infected and affected
 11 community as well?

12 **MR WRIGHT:** Yes, we were all grumpy Scotsmen at that
 13 point.

14 **SIR BRIAN LANGSTAFF:** Can you just help me: was there any
 15 official reaction, published reaction, to the Ross
 16 Report?

17 **MR WRIGHT:** [Laughs]. I think this --

18 **SIR BRIAN LANGSTAFF:** Considered reaction, I mean.

19 **MR WRIGHT:** I would need to write to you, sir, about that.
 20 Unfortunately, I'm -- the horrible words "I cannot
 21 recollect" is the situation there.

22 **MS FRASER BUTLIN:** In terms of your letter to The Herald,
 23 did you get any response from anyone within the
 24 Scottish Government, the Scottish Parliament, about
 25 that issue of waivers?

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1 that Shona Robison in particular at that point was
 2 strongly in support. But also, in terms of -- in
 3 earlier times, Nicola Sturgeon asked some very
 4 searching questions of Government, via the Health
 5 Committee. I was also very fortunate in that my own
 6 MSP was John Swinney, who went on to become the Deputy
 7 First Minister and also, at the critical period in
 8 2016, when the financial review took place, that he
 9 was Finance Minister at that point. If you look at
 10 the Parliamentary record in Scotland, he actually, in
 11 supporting the idea -- in our support, he refers to --
 12 and I think this is characteristic of the different
 13 position that was being taken by opposition MSPs to
 14 an intransigent Government. He referred to the words
 15 that are on the mace of the Scottish Parliament -- big
 16 silver mace like the one you have in Westminster --
 17 and those words are "Wisdom, justice" -- [laughs] --
 18 "compassion and integrity".

19 Now, John Swinney used those words and that's in
 20 stark contrast and I think those words are extremely
 21 valuable in all of this. And he drew on those words
 22 at that time, and that was in very stark contrast to
 23 what we were facing. So we'd got these three people
 24 and, I hasten to add, we'd also got people like
 25 Margaret Smith and the Liberal Democrats, we were

44

1 talking to backbench Tories, we were talking to Labour
 2 Party MSPs as well. In fact, at one point the
 3 Scottish Socialists had seven MSPs in the Scottish
 4 Parliament and a woman called Carolyn Leckie, who was
 5 an MSP, was very supportive of us, so we were working
 6 very hard in the Parliament, and Bruce referred to it
 7 yesterday, to gain their support. But those three
 8 individuals were particularly critical because they'd
 9 seen the story, they had learned the story during
 10 their period of opposition and they then went on to
 11 become First Minister, Finance Minister, and Health
 12 Minister.

13 **MS FRASER BUTLIN:** I want to pick up in 2005, 2006, which
 14 was also the point in time you've said in your
 15 statement when you withdrew from active involvement in
 16 advocacy.

17 **MR WRIGHT:** Mm.

18 **MS FRASER BUTLIN:** Can we look at some documents from that
 19 period of time first and then I want to ask you some
 20 questions about them. If we could have WITN2287040,
 21 please. Second page, please.

22 We can see of the date, 16 June 2006 and, in the
 23 very first paragraph, this is a letter I should have
 24 said from Mr Andy Kerr. The first, at paragraph --
 25 indicates that he is:

45

1 difficult to construct a clear and detailed picture of
 2 what took place.

3 "An inquiry would not add significantly to our
 4 understanding of how the blood supply became infected
 5 with Hepatitis C, or the steps needed to deal with
 6 problems of this kind now or in the future."

7 Then the final paragraph of the letter:

8 "I have considered very carefully the points
 9 which were put before the Committee, and discussed by
 10 it on 18 April. I do not believe a public inquiry
 11 would either uncover any new evidence or information
 12 that is relevant to the causes of the infection of NHS
 13 patients through blood and blood products, or lead to
 14 significant lessons for the future. It would be
 15 a diversion of effort from delivering and improving
 16 health services today. I cannot see that there is any
 17 possible justification for the efforts and costs that
 18 would be involved, or that this would bring any
 19 benefit to the patients involved."

20 Then one more document before I ask you
 21 a question about this, Bill. You were then sent
 22 a copy of this as well, and if we can look at the
 23 letter that you received, WITN2287042. Thank you.

24 If we just look at his last paragraph, in which
 25 he says:

47

1 "... writing in response to [a] letter ... on
 2 the decision of the Health Committee to call for
 3 a full judicial inquiry into infection with
 4 Hepatitis C through NHS treatment, with a particular
 5 focus on the efficacy of the 'look-back' exercise."

6 He says:

7 "I have put on record on a number of occasions
 8 our sympathy for those who have contracted Hepatitis C
 9 through NHS treatment. This has had serious
 10 consequences for the lives of many people, and we do
 11 not underestimate or minimise these consequences."

12 He then speaks about the look-back exercise,
 13 communication with patients and testing for
 14 hepatitis C. Then if we pick up on internal page 5,
 15 please. Sorry, the next page, please. Under the
 16 heading "Public Inquiry":

17 "I cannot accept that there is any need for
 18 a full public inquiry into the infection of patients
 19 with Hepatitis C through treatment with NHS blood and
 20 blood products."

21 Then a few paragraphs further down:

22 "A full judicial inquiry would be a major and
 23 time-consuming exercise which would depend on the
 24 recollections of witnesses about events which took
 25 place twenty or more years ago. This would make it

46

1 "I have had to reach a balanced view on the
 2 justification, or otherwise, for a public inquiry into
 3 these events. This has been a difficult decision for
 4 me, but I have concluded that an inquiry would be
 5 unlikely to uncover any new evidence or lead to
 6 significant lessons for the future. It would also
 7 depend on the recollections of witnesses about events
 8 which took place twenty or more years ago. An inquiry
 9 would also place major pressure on our blood
 10 transfusion service and would not add significantly to
 11 our understanding of how the blood supply became
 12 infected with Hepatitis C; rather it would be
 13 a diversion of effort from delivering and improving
 14 health services today."

15 Bill, when you received this letter, and the
 16 fuller letter that we've looked at, what was the
 17 impact of that on you?

18 **MR WRIGHT:** Can we just check the date on this again,
 19 please?

20 **MS FRASER BUTLIN:** It's April 2007.

21 **MR WRIGHT:** Yeah. This coincided with -- I really would
 22 wish to avoid going into -- I'd had quite a dark
 23 period in my life personally, in the lead-up to the
 24 end of 2005. I was later that year to attempt
 25 interferon treatment for the fourth time and I had

48

1 a collapse in my physical health. The culmination
 2 of -- frankly I got completely fed up with this stuff
 3 and I can't avoid saying it, sir, but I would really
 4 welcome Mr Kerr -- can we go back to the paragraph,
 5 please, I'm sorry, but I would really welcome it if
 6 Mr Kerr were asked to come and appear --
 7 **SIR BRIAN LANGSTAFF:** We're going back to the paragraph.
 8 The last paragraph, do you want?
 9 **MR WRIGHT:** Yeah:
 10 "It would also depend on the recollections of
 11 witnesses about events which took place twenty or more
 12 years ago."
 13 So hang on, if you add on 14 years to 20, that's
 14 34. I'd really welcome it if he comes and appeared
 15 before you and established if he still was of that
 16 opinion, that he had back then. Sorry, sir.
 17 **MS FRASER BUTLIN:** It's fair to say, isn't it, that at
 18 this point personally things were very difficult but
 19 it was also at a time when you with through from
 20 active advocacy?
 21 **MR WRIGHT:** Yes. Yeah. It was a very difficult time.
 22 I also, after the fourth attempt at interferon
 23 treatment, there was effectively a collapse in my --
 24 I suffered enormous fatigue and, having experienced
 25 what I'd had -- I'd experienced in the lead-up to the

49

1 was relevant to the causes of the infection, or lead
 2 to significant lessons for the future.
 3 **SIR BRIAN LANGSTAFF:** Does he answer the question which
 4 Mr Wright has posed, whether he is still of the same
 5 view today?
 6 **MS FRASER BUTLIN:** Sir, no, he doesn't.
 7 Sir, I am about to pause in relation to Scotland
 8 and move on to some other matters in the timeline and
 9 I wonder if now is a good time to take a break?
 10 **SIR BRIAN LANGSTAFF:** Yes, certainly. Well, we will take
 11 a break until ten to 12.
 12 **(11.20 am)**
 13 **(A short break)**
 14 **(11.50 am)**
 15 **SIR BRIAN LANGSTAFF:** Yes.
 16 **MS FRASER BUTLIN:** I just want to make sure that we have
 17 Simon back with us as well.
 18 **SIR BRIAN LANGSTAFF:** Yes, he is.
 19 **MR HAMILTON:** Yes, thank you.
 20 **MS FRASER BUTLIN:** There he is.
 21 Lynne, can I turn to you, and what was happening
 22 for you in Wales. Following the Archer Inquiry,
 23 a recommendation was made that the Haemophilia
 24 Alliance would be established. And you attended --
 25 that was in 2009. You attended for the first time on

51

1 end of 2005, I wanted to protect my, effectively,
 2 mental health, and I had to give up work, actually,
 3 eventually, because of the collapse in my physical
 4 health, and it took me another three or four years
 5 before I was able to get to the point where at least
 6 I could get through a day with a sleep in the
 7 afternoon and -- you know, and then I started to play
 8 golf, and so on and so forth.

9 So it just had become -- the Penrose Inquiry of
 10 course then came along in 2008, and I was engaged in
 11 that as a Core Participant. But I didn't -- I wasn't
 12 involved with the Scottish Haemophilia Groups Forum or
 13 people like Bruce, or Alice, or whoever, during that
 14 period. I was trying to, I guess -- and my wife was
 15 trying to protect me during that period.
 16 **MS FRASER BUTLIN:** Mr Kerr, sir, has provided a response
 17 to Bill's statement and it will be published on our
 18 website in due course. He states that he's
 19 disappointed at the characterisation of his position
 20 during this period on this very sensitive matter, the
 21 whole issue has been devastating for individuals and
 22 their loved ones. He reiterates his view that, on the
 23 basis of the evidence and information before him, he
 24 didn't believe that a public inquiry in Scotland would
 25 either uncover any new evidence or information that

50

1 14th November 2011 as a patient representative.
 2 **MS KELLY:** Yes.
 3 **MS FRASER BUTLIN:** Knowing about the Haemophilia Alliance,
 4 what were your expectations of those meetings?
 5 **MS KELLY:** Well, I thought that when the Archer
 6 recommendations were made, that the Alliance was meant
 7 to be a group comprising of patients, clinicians,
 8 Department of Health; and that group, as per Archer
 9 was meant to include issues about care and support.
 10 But when I went to those meetings, they'd already been
 11 going on for two years -- you know, I didn't start
 12 going until 2011 -- and support had been omitted from
 13 the terms of reference.
 14 So that was a concern to me. My cousin had just
 15 died so obviously we'd lived through the experience of
 16 a family member dying. And I felt that all the issues
 17 that I'd gathered from the patients in Wales
 18 regarding, obviously, lack of financial support, lack
 19 of provision for hepatology, monitoring of hepatology,
 20 there just wasn't an appetite at those meetings for
 21 those issues to be covered.
 22 I went obviously as a Welsh representative, and
 23 my feeling was that they saw Wales as very much a side
 24 issue, and that was something that needed to be sorted
 25 out in Wales, whereas I felt if the cohort were

52

1 infected, you know, UK-wide, I knew there would be
2 other people who were in the same position as my own
3 family had been in, and many other people that I'd
4 spoken to and gathered experience from in Wales. But
5 I found that the Department of Health meetings -- you
6 know, the chair was -- the Department of Health -- can
7 I say the names?

8 **MS FRASER BUTLIN:** I don't believe it's been redacted so
9 yes.

10 **MS KELLY:** Right. So the chair of the meeting was
11 Rowena Jecock, who was head of Blood Policy, and in
12 her absence Ben Cole would take over. They were
13 jointly chaired by The Haemophilia Society. But
14 basically the whole day would be taken up by some sort
15 of Department of Health, it would be -- there would
16 always be presentations by the Department of Health,
17 and you wouldn't really know you were in a meeting to
18 do with haemophilia or infected blood or any of those
19 issues. And then I just felt that there were no real
20 focus on the issues that I knew were affecting the
21 community in the Wales, and as I say, I thought the
22 same would be happening in the UK.

23 And at those meetings I met many people from
24 England -- I actually met somebody from Scotland as
25 well, but not Bill, and basically they were all saying

53

1 a troublemaker. How did you get that perception?
2 **MS KELLY:** Well, basically because there would be the
3 Department of Health officials, the haemophilia
4 doctors. There weren't any Welsh haemophilia doctors
5 there so, you know, I didn't personally know them.
6 But it was very much -- they'd look at each other and
7 think: oh, well, that's your problem, you know, that
8 isn't really our problem.

9 And I was arguing for a national policy. If
10 they had put this into the national service
11 specification on haemophilia, where people with
12 contaminated blood had access, not just to hepatology
13 services. We were asking for access to consultant
14 hepatology opinion, because we knew so many were dying
15 and they weren't being monitored, they weren't being
16 diagnosed with advanced liver disease, and basically,
17 by the time it was picked up, they were presenting at
18 A&E, you know, swollen, with ascites, on trolleys,
19 without beds. And all the people were saying the same
20 thing. But the haemophilia doctors, it was as if it
21 was a separate issue. It was a side issue to them.

22 And that wasn't the position of our clinicians
23 in Wales. We had good support from them, because
24 obviously they knew their patients very well. Our
25 centres are, you know, relatively small to compared to

55

1 the same things, that they were coming to those
2 meetings, they were desperate. There were people
3 dying and they were trying to get to the meetings.
4 They'd travel for miles and miles to get there,
5 expecting that there would be some -- something done.
6 They'd think that if they told the Department of
7 Health what was going on, they really felt that
8 something would be done. But it all fell on deaf
9 ears. We'd find that, during the course of the time
10 I was attending, the minutes would never be
11 circulated. We wouldn't get an agenda. You'd be
12 missed off the circulation list.

13 I just felt that I was perceived as a bit of
14 a troublemaker, really, because I'd go with my list of
15 issues. I'd present on the issues that were affecting
16 people in Wales. So basically they'd just move it on
17 to the next item and say, "Oh, well, that's a Welsh
18 problem."

19 Do you want me to go on?

20 **MS FRASER BUTLIN:** We're going to come to the specific
21 issues, the clinical issues that you campaigned on in
22 Wales towards the end of the evidence today, because
23 it's a very important part of your evidence. But just
24 staying with the Haemophilia Alliance and how that was
25 functioning, you've said you were perceived as

54

1 England. And I just couldn't believe that -- you
2 know, as well as the Department of Health, there was
3 the UKHCDO. They didn't seem to want to address any
4 of the problems. The Haemophilia Society would come
5 to the meetings and they'd present on some other
6 initiative -- some or other initiative they were
7 trying to, you know, get funding for at the time.

8 I just felt it was sickening, really, that
9 people were coming, and they were desperate, and
10 I actually met -- it's one of the campaigners, and
11 I didn't know they were related at the time, but his
12 uncle, and he'd come to the meeting and, you know, he
13 was waiting on a liver transplant and he wanted some
14 answers from these people, and they'd just keep
15 saying: "Well, we can't distinguish between route of
16 infection, you know. You shouldn't be having priority
17 over other people."

18 And we would say: "Well, yes, we should,
19 because, you know, we were infected, infected by the
20 State, infected by the NHS. It's not covered in the
21 haemophilia care, it's not in the national service
22 specification."

23 And that would have been a way that they could
24 have come together and had a national policy on how to
25 deal with this cohort of people. And from what we'd

56

1 seen in Wales there were massive gaps in care. And
2 basically people were just dying. They'd been
3 admitted through A&E. Their deaths weren't being
4 recorded as attributable to liver disease or liver
5 failure. The Department of Health -- that was another
6 issue, I always brought it up with them: why don't you
7 record the cause of death? They would just record the
8 fact of death, and they'd put the onus back onto the
9 doctor who was there at the death.

10 **MS FRASER BUTLIN:** Why was that so important to you,
11 Lynne?

12 **MS KELLY:** Well, because it had to be documented that they
13 were dying as a result of infected blood, and that
14 wasn't happening. So unless the family specifically
15 asked for "Can you put HIV" or "Can you put
16 hepatitis C on the death certificate", that wasn't
17 happening. Obviously I do know about -- you know,
18 there are families who didn't want HIV -- you know,
19 obviously I know the group very well -- but the
20 hepatitis C was a real issue.

21 I just felt that those deaths, and -- you know,
22 from liver disease, it was just swept under the
23 carpet. They just grouped them all with the same
24 cohort of people who were, you know, alcohol, drugs,
25 whatever. There was no priority given. And, you

57

1 a hepatology appointment made in Wales.

2 So they didn't really know what was going on,
3 basically. And I felt that they weren't really
4 interested at the time.

5 **MS FRASER BUTLIN:** And just a moment ago you said that
6 financial support was included from the remit of the
7 Haemophilia Alliance.

8 **MS KELLY:** Yes.

9 **MS FRASER BUTLIN:** Was that ever raised at any of the
10 meetings you --

11 **MS KELLY:** Yeah, I raised it a lot. But it was never
12 minuted, like lots of things weren't minuted, and they
13 would just say, "It's not within our remit". So any
14 discussion about money or finance was just excluded.

15 **MS FRASER BUTLIN:** It was later decided that the
16 Haemophilia Alliance would be replaced by clinical
17 reference groups. What was the effect of that on
18 Welsh patients?

19 **MS KELLY:** Well, I strongly objected to that. And the
20 last meeting I attended, I made -- you know, I did
21 make a big fuss about that, because I said we have
22 no -- we don't have a UK-wide group now, as Archer
23 intended. This was meant to be a group that came
24 together with patients, you know, who were experts in
25 their condition. Haemophilia clinicians, should have

59

1 know, knowing the people, knowing the people who died,
2 the stigma was terrible, because that left such
3 a lasting effect on the family, the fact that their
4 loved one had died, and the nurse who was looking
5 after them on a general ward didn't even know how they
6 became infected.

7 You know, it happened with my own cousin as
8 well. There was -- you know, the nurse is, "Oh, you
9 know, you can't touch him, he's got hep C, wear
10 gloves", and that was said, you know, in the open.

11 **MS FRASER BUTLIN:** In the Haemophilia Alliance meetings,
12 you've said that a lot of things were seen as a Welsh
13 issue?

14 **MS KELLY:** Yes.

15 **MS FRASER BUTLIN:** How involved were the Welsh Government
16 or officials in those meetings?

17 **MS KELLY:** Well, at that point, at the very beginning,
18 before we, you know, before we sort of told them -- we
19 weren't happy about it then, Welsh Government were
20 really disinterested in it. They were invited to the
21 meetings, but they would come to meetings --
22 I remember one particular meeting where there was some
23 patients who were quite ill; Welsh Government reported
24 back to the meeting that there was no progress, but
25 we'd actually had a major breakthrough and we'd had

58

1 been -- hepatologists should have been on that group,
2 HIV specialists, dentists should have been there. All
3 those gaps in care with haemophilia that everybody was
4 experiencing, that was the forum for it. And it was
5 meant to be -- you know, you're meant to -- an
6 exchange of good practice around the UK.

7 In the last meeting I attended, I really, you
8 know, stood up and said, "Look, this is just --
9 shouldn't happen", and nobody supported me. I just
10 was the only one in the meeting who wanted the
11 Haemophilia Alliance to go on, because I felt, well,
12 for Wales, we'd lost that contact. Scotland, the
13 same. Obviously Northern Ireland. All the devolved
14 powers. Because our care in Wales is managed
15 differently. We don't have CRGs; we have WHSCC, who
16 are the Welsh Health Specialist Services Commission,
17 so they're in charge of haemophilia care in Wales, so
18 we had no forum to take any of our issues to.

19 **MS FRASER BUTLIN:** And so, I think in your statement the
20 sense is that there was the Archer recommendation, and
21 the Haemophilia Alliance in that petered out?

22 **MS KELLY:** That petered out. And, you know, that was done
23 for a reason, because basically, my opinion is that
24 they didn't want to resolve the issues. They wanted
25 to sweep the whole infected blood cohort under the

60

1 carpet.
 2 And as each family -- as a family member dies,
 3 lots of people drop away, and I think bit by bit they
 4 thought they'd all be dead and there would be nothing
 5 to do. And, you know, the haemophilia doctors that I
 6 saw at the Haemophilia Alliance, they obviously -- you
 7 know, they had patients with infected blood, but
 8 I felt the fact that they couldn't relate to that with
 9 the stories that we had from Wales, and there was
 10 nobody representing us from Wales except me, I just
 11 felt that they -- you know, they didn't really show
 12 any concern about that.

13 We had issues regarding endoscopies, where
 14 people couldn't get access to endoscopies when they
 15 were in -- you know, when they had cirrhosis. They
 16 were denied access to that because of the variant CJD.
 17 I took a letter to the -- one of the Haemophilia
 18 Alliance meetings about that and, again, they said
 19 it's a Welsh problem. But this had actually happened
 20 in Birmingham. Because that was the liver specialist
 21 centre that our patients would go to from Wales.

22 And it would have been so easy to resolve, to
 23 have a strategy in place where all this group of
 24 patients -- there are not that many of them -- were
 25 looked after, you know, and they had the care that

61

1 accessible. So if an MSP -- and I have to pay tribute
 2 to Richard, the former MSP Richard Lyle, here, he
 3 organised for us to have several presentations to MSPs
 4 actually, one of them was memorable. It was actually
 5 in the garden lobby of the Scottish Parliament.
 6 I happen to think it's a magnificent building and
 7 that's where everybody gets together. It would be a
 8 bit like -- well, I'm not that familiar with the
 9 Houses of Parliament but the great hall, or whatever,
 10 the place where people go. And it was extraordinary
 11 because we actually got 20 MSPs along, I think, to the
 12 first one, and Alex Neil came and spoke and he spoke
 13 at a subsequent one in one of the committee rooms.

14 So we'd got not only MSPs hooked in but we'd got
 15 ministers hooked in by this point.

16 **MS FRASER BUTLIN:** As an organisation, Haemophilia
 17 Scotland were gradually drawn into the Inquiry as
 18 well --

19 **MR WRIGHT:** Yes.

20 **MS FRASER BUTLIN:** -- and became a Core Participant in
 21 February 2014.

22 **MR WRIGHT:** Yes.

23 **MS FRASER BUTLIN:** We'll come to the interactions with the
 24 MSPs after the Penrose Report in a moment and you'll
 25 be aware that this Inquiry is not an inquiry into

63

1 they were entitled to.

2 **MS FRASER BUTLIN:** In terms of the chronology, we've
 3 talked a little bit about the Archer and the outcomes,
 4 the recommendation from that.

5 That takes us back, Bill, to you, in terms of
 6 the Penrose Inquiry.

7 If we pick up in about 2011, when you really
 8 returned, it seems, to the fray of advocacy and
 9 campaigning, prior to that you'd been writing letters
 10 to MSPs to press for the Inquiry and press for
 11 progress with the Inquiry, but if I can pick up your
 12 position as chair of the Scottish Management Committee
 13 in 2011. We'll pick up there.

14 Part of your work at that point was to rebuild
 15 the political connections that had previously existed;
 16 is that right?

17 **MR WRIGHT:** That's correct.

18 **MS FRASER BUTLIN:** So you've said in your statement that
 19 in 2012 and 2013, you held some Parliamentary
 20 briefings, including one in April 2013, where Alex
 21 Neil spoke about what the Government intended to do
 22 after Penrose was published.

23 **MR WRIGHT:** Yeah, the way things work in Scottish
 24 Parliament is that it was trying to -- the new
 25 Parliament had tried to make itself open and

62

1 an inquiry. But thinking about the process of the
 2 Inquiry and the report itself, I want to ask you what
 3 the impact of the Penrose Inquiry was on you.

4 **MR WRIGHT:** Exhausting. Utterly exhausting. And that
 5 very much coloured our judgment when this -- there
 6 were proposals coming about for this particular
 7 Inquiry, and we learned so much from the Penrose
 8 Inquiry, not necessarily from its report, albeit there
 9 was a substantial body of evidence that came forward
 10 that clearly this Inquiry, in its PRAC documents is
 11 drawing upon, but we learned about -- I'd written
 12 a letter to the then Health Minister, Nicola Sturgeon,
 13 which is one of my submissions, where I made various
 14 suggestions about what should happen in terms of the
 15 conduct of the Penrose Inquiry.

16 I suggested, for example, that we use the Web.
 17 Most people that our watching today are not in this
 18 room, they're on the Web. Now, Scotland is still
 19 a pretty big country stretching from Shetland down to
 20 the Borders, and Lord Penrose didn't accede to that.
 21 He wasn't that keen on the press attending. You know,
 22 I was very keen that this was a public Inquiry, and
 23 remarks were made by the chair of that Inquiry at
 24 times about the presence of the press and media.

25 We weren't actually funded to go and watch, so

64

1 we weren't getting -- seeing the Inquiry on the Web,
2 we weren't being funded to actually attend it as
3 people are here today and, in terms of the evidence,
4 Lord Penrose was very much leaning toward anonymity on
5 the part of us who'd been infected or affected. We
6 didn't have the choice. I would have been perfectly
7 happy to be Bill Wright in my statements but
8 everything was redacted.

9 The witnesses who appeared in total, unlike --
10 there's been a huge number of witnesses appeared here,
11 of people who have been affected and infected. I'm
12 looking at some, and there were only, I think --
13 Philip, the dear departed Philip said about six, it
14 was actually a bit more than that, I think it was
15 about 12 or 14, so you didn't get the impact of the
16 personal stories in the way that there has been in
17 this Inquiry, and that was really hard because we
18 didn't feel we were being listened to.

19 So we didn't get that personal input. The terms
20 of reference I'd made various suggestions about. One
21 of the -- we'd expected, when the -- there was a terms
22 of reference about examining matters generally and we
23 felt that that was an enabling term, in order to --
24 for Lord Penrose to look quite widely at the various
25 issues that arose around it. He narrowed that right

65

1 **MS FRASER BUTLIN:** Is there anything else you want to say
2 about the impact on you personally, how it felt?

3 **MR WRIGHT:** It did colour my judgment towards inquiries.
4 And we'll come on to the dramatic week that the report
5 came out, which I will never forget -- boy. But
6 I think the period of Maxwellisation, the
7 two-and-a-half years between the final sitting and the
8 day the Report came out, was a weird, weird, weird
9 time, because it came out March 2015 and the final
10 hearing, which was an additional hearing that frankly
11 would force Lord Penrose back to the -- back to
12 a public hearing about statistics, and that was
13 a really grim day, because unfortunately, sadly
14 lord Penrose had just had some very bad news about the
15 health of his wife, he wasn't in the best of moods
16 that day.

17 But that period between October, when we were
18 developing as a charity, and March 2015 was a very
19 strange time because we'd had this frustrated period
20 where -- I haven't necessarily got the correct terms
21 of reference, they weren't looking at, for example,
22 financial support, they were never within the terms of
23 reference of Penrose, rightly or wrongly.

24 I think, at the time, we kind of felt that we'd
25 had these undertakings from Alex Neil and his

67

1 down, and I had personal experience of that in
2 relation to my own story, that the word "generally" --
3 he always wanted to keep things general, rather than
4 look at individual stories and put the pieces of the
5 jigsaw together in that respect, in terms of people's
6 different experiences.

7 So I also -- I have to confess, I'm experiencing
8 from time to time similar experience with this
9 Inquiry, the issue of pace, it felt like our counsel
10 was asked to respond to huge long documents within
11 a few days. They came to us for instructions, and we
12 tried to respond. I was in the Island of Colonsay at
13 one point, and you can imagine, you know, what the
14 broadband connections are in the Isle of Colonsay, and
15 it was a matter that I knew particularly about.

16 So my wife and I were staying in a self-catering
17 accommodation, we were dashing backwards and forwards
18 to the local hotel trying to sort of, you know, talk
19 to Thompsons Solicitors, and to email them, and it was
20 a nightmare, whereas it felt like Lord Penrose gave
21 himself quite a number of months at times, to deal
22 with various issues.

23 **MS FRASER BUTLIN:** You've said the impact on you was
24 exhaustion.

25 **MR WRIGHT:** Yeah.

66

1 successor that they would look at it at the end of the
2 Inquiry. We didn't think we were going to have to
3 wait two-and-a-half years for that report to come
4 through, and that was problematic for us, because
5 people were still dying during that period. And there
6 is a particular instance of someone who died.

7 There was another really weird situation in that
8 there was a sort of Core Participants group that
9 Thompsons drew together in order to take soundings
10 from us. It was about something like a dozen, 14
11 people. So we meet in this room in Thompsons, and
12 counsel was there. Counsel would instruct us "You're
13 not allowed to tell each other what your names are".
14 That was the degree of anonymity that was forced upon
15 us by the chair. In other words, he said, "You cannot
16 identify each other".

17 So we had this weird thing that more than half
18 of us knew each other and we were sort of saying,
19 "Well, I'm going to tell" -- you know, it was really
20 weird. I mean, these were people we knew really well,
21 and so we had this weird sort of situation that we
22 were sort of giving our views on. It was a weird and
23 difficult, difficult time.

24 **MS FRASER BUTLIN:** That evidence, Bill, is that
25 a reflection of your own experience of the impact

68

1 of it or do you draw on the broader impact on the
2 infected and affected community in Scotland? Was that
3 the similar experience of the rest of the Scottish
4 community?

5 **MR WRIGHT:** I would say there was a lot of frustration.
6 And I pay tribute to -- there's an individual here
7 today who was involved in the briefing group that
8 instructed -- the sort of working group that I wasn't
9 initially involved in, and people like Bruce and Alice
10 and Philip, who gave some really good input into the
11 Inquiry. But whether it was listened to, I'm not
12 sure.

13 **MS FRASER BUTLIN:** The report, as you say, came out on
14 25 March 2015. That afternoon there was a private
15 gathering of Haemophilia Scotland --

16 **MR WRIGHT:** Yes.

17 **MS FRASER BUTLIN:** -- together with Nicola Sturgeon and
18 Shona Robison.

19 **MR WRIGHT:** Yes.

20 **MS FRASER BUTLIN:** Can you tell us what happened at that
21 gathering?

22 **MR WRIGHT:** Well, I'll never ever forget that day and the
23 following day, and the week running up to it.

24 Might I set the context here, in terms of what
25 had happened in the morning?

69

1 actually spoken -- we'd made contact. So we decided
2 to make it in the same place.

3 So we got a whole bunch of people really angry
4 at the back shouting "Whitewash!", we'd got the
5 nascent press at the front, and we -- because we had
6 to react to this publicly, so I've got the combination
7 of people sort of wanting a bit of drama and awkward
8 questions, press people and people just filling at the
9 back. However, we knew, because we'd been in touch
10 with Scottish Government, that we could move forward,
11 because -- and I made a speech to that press
12 conference.

13 And I'd gone up to this secretary and said,
14 "That must have been dreadful for you", the poor
15 woman. And I think some of the people at the back
16 didn't necessarily recognise me. "Who's he?" So
17 here's a guy in a suit, we'll just shout at him as
18 well.

19 So I thought: how the hell do I rescue this? So
20 what I did was I grabbed the Penrose -- one of these
21 sticky things in front of the table, grabbed it, and
22 threw it away. And I think that actually -- that did
23 get to the television that night, in ITV and BBC. And
24 then I started to make my presentation, so --
25 however -- we'd decided that we had to deal with the

71

1 We'd, as Core Participants, been given advanced
2 sight of the report and we knew in Scotland that this
3 was going to be really, really bad news. One single
4 recommendation from a £12 million inquiry. And we
5 were looking at this, and we're thinking: wow, what do
6 we do here?

7 However, what we also knew was that we had
8 supportive ministers, and -- so we got to that
9 morning -- we'd already been working very hard that
10 week to read the report, talk to solicitors, prepare
11 the press and media, because we'd organised a press
12 conference that morning.

13 And I think you were there, Lynne, that
14 morning --

15 **MS KELLY:** Yes, I was there --

16 **MR WRIGHT:** -- at the press conference when the report was
17 presented. And the report was presented by the
18 Secretary to the Inquiry, and -- there were sort of
19 two tiers. There were people who had come from Wales
20 and England, who hadn't been Core Participants, who
21 were shouting "Whitewash!" And this poor relatively
22 junior member of staff had had to present this. And
23 I'm a guy in a suit and I -- what we'd decided to do,
24 we'd been advised, is don't have a press conference in
25 another place. Do it in the same place. And we'd

70

1 press and media. However, we knew that people were
2 going to be very, very upset, and Dan and I and others
3 had talked around this and we thought -- people need
4 to go to a quiet place in such circumstances.

5 So what we did was we organised a get-together
6 along the road -- and I think you maybe came to that
7 as well, Lynne?

8 **MS KELLY:** I came, yeah.

9 **MR WRIGHT:** In fact you that the opportunity to speak to
10 a minister.

11 **MS KELLY:** I did, yes.

12 **MR WRIGHT:** And what we'd organised was for the First
13 Minister and the Health Minister to come and meet
14 people without the press there. And that was so
15 important to do that, because that way you get in your
16 face the real stories, when people have settled down,
17 and they start to tell the stories.

18 And I remember Shona Robison, the Health
19 Minister, saying afterwards, "It was those women that
20 made me want to act". She sat at a table, I
21 remember -- actually, my wife was sitting at another
22 table and she said to me, "Who is that woman who was
23 sitting at the table with us?" And I said, "That was
24 Maureen Watt", the Public Health Minister, junior
25 minister to Shona Robison. I think John Swinney might

72

1 have been there as well.
 2 So we were working away to get these messages
 3 over. And the good thing is that the likes of Lynne
 4 was able to bring Welsh experience as well. So that
 5 was the start of a whole new chapter, and a very
 6 important chapter for us.
 7 **MS FRASER BUTLIN:** And the next day a question was asked
 8 in the Scottish Parliament.
 9 If we can go to that WITN2287078, please.
 10 Page 2, please.
 11 We can see on the right-hand column, the heading
 12 "Penrose Inquiry", and Nicola Sturgeon was asked what
 13 the Government's position was on the Penrose Inquiry,
 14 and she was challenged that it was a whitewash.
 15 If we go to the bottom of the second column, we
 16 can see her response about the question of it being
 17 a whitewash.
 18 "I can obviously understand the feelings,
 19 frustration and, even, disappointment of all those who
 20 are affected by the dreadful events. However, I was
 21 struck particularly by comments that Bill Wright of
 22 Haemophilia Scotland made yesterday. I thought that
 23 he was correct in his assessment that, despite his
 24 disappointment,
 25 "there is a narrative setting out the case that

73

1 That day, when I heard that -- and it's really
 2 funny, I was speaking to Bruce about this yesterday,
 3 I think he mentioned it in his evidence -- it's not
 4 because I was name checked but it was because there'd
 5 been -- the press conference that I'm talking about,
 6 there'd been -- we gave them a copy of what my
 7 words -- my speech. That ended up in a briefing from
 8 a senior civil servant to the First Minister, and --
 9 about how Government was going to respond. So it
 10 wasn't the fact that I was name checked; it was these
 11 words:
 12 "There is a narrative setting out the case that
 13 cannot be avoided by Government and its moral
 14 responsibility on behalf of the Scottish Government.
 15 I certainly accept that responsibility."
 16 That is one hell of a thing for any politician
 17 to hang themselves with. And I remember at that
 18 point, I had to leave the chamber. Here I was,
 19 a middle-aged grumpy Scotsman, I was exhausted and
 20 I ended up howling like a baby because, like Bruce --
 21 what I didn't realise was that he was howling as well.
 22 And Susan grabbed me and hugged me, and I -- all the
 23 way down in that lift, I wept my eyes out because
 24 I knew that that was the big breakthrough for us in
 25 Scotland. Because of those words.

75

1 cannot be avoided by the government and its moral
 2 responsibility.'
 3 "On behalf of the Scottish Government,
 4 I certainly accept that responsibility."
 5 And it carries on:
 6 "Taking account of the wider findings of the
 7 report, and in consultation with patients and
 8 families, we will act to implement the report's
 9 recommendation and take forward the review of
 10 financial support as a matter of urgency."
 11 And that afternoon Shona Robison made an
 12 announcement in the Scottish Parliament, didn't she,
 13 that further work would be done on financial support
 14 and in relation to additional psychological support.
 15 That, as you say, was the start of a different
 16 phase in Scotland; is that fair?
 17 **MR WRIGHT:** Can I just say two things about this? First
 18 of all, until this point, until the Scottish
 19 Government felt able to move following the report from
 20 the Penrose Inquiry, we'd been facing a sort of
 21 approach that had been taken that's represented in the
 22 submission I made about Susan Deacon's comments: force
 23 them to the courts. Let's force them to the courts;
 24 we're not interested in morals, let's go to the
 25 courts.

74

1 And, of course, we then went on to have
 2 a dialogue, a proper constructive dialogue with
 3 Government that I hope to hell Sir Robert Francis has
 4 with people here, when it comes about the
 5 announcements in -- we follow up in the announcements
 6 in March.
 7 So Bruce was -- what I didn't realise, Bruce was
 8 howling, I was exhausted, and then we had to go and
 9 meet the Minister in the afternoon, a group of us, and
 10 talk about what happened next.
 11 We had already made proposals to the Minister
 12 about what happened next, and it had to be
 13 an inclusive process, unlike the bit that I've missed
 14 here, was the David Cameron response. At the very
 15 same time as I was on my hind legs in Edinburgh, the
 16 Prime Minister was in London saying, "I apologise".
 17 He didn't actually explain what he was apologising
 18 for. My bet is that the First Minister in Scotland
 19 would have a better idea about what she was
 20 apologising for and the Scottish National Blood
 21 Transfusion Service would have a better idea about
 22 what they were apologising for than Mr Cameron in
 23 London, because he also said, "Well, here's an extra
 24 25 million".
 25 This is the wrong -- I'm sorry, sir, but this is

76

1 the wrong way to do Government! You have to engage
2 with people. You don't just throw money at people.

3 I wrote a letter that night, I was up all the
4 night, all night, between the 25th and 26th, writing
5 this letter to David Cameron. The Haemophilia Society
6 were a bit annoyed because I'd got in before them, but
7 that's old history. And I asked him questions "Where
8 does this figure of 25 million come from? What's it
9 for? How's it arrived at?" I never got an answer.

10 No answer from the Prime Minister. I learned
11 from a journalist that was at the press conference
12 that day about that announcement that was taking place
13 hundreds of miles away. Where's the decency in all of
14 this?

15 I'm sorry, sir.

16 **SIR BRIAN LANGSTAFF:** What are you sorry for?

17 **MR WRIGHT:** I can become very passionate about that
18 particular episode.

19 **SIR BRIAN LANGSTAFF:** That's part of giving evidence,
20 I think.

21 **MR WRIGHT:** I mean, what the hell was going through
22 Cameron's mind, for Christ sake? What was his
23 briefing? Where were these people? Were they talking
24 to us? 25 -- oh yeah, just -- let's give them
25 £25 million.

77

1 April 2013, could we have WITN3988072, it's page 5.
2 Sorry, if we start at page 2, we can see what it is.

3 We can see the heading at the top, that it's the
4 APPG on haemophilia and contaminated blood at the
5 House of Commons, and various MPs were there. Was
6 this a regular meeting that you attended, Lynne?

7 **MS KELLY:** Yes, yeah. I always attended. We had a lot of
8 support from the Welsh MPs, so when it was obvious
9 that the Archer recommendations weren't going to be
10 implemented, we started gathering our forces, really,
11 together, and encouraging people to write to their
12 MPs, as well as their Assembly members, to try to
13 address some of the issues. We were doing the same
14 thing down in Wales as well and, at that point, we had
15 had -- a Task and Finish Group had been recommended to
16 address the gaps in care in Wales and I was part of
17 that group.

18 And I gathered patient experiences, and they
19 were all the things we already knew, but we had to get
20 them documented. And then, as well as that,
21 I obviously used to go to the all-party group because
22 we had supportive MPs, people like Owen Smith, you
23 know, he'd instigated the Backbench Business Debate in
24 2010 or 2011, but then he was promoted to become
25 a minister, so it was Geoffrey Robinson who took over

79

1 The journalist says to me, "David Cameron has
2 just announced an extra £25 million, how do you react
3 to that?" I'm sitting there with all these people
4 there. And I said, "That's a damned insult", I had to
5 think on my feet. There are some people here that
6 were there at that moment and The Times journalist
7 came back to me and said, "Well, what do you think is
8 a fair amount?" and I said, "That's something that we
9 will discuss, with due respect to you, directly with
10 Government, not via the press and we will try and
11 engage people in that process, the people who have
12 been infected".

13 And that's why I feel very strongly that in the
14 exercise that's about to come about here, announced in
15 March, that everyone in this room, and everyone out
16 there watching this, feels they have some ownership
17 in. That is good government. Taking views, taking
18 ideas, not just chucking money. I mean, 25 million?
19 It was a damned insult. I stand by that. Sorry.

20 **MS FRASER BUTLIN:** You don't need to apologise, Bill. I'm
21 going to pick up financial recompense in a moment.
22 I want to turn to Lynne and Simon in relation to
23 a couple of matters in relation to the Public Inquiry.

24 Lynne, if I can pick up with you, just before
25 the Penrose Report at an APPG meeting on 17

78

1 the debate.

2 But we heard from all the MPs in Parliament
3 about the real issues that were affecting their
4 constituents, and then that led to another weak
5 review, shall I say, by the Government, and
6 an announcement in 2011, which meant that people
7 weren't really any better off.

8 **MS FRASER BUTLIN:** Just pausing there, the point I want to
9 pick up with you from this document, it's slightly
10 different. Could we turn to page 5 of the document.
11 At the bottom of the document, we can see your -- one
12 of your contributions. There are many in this
13 document but one of the contributions is you explain
14 that an acknowledgement of what happened is what
15 everyone wants. I think it's Jason McCartney from
16 Colne Valley then confirmed MPs made that point in the
17 2010 HOC debate --

18 **MS KELLY:** Right.

19 **MS FRASER BUTLIN:** -- and there was a suggestion on the
20 next page of another backbench business committee
21 debate.

22 **MS KELLY:** Yes, so --

23 **MS FRASER BUTLIN:** Just in terms of that work you were
24 doing, seeking a public inquiry and, as you say,
25 seeking acknowledgement of what had happen, what was

80

1 happening at this time?
 2 **MS KELLY:** Nothing. Nothing, really. It was the same old
 3 thing, you know. Government -- they'd have
 4 a consultation, they'd make the questions so narrow
 5 that people couldn't answer the questions or they
 6 couldn't highlight the issues they were having. We
 7 had real issues with people regarding financial
 8 support. The Government would then -- they'd just do
 9 as little as they possibly could. It would be, as
 10 Bill said, an insult. People were relying on
 11 something being done, because they -- you know,
 12 morally, as we've just heard, morally, Government had
 13 a responsibility to do that. And every time there was
 14 an announcement at Westminster, there wouldn't really
 15 be very much in the announcement but it would be, you
 16 know, a big PR exercise for the Government where
 17 they'd announce how much money they'd already given
 18 the scheme since they were set up.

19 Then in the devolved nations, we'd always have
 20 the same thing. Same pattern. The Minister wouldn't
 21 know that Westminster was going to make
 22 an announcement, there'd always be a delay. Because
 23 we had better communication with Welsh Government,
 24 we'd always have an opportunity to going and speak to
 25 the Welsh Government, I think it was Edwina Hart at

81

1 Julie Morgan one of them, but, you know, Mick Antoniw
 2 and Dr Dai Lloyd, they had all been involved since the
 3 beginning of the assembly, Dai Lloyd, they knew how
 4 strong the feeling was in Wales, so they started to
 5 veer away from Westminster in that regard because they
 6 heard the personal stories. And basically many people
 7 at the meetings, they were never going to benefit from
 8 financial support because they weren't included in any
 9 schemes anyway.

10 And the fact that we were still asking for, you
 11 know, partners to be included in the scheme after
 12 30 years, it was just a joke, really. So Welsh
 13 Government, then, they started to support the calls
 14 for the public Inquiry. That was a big turning point.
 15 You know, obviously Julie Morgan, she led that, but it
 16 wasn't like that in Westminster. It was a battle all
 17 the way. And then, eventually, in 2017,
 18 Welsh Government voted in favour of a public inquiry,
 19 and that was a real breakthrough.

20 **MS FRASER BUTLIN:** And that was a unanimous vote
 21 by -- (overspeaking) --

22 **MS KELLY:** Yeah, a unanimous vote.

23 **MS FRASER BUTLIN:** -- on 25 January 2017.

24 **MS KELLY:** Yeah, and we had a big debate in the Assembly
 25 and we had the names of all the people who had died,

83

1 the time, and the Welsh Government would make any
 2 tweaks to whatever the announcement had been, so we
 3 would relay issues about again, monitoring, so they'd
 4 agree they'd have FibroScans to monitor --

5 **MS FRASER BUTLIN:** Just staying on the much more narrow
 6 point for now, Lynne, about the Public Inquiry and the
 7 campaign for a Public Inquiry --

8 **MS KELLY:** Yes, so there was --

9 **MS FRASER BUTLIN:** We've got this in 2013.

10 **MS KELLY:** Yes.

11 **MS FRASER BUTLIN:** I think at the time you were also
 12 having meetings and writing letters to Alun Cairns,
 13 Carwyn Jones and Vaughan Gething.

14 **MS KELLY:** Yes.

15 **MS FRASER BUTLIN:** What response did you get in relation
 16 to the seeking of a public inquiry?

17 **MS KELLY:** The Public Inquiry. Initially I would say that
 18 obviously the Welsh Government had been briefed by
 19 Westminster so they didn't feel there was any need for
 20 a public inquiry. You know, the usual thing, Archer
 21 Inquiry had said there was no fault, there would be no
 22 benefit in having another inquiry.

23 As a cross party group, as we gathered more and
 24 more strength with that and we had more and more
 25 meetings, obviously the key politicians in Wales,

82

1 and they ran around the Senedd as all our Assembly
 2 members spoke. The Assembly members knew all their
 3 constituents and obviously they were able to relay the
 4 stories. And we had, you know, a vote. It was
 5 a voteable motion and there was a unanimous vote for
 6 a public inquiry.

7 We'd had similar debates in Westminster, the
 8 Backbench Business debate we'd had, same stories about
 9 the hardship, the suffering. The MPs themselves,
 10 Welsh MPs, they -- you know, they -- obviously the
 11 same, they knew their constituents. They all
 12 supported it. But then Government would bring in
 13 a three-line whip and that would just all be decimated
 14 or they'd try and bring in a wrecking motion. They'd
 15 change the -- they'd change the -- you know, the Bill.
 16 And then we'd share in the House of Lords, then,
 17 from -- can I say Bill Howe?

18 **MS FRASER BUTLIN:** I'm not aware of the name being
 19 redacted.

20 **MS KELLY:** So the Government would introduce a wrecking
 21 motion, and you'd have the likes of Earl Howe in the
 22 House of Lords, because we were obviously lobbying at
 23 that time that it was something along the Irish
 24 settlement we were looking for, because it was a much
 25 broader scheme that included more of the affected

84

1 people. It had life assurance, mortgage protection,
2 priority access to healthcare. And members of the
3 House of Lords such as Lord Howe would say that -- why
4 should they introduce that? They couldn't
5 discriminate between the route of infection, all it
6 would lead to would be people jumping the organ
7 donation queue.

8 **MS FRASER BUTLIN:** Again, just returning to the question
9 of the public Inquiry, there was the unanimous vote in
10 the Welsh Assembly.

11 **MS KELLY:** Yes.

12 **MS FRASER BUTLIN:** Then I understand you met with
13 Vaughan Gething on 23 November 2017 about the public
14 Inquiry.

15 **MS KELLY:** Yes.

16 **MS FRASER BUTLIN:** Can you tell us about that.

17 **MS KELLY:** He agreed when that he would write to
18 Jeremy Hunt, in support of a public inquiry. At that
19 time we'd had consultations in Wales. This was after
20 the Task and Finish Group, we had workshops around
21 Wales, where Welsh Government met then, again, with
22 all the families, and the stories were told again.
23 And basically the strength of feeling was so strong
24 that Vaughan Gething, the Health Minister, said, well,
25 he had to write, and obviously we were delighted,

85

1 that certain issues would also be resolved by the
2 Penrose Inquiry?

3 **MR HAMILTON:** That's a very good question and I'll answer
4 that in one second. If I could first of all say,
5 having listened to Bill and Lynne, I'm in some ways
6 a Johnny Come Lately to this process. I've been
7 canvassing or campaigning or advocating for about
8 six years. But to listen to their stories, they have
9 been pioneering in setting up, with others, the
10 context for where we are now. In terms of the
11 situation across the devolved assemblies and in terms
12 of the constituency of Northern Ireland, I would say
13 haemophiliacs here have had less access to the
14 political awareness and the political interaction that
15 has taken place in England -- in Wales and Scotland,
16 rather, with England. We in Northern Ireland, as
17 a cohort of victims, as a cohort of people who have
18 been enduring the process, have been enduring the
19 process.

20 I think, to answer you very briefly, people
21 didn't have a lot of hope. There's a difference
22 between hope and expectation, and hope and reality.
23 And I think most people felt this is just another go.
24 If there is anything, if there is further
25 consideration, we might get something, we might get

87

1 because it was a massive breakthrough. You know,
2 there'd never been a Government that would support it.
3 But the Welsh Government said, well, they had
4 nowhere -- you know, that's what they had to do. They
5 knew it wasn't going to work any other way. So that
6 was a huge breakthrough for us.

7 **MS FRASER BUTLIN:** Just pausing there in terms of the
8 campaign work you did for the public Inquiry. What
9 was the impact of devolution on your campaigning?

10 **MS KELLY:** So, as far as devolution was concerned, I think
11 it was good insofar as we had good access to Welsh
12 Parliament. It caused confusion when an announcement
13 was made, but it gave us the strength to lobby our
14 Welsh Government, and obviously they supported us then
15 in our calls for the public inquiry. So I suppose it
16 was twofold, really.

17 **MS FRASER BUTLIN:** We're going to come back to the
18 financial recompense in all three nations in a moment.

19 Simon, you've described in your statement --
20 thank you for your patience -- you've described in
21 your statement --

22 **MR HAMILTON:** Not at all.

23 **MS FRASER BUTLIN:** You've described Penrose as
24 a whitewash. To what extent did the infected and
25 affected community in Northern Ireland hold out hope

86

1 some benefit from it. But there wasn't any strong
2 belief that we would -- we would have any issues
3 addressed. And bear in mind the history of Northern
4 Ireland being under direct rule.

5 Our Department of Health would have responded to
6 the guide and direction from central Government, from
7 the Department of Health in England. So that was the
8 process, by and large. And people had come to accept
9 their lot, reluctantly, but in reality, that appeared
10 to be it. So we wouldn't have had a great
11 expectation. It didn't give up hope but we wouldn't
12 have had a great expectation.

13 **MS FRASER BUTLIN:** And after the Penrose Inquiry Report,
14 you wrote to all Northern Irish MPs in relation to --

15 **MR HAMILTON:** Yes.

16 **MS FRASER BUTLIN:** -- a public inquiry. Can you tell us
17 what you were seeking in those letters.

18 **MR HAMILTON:** Yeah, I did indeed. Actually, first of all,
19 when I saw -- and I listened to what Bill was saying.
20 I felt anger. I felt anger at what had come out of
21 that. I felt that it had been -- underwhelming would
22 be a very generous way of putting it. It had not
23 achieved its aim. It had not served the people. It
24 had not -- perhaps it served Government but it didn't
25 serve anybody else. And I felt that there was a moral

88

1 issue at stake and the moral issue was that the
2 Government would do what was right, and I felt
3 personally that I should write to all the Westminster
4 MPs in Northern Ireland to make contact with them,
5 raise the awareness of the issues, encourage or
6 challenge them to be more aware of the needs coming
7 out of these failed inquiries and that haemophiliacs
8 and people infected across the realm with the blood --
9 contaminated blood issues should be better served and
10 be given a voice and their voice be recognised.

11 After Penrose, there was a great feeling that
12 we'd just been beaten down.

13 **MS FRASER BUTLIN:** I want to move on to the question of
14 financial recompense with each of you.

15 **MS KELLY:** Could I just add something, because obviously
16 you put the APPG in front of me? What I would say is
17 that at that meeting, I think I am right in saying it
18 was Anna Soubry who attended that meeting. Is that
19 the right one?

20 **MS FRASER BUTLIN:** Yes.

21 **MS KELLY:** And I would say that one of the Welsh MPs
22 remarked that she was the worst briefed minister that
23 he'd ever met. So she came to the meeting just
24 completely just not briefed at all. She'd been sent
25 the questions ahead beforehand, I think, by Diana

89

1 **MS FRASER BUTLIN:** Thank you.

2 Before we look at financial recompense, Lynne,
3 I've been asked to invite you to explore one issue we
4 talked about this morning a little bit more.

5 Your experience of seeking a public inquiry.

6 Can you tell us what -- any -- whether there were any
7 particular obstacles you faced when you were
8 campaigning for a public inquiry?

9 **MS KELLY:** From the very beginning. Well, I think it was
10 the fact that the Government kept saying that there
11 was no fault, and then, when we had the
12 Lindsay Tribunal, obviously in Ireland they
13 compensated on moral grounds, and they took
14 responsibility but the Government changed that line
15 and the Government kept saying that the situation in
16 Ireland was different. Therefore that was repeated
17 and repeated and repeated, so obviously all the civil
18 servants over the years were briefed and everybody
19 kept saying the same thing, and then that went -- the
20 same was said in Welsh Government. They just repeated
21 the mantra, really, that it was different and there
22 would be no -- there was no fault, the circumstances
23 were different.

24 Therefore, they'd come back and say: well, you
25 know, there will be no public inquiry but we'll offer

91

1 Johnson, she couldn't answer any of the questions, and
2 she obviously had no understanding of what people were
3 looking for.

4 So, again, it was just that lack of interest in
5 Government, just deny it and push it away and they'll
6 stop coming, you know. That was what I wanted to --

7 **MS FRASER BUTLIN:** Thank you. I want to move on to
8 financial recompense and, I'm afraid, Bill, it comes
9 back to you to start with.

10 **MR WRIGHT:** Can I stop you there? I'm not sure how long
11 we've got to go before lunch but, this is all rather
12 embarrassing, I might have a very quick comfort break,
13 sir?

14 **SIR BRIAN LANGSTAFF:** Well, let's take a lunch break now,
15 since we are going on to something else.

16 **MR WRIGHT:** Sorry, sir.

17 **SIR BRIAN LANGSTAFF:** No, don't apologise, for goodness
18 sake. So let's come back, shall we, at ten to two?

19 **MS FRASER BUTLIN:** Thank you, sir.

20 **SIR BRIAN LANGSTAFF:** So ten to two.

21 **MR WRIGHT:** Thank you.

22 (12.47 pm)

(The luncheon adjournment)

24 (1.50 pm)

25 **SIR BRIAN LANGSTAFF:** Yes.

90

1 a bit more assistance, really. So it was only really
2 when it was 2015, 2016, when the Department of Health
3 issued the proposals for financial support and they
4 were only including widows at £10,000 each, we then
5 thought as a charity that we had to seek legal advice
6 on it. We tried some solicitors and we didn't find
7 anybody, and then I wrote to barristers in Cardiff
8 asking did they know of a barrister who could advise
9 us legally, because we knew it was the only answer --
10 it was the only way of getting to the truth.

11 Obviously as a group of trustees we're all
12 affected or infected volunteers and there were people
13 there that just didn't have time to wait. So we
14 thought, well, we'd try and get some legal advice.
15 And the lawyers in -- the barristers in Cardiff, they
16 said, well, you know, it was going to be expensive,
17 obviously, to get legal advice in the first instance.
18 And I said: well, could you -- I didn't know any
19 barristers at the time, I just sent a general enquiry
20 with, like, a paragraph about what we were looking
21 for. And I said, well, could they recommend any kind
22 solicitors who would see us free of charge?

23 And that's when we came into contact with
24 Watkins & Gunn -- I can say? Yeah, so
25 Michael Imperato of Watkins & Gunn. And as a group of

92

1 trustees we went in to see him, we all went, and we
2 just explained what had happened to each one in our
3 group. And it was the first time, really, we'd had
4 any interest from anyone to take on the cause because
5 I think it was seen as such a massive problem.

6 And when people actually in a group -- I'm sure
7 other people will have felt this -- once you start
8 telling your story to members of the public who don't
9 know anything about it, they actually think you're
10 a bit crazy because they would think: well, you know,
11 why -- this wouldn't -- the Government wouldn't do
12 this, this wouldn't happen. And it has happened.

13 So it was only by meeting Michael. Michael
14 said: well, they can't have a consultation in England
15 and expect Wales to contribute because Wales is
16 a country in its own right.

17 **MS FRASER BUTLIN:** And that consultation was about
18 financial assistance, just so that everyone is
19 understanding -- (overspeaking) --

20 **MS KELLY:** To start with, yes, yeah. And we raised funds
21 through CrowdJustice, then we put out an appeal, but
22 the ultimate goal was to get the public inquiry. And
23 from that time onwards, that's how we started getting
24 progress, because, you know, we didn't know how to go
25 about doing that, really, and we needed legal advice

93

1 Penrose Report. The first step that was then taken
2 was the financial review chaired by Ian Welsh.

3 **MR WRIGHT:** Yes.

4 **MS FRASER BUTLIN:** And you were part of that group.

5 **MR WRIGHT:** Yes.

6 **MS FRASER BUTLIN:** You've described several principles
7 being established that you regard as being central to
8 the schemes. Can you tell us what those central
9 principles are.

10 **MR WRIGHT:** Well, as Bruce said yesterday, nobody gets any
11 less as a result of that exercise. And I am referring
12 to -- sorry, my memory, I sometimes need to refer to
13 documentation. I'm referring to witness 051. The
14 reason I refer to this is because it sets the context
15 of what happened during the financial review, because
16 the context was set the day after the Penrose Report
17 came out. And there's reference in there -- it seems
18 that the particular official has put words in the
19 mouths of the First Minister.

20 But basically, they've put -- he's advised
21 ministers that:

22 "We agree with Mr Wright's observation and that
23 is why we will carry out an immediate commitment to
24 review and improve the financial support schemes on
25 offer to the people affected and their families" --

95

1 to do that. And it was just a stroke of luck, really,
2 that -- you know, that we started speaking to Michael
3 about it.

4 **MS FRASER BUTLIN:** I'm sure if there are further questions
5 arising from that --

6 **MS KELLY:** Sorry, I do have something else to say, if
7 that's okay.

8 The other thing that was fortuitous as well is
9 that I met my friend at the Haemophilia Alliance
10 meetings and, through her, I met her sister, who was
11 an MP at the time, and she is now [redacted]. Because
12 of her position, she was able to open doors at the
13 Department of Health. We'd have never been able to
14 get a meeting with, you know, Lord Prior or -- yeah,
15 at the Department of Health. We wouldn't have got to
16 see Sir Chris Wormald, and that was just through
17 [redacted], because obviously we would have just been
18 ignored, so she opened the door. And that was through
19 my friend.

20 **MS FRASER BUTLIN:** I want to move on now to issues of
21 financial recompense, and I'm conscious that some of
22 what we've talked about is woven into that so we'll
23 pick different things up.

24 In terms of Scotland, Bill, we spoke about the
25 announcement by Shona Robison the day after the

94

1 and this is the important bit -- "to be concluded
2 before World Haemophilia Day in April 2016."

3 Now, we were very conscious of avoiding drift,
4 so we'd put that idea into Government's mind about
5 time. And I remember having this debate with Dan
6 about, you know, let's set them a target date. Let's
7 not have the sort of ongoing yearly, "Oh, well, we
8 need to review this, we need to review that". And in
9 a sense we were setting ourselves a very tight
10 deadline.

11 So we wanted people to be involved in this
12 exercise. That was the second principle, that it
13 wasn't just going to be, you know, a bunch of the
14 great and the good, maybe with us tagged on to it.
15 There was a strong representation. Bruce was there,
16 Alice was there. The SIBF, our partner organisation
17 in Scotland, were there.

18 And it was actually a good exercise, if I can
19 say that.

20 **MS FRASER BUTLIN:** Just in terms of the core principles
21 that you felt were central, nobody was worse off.

22 **MR WRIGHT:** Yeah.

23 **MS FRASER BUTLIN:** And that people were --

24 **MR WRIGHT:** Involved.

25 **MS FRASER BUTLIN:** -- central and involved.

96

1 **MR WRIGHT:** Yes.

2 **MS FRASER BUTLIN:** And part of the involvement of people
3 was a consultation exercise that Haemophilia Scotland
4 were commissioning to undertake.

5 **MR WRIGHT:** The Dan roadshow. Our chief executive. He
6 went out and he listened to what people had to say.
7 He went to Aberdeen, Dundee, Inverness, Glasgow,
8 Edinburgh. But the other thing that Dan did that was
9 really important was that -- you know, there are some
10 people who don't actually like talking in a forum like
11 this, so he did one-to-one stuff. Sometimes
12 face-to-face and sometimes on the telephone. And he
13 brought all that stuff back, and that -- that was
14 really constructive. And there were some messages
15 came out of that particular exercise, one of which
16 reinforced the point about -- points about time and
17 points about not being any worse off.

18 There was a third thing that came through loud
19 and clear from that exercise and this relates to what
20 then was subsequently the review during the clinical
21 review -- that the clinical review came up with. And
22 that was people did not want assessment. They didn't
23 want to have to go through the big rigmarole. If you
24 go through assessment -- and I have personal
25 experience of this -- it takes a very, very long time.

97

1 across, as to a certain extent is represented in the
2 minority report. We've moved on from that since in
3 our thinking.

4 But there was this -- you know, there were these
5 very clear messages coming through. One of the -- on
6 reflection, one of the things that I think we maybe,
7 because of the time imperative that in effect we'd
8 said, that we maybe didn't quite get right was we were
9 still very stuck to the stage 1, stage 2 hepatitis
10 thing. Hands up, you know. And the signals we were
11 getting from Government was that they didn't really
12 want to break that because of what was, at that time,
13 prior to the clinical review, seen as a clinical
14 element in all of this: you can prove somebody has got
15 cirrhosis, they've got, you know, cancer, so on and so
16 forth.

17 So that was a bit of a shibboleth that we
18 couldn't really knock down.

19 **MS FRASER BUTLIN:** I think you've said that there's
20 a second element that you feel the group got wrong in
21 some ways and that was the position of widows?

22 **MR WRIGHT:** Well, ah, no. Actually, we fought very hard
23 for widows. But it was stage 1 widows that we let
24 down at that particular point. There was
25 a misunderstanding about stage 1 widows. I'll come on

99

1 **MS FRASER BUTLIN:** I want to pick up assessment with the
2 clinical review in a moment.

3 **MR WRIGHT:** Okay.

4 **MS FRASER BUTLIN:** But can I just finish off the financial
5 review.

6 In addition to those principles, can I ask, were
7 there any financial limits or parameters placed on the
8 group in relation to what they could recommend?

9 **MR WRIGHT:** No. One of the reasons we wanted to do this
10 was we wanted to do exactly the opposite to what
11 David Cameron had done to us the day before. We
12 wanted to build this from the ground up.

13 Now, you know, Government has to look at probity
14 and so on and so forth, but at the end of the day, we
15 wanted to say to Government: look, let's look at
16 a scheme -- and we arrived at -- because we'd got
17 completely fed up, we invited Jan Barlow during the
18 financial review to come and present to us. And, I'm
19 afraid, after we received her presentation we decided
20 we definitely didn't want to go down the road of
21 staying with the Alliance House organisations.

22 So we were really keen that this was a bottom-up
23 exercise, and the minister went for that. And that
24 was so important. To give people the voice. And
25 obviously, there were conflicting messages came

98

1 to the percentage business because -- no, we --
2 I remember there was a point at which, when we were
3 starting to talk figures, that the whole thing was
4 based on a principle of the median wage. We talked
5 around average wages, and we arrived -- Government
6 agreed that £27,000 at that point was the median wage,
7 so the whole scheme was constructed around that.

8 10,000 added on for those co-infected and there
9 was a figure of a one-off figure for stage 1s. So the
10 widows -- I remember the moment -- I can't remember if
11 it was Bruce or I, when we were saying, well, what's
12 going to happen here? This is something I feel so
13 passionately about because I haven't -- I've sat in
14 widows' houses and they pour out their stories. It's
15 a very intimate experience. And they'll be in tears.

16 And I remember Bruce and I, between us somehow,
17 the original proposal that I think came from
18 Government was about 50 per cent, and it was either
19 Bruce or I said, "What about 75?" And we didn't have
20 to push too hard. They went for it.

21 So the scheme was built around that, but the
22 point that I regret was we didn't also make clear
23 that -- the payments to stage 1s at that point.
24 I think we probably should have nailed it. Let's call
25 it a misunderstanding.

100

1 **MS FRASER BUTLIN:** You then appeared before the Scottish
2 Parliament's Health Committee on 9 February 2016 and
3 that address -- that issue was addressed at that
4 point. Is that right?

5 **MR WRIGHT:** Yeah, I was pushing the committee pretty hard
6 not to delay anything, let's not get into party
7 politics here, let's get this money -- I've -- money
8 in the pocket is the thing that matters. We can wait
9 another two, three, four years after this Inquiry,
10 and, you know, how many people are going to be left?
11 So I wanted to get money into people's bank accounts.

12 If I can illustrate this -- time was moving on,
13 we'd presented the financial report. There's a bit in
14 between here. We presented the report to Government,
15 Government indicated they would accept it in full, but
16 there was a bit in between. We were getting a bit
17 close to World Haemophilia Day.

18 In the meantime, there was a man dying and, my
19 God, that was hard, because he was one of -- I need to
20 be very careful here because I'm conscious of
21 protecting the family. But he was one of, let's just
22 say, a family of brothers and he'd been through hell
23 and we thought he'd made it: transplants, Hodgkins,
24 come out the other side, got treatment. And we knew
25 his daughter. His daughter had two severe haemophilia

101

1 **MR WRIGHT:** Yes.

2 **MS FRASER BUTLIN:** -- chaired by David Goldberg.

3 **MR WRIGHT:** Yes.

4 **MS FRASER BUTLIN:** You were one of the patient
5 representatives on it.

6 **MR WRIGHT:** Yes, there was myself, the chief executive of
7 Haemophilia Scotland, and Tommy Leggett, who's the
8 manager of the Scottish Infected Blood Forum. I'd
9 like to place on record, please, that our partner
10 organisation, the Scottish Infected Blood Forum,
11 Tommy -- I can't remember if at that time he was paid,
12 but he still continues to be the manager but he does
13 it on a *pro bono* basis without pay.

14 **MS FRASER BUTLIN:** I'm going to pick up issues of funding
15 towards the end of today.

16 **MR WRIGHT:** Sorry, yes okay.

17 **MS FRASER BUTLIN:** Can we just focus on one particular
18 matter in relation to the clinical review, and that is
19 that you've said in your statement that one of the
20 most difficult issues that you had to address during
21 the Clinical Review Group was the issue of assessment.

22 **MR WRIGHT:** Correct.

23 **MS FRASER BUTLIN:** What were the difficulties and the
24 issues that were being discussed in the Group about
25 assessment?

103

1 sons. So we were in contact, you know, with that
2 family, and the daughter texted me. I actually
3 remember about four months earlier, I was on the Isle
4 of Skye when she phoned me and said, "Dad's had
5 a really bad diagnosis". He'd developed -- because of
6 the treatment he'd had during Hodgkins, he'd developed
7 leukaemia.

8 I remember she phoned me. I couldn't actually
9 believe it at the moment because he'd been so lively.
10 And so she texted me to say "Where are we up to with
11 the financial review?" because he would want to ensure
12 that his widow was looked after. So I got back to
13 her, and I said "Would you allow me to take the
14 wording of that text to the Minister?"

15 She agreed, and I did, and the Minister agreed.
16 And that's the sort of personal impact that's
17 important in all of these, these personal stories, in
18 that they weren't just seen as cases or figures or
19 statistics. And so I think it's important to bear
20 that in mind in relation to what then happened,
21 because I think the Minister appeared before us that
22 day at the financial -- sorry, at the Health
23 Committee.

24 **MS FRASER BUTLIN:** Then I want to move you forwards to the
25 Clinical Review Group in mid-2017 --

102

1 **MR WRIGHT:** Well, we were asked, because we were still in
2 this stage 1/stage 2 situation, we were asked examine
3 the whole situation in relation to those who'd -- who
4 from a clinical -- you know, in a clinical perspective
5 in terms of the liver and hepatitis, had not gone on
6 to transplant, carcinoma, cirrhosis, and there's a big
7 issue there because, as I think Bruce indicated
8 yesterday, it's not a simple matter, infects other
9 parts of the body.

10 However, we were there really to look at the
11 stage 1 situation and the Minister in the terms of
12 reference for the clinical review had specifically
13 asked us to look at this question.

14 So we started kicking this around, and what was
15 really interesting -- during the financials review,
16 patients had already said, "Don't want assessment".
17 When it came to the clinical review, the clinicians
18 were saying, "We don't want to do assessment", because
19 it affects the relationship between the patient and
20 the -- and their consultants.

21 Now, there were psychologists, hepatologists,
22 haematologists on that clinical review along with the
23 three of us, and a specialist nurse, and David as
24 chair, as epidemiologist. So it was actually one of
25 the consultants came up with the idea, one of the big

104

1 problems we've had in all of this is that patients --
 2 I hate the word "victims" -- but victims have never
 3 been trusted so why not let's give this back, why not
 4 let them assess themselves? We thought: the
 5 Government's never going to swallow that. And it was
 6 unanimous: let's go for it.

7 I've still got an outstanding bet with the
 8 manager of the Scottish Infected Blood Forum about how
 9 the proportions were going to break down. I think
 10 I owe him lunch.

11 But what then happened was we put it back,
 12 people were able -- you know, are you severely
 13 affected, are you moderately affected, or -- on
 14 a day-to-day type basis it's not really affecting you?
 15 And Government accepted the report.

16 **MS FRASER BUTLIN:** And, as you say, those recommendations
 17 were accepted by the Scottish Government, and so the
 18 position, as the Inquiry has heard from previous
 19 evidence, is of self-declaration.

20 Lynne, picking up the position in Wales, can we
 21 go all the way back to 2013, 2014, in relation to the
 22 Macfarlane Trust. Your statement talks about the fact
 23 that you gathered information about the difficulties
 24 people were having with the Trust. Can you tell us
 25 a little bit about what those difficulties were?

105

1 was set up in that way to divide the community,
 2 because if you're in a meeting with a lot of people
 3 and there would be maybe 30 or 40 people in a meeting
 4 at the Welsh Assembly and you've got parents of
 5 children, you know, and children, adult children who
 6 lost their parents. Once you start getting into
 7 detail about schemes and stage 1s and stage 2s and --
 8 it becomes an impossible meeting. So we had to think
 9 of a way forward where we would stay as group, and we
 10 wouldn't really get into all the details of the
 11 schemes. We obviously knew what was going on in
 12 Scotland and we knew that, you know, the widows were
 13 included, but that wasn't the whole answer.

14 You know, again, we looked to a wider settlement
 15 which was the Irish settlement, and we just felt that
 16 that would address all the issues that people in
 17 a room were having. We felt, well, that scheme, it
 18 wasn't -- it was the best we knew of. We didn't know
 19 of anything that was better than that. And you could
 20 sort of pinpoint the issues people were having, and
 21 you'd think: ah, well, if they were under the Irish
 22 scheme, you know, that would work, that could work.
 23 So we were really reticent to get into the detail.
 24 But we were sort of forced into that position then.
 25 And it's as if, that's -- when you come to meetings in

107

1 **MS KELLY:** Well, they basically couldn't get any money out
 2 of the Trust. People would ring and the calls
 3 wouldn't be returned. They were asking for support,
 4 but there would always be a really lengthy grant
 5 process. People weren't given guidelines of what they
 6 could -- and could apply for, and basically there was
 7 just no money coming forward. And that was a major
 8 issue. Those experiences had been combined with --
 9 we'd had a review of care, and obviously grouped in
 10 with care is obviously financial support. And we just
 11 had lots and lots of patients' experiences about the
 12 whole -- about the whole issue.

13 So obviously I'd -- you know, I would just --
 14 the people that came to the meetings, at the Cross
 15 Party Group meetings, they'd talked about their
 16 personal experiences. There was then the debate in
 17 Parliament, where the experiences were the same
 18 wherever you lived.

19 And we just felt, well, it was difficult because
 20 we didn't really want to engage with the schemes
 21 because we didn't believe in the schemes. We knew
 22 they'd been set up to give as little as possible to
 23 people. And we knew a large part of our group weren't
 24 included.

25 So it was a difficult situation. Obviously it

106

1 Parliament, then you'll get maybe a minister or
 2 a politician thinking: oh, you just want this,
 3 a better deal than, you know, the next scheme. But
 4 the schemes were all wrong anyway.

5 So we sort of avoided that, and we just thought
 6 well, as a group, people told us they weren't
 7 interested in tweaks to the schemes; they wanted the
 8 truth. They wanted the truth. They wanted to know
 9 what had happened to their loved one. You know, they
 10 wanted justice. And they wanted compensation,
 11 because, you know, they were entitled to compensation.
 12 And everybody knew it. Everybody in our group knew
 13 that, and they knew how wrong they'd been. So there
 14 was a reticence to try to push for a better -- an
 15 increase on a stage 1 or a stage 2, because it was
 16 very divisive by nature and we had to -- like, we're
 17 small, but we had to keep our group together. You
 18 know, we represent -- like, there's 300 people, and we
 19 thought, well, we're not funded by Government, we can
 20 do what we want as a charity. We're representing the
 21 interests of our people, and they're telling us what
 22 they want.

23 You know, and people -- if it was a meeting like
 24 that, they could put their hand up and they can say
 25 whatever they want and we're not beholden to

108

1 Government because we're relying on them for funding.
 2 So it was just a last, desperate attempt to get -- try
 3 and get the right thing for the community.
 4 **MS FRASER BUTLIN:** In terms of the Macfarlane Trust, when
 5 the monies were being transferred to the Terrence
 6 Higgins Trust.
 7 **MS KELLY:** Yes.
 8 **MS FRASER BUTLIN:** You lobbied against that.
 9 **MS KELLY:** I did, yes.
 10 **MS FRASER BUTLIN:** What was your concern?
 11 **MS KELLY:** Well, we -- I attended most -- well, all of the
 12 Cross Party, All Party Group meetings in Westminster,
 13 and the concern was, particularly by our Welsh group
 14 that we already had -- we had the different scheme by
 15 that time. We already had the Wales Infected Blood
 16 Support Scheme, so sort of going back a stage, we --
 17 obviously, we were heavily involved in the Wales
 18 Infected Blood Support Scheme and we fed our concerns
 19 into Welsh Government and they tried to set up a more
 20 holistic approach. So we felt we'd -- they'd sort of
 21 listened in that regard but there wasn't enough money
 22 in the scheme, so, you know, it could never work
 23 properly.
 24 But as regards the Macfarlane Trust, we just
 25 thought, well, we just wanted it to do all the things

109

1 that the other trusts weren't doing, Macfarlane,
 2 Skipton and what have you. But there was a particular
 3 issue with the Welsh people, you know, the infected,
 4 the HIV infected community, because they weren't
 5 consulted about it, they had no input into it.
 6 I would go to the All Party Groups and I'd make it
 7 clear that we didn't want the money to go into the
 8 Terrence Higgins Trust. People, they were just really
 9 deeply offended by that, and we asked that the money
 10 be divided. We understand that they didn't have
 11 psychological support in England, which we had in
 12 Wales, but we just said: "Well, why can't the Welsh
 13 beneficiaries just have their share of the reserves
 14 that are left?" And that -- I voiced that, you know,
 15 at lots of APPG meetings. Jackie Doyle-Price attended
 16 one of the meetings as well. But it just was ignored.
 17 And then the next thing, we weren't told, but
 18 the money had gone to the Terrence Higgins Trust.
 19 I then started to engage with the Terrence Higgins
 20 Trust, and I think I've spoken to three separate
 21 administrators who were administering the fund and
 22 basically they're doing another -- they're assessing
 23 need, is what they told me. And I said, "Well, are
 24 you providing grants? Because in Wales people would
 25 prefer to have grants."

110

1 "Oh, no, we're just providing services, and
 2 counselling services."
 3 Great, you know, if you don't have counselling,
 4 that's good. But in Wales we already had
 5 psychological support, we had welfare and benefits
 6 advice. We'd already got that under the Wales
 7 Infected Blood Support Scheme. So we thought it was
 8 really unfair that, you know, the HIV infected, why
 9 they didn't get their proportion of that.
 10 So, again, it was one of those issues where we
 11 felt in Wales that, as involved as I was, my voice
 12 wasn't being heard. And I felt that we that the
 13 support of our group. We'd asked our group what they
 14 wanted, what did they want to do. All the replies
 15 came back: they didn't -- you know, they didn't want
 16 it going to the Terrence Higgins Trust. And our worry
 17 was that the money would be used on various
 18 administrators and there wouldn't be any money left
 19 anyway. So it was just one of those examples again
 20 where -- you know, as a small charity, like, we're all
 21 volunteers. I run the charity from my home. But we
 22 have a really good understanding of our members in our
 23 group and we knew -- like, at a meeting I can say,
 24 "This is what our group want". And we don't have
 25 other groups in Wales. We don't have any other

111

1 campaigning groups. You know, we represent everybody
 2 who has had infected blood or blood products,
 3 families, bereaved families, and we pretty much
 4 thought, well, we can say what we like. We can say
 5 what we want to say. And that's the voice of all the
 6 people in Wales that can't come up to these meetings.
 7 You know, I'm trying to speak for them, but
 8 I just felt that I was ignored.
 9 **MS FRASER BUTLIN:** You had a particular query about
 10 something called the Honeycombe Fund and the Wilson
 11 Fund --
 12 **MS KELLY:** Yes.
 13 **MS FRASER BUTLIN:** -- and where they'd gone. What were
 14 your concerns about those?
 15 **MS KELLY:** Well, they were legacies that had been set up
 16 and they were specifically for HIV widows, so that
 17 they could retrain to -- well, I wouldn't like to use
 18 the phrase, I think it was used during the evidence,
 19 to move on, then, but to train -- you know, to have
 20 courses or training to get back to work. And when
 21 I asked questions about that, at the All Party Group
 22 meeting, you know, other people would say, "Oh, yeah,
 23 I might have heard of it", but it wasn't really very
 24 well known. This came from some of the older widows
 25 who remembered the very early days of the Macfarlane

112

1 Trust.
2 So we asked: well, when the Macfarlane Trust
3 most wound up, where did that money go? You know,
4 where was the Wilson Fund and the Honeycombe Legacy?
5 And basically I don't think anybody knew where it had
6 gone. So I contacted Welsh Government, Department of
7 Health official there, and asked her to -- if she
8 could find out what had happened. But the reply came
9 back from the Department that the Macfarlane Trust was
10 a charity and they had no influence over where that
11 money went. So we are still trying to find out about
12 that.

13 The other issue we had with the Macfarlane Trust
14 was the fact that they transferred all the data to
15 Russell-Cooke Solicitors, but we didn't know about
16 that. That came, you know -- and there were people
17 then coming forward. They'd heard about the Inquiry,
18 and that they couldn't access their data, and we were
19 just told, well, you know, that's what happened to
20 them.

21 I did speak to them and, you know, the solicitor
22 there was very helpful but again, it's one of these
23 officials who doesn't know anything about the
24 background, about what has happened. They've just put
25 it in. It's like another new system of -- you know,

113

1 need to have a Wales-specific consultation.
2 **MS FRASER BUTLIN:** Just before we get to the
3 Wales-specific consultation, can we look at the
4 response that Haemophilia Wales did to the English
5 consultation?
6 **MS KELLY:** Right.
7 **MS FRASER BUTLIN:** WITN3988008, page 2, please, Soumik.
8 Thank you.

9 We can see at the top of the page, it says,
10 "Response to Department of Health Proposals and
11 Consultation Infected Blood 21st January 2016 England
12 only.

13 "The proposed scheme is for England only. Welsh
14 affected people have been asked to complete the
15 consultation questionnaire by Carwyn Jones and Mark
16 Drakeford but the proposals do not apply to Wales.

17 "The Proposals for England do not provide either
18 the infected or the affected with a basic level of
19 financial security. No one will be better off and
20 many claimants will be worse off."

21 Then if we carry on to page 4, please. In the
22 second paragraph, very pithily in your response,
23 you've said:

24 "As these proposals are totally inadequate we
25 believe the Welsh [Government] should commit to doing

115

1 just making it more and more difficult, really, for
2 people to get any information from.
3 **MS FRASER BUTLIN:** In terms of financial support for
4 hepatitis C, in your statement you said that
5 Haemophilia Wales has been instrumental in maintaining
6 pressure for adequate financial support. Starting in
7 2016 --
8 **MS KELLY:** Right.
9 **MS FRASER BUTLIN:** -- there was a consultation running
10 about infected blood support. Who did you understand
11 that consultation applied to?
12 **MS KELLY:** Well, we didn't know, basically. We assumed
13 when the Department of Health, you know, started the
14 consultation, it was like -- it was for the whole of
15 the UK. And then you're sort of in this dilemma,
16 well, if you advise people not to engage with it,
17 they're not going to have their views known. And,
18 again, that's how we went, you know, we sought legal
19 advice on that because we really didn't know what was
20 happening. Once -- you know, once the apology had
21 been made by David Cameron, and then there was the
22 other announcement where they said, well, you know,
23 the schemes were going to be the responsibility of the
24 devolved powers, we didn't really know.
25 So it was -- our lawyers then said, well, we

114

1 something better in Wales."
2 That was your position in relation to the -- if
3 I can call it the English consultation. How had you
4 reached the understanding that it was England only?
5 **MS KELLY:** It was from the advice from our lawyers because
6 obviously we were a devolved power, you know, we had
7 our own Government. And that we needed to challenge
8 Welsh Government to do more.
9 **MS FRASER BUTLIN:** You then had a meeting with Vaughan
10 Gething on 6 July 2016 and we've got a letter
11 following up from that meeting, that's dated August.
12 Before we get to the letter, can you tell us what that
13 meeting was about? What happened at that meeting?
14 **MS KELLY:** Can you remind me?
15 **MS FRASER BUTLIN:** Of course, we can go to it, that's
16 fine. It wasn't meant to be a memory exercise
17 WITN3988009.
18 **MS KELLY:** Sorry, there's so many -- (overspeaking) --
19 **MS FRASER BUTLIN:** If we could have page 2, please,
20 Soumik.

21 Two particular paragraphs. The second paragraph
22 from Vaughan Gething:

23 "I appreciated you conveying the community's
24 views about the consultations and surveys that have
25 taken place over a number of years; recent

116

1 announcements about reform in Scotland; and likely
2 implications for those in Wales if the England reform
3 proposals were adopted."

4 Then skipping a paragraph:

5 "I appreciate you were concerned about the mixed
6 messages you were receiving about responsibilities for
7 the HIV/hepatitis C schemes. I am pleased to advise
8 that the Department of Health has now confirmed it
9 will continue to fund payments for the current
10 Spending Review Period ..."

11 That, I don't think, can be right, the date
12 that's given there:

13 "... and that future arrangements will be
14 determined as part of the subsequent Spending Review."

15 It references a meeting on 6 July. Do you
16 recall what was discussed then?

17 **MS KELLY:** Yeah, so I think we were just saying that
18 people in Wales would be worse off under the new
19 proposals, and if Wales were going to implement that,
20 they were doing the wrong thing. That -- I think they
21 basically, in England, they'd said that the widows
22 could have a £10,000 one-off payment, which we thought
23 was disgusting, and we just asked could something more
24 be done.

25 I think that's when they decided that they would

117

1 what came out of it was that people, you know, they
2 needed more support. They needed welfare and benefits
3 advice. There was obviously the problem with the
4 widows who weren't getting any money but it didn't
5 look at the wider picture because none of the -- the
6 rest of the affected community, the children and the
7 parents, they wouldn't have been invited to those
8 consultation meetings and that caused a problem for us
9 because they weren't labelled as beneficiaries. And
10 those people were leading people in our campaign,
11 which made our group very strong. They weren't
12 beneficiaries so they couldn't engage.

13 So, again, it was that issue where, as the chair
14 of the charity you've got to explain to people, look,
15 we're having these meetings and you can't come. That
16 had never happened before, we'd never done it that way
17 in Wales, we just invited anybody who wanted to come,
18 could come. That was a particular problem and then
19 out of the back of that consultation did come some
20 improvement. They did offer the three-year equivalent
21 payment for widows. But, again, after the three years
22 there was nothing.

23 So the Welsh widows, you know, they had a little
24 bit more money, but when you think that they're paying
25 off debts and a lot of them have lived in real poverty

119

1 have the workshops and consultations in Wales.

2 **MS FRASER BUTLIN:** What can you tell us about those?

3 **MS KELLY:** Yeah, so what happened, I think we had a few
4 meetings in between this, but basically Welsh
5 Government said that they would want to hear the
6 views, you know, of everybody across Wales. Of
7 course, as a group we already knew -- we knew all the
8 views anyway but they had to have their consultation
9 process. But again, it was a bit like the Alistair
10 Burt survey they did for the -- in England of the UK.

11 When Alistair Burt did his survey they asked
12 people what they wanted, and one of the main -- one of
13 three was that everybody wanted the statutory inquiry.
14 But the Department of Health then they issued their
15 next bit of the consultation and they took that, that
16 first answer, out of it. So that wasn't even asked.

17 And the survey we had for Welsh Government was
18 basically just focused on the scheme, you know, the
19 financial support: what can we do better to support
20 you? This sort of thing. But it was good because
21 people had an opportunity then to engage directly with
22 the Welsh Government officials and they were done
23 across Wales so, you know, it was -- that was good.

24 But there was a feeling within our group that it
25 didn't get to the nitty-gritty of it, you know. But

118

1 for years and years and brought their children up, you
2 know, that money didn't last at all because they were
3 paying off debts that they'd incurred or money they'd
4 borrowed from family.

5 So we felt Welsh Government, they did listen
6 but, again, the consultation was so narrow. It didn't
7 even touch the surface, really, of what was needed.
8 But out of the back of that, then, the Wales Infected
9 Blood Support Scheme was set up, and as per, you know,
10 issues that were raised during the consultation,
11 psychological support was provided, and also welfare
12 and benefits advice.

13 So they did try and make it a more holistic
14 scheme. And all the issues people had had with the
15 previous Alliance House trusts like, you know, they
16 couldn't get through, they couldn't talk to people,
17 they had a single point of contact. And, you know,
18 the scheme was set up. There's a hospital, a Velindre
19 Cancer Hospital in Cardiff, and the welfare and
20 benefits advisers there, they're specialists, they
21 worked there previously, but they are part of the
22 Wales Infected Blood Support Scheme, so they're really
23 good at getting, you know, where you have appeals
24 for -- you know, PIP appeals and things like that --
25 we were really struggling -- well, you know, as

120

1 a charity we were really struggling to advise people
2 on that because we're not experts.
3 But they've got really good support there and
4 that bit of it works well and it is much needed.
5 The psychological support, we did already have
6 psychological support in Wales. Am I okay to go on?
7 **MS FRASER BUTLIN:** Yeah, of course.
8 **MS KELLY:** Yeah, we did already have psychological support
9 in Wales and that was as a result of the 2011 Task and
10 Finish Group review. And that review was -- we took
11 part in that, but basically it was
12 a multi-disciplinary input then to the review and,
13 even though the number 1 concern for the patients was
14 the hepatology, what came out of the back of it was
15 that psychological support was provided.
16 So we already had four psychologists should be
17 appointed in 2011, and they were in the Haemophilia
18 Centres but that didn't then -- that was of no
19 consequence to the people who had had transfusions.
20 So they hadn't had any psychological support. So that
21 was included in the Wales Infected Blood Support
22 Scheme.
23 And that works well, because if families -- if
24 they're haemophiliacs, they can go to the Centre if,
25 you know, they're affected or infected by contaminated

121

1 Mechanism?
2 **MS KELLY:** One of our trustees is under the English scheme
3 because of this silly, um -- well, what would --
4 I don't know why it happens like that. When they made
5 these schemes devolved, obviously it was the country
6 of infection. So he lives in Wales now and he's
7 a trustee of Haemophilia Wales but he was infected in
8 England, so he comes under the English scheme. So we
9 knew he'd had terrible difficulty proving that he was
10 the -- proving the SCM in England but, to us, he is
11 badly impacted, and we just thought that was wrong.
12 Because we had -- as part of the haemophilia
13 review in 2011, the Minister, Edwina Hart, she
14 announced that we would have a group in Wales which
15 was called the All Wales Advisory Group on Inherited
16 Bleeding Disorders, which we sit on as Haemophilia
17 Wales, and patients can come and they can relay any
18 issues they have to them. But basically -- I've
19 forgotten the question!
20 **MS FRASER BUTLIN:** Oh, I'm sorry. Why you weren't in
21 favour of a Special Category Mechanism.
22 **MS KELLY:** Right, yeah, so basically, we -- obviously we
23 were in close contact with the haemophilia doctors
24 and, you know, they're always very helpful and, you
25 know, we work collaboratively with them to make sure

123

1 blood and we did make sure of that in 2011, that the
2 haemophilia psychological support wasn't just for the
3 infected person, it was for the affected family, as
4 well, and anybody can access that. Bereaved families
5 as well. And we wanted to make sure that that
6 happened with the Wales Infected Blood Support Scheme.
7 And there are some families who would just find it too
8 upsetting to go back to the Haemophilia Centre. So
9 that works well, that it's somewhere -- it's in
10 another hospital.
11 And, you know, the feedback I get is the
12 advisers, you know, they're very good and they offer
13 the right approach, and people feel that they can
14 speak to them openly, and they do help, you know, with
15 regards to benefits and the things that we were really
16 struggling to do as a charity.
17 **MS FRASER BUTLIN:** So that holistic approach, that side of
18 it, from what you say, seems to be working well.
19 **MS KELLY:** Yes.
20 **MS FRASER BUTLIN:** In terms of the financial side, some
21 campaigners in Wales were seeking -- or some
22 campaigners were seeking the introduction of a Special
23 Category Mechanism in Wales. Haemophilia Wales wasn't
24 in support of that. Can you tell us why that was?
25 What were your concerns about a Special Category

122

1 that any issues we have, you know, we try and bring
2 everybody together so everybody is on the same page.
3 And the consultant that was a member of our group, he
4 said that he knew there were difficulties in England
5 with the UKHCDO in England, because they were having
6 to go basically jump through hoops to prove this
7 Special Category Mechanism.
8 So we decided as a group that it wouldn't be the
9 right thing, just because England had it, why do we
10 want to copy something that isn't working in England?
11 So we asked, we put up a proposal and we thought:
12 well, if we had a panel, and under the Wales Infected
13 Blood Support Scheme and the work I've done at the
14 Welsh Assembly with hepatitis C elimination, and there
15 are really good hepatologists on that group and
16 they're very nice and very approachable, and we had
17 this idea that maybe they could be, sort of, a panel
18 and if somebody felt they were more impacted than
19 stage 1, they could go and they could relay their
20 concerns and it would be done in a very nice way. It
21 wouldn't be bureaucratic.
22 So that was one proposal. And then, obviously,
23 there was the self-assessment where people would -- if
24 they felt they were more impacted psychologically,
25 they could relay that as well, and then out of the

124

1 back of that, Welsh Government game up with a better
 2 proposal which was that people could self-assess to
 3 get an enhanced payment, and we looked at the form,
 4 and we obviously fed into it just to make it really
 5 simple and it's just three questions, and you don't
 6 need medical support in evidence. And anybody who has
 7 been infected, you know, they can fill that in
 8 themselves. They don't have to tell anybody and then,
 9 obviously, they can apply for the higher payment.

10 **MS FRASER BUTLIN:** That's the scheme that's been in place
 11 for those needing additional support?

12 **MS KELLY:** Yes, yeah. But, as I say again, it was about
 13 speaking to the doctors who were having -- who would
 14 have that additional workload then, to go through all
 15 the -- you know, the applicants. And obviously the
 16 Haemophilia Centres, they could do it, but then when
 17 you've got a transfusion person, they don't have any
 18 direct contact with a multi-disciplinary team because
 19 often they're not even being monitored if they're
 20 stage 1, which is a real problem. And that does need
 21 to be addressed, that these people are stage 1,
 22 they've had the new treatments, after a huge battle,
 23 but they need ongoing monitoring and support. But
 24 they don't have access back in -- they have to start
 25 with their GP again. And the GP will say "Oh, you

125

1 Remember the situation for us was, up until
 2 1998, we had direct rule and then we had a very
 3 sporadic and broken system until we got to 2017 when
 4 it fully collapsed under HRI, and then we were back in
 5 full -- well, effectively direct rule but it was
 6 direct rule from a distance, if you like, almost by
 7 proxy. And that has only come -- that has only
 8 changed again. And during that period, during the --
 9 a couple of sittings of Government, the block -- the
 10 majority block of the DUP MPs had a greater
 11 significance of influence, and therefore we felt it
 12 would be useful to communicate with them and try and
 13 get them to highlight the issues that we had as
 14 a community of sufferers in Northern Ireland, in
 15 relation to payment schemes, because we were watching
 16 schemes changing and we were watching schemes varying,
 17 and there was an anxiety that we would be left behind
 18 once more, in that situation.

19 So that was the main purpose, to try to keep us
 20 at the forefront.

21 **MS FRASER BUTLIN:** You received a reply. We have that.
 22 WITN2339018, please, Soumik. If we could have
 23 page 2, please.

24 In the first two paragraphs we can see that he
 25 thanks you for your recent letter about the English

127

1 don't need it because you've had the treatment".

2 **MS FRASER BUTLIN:** So there's nobody who could write that
 3 clinical letter, is that --

4 **MS KELLY:** Yeah, there's no -- there isn't anybody. So
 5 it's harder for transfusion people because they are
 6 completely -- you know, they're not even part of, you
 7 know, a haemophilia cohort then.

8 **MS FRASER BUTLIN:** Simon, if I can pick up with you. You
 9 started lobbying and campaigning in relation to
 10 financial recompense, I think, in about 2015.

11 **MR HAMILTON:** Yes.

12 **MS FRASER BUTLIN:** After the English consultation was
 13 announced, you wrote to the leader of the DUP in
 14 Westminster, Nigel Dodds. Go ahead.

15 **MR HAMILTON:** Sorry, yes, I did. There was a large block
 16 of DUP MPs and, as a consequence, my original idea was
 17 to try to communicate with as many constituency MPs as
 18 possible, and I did, and there were a number of those
 19 from other parties as well who were on the APPG. And
 20 they were very helpful in raising issues and generally
 21 discussing issues within that Westminster community,
 22 not only of the Northern Ireland Westminster MPs but
 23 of sharing discussion with others, and anything which
 24 raised the issue in relation to Northern Ireland was
 25 important.

126

1 consultation, and says:

2 "I have noted your concerns and will bear them
 3 in mind if and when the matter is raised in
 4 Parliament. However, health in Northern Ireland is
 5 a devolved matter and comes under the [it says remind,
 6 I think it probably means remit] of the Department of
 7 Health here. Any changes to health schemes in England
 8 does not mean there will be automatic changes to any
 9 such schemes in Northern Ireland as that would be
 10 a matter for our Minister for Health to decide on."

11 **MR HAMILTON:** Yes, well, we can untangle the semantics of
 12 that in reality because effectively I have submitted
 13 other letters for evidence where it indicates also
 14 that there was a reference back to the Minister of
 15 Health in Northern Ireland.

16 **MS FRASER BUTLIN:** We're absolutely going to come back to
 17 that in a moment, Simon. If we can just take it in
 18 stages.

19 **MR HAMILTON:** Sorry?

20 **MS FRASER BUTLIN:** In terms of this letter, what was your
 21 feeling when you received it?

22 **MR HAMILTON:** Well, I was less than enamoured.
 23 Effectively, I knew that in reality the Department of
 24 Health in Northern Ireland looked over its shoulder at
 25 England in order to get its guidance, and that had

128

1 been a traditional system within the Civil Service
 2 because we had so many years of direct rule. So I was
 3 rather sceptical of that and saw it as the beginning
 4 of a process of delay. Now I'm sure the minister --
 5 I'm sure Mr Dodds meant very well, and was trying to
 6 be helpful but the reality was something else.

7 **MS FRASER BUTLIN:** And so you wrote to Margaret Ritchie
 8 raising concerns and she made representations to the
 9 Department of Health.

10 **MR HAMILTON:** She did, yes. She did indeed. And of
 11 course, there was reference back to members of the
 12 constituency parties who were in the Assembly. But
 13 the reality of all of that was that it was actually
 14 Central Government that made decisions and was the
 15 guiding instrument for even our own department in
 16 terms of the treatment and payment schemes and support
 17 for haemophiliacs and infected and affected.

18 **MS FRASER BUTLIN:** And we've got the reply from the
 19 Department of Health, if we could put that up, please,
 20 Soumik. WITN2339020.

21 If we can pick up the second and third
 22 paragraphs, please.

23 "We have acknowledged that while the existing
 24 ex-gratia schemes of support have made a significant
 25 difference to the lives of many beneficiaries, many

129

1 continue regardless of that. And therefore, that in
 2 itself was an unsatisfactory answer with an
 3 unsatisfactory conclusion.

4 **MS FRASER BUTLIN:** And in terms of how valuable your
 5 response to any consultation would be, you also
 6 received a letter, a response from Sylvia Hermon MP.
 7 If we could have that, WITN2339021.

8 **MR HAMILTON:** Yes, Lady Sylvia was on the APPG for
 9 a period of time and therefore she was well informed.

10 **MS FRASER BUTLIN:** She refers to a letter from
 11 Simon Hamilton MLA which you've not been able to trace
 12 at this stage --

13 **MR HAMILTON:** Yes.

14 **MS FRASER BUTLIN:** -- but which we will hopefully track
 15 down. We can see that she is providing you with
 16 a copy of his letter but she also quotes part of his
 17 reply. In the third paragraph:

18 "You will note, however, he has stated in his
 19 reply that ... 'The consultation is an opportunity for
 20 all those who have been affected to express their
 21 views and although the proposals in the consultation
 22 paper are for England only, all UK patients have been
 23 invited to respond'."

24 **MR HAMILTON:** Yes. Well, as I said earlier, that is
 25 indicative of -- if it's read carefully by people like

131

1 people remain unhappy with the current system of
 2 financial and other support. Reforming the current
 3 payment schemes remains a priority and we are keen to
 4 get this right for those affected.

5 "The consultation seeks views on providing
 6 discretionary payments for travel and accommodation
 7 costs relating to ill health. However, the scheme
 8 bodies have always been clear that any discretionary
 9 payments they have made to registrants of the schemes
 10 will not necessarily continue to be made in the
 11 future."

12 And then, at the end of the document, you're
 13 referred to the consultation document, and encouraged
 14 to provide responses.

15 **MR HAMILTON:** Yes, I --

16 **MS FRASER BUTLIN:** What was your view of this response?

17 **MR HAMILTON:** Unsurprising. Unsurprising. And
 18 representative of the general approach, that we were
 19 being kept at arm's length. And effectively we were
 20 being -- we were being kept under control. I found it
 21 insulting, and so did a lot of my fellow sufferers,
 22 when we were told that this was something which may
 23 not necessarily continue in the future, considering
 24 the fact that the needs and also the health needs and
 25 the welfare needs of a number of sufferers would

130

1 myself, that's indicative of a message which says that
 2 what happens in England will ultimately happen in
 3 Northern Ireland, and therefore it was essential that
 4 we should respond to that under the circumstances.

5 **MS FRASER BUTLIN:** And if we go to the bottom we can see
 6 that in fact she has put a PS in handwriting:

7 "Please do submit comments as part of the
 8 consultation."

9 **MR HAMILTON:** Yes, indeed. And we did. Lady Sylvia has
 10 been very helpful.

11 **MS FRASER BUTLIN:** In trying to navigate this question of
 12 an English consultation, where you were being asked to
 13 respond, how did you understand what was going on?

14 **MR HAMILTON:** Well, this was really a way of gathering
 15 further information from a broader field of people.
 16 But the decision-making process was going to be
 17 Anglocentric. And if there was a follow-up, it would
 18 be the template in England that our Department of
 19 Health would address, would respond to. So, from that
 20 point of view, if you, if you like, the blueprint
 21 would be an English blueprint and then we would follow
 22 from that.

23 And that's indicative of the letter response
 24 I got from Simon Hamilton MLA, who was the Department
 25 of Health's minister, the one that you referred to

132

1 earlier. That would have been indicative of his
2 response, where he really said: we take our direction
3 from the Department of Health in England in relation
4 to support mechanisms.

5 **MS FRASER BUTLIN:** So how valuable did you think your
6 contribution from Northern Ireland was going to be to
7 that consultation?

8 **MR HAMILTON:** Well, I wouldn't flatter myself. I think at
9 the end of the day the Government had to make this, as
10 far as they could, a public responsive document, and
11 they were trying to gather and garner information.
12 But I don't think, at the end of the day, any
13 contribution we would make would have necessarily had
14 any significant value in that, unless it was being
15 delivered directly through our own system of
16 Government in Northern Ireland.

17 **MS FRASER BUTLIN:** Subsequently you received a call from
18 Julian Smith MP, what can you tell us about that?

19 **MR HAMILTON:** That was from -- Julian Smith was -- in
20 January '20, he was still the Secretary of State for
21 Northern Ireland. And this came on the heels of a lot
22 of work that I'd been doing, and some of my colleagues
23 had been doing, to try to promote issues around the
24 parity of schemes of payment, so that Northern Ireland
25 wasn't being left behind.

133

1 So obviously the campaign group who were invited to
2 that meeting in Portcullis House included
3 representatives from a number of the campaign groups
4 across the United Kingdom.

5 And forgive me, I've --

6 **MS FRASER BUTLIN:** I was asking you quite a specific
7 question about the figure of £55 million.

8 **MR HAMILTON:** Oh, sorry, yes.

9 At the meeting I noted from where I was sitting
10 that David Lidington sat very quietly, listening very
11 carefully to everything that was being said but didn't
12 spend much time for eyeservice with anybody else. As
13 a consequence, he was playing -- or he was writing
14 down and making notes, and the only comment he made at
15 the end of the meeting was, "How much is this going to
16 cost?" And we had done some calculations and we had
17 actually proposed what we felt was a fair and
18 reasonable solution to the financial issues that were
19 being raised by us, and that figure was roughly
20 a figure which was being presented.

21 **MS FRASER BUTLIN:** So that figure was presented by the
22 campaign groups?

23 **MR HAMILTON:** It was, yes.

24 **MS FRASER BUTLIN:** In terms of Northern Ireland
25 specifically, you had some meetings with Sue Gray,

135

1 **MS FRASER BUTLIN:** Simon, that's my misreading of your
2 statement. Then let us come back to it, if it is
3 January '20. I had picked up that it was rather
4 earlier. Let's take it in sequence. My fault.

5 **MR HAMILTON:** Yeah.

6 **MS FRASER BUTLIN:** Could we pick up then on
7 22 January 2019 at Portcullis House.

8 **MR HAMILTON:** Yes.

9 **MS FRASER BUTLIN:** You attended a meeting with a number of
10 representatives from a number of campaign groups,
11 meeting David Lidington and Jackie Doyle-Price.

12 **MR HAMILTON:** Yes.

13 **MS FRASER BUTLIN:** You've said in your statement that
14 a figure of £55 million was said to be the roundabout
15 figure which would resolve the parity issue. Do you
16 know where that figure came from?

17 **MR HAMILTON:** Well, yeah, I know that we had made -- as
18 a group, that -- Bill was involved in that, in that
19 meeting, and Lynne had a colleague in that meeting, so
20 they'll be both familiar with the circumstances. And
21 this -- the meeting came about as a consequence of
22 a number of correspondences between Sir Brian and
23 David Lidington when a request was made that the
24 Government would be responsive to issues around need,
25 and support for sufferers across the United Kingdom.

134

1 Permanent Secretary for Northern Ireland's department
2 of finance.

3 **MR HAMILTON:** I did, yes.

4 **MS FRASER BUTLIN:** What can you tell us about them?

5 **MR HAMILTON:** Well, Sue Gray was senior sponsoring officer
6 of the public inquiry at the time. She was also --
7 had also moved to Northern Ireland as the Permanent
8 Secretary for finance. And after that particular
9 meeting, I happened to meet her in the airport when we
10 were both travelling back and we had a conversation
11 and she said that she had been very positive about the
12 meeting, as had other civil servants at the time, and
13 she suggested we meet again. So we had an opportunity
14 for a couple of further meetings. And Sue Gray was
15 very positive about -- and very, very clear on the
16 need for a resolution to the parity issues as soon as
17 possible.

18 So I found her very encouraging in that regard.
19 It wasn't -- she was actually a breath of fresh air,
20 because, in a sense, the body of the Civil Service
21 tended to be slow moving and reluctant to accept that
22 there was a need to acknowledge the issues that we
23 were raising, that would have been addressed and dealt
24 with in a simple way through -- initially anyway
25 through a form of financial parity. But she had

136

1 a very clear, positive prospective and was quite
2 lateral thinking in how we should -- you know, how
3 things should go.

4 So from her I gained a lot of encouragement to
5 proceed because she didn't sound -- she didn't put me
6 off, you know, in the sense that she could see around
7 the corner, whereas other civil servants that I did
8 encounter were quite reluctant to move at all.

9 **MS FRASER BUTLIN:** Was there an additional benefit in your
10 conversations with her, by virtue of her role as
11 Permanent Secretary for the Department of Finance?
12 Did that give an additional assistance to, or
13 importance to, your contact with her?

14 **MR HAMILTON:** Well, I, in no way, tried to exploit her
15 position because I respected her position but, beyond
16 that, she facilitated a number of meetings and, in her
17 role as Permanent Secretary for Finance, she was
18 bringing her awareness of the situation around the
19 contaminated blood issues and issues around parity.
20 And, therefore, when issues of parity equivalence, ie
21 the payment schemes being uplifted, was being
22 addressed -- were being addressed, she was in a prime
23 position to indicate to the Finance Minister, Conor
24 Murphy, that this was something that was potentially
25 worthy.

137

1 servants who contacted me a few hours before the
2 moratorium was lifted on the document, and thanked me
3 on his behalf for my contribution. But my
4 contribution was representative of a lot of people's
5 so I would share that with many other people in
6 Northern Ireland.

7 However, interestingly enough, within that
8 document, at the very end of a series of agreements or
9 commitments on page 9, under the title "Delivering
10 a fair and compassionate society", and that's relates
11 back to what Bill had been talking about earlier on,
12 in regards to the Mace: compassion. The issue of
13 compassion has been represented or recognised here.
14 Under section 9 there was a commitment to provide
15 parity with the English scheme.

16 And that was a sense for us of real victory.
17 Regardless of what that meant, it meant that
18 Government was finally in Northern Ireland recognising
19 the importance of addressing this issue, and that
20 would -- I would say could be interpreted partially on
21 moral grounds. And I say that now because, having
22 listened to Minister Swann a few weeks ago where he
23 acknowledged the moral issue, and others, the moral
24 battle has already been won, in terms of addressing
25 the needs and issues of victims within this process.

139

1 Now, I would say, as well, that there was the
2 new document -- the new document, the new agreement,
3 which spawned the parity -- and you maybe wanting to
4 go on to that but, nevertheless, she would have had an
5 input into that as others did.

6 **MS FRASER BUTLIN:** Perhaps you can --

7 **MR HAMILTON:** -- (overspeaking) --

8 **MS FRASER BUTLIN:** Simon, do take us on to that, that's
9 exactly where I'm going, about how parity and your
10 work on parity has happened.

11 **MR HAMILTON:** Yes, really, and a lot of the evidence I've
12 submitted relates to the years 19 -- 2019 and 2020,
13 when we were moving from a position in Northern
14 Ireland of having no Government, to a position of
15 having our Government back. And the new -- the NDNA
16 document was an agreement document brought together by
17 all the parties, under Julian Smith and Steven Coveny
18 in the Republic of Ireland, and that document enabled
19 the parties to move forward. And it was a series of
20 agreements and negotiated arrangements, and within
21 that, issues that we had been very strongly advocating
22 and lobbying for, ie a parity scheme, those were
23 raised.

24 I did -- as you referred to earlier, I did hear
25 from Julian Smith's, one of his advisers, civil

138

1 So that has been contributory to that.

2 **MS FRASER BUTLIN:** Before we move on from January 2020
3 into the present day, I just want to pause and explore
4 with you, what were the difficulties that you faced,
5 given the political vacuum and the collapse of the
6 political situation?

7 **MR HAMILTON:** It's a very pertinent question. The reality
8 is -- and I know from other aspects of my professional
9 life -- that the Civil Service in Northern Ireland
10 asks a question with doubt if it has to pay money out.
11 And if there's a sense that there's a profit in this
12 for someone other than the Department, they would be
13 very reluctant to do it.

14 And that was part of the stalling mechanism we
15 experienced during the period of suspension of the
16 Northern Ireland Assembly. There was an acting Civil
17 Service. The Permanent Secretaries of the Civil
18 Service had power to make decision, but there had been
19 a number of legal cases against decisions they made
20 when significant amounts of finance were spent. And,
21 as a consequence of that, they had been -- they'd lost
22 their power and they realised that there was
23 a difficulty in making financial decisions. So we
24 were immediately up against it in trying to promote
25 the idea and trying to advocate for the idea of the

140

1 parity scheme, and we were aware that lots of meetings
2 were taking place and very little was happening.

3 The other issue, in answer to your question, is
4 this: and that is one of the big problems we found
5 with the Civil Service, that I found and colleagues
6 found with the Civil Service here, and perhaps it
7 spreads across Government in general, and that is
8 that -- and Bill has referred to it and Lynne has
9 referred to it in their experience as well, and that
10 is that sometimes there is a reluctance to be
11 transparent or a reluctance to explain the process.
12 By keeping us in the dark, we are not helped. By
13 keeping us in the dark over this period, many people
14 became quite disillusioned, very distressed,
15 despairing, losing confidence and faith in a system
16 which is supposed to protect them and, therefore,
17 that's not good for their mental health or anything
18 else either.

19 So there were negative impacts during this
20 period. I found the prevarication, the obfuscations,
21 the delaying tactics, the fear that this was going to
22 spring to another consultation and then another
23 consultation, until we were consultation exhausted
24 before anyone could make a decision. So we were left
25 really in the wilderness until the Minister was

141

1 needs of our beneficiaries. Whilst I welcomed this
2 short-term funding, a non-recurrent allocation of
3 temporary funding towards the end of a financial year
4 is not sufficient to address all the issues
5 sustainably. Consideration needs to be given to how
6 this issue can be sustainably resolved going forward.

7 "Financial support schemes across the UK vary
8 significantly, and simply replicating the English
9 regular annual payments to those infected may not
10 necessarily best address the needs of our
11 beneficiaries. As well as regular payments to those
12 infected individuals, there are a number of other
13 areas that need to be taken into consideration in any
14 future reform, which would increase the additional
15 costs of the [Northern Ireland] scheme on a recurrent
16 basis."

17 I think that's what you had discussed with him
18 at your meeting. Is that right?

19 **MR HAMILTON:** It is indeed. It is indeed, yes. In fact,
20 colleagues from one of the other groups, campaign
21 groups, their friends and families group, had met with
22 the Permanent Secretary for Health on a previous
23 occasion as part of our lobbying approach, and they
24 had struggled to make progress. And, I have to say,
25 that Government, once we got our Government back and

143

1 appointed.

2 **MS FRASER BUTLIN:** If we can pick up there when the
3 Minister was appointed. You had a meeting with Robin
4 Swann on 13 February 2020, and he wrote a letter to
5 Mervyn Storey MLA, recording what happened at that
6 meeting. If we can put that up on the screen,
7 WITN2339034, please, Soumik. Could I have page 2.

8 We can see at the bottom of this page, the
9 following:

10 "As you've highlighted in your correspondence,
11 following a January monitoring round allocation of
12 £1.03 million to my Department, I announced on
13 27 January interim payments for infected beneficiaries
14 of the NI Infected Blood Payment Scheme, ranging
15 between £4,000 and £8,000 per person. These interim
16 payments were intended as an immediate measure to
17 address the hurt caused by the uplift in England and
18 to alleviate the financial hardship that may be
19 endured by those infected and/or affected by
20 contaminated blood."

21 Then over the page:

22 "I was not in a position to allocate the full
23 £1.03 [million] at that point as I needed first to
24 consider how to make the best use of the remainder of
25 the monitoring round allocation in addressing the

142

1 the commitments in place, and fundamentally, in
2 fairness to Mr Swann, with a Minister who was
3 committed to doing the right thing, progress occurred
4 quite quickly.

5 What's interesting in this process is the
6 reality about the cost of support and the fact that
7 the budget within Northern Ireland is rather
8 restricted. And I think this is a bigger issue that
9 the Inquiry must take note of because, effectively,
10 while David Lidington found it quite a useful strategy
11 to devolve issues around payment the reality is, and
12 still remains, that the devolved assembly, certainly
13 in Northern Ireland and -- I can't speak for Wales but
14 I'm sure -- I'm aware that Wales are still battling
15 with this too, with Lynne. I'm aware that the money
16 isn't -- isn't in abundance and, therefore, central
17 Government has a responsibility. It's very easy for
18 a Minister to say, "Oh yes, this is definitely
19 a devolved issue, we must respect the devolution --
20 the system". Quite right, devolved assemblies have
21 their part, very importantly, in managing and
22 administering the health and support mechanisms but
23 because of the way our fiscal operation works in
24 Northern Ireland we may gather taxes, it goes to
25 England, and it comes back. And, therefore, the

144

1 Treasury has a key role in moving forward.
 2 If there were a compensatory arrangement at
 3 the end of this process, if there were, and it was
 4 left under the argument of David Lidington, for
 5 example, that it should be left to the devolved
 6 assemblies to arrange and make, then it would never
 7 happen, and we would be right back to where we
 8 started.
 9 **MS FRASER BUTLIN:** Simon, I'd very much like to pick those
 10 points up with all three of you on the panel in
 11 a moment but if we can finish the chronology in
 12 Northern Ireland --
 13 **MR HAMILTON:** I'm sorry.
 14 **MS FRASER BUTLIN:** -- no, not at all -- then we can pick
 15 up those general points. 25 March 2020, Robin Swann
 16 formally announced that those in Northern Ireland
 17 would receive the same payments as those in England,
 18 and payments would be made to non-affected widows and
 19 widowers.
 20 **MR HAMILTON:** Yes.
 21 **MS FRASER BUTLIN:** At that point you still had some
 22 concerns. What were they?
 23 **MR HAMILTON:** Yes, we that some concerns, I must say
 24 again, in praise of the Minister, he made
 25 a commitment. He was willing to meet us and he also

145

1 **MR HAMILTON:** Yes.
 2 **MS FRASER BUTLIN:** He has also provided a statement in
 3 response to your statement which, at the time, was
 4 critical of him --
 5 **MR HAMILTON:** Yes.
 6 **MS FRASER BUTLIN:** -- noting that things have moved on.
 7 He's states he's taken considerable steps to
 8 communicate openly with beneficiaries and has
 9 increased payments and widened eligibility to include
 10 the bereaved. He says that work continues at pace
 11 with the other UK nations to achieve greater parity of
 12 support across the UK for beneficiaries and says he'll
 13 be making further announcements in due course.
 14 **MR HAMILTON:** And I would totally concur with that. That
 15 evidence is much more up to date. The reality is
 16 we've moved on considerably and I would commend him
 17 for the way he has committed himself and the plans he
 18 has transparently laid out to us as well.
 19 **MS FRASER BUTLIN:** In your statement, Simon, you were very
 20 pessimistic and said that you now seriously have
 21 doubts that effective campaigning and good advocacy
 22 will eventually bring about change.
 23 **MR HAMILTON:** Yes.
 24 **MS FRASER BUTLIN:** Is that still your view?
 25 **MR HAMILTON:** I'll refer to that in my closing statement,

147

1 met the widows and he was willing to respond and he
 2 did make a commitment that he would meet the needs of
 3 the widows in some way, which he did, and further to
 4 that now, we're in a much better position because of
 5 the follow through with the current funding uplift, as
 6 it's being finalised.
 7 Mr Swann made commitments but those were
 8 commitments -- were temporary, if you like. There was
 9 a question mark over their longevity and he explained
 10 that there was a mechanism that would be required in
 11 order for that to happen and he had to do this
 12 a certain way. And he explained that in his own
 13 evidence recently as well, that he made the interim
 14 payment in the short-term, it amounted to over £1
 15 million -- 1.3, I think -- and subsequently, once that
 16 had been carried -- had been provided, in further
 17 rounds, monetary rounds, which is the way budget is
 18 divided and separated in Northern Ireland, that that
 19 funding would become established.
 20 And I received a letter from him very recently
 21 which also reassured me of that fact outside of the
 22 period of the evidence I submitted to you.
 23 **MS FRASER BUTLIN:** As you say, things have moved on in
 24 Northern Ireland and the Inquiry has heard evidence
 25 from Mr Swann himself.

146

1 if I may.
 2 **MS FRASER BUTLIN:** Of course.
 3 **MR HAMILTON:** I think that will be suitable then.
 4 **MS FRASER BUTLIN:** I won't steal your thunder.
 5 Can I just open the questions to the whole panel
 6 to finish off financial recompense before we take
 7 a break.
 8 **MR WRIGHT:** The break, can we bring it forward? I am
 9 afraid I've found myself in serious discomfort once
 10 again, and very embarrassing. Is that possible?
 11 **MS FRASER BUTLIN:** Yes.
 12 **SIR BRIAN LANGSTAFF:** Absolutely possible. We'll take
 13 a break, then, until twenty-five to four.
 14 **MR WRIGHT:** Thank you.
 15 **SIR BRIAN LANGSTAFF:** Twenty-five to four.
 16 **MR WRIGHT:** Thank you.
 17 **(3.10 pm)**
 18 **(A short break)**
 19 **(3.35 pm)**
 20 **(Proceedings delayed)**
 21 **(3.39 pm)**
 22 **SIR BRIAN LANGSTAFF:** Yes.
 23 **MS FRASER BUTLIN:** Just to round off the financial
 24 recompense part of today, can I ask all of you what
 25 your view is on whether financial recompense should be

148

1 a devolved matter. What the advantages and the
2 disadvantages of it, from your perspective, might be.
3 Simon, I don't know whether you want to start.

4 **MR HAMILTON:** I will, yes.

5 I think I've already outlined my concerns about
6 that, in the sense that money needs to come from
7 central Government. It is morally the responsibility
8 of Government prior to devolution at any stage,
9 central Government, and practical issues relating to
10 healthcare were derived from the core, and I think
11 that issues around finance are tied to that
12 responsibility and it's not a responsibility of the
13 devolved nations.

14 I believe the money must come from the Treasury
15 and I believe the Government must do that as part of
16 its recognition and acknowledgement of the situation.

17 The reality is, on the basis of the last couple
18 of years, even if we'd had a minister in prior to
19 that, he would have been or she would have been
20 struggling to find the finances to provide the uplift.

21 And bear in mind an uplift in Northern Ireland
22 was £1.3 million. Not 45 million, not 33 million,
23 not 23 million. So under those circumstances, it
24 would be meaningless, it would be a meaningless
25 gesture to make it a devolved matter. It would be

149

1 the problem going back, was frankly, the Treasury.
2 There's early -- if you look at a statement associated
3 with the Chief Secretary to the Treasury, then -- who
4 is the person responsible for the control of public
5 spending, in other words, they're the person who stops
6 money coming out -- then we need to go to the door of
7 the Treasury.

8 My qualification is responsiveness and
9 accountability. And that's where we see an advantage
10 in Scotland. You know, it's bloody hard work coming
11 down here to pin down people in power. It's a lot
12 easier to build relationships positively with devolved
13 Government, and therefore, I firmly believe that we
14 need to stick with a responsive Government in
15 Scotland.

16 One of the questions we were asked during the
17 financial review was: do you want to stick with a sort
18 of charity type -- Lynne talked about the problems of
19 the Macfarlane Trust. One of the problems we had was
20 that we were asked by the minister, "Do you want that
21 sort of arrangement, but with a Scottish set-up, or,
22 do you want a responsive, directly accountable
23 scheme?"

24 Now, SIBSS is part of, in effect, the Scottish
25 Department of Health. And she was very interested in

151

1 senseless.

2 **MS FRASER BUTLIN:** What do the others --

3 **MS KELLY:** I agree, yeah. I agree entirely with Simon.
4 The money has to come from the Treasury. It shouldn't
5 come out of the Health budget, because of all the
6 additional stress that causes people. And that's
7 often been used by blockers in the Department of
8 Health to say, "Oh, well, you know, this money needs
9 to be used for something else", and people are made to
10 feel that they're begging for money, and that just
11 is -- it's just horrific for people to think that.
12 And then when they speak to members of the general
13 public who don't understand what's gone on, people
14 think: oh, those people are stealing money from the
15 NHS budget. And they don't get the sympathy they
16 rightly deserve.

17 **MR WRIGHT:** I agree with both Simon and Lynne, but I'll
18 qualify it.

19 When the Scotland Act was passed, who could have
20 thought that there would be a liability on the new
21 Scottish Parliament and the Scottish Parliament -- and
22 this takes me back to my point about how much
23 devolution there was -- prior to 1999?

24 So I've actually discussed this at quite a high
25 level. And I see my conclusion in all of this, that

150

1 that and she backed us, because we made the decision
2 that we wanted to nail people. And when I'm dead and
3 gone, they'll be, you know -- people can be nabbed.
4 And I think that that's an element of this, that we --
5 what I want to avoid is a situation where there's
6 a ding dong battle between Government in Scotland and
7 Government down south.

8 So that's my qualification.

9 But there is clearly an issue in terms of
10 ultimately who pays, and I would very -- one other
11 point that I'd overlooked was when we had the
12 financial review in Scotland, the Scottish Finance
13 Minister in 2016 came up with £20 million from the
14 Health budget in Scotland. Going back to this Susan
15 Deacon attitude -- and I'm sorry, sir, but I think
16 this just illustrates what we've been through -- this
17 is when she's talking about affairs, about --

18 **MS FRASER BUTLIN:** Do you want to give me the number of
19 the --

20 **MR WRIGHT:** Yeah, 029. Witness 029.

21 **MS FRASER BUTLIN:** WITN2287029.

22 **MR WRIGHT:** If you go to the page with her picture on.

23 **MS FRASER BUTLIN:** It's page 5, Soumik.

24 **SIR BRIAN LANGSTAFF:** Have you got it?

25 **MR WRIGHT:** Yeah, if we maybe could scroll down, rather

152

1 than her teeth.
 2 If you look at the second --
 3 **SIR BRIAN LANGSTAFF:** I'm not sure everyone has --
 4 **MR WRIGHT:** Oh, sorry.
 5 **SIR BRIAN LANGSTAFF:** Thank you.
 6 **MR WRIGHT:** If you look at the second bottom line there,
 7 this was Susan Deacon in -- I mean, let me work this
 8 out -- around about 2001, 2002:
 9 "A worse-case scenario (sic) involving
 10 compensation to around 400 people might cost us £20m."
 11
 12 It took us 15 years to get there, because of
 13 that point of view!
 14 So yes, the money, the money has to come from
 15 the Treasury.
 16 **MS FRASER BUTLIN:** Lynne, Simon, do you have any views on
 17 that point of, yes, it comes from the Treasury but
 18 there's a qualification?
 19 **MR HAMILTON:** Sorry, Lynne first.
 20 **MS FRASER BUTLIN:** Go on, Lynne.
 21 **MS KELLY:** Yeah, I would say, from our perspective, that
 22 we -- at this time, at this moment in time, we
 23 wouldn't be able to say that we would want to have any
 24 sort of scheme because we've got -- we haven't
 25 consulted with our group and that's what we're going

153

1 to be doing over the next -- and obviously I've sent
 2 out to our members that our next meeting will discuss
 3 this very issue. So I don't really -- but definitely
 4 the money has to come from the Treasury. It shouldn't
 5 be left to the devolved governments.
 6 **MS FRASER BUTLIN:** Simon, did you want to chip in?
 7 **MR HAMILTON:** I just make a comment, yes. I think the
 8 reality is that the Government cannot pay currently
 9 for its responsibilities in Northern Ireland, and they
 10 would be looking to Government in England to increase
 11 payments that come in so that they could manage their
 12 responsibilities. From that point of view, it's
 13 illogical that they could possibly deal with this.
 14 In terms of constraints on Government, this is
 15 early -- it's early days in terms of how monies would
 16 be agreed. Similarly, with Lynne, we were talking to
 17 colleagues in relation to how arrangements for
 18 compensation might be delivered, and considering
 19 different routes for that. So beyond that, at this
 20 point, I wouldn't really want to comment.
 21 **MS FRASER BUTLIN:** I want to move on to two issues.
 22 Firstly, a question about look-back in Scotland and
 23 then quite a lot on clinical treatment in Wales and
 24 also in Scotland and Northern Ireland.
 25 But in relation to the look-back, Bill, there

154

1 was a particular series of documents you wanted to
 2 raise. So if we could have WITN2287053, please. And
 3 if we could have page 5 of it.
 4 What we're looking at is a note of a meeting on
 5 10th February 2000.
 6 In fact, sorry, Soumik, could we have page 2 so
 7 we can all see what this meeting was?
 8 We can see at the top:
 9 "Note of [a] meeting ... in SAH to discuss the
 10 information required to assist in the examination of
 11 circumstances surrounding the safety of SNBTS blood
 12 products from hepatitis C."
 13 And if we go on to page 5, please.
 14 **MR WRIGHT:** Before we do that, could I just point out that
 15 the handwritten note, the annotation on the front page
 16 about the attendance, is my wife's handwriting.
 17 **MS FRASER BUTLIN:** If we look on this page we've got
 18 paragraph 9, and there's lots of underlining and
 19 annotation and I think, as you say, the annotations
 20 that your wife's made during the Penrose Inquiry. Is
 21 that right?
 22 **MR WRIGHT:** Yes.
 23 **MS FRASER BUTLIN:** The paragraph reads:
 24 "Professor Lowe pointed out that most patients
 25 would have been infected whilst their predecessors

155

1 were in post and asked whether it was necessary to
 2 contact them to make them aware of the situation.
 3 Mrs Towers explained that this was a factual
 4 information gathering exercise but that it should be
 5 borne in mind that the information might be used in
 6 future Court actions. Professor Ludlam also sought
 7 advice on whether [the haemophilia directors] should
 8 be looking back to try to identify what had happened
 9 to patients whose whereabouts and status were unknown.
 10 Mrs Towers confirmed that Central Legal Office was
 11 representing the Trusts and SNBTS and that their HDs
 12 should therefore follow CLO advice on whether any
 13 further investigation or the tracking down of patients
 14 was necessary."
 15 In relation to Mrs Towers, do you know who she
 16 is? Was?
 17 **MR WRIGHT:** She was from the solicitors office within
 18 Government.
 19 **RACHEL:** I want to look at the next document and then ask
 20 you about the two documents at the same time.
 21 If we can go to WITN2287054.
 22 This is the report of a Scottish Government
 23 commissioned short-life working group, published in
 24 August 2016. And if we can turn to page -- I think
 25 it's probably your page 6, Soumik.

156

1 Under the heading "Executive Summary" we see
2 that it says:

3 "The Penrose Inquiry, published on March 25,
4 2015, recommended 'that the Scottish Government takes
5 all reasonable steps to offer an HCV test to everyone
6 in Scotland who had a blood transfusion before
7 September 1991 and who has not been tested for HCV'.

8 "A Short-Life Working Group, established by the
9 Scottish Government, was asked to consider what
10 specific actions should be taken in the context of the
11 Inquiry recommendation."

12 Then it carries on:

13 "To assess the extent of the problem -- ie,
14 estimated numbers of living HCV infected individuals
15 who acquired their infection through blood transfusion
16 in the UK pre-1991 and who remain undiagnosed ..."

17 It then carries on to say that it's estimated
18 that:

19 "... approximately 100,000 people ..."

20 If we can go over the page:

21 "... who received a blood transfusion pre-1991
22 in Scotland are still alive;

23 "approximately 100 of those 100,000 (0.1%) are
24 HCV infected;

25 "around 30 of the 100 remain undiagnosed."

157

1 the questions from Professor Ludlam?

2 **MR WRIGHT:** This issue has haunted me. And it's, to
3 a certain extent, sir, already partly been addressed
4 by questions to both Professor Ludlam, Professor Lowe,
5 when they gave evidence. But my conclusion is that
6 people, as a consequence of the Central Legal Office's
7 advice, in February 2000, were allowed to die. And
8 it's haunted me, because I went and asked some
9 questions about what had happened. I asked Dan to see
10 if he could follow it up with Government.

11 We see a number here of 13 had died. We don't
12 know how they died. Now, bear in mind that during the
13 Short Life Working Group, Professor Campbell Tait was
14 asked to go -- not only in the follow-up to the
15 Penrose Inquiry did they look for those who'd been not
16 identified, who'd had a blood transfusion, but
17 Campbell Tait actually went away to look at those
18 who'd been, like myself, a male haemophiliac, where
19 contact had been lost.

20 Campbell found I think it was 69 names. And,
21 you know, we've got some stats in front of us here.
22 36 could not be traced. If this exercise had been
23 conducted 15 years before, it would have been a lot
24 easier to find those 36 people and not worry about
25 whether or not they might bring out a lawsuit. You'd

159

1 If you bear with me, following through to 2021,
2 WITN2287055.

3 Page 2, please, Soumik.

4 We have a Freedom of Information Request which
5 asked:

6 "With regard to the implementation of the second
7 recommendation of the Penrose Short Life Working
8 Group, you asked for:

9 "1. How many individuals were traced; and how
10 many couldn't be traced?"

11 "2. How many of those traced were alive and how
12 many had died?"

13 If we go to the next page, the response. Just
14 under the heading "Response".

15 "Based on the information we received from
16 Health Protection Scotland in 2018, of 69 patients
17 whose status was investigated as a result of the Short
18 Life Working Group recommendation, 33 patients were
19 traced by CHI linkage analysis, and 36 could not be
20 traced.

21 "2. Of those traced, 20 were alive and 13 had
22 died."

23 Bill, you wanted to draw our attention to these
24 documents. Can you tell us what your concerns are,
25 particularly about that first document in relation to

158

1 actually treat them, support them, save their lives!

2 Now I realise that this is a very serious
3 accusation but why on earth were lawyers determining
4 public health decisions? Because we were a walking
5 public health issue. Why were those lawyers -- and
6 remember, this was during the time of Susan Deacon.
7 The Deputy Chief Medical Officer was at that meeting.

8 The other thing that scares me about this
9 is: where did the power lie at that time? We'd got
10 senior consultants from the haemophilia world, but
11 their lawyers were calling the shots. It's
12 a disgrace, this. It's an absolute -- we talked about
13 this being a public scandal, this is one of the worst
14 scandals that happened in Scotland.

15 I'm sorry, sir, but I have been very deeply
16 disturbed about this, and this is worthy of very deep
17 investigation. People need to be held to account
18 here. You can't just allow people to wander around
19 and not go and try and find them. The fact that that
20 Short Life Working Group managed to do that exercise
21 15 years later shows that you can at least make the
22 effort. They didn't make the effort.

23 I'm sorry, sir, but I -- it's wrong. I'm sorry,
24 Lynne.

25 **MS KELLY:** Can I add something to what Bill has just said?

160

1 **MR WRIGHT:** Yeah.

2 **MS KELLY:** I've got two points to make. What always
3 concerns me is the fact that this is the 1991 cut-off
4 date and we know there's people in Wales who were
5 infected after 1991, so why is that the cut-off date,
6 and that means that people aren't able to claim
7 support?

8 The second point is that the point you raise
9 about -- specific to Scotland, my experience is that
10 that is happening in the Department of Health in
11 England. I've been in meetings where they've talked
12 about hepatitis C look-back exercise. I don't think
13 it ever happens and, particularly for the haemophilia
14 cohort, all that would need to happen is the national
15 haemophilia database holds all the data on the
16 patients, the clinic notes at all the Haemophilia
17 Centres would have all the information. We know there
18 was nearly 100 per cent infection rate with
19 hepatitis C, so it would be fairly easy to find those
20 figures for the haemophilia cohort.

21 Again, more difficult for transfusion, because
22 they are -- you know, they're individuals and they're
23 not part of a cohort.

24 But my opinion is that the Department of Health
25 and Government don't want to find out how many people

161

1 this episode characterises Government's attitude on
2 this whole episode. We've talked about the word
3 "cover-up". This is indicative, this characterises
4 the cover-up.

5 And these are people. They're not just numbers.
6 They're people. And I think in respect of what Lynne
7 is saying here, you know, this wasn't about them,
8 whether or not they'd qualify for the money and let's
9 get it -- this was about treatment, the NHS, saving
10 people's life.

11 Lynne's right. In the early days of the
12 Scottish Government, it was still happening.

13 **MS FRASER BUTLIN:** Simon --

14 **MR WRIGHT:** I'm sorry, sir. This is just horrible.

15 **MS FRASER BUTLIN:** Simon, is there anything you want to
16 add?

17 **MR HAMILTON:** Yes, again, I think this comes back to the
18 heart of the issue of responsibility, and
19 responsibility is vested in those whom we put our
20 trust in. And obviously, preventative care is also
21 about being prognostic and knowing the scope of
22 what -- of the problems that have to be dealt with in
23 relation to healthcare and health treatment. If the
24 reality is that there is an assumption, an --
25 a reasonably well-informed assumption, that there is

163

1 are infected because, if they did, they wouldn't be --
2 they would just argue that they couldn't pay for it
3 and they couldn't afford it. And yet, at the same
4 time, we go to Parliamentary debates and we hear about
5 these -- the massive figures, the amount it's going to
6 cost compensate all these people. They just pluck
7 a figure out of the air. So they overestimate but
8 they make no attempt to find these people. And, you
9 know, most people, they just die, and it's never
10 recorded.

11 And, again, it goes on to this issue about why
12 aren't -- why isn't everybody offered a hepatitis C
13 test? Why do people have to go and seek one out? Why
14 have they got the '91 cut-off point? Why don't they
15 just offer it to everybody? Or just a really simple
16 question to the patient: "Have you ever had a blood
17 transfusion?" It's not difficult to ask a patient
18 that.

19 Some people might have had an operation and they
20 don't know they've had one but, generally, I think
21 most people would know if they'd had a blood
22 transfusion or not. And if they wanted to find the
23 people, they would do that. They don't want to find
24 them, that's the reason why.

25 **MR WRIGHT:** I absolutely agree with Lynne here, because

162

1 a bigger problem out there, without actually trying to
2 address it, then that is a mistake, because that
3 bigger problem will be a bigger problem. And a bigger
4 problem is what we want to try to avoid on the back of
5 this Public Inquiry. This is about lessons learned,
6 and lessons learned means that action needs to be
7 taken.

8 And, in terms of Northern Ireland, I would have
9 relative confidence that, certainly in terms of the
10 infected blood community contaminated haemophiliacs
11 are well protected and well looked after, there's
12 a knowledge of their need and we've got a very good
13 health centre here for haemophiliacs under Dr Benson.

14 I would have a greater concern in terms of the
15 broader victims, the broader infected contaminated
16 group and how clear Government is about the numbers
17 that that actually entails. And, unless we know, we
18 don't know. And that's is -- saying that makes it
19 simple and clear.

20 **MS FRASER BUTLIN:** If I can move on to a different topic.
21 Lynne, a lot of your work over the years has also been
22 in campaigning for the provision of services within
23 Wales. You mentioned the psychological support and
24 the outcome of that, I think, was that there's now
25 four haemophilia psychologists in Cardiff, Swansea and

164

1 Bangor. The hepatology provision in Wales has been
2 much more vexed, from your statement.

3 It's right, isn't it, that from 2007 there was
4 no hepatology care in Wales after the hepatologists
5 left his post --

6 **MS KELLY:** In South Wales, yes. In South Wales. Sorry,
7 I need to correct that. I mean, in Cardiff area.

8 Excuse me. There was a hepatologist at Swansea but
9 there wasn't one at Cardiff.

10 **MS FRASER BUTLIN:** A Task and Finish Group was established
11 in 2011, to consider haemophilia care in Wales and it
12 reported in June 2011.

13 Can we look at that. I want to turn to a couple
14 of documents and then I'll ask you about them.
15 WITN3988013, please, Soumik. If we start at page 2,
16 please.

17 We can see under the heading "Background":

18 "On the 8th March 2011 the previous Minister for
19 Health and Social Services made a statement about the
20 support available to individuals infected with
21 hepatitis C and/or HIV by NHS supplied blood
22 transfusions or blood products and their dependents.
23 As a result of a commitment made during her statement
24 a Ministerial Task and Finish Group was established
25 under the chairmanship of the Medical Director for NHS

165

1 Cardiff."

2 Before I ask you about that, Lynne, could we
3 also look at the ministerial announcement, WITN3988014
4 please, page 2. This was on 1 November 2011, arising
5 from the review, and if we see in the second
6 paragraph:

7 "The effective management of patients with
8 inherited bleeding disorders is complex and involves
9 the provision of comprehensive care by a team of
10 healthcare professionals with diverse skills. The
11 Group, therefore, considered a range of issues raised
12 by patient groups on the planning and delivery of
13 diagnosis, treatment and support services, including
14 physiotherapy, counselling and social services
15 support, for people with inherited bleeding disorders
16 in Wales."

17 Then just after that:

18 "The Review made a number of recommendations.
19 The Welsh Government is providing £96,369 additional
20 funding on a recurrent basis to support counselling
21 services for those with inherited bleeding disorders
22 which was one of the main recommendations contained
23 within the report."

24 When this ministerial announcement was made,
25 what was said about hepatology?

167

1 Wales to review services for people with inherited
2 bleeding disorders."

3 Then we have a heading "Summary of patient
4 concerns" and we can see a number of matters which are
5 underlined but if we carry on over the page, we see as
6 number 8, "Clinical Support Services", and it's noted:

7 "Gaps in the provision of various Clinical

8 Support Services are apparent. This is most
9 significant with regard to the hepatology service at
10 Cardiff and Vale University Health Board ..."

11 Then if we carry on to page 5, please, Soumik.
12 We have a heading "Gaps identified by the Task and
13 Finish Group":

14 "The main gaps in services identified by the
15 Group were:

16 "Lack of counselling and social work support
17 across Wales

18 "Lack of hepatology support particularly in
19 Cardiff ..."

20 We then carry on to page 8, where hepatology is
21 picked up again, where the recommendation is that:

22 "LHBs through their joint work on WHSSC should

23 "Ensure appropriate consultant and specialist
24 hepatology nurse input into the treatment of patients
25 with inherited bleeding disorders must be provided in

166

1 **MS KELLY:** Nothing.

2 **MS FRASER BUTLIN:** What concerns did that --

3 **MS KELLY:** So, obviously, when they talk about patient
4 groups, that's our group, and we know everybody, and
5 we got all the patient experiences together, and the
6 number one concern was access to consultant hepatology
7 opinion.

8 And when they announced -- so that was -- we
9 obviously -- we work collaboratively with the
10 haemophilia clinicians in Wales and I know -- you
11 know, we know them all, and there were patient
12 representatives as well. And that was the number one
13 concern that was put forward to Government. And when
14 the announcement came, the funding was allocated for
15 psychological support, which was needed, but it wasn't
16 the priority at the time, because the psychological
17 support was already too late because people had
18 already died, and why couldn't those support services
19 have been in place before they died? And maybe they
20 wouldn't have died.

21 So it could never really resolve that issue and
22 what made our group really cross was the fact that the
23 £96,000 was allocated but we felt that was just in
24 an easy win to put that in the announcement. It
25 looked like Welsh Government were doing the right

168

1 thing, and we are grateful for that because,
2 obviously, we did end up with our four psychologists,
3 but there were issues around physiotherapy as well,
4 and obviously we spoke to the haemophilia clinicians
5 and the other members of the Task and Finish Group,
6 gastroenterology lead, and there were all sorts -- all
7 multi-disciplinary input -- haemophilia nurses as
8 well, physios, social workers. And, basically,
9 I don't know whether you're going to show these emails
10 but there are emails in my statement which shows the
11 support that the haemophilia doctors in Wales had for
12 the patients' number one concern, because they knew
13 that it was such a concern.

14 And the haemophilia doctor, particularly in
15 Cardiff, felt that, you know, it was much needed, and
16 he had made a case for that to the health board, to
17 Cardiff and Vale. But there was -- you know, nothing
18 happen. Basically, they were ignored.

19 So we had group of haemophilia doctors, the
20 Welsh doctors, they were supporting what the patient
21 group was saying. We documented all the patient
22 experiences. We had various meetings. But basically
23 there was no money, and, unless -- well, we knew that
24 unless Welsh Government allocated funding for it, it
25 would then turn into an argument before -- between

169

1 **MS KELLY:** Yes, yeah.

2 **MS FRASER BUTLIN:** You were campaigning for a specialist
3 hepatologist --

4 **MS KELLY:** Yeah.

5 **MS FRASER BUTLIN:** -- to deal specifically in hepatology.

6 **MS KELLY:** Yeah, so the clinicians, they all wrote to the
7 Welsh Government, and -- or Dr Chris Jones who was the
8 Deputy Chief Medical Officer, in Wales, voicing their
9 concerns, and they also wrote to the Welsh
10 Commissioners, WHSSC, because we felt that as
11 haemophilia care, the Commissioners in Wales should
12 pay for that, because this is part of haemophilia
13 care. These people didn't just go out in the street
14 and catch these viruses. It should be part of the
15 National Service Specification.

16 And, basically, the clinicians were ignored.
17 And we just had to go back to lobbying through the
18 Cross Party Group then. And without their
19 intervention, it would have been ignored, we wouldn't
20 have got anywhere. So obviously all our Assembly
21 members started asking questions in the Assembly and
22 putting the Health Minister on the spot.

23 And, without that, without that collaboration
24 from both the medical profession and the politicians,
25 we would never -- we just wouldn't have got it.

171

1 Cardiff and Vale Health Board, and the Commissioners
2 in Wales for haemophilia care, which are Welsh --
3 they're called Welsh Health Specialist Services
4 Committee, because neither of them would want to fund
5 the appointment.

6 And the critical thing was that, if they
7 appointed a hepatologist at Cardiff -- at the Heath
8 Hospital in Cardiff, that -- if they weren't -- if it
9 wasn't dedicated for monitoring of haemophilia
10 patients or, better still, monitoring infected blood
11 patients, nobody would want to fill that post because
12 they'd have to do all the general day-to-day
13 gastroenterology duties and emergency. So our group
14 of patients still wouldn't have any benefit out of it.

15 So the only way it could work is if the funding
16 was specifically allocated for access to consultant
17 hepatology for the infected blood group. And that
18 would mean that they would have a priority access and
19 they would get regular clinic appointments, and they
20 would be monitored, and, you know, that -- it does
21 happen in Cardiff. But I think across the UK it's not
22 happening. And I know people it's -- you know, that's
23 true.

24 **MS FRASER BUTLIN:** Your concern was that you didn't want
25 a generalist -- a general gastroenterologist.

170

1 **MS FRASER BUTLIN:** Ultimately you asked Assembly member
2 Julie Morgan to write to the new Health Minister --

3 **MS KELLY:** Yes.

4 **MS FRASER BUTLIN:** -- who agreed to reconvene the Task and
5 Finish Group --

6 **MS KELLY:** Yes.

7 **MS FRASER BUTLIN:** -- just for a single meeting to discuss
8 the implementation of the earlier report. Is that
9 right?

10 **MS KELLY:** Yeah, because basically there was no progress,
11 no one was going to pick up the bill for this.

12 Neither the Health Board nor the Commissioners. And,
13 basically, we were just being fobbed off. So we made
14 some very angry representations at one of the group
15 meetings, and Julie agreed that she would start
16 lobbying on our behalf to make sure that the Task and
17 Finish Group recommendations were implemented.

18 **MS FRASER BUTLIN:** Ultimately, a gastroenterologist was
19 appointed.

20 **MS KELLY:** Yes, after all of that, and after all the clear
21 representations -- as I say, we knew -- the patients
22 know what they want, they know what they need. They
23 are the experts by experience, and they are the people
24 who -- they can -- if you ask any patient, you know,
25 some people are a little bit more reticent but,

172

1 basically, when somebody says in a meeting "Oh, I'm
2 having difficulty with this", you'll always get other
3 people, and that gives people confidence then to talk
4 about it. But, basically, we obviously spoke to our
5 clinicians about it and they gave us direction about
6 the sort of post we were looking for, and that was
7 because, you know, we have a good relationship with
8 them, and we want, you know, we want to work to try to
9 get the best for the survivors.

10 But, basically, they ignored that, to,
11 I suppose, dampen down the, you know, the angry noises
12 then. They said, well, they were appointing
13 a gastroenterologist but, again, this
14 gastroenterologist, he was just up to here with all
15 his general gastroenterology, so he wouldn't have
16 time -- he wouldn't have time to see the haemophilia
17 patients unless it was an absolute emergency and that
18 was the very scenario we wanted to avoid, because we
19 felt that our group of patients, under the
20 circumstances of their infection, they deserved to
21 have that care where they're monitored and they have
22 a comprehensive care package, to avoid people
23 decompensating and not being referred to the
24 appropriate specialist.

25 If they're under the care of a consultant

173

1 important that that monitoring takes place to, you
2 know, to prevent, you know, it being an emergency
3 admission.

4 And as I say, but that's of no consequence to
5 the transfusion people, because unless they're
6 attending the hospital, the stage 1s will just --
7 they're just off the radar and they say they're cured.

8 And they're not cured, and they're not called back.

9 **MR WRIGHT:** Counsel, might I support what Lynne is saying
10 here. We've got a bit of an obsession in Scotland
11 about care plans, and we've had different experience
12 in relation to hepatology support. In 2006 there was
13 an action plan to eventually rid Scotland of
14 hepatitis C. That's for everyone. And in some parts
15 of Scotland that's almost been achieved.

16 And now, within the haemophilia community, it's
17 certainly, as far as I'm aware of, if you wanted
18 treatment, you could get hepatology treatment. But
19 the point here that's coming out from this sort of --
20 what Lynne's talking about, where you've pioneered in
21 Wales in relation to psychological support, you've
22 also got support in terms of benefits. But hepatology
23 hasn't necessarily always been there.

24 And there are psychological -- you know,
25 psychological support. What we actually -- my

175

1 hepatologist, they're monitored, there's specialists,
2 they know exactly -- if things start to go wrong,
3 those patients get a chance then, because they -- you
4 know, they can be put forward for liver transplant.
5 Whereas if they're unmonitored, you know, liver
6 disease is called the silent killer and there are lots
7 of people in our group who, you know, maybe outwardly
8 aren't showing many symptoms, but they're -- inside,
9 their liver is failing. And they may go on for years
10 without decompensating, but, you know, it -- very
11 often it'll happen very suddenly and then its an
12 emergency admission, and then it's too late and
13 a cancer has grown and, you know, people just die
14 because of that.

15 **MS FRASER BUTLIN:** And there was also some delay in the
16 person joining the Trust because they were doing some
17 further hepatology training and -- (overspeaking) --

18 **MS KELLY:** Yeah, and he wasn't -- he wasn't a specialist
19 hepatologist, but we did eventually get our consultant
20 hepatologist then, 2015, Dr Srivastava, he started.
21 And again, he sees the haemophilia clinic patients
22 during clinic time.

23 We still feel that the stage 1s should be
24 monitored even though they've cleared the virus, they
25 don't have an active virus now. But it's really

174

1 obsession is for a care plan for people who have been
2 affected by this. And in some cases I include
3 families in that. And I see huge benefit in that.

4 One of the problems we've identified with this,
5 and I think Lynne is touching on it here in relation
6 to blood transfusion, is who would be the lead
7 professional? You know, from which particular field
8 would they come from, in terms of that agreement
9 between the patient and the NHS? Because we know that
10 there are very complex needs and co-morbidities, and
11 it's something that we've been seeking to raise
12 through our network in Scotland, Inherited Bleeding
13 Disorders Network, but as Lynne says, it's about
14 people with blood transfusions as well.

15 **MS FRASER BUTLIN:** Just picking up on the network in
16 Scotland, because one of the things you've also been
17 trying to work on is improving the psychology service
18 in Scotland. Differently to Wales, because Wales, you
19 were successful in it. What's happened with Scotland
20 in terms of psychology?

21 **MR WRIGHT:** Well, until very recently, Wales were ahead of
22 us. And I think it goes back to the report, the
23 King's Fund throughout Wales, way, way, way back.

24 We had support for some years now and initially
25 it was on a sort of pilot basis for two or three years

176

1 for people with haemophilia. That was extended from
2 the Lothian region across Scotland, but only very,
3 very recently. In fact appointments have just been
4 made within the last couple of weeks for people who
5 are -- either had blood transfusions, who are in
6 a nearby hospital or, in some cases, frankly, families
7 who have lost loved ones, they don't want to go near
8 a haemophilia unit. So that's available to them. But
9 I am aware that there's been close liaison between
10 those two parts.

11 **MS FRASER BUTLIN:** And that's been through the Scottish
12 Inherited Blood -- sorry, Scottish Inherited Bleeding
13 Disorders Network?

14 **MR WRIGHT:** No, let me clarify here. This is Scottish
15 Government's -- the other part of it, the
16 non-haemophilia part of it. But I believe the
17 psychologist from the haemophilia world was actually
18 involved in the interview panel for the people with
19 transfusions and families.

20 **MS FRASER BUTLIN:** Just staying on psychological support
21 while we're on it, Simon, in relation to Northern
22 Ireland, we heard from Dr Benson that there's been
23 additional psychological support established at the
24 Belfast Centre in the context of this Inquiry. What's
25 your involvement been in relation to that?

177

1 that this service is a service which will have
2 a broader use and a broader usefulness in terms of the
3 patient care and family care for those suffering or
4 within the contaminated -- blood contaminated
5 community. Certainly in terms of haemophilia, and
6 anyone related to the public Inquiry.

7 In relation to the other issues that were raised
8 earlier on about hepatology and the service itself,
9 I can only speak personally. We haven't had any real
10 anecdotes of people who are not happy with that
11 service. So I can't identify that. I can say in
12 terms of myself, as a stage 2 cirrhosis sufferer, that
13 only the other day I had a phone call asking me to go
14 for a blood test. So that reassures me that even
15 through this process, when it's difficult to access
16 monitoring, monitoring continues. And that's
17 reassuring.

18 And in terms of my brother, who -- my twin
19 brother, who developed cancer and had a liver
20 transplant, that service delivered him into good
21 health very well. And I hope that is the case for
22 others.

23 My understanding of any folk that we have come
24 into contact with has been that it has been
25 a reasonable experience.

179

1 **MR HAMILTON:** Yes, absolutely. I think, really -- and
2 I was listening to what Lynne and Bill were saying.
3 I think really, in terms of dating it, it certainly is
4 something which was post the beginning of the Inquiry.
5 In a sense, I would probably associate that with the
6 terms of reference of the Inquiry. I think there's
7 been a movement by the Belfast Trust to acknowledge
8 issues around mental health.

9 We have a dedicated psychologist. That post is
10 very shortly going to be made permanent. In fact that
11 date might already have passed, I haven't heard the
12 final result. But I'm aware that that service has
13 been used and utilised and is offered right across the
14 province. Under the pandemic, that process has been
15 promoted through Zoom or Teams, and accessibility
16 continues.

17 And some of the benefits of that process are
18 that it has enlightened us, really, that there's a
19 need not just in terms of dealing with the traumas
20 that have arisen out of the public Inquiry and
21 contaminated blood, but the general issues of trauma
22 and psychological disturbance which come for families
23 when they have haemophiliacs who have serious bleeds,
24 and serious accidents which occur. And also for
25 individuals as well. So I think there's a realisation

178

1 **MS FRASER BUTLIN:** Just before we leave the campaigning in
2 relation to clinical issues, Lynne, you were heavily
3 involved in lobbying for access to interferon-free
4 treatments. What response did you get when you raised
5 the question of providing that?

6 **MS KELLY:** Right. So that came about because when I was
7 a trustee of The Haemophilia Society, I was asked
8 by -- well, the chair basically couldn't attend
9 a meeting and he asked one of us to attend. And when
10 the email came through, I saw that it was going to be
11 an important meeting and it was in the Department of
12 Health, and it was a hepatitis C workshop.

13 And the chair of the meeting was Ben Cole, who
14 was somebody that I'd met previously, and who had
15 walked out of meetings when the Haemophilia Alliance
16 was dissolved and nobody would stand up and agree with
17 what I was saying. So I had a bit of a history with
18 him. So I thought, right, I'm going to go to that
19 meeting.

20 And when I went there, there were presentations
21 from leading hepatologists on the new interferon-free
22 treatment. So this was December 2013.

23 And basically I spoke to Professor Dusheiko from
24 the Royal Free after the meeting. I obviously spoke
25 at the meeting and said we were having difficulty

180

1 because we couldn't even get our patients monitored at
2 that time. And he told me that there had been no
3 input from the infected blood cohort to any of the
4 previous meetings. Which shocked me. There had been
5 input from the Hepatitis C Trust through lived
6 experience, but the person hadn't been infected
7 through contaminated blood. That person had had
8 hepatitis C through other means.

9 And basically, he said that, "We are trying
10 to -- as hepatologists, we're trying to lobby for an
11 early access scheme", prior to NICE approval.

12 So I emailed -- he gave me his email address and
13 I emailed him, and he gave me the information which
14 demonstrated that, you know, they were basically
15 lobbying NHS England to pay for these drugs because
16 they knew there was near to a 100% success rate,
17 particularly with the non-responders or the people who
18 hadn't cleared the treatments with three or four
19 previous interferon treatments.

20 So he sent me the email, and then I contacted
21 one of our Welsh patients who was at the stage where
22 their liver was decompensating and, as a favour, we'd
23 asked for Professor Thursz, who -- I can say the
24 doctor's name? Right, Professor Thursz, who is at
25 Saint Mary's in London, to monitor him. And

181

1 So, basically, I reported -- I -- actually,
2 I reported all of that back to the Haemophilia
3 Society, and I should add that when I went to the
4 workshop, which was chaired by Ben Cole, I did
5 actually ask for Joseph Peatty to come with me because
6 he's got a background in statistics. He's one of
7 the -- oh, can I say his name?

8 **MS FRASER BUTLIN:** Can we just pause the transmission just
9 in case. I didn't think it was redacted.

10 [Pause in transmission]

11 I don't think the name is mentioned in your
12 statement, so I'm not sure if it is due to be
13 redacted.

14 **SIR BRIAN LANGSTAFF:** I think better refer to him
15 neutrally if you can.

16 **MS KELLY:** Sorry, can you say that again?

17 **SIR BRIAN LANGSTAFF:** If you refer to him neutrally, if
18 you can, rather than by name.

19 [Pause in transmission]

20 We're back on.

21 **MS FRASER BUTLIN:** Thank you, sir.

22 **MS KELLY:** One of the campaigners in England, he had
23 a background in statistics and I knew that he would be
24 able to help me at the meeting, and I asked for him to
25 come, and that was refused. So that's how I went on

183

1 Professor Thursz is a leading hepatologist and he
2 kindly agreed to see one of our patients because this
3 man was going to die, basically, if he hadn't been
4 seen, and he didn't want to wait. His brother had
5 already died, so he didn't want to wait to get to the
6 stage where the liver -- the cancer had developed
7 outside the liver.

8 And Professor Thursz saw him, and when I emailed
9 him, he immediately replied back to me and said --
10 I think you've got the emails in my evidence -- but he
11 says that we're trying to lobby for early access, and
12 he said, "There's no representation from the infected
13 blood community". He said there's a press conference
14 the next day at the Kings Fund, and he said, "We're
15 trying to push NHS England to pay for these treatments
16 because we know they're working".

17 So he said, "Would you be able to come?" And
18 myself and a few others from our group, we went up to
19 the Kings Fund, and we spoke about what was happening
20 and, of course, the people there -- you know, we
21 met -- there were obviously all sorts of, you know,
22 people who had been infected by different means, but
23 everybody was really friendly to us, and, you know,
24 they said "Oh, we had no idea that, you know, your
25 group could be infected in that way".

182

1 my own. And, again, I thought that that was wrong,
2 because there was no other representation at the
3 meeting, apart from the Hepatitis C Trust.

4 So, basically, we went to the meeting and to the
5 press conference, and we spoke about, you know, how
6 our group were being denied the drugs.

7 I reported all of this back to The Haemophilia
8 Society because I was a trustee at the time, so if
9 I did anything, I would always have to report it back
10 to the Board. And, you know, to get sort of Board
11 approval to do these things. So I sent an email to
12 the -- to Bernard Manson and Liz Carroll, reporting
13 what I'd found, and I said, "Look we need to be really
14 lobbying Government now to get this moving".

15 And, basically, they just didn't understand.

16 They didn't understand what the urgency was about.

17 But when you know the people so well, you know them
18 personally, and you know it could save their lives,
19 you think, well, for many that was the only hope they
20 had. And --

21 **MS FRASER BUTLIN:** Sorry, sir, we've had a response from
22 Bernard Manson challenging that position and he would
23 say he did understand.

24 **MS KELLY:** Right.

25 **MS FRASER BUTLIN:** Can I just focus your answer, Lynne,

184

1 back on what I was asking about --
 2 **MS KELLY:** Sorry, yes.
 3 **MS FRASER BUTLIN:** -- and that was about what you did in
 4 relation to lobbying the Welsh Government for access.
 5 **MS KELLY:** Right, okay. So what I did then was I sort of
 6 felt -- I was just blocked, really, in both areas.
 7 And so I resigned and I just thought, well, it was
 8 easier to not have to report back to The Haemophilia
 9 Society that we would do it ourselves in Wales. We
 10 already knew all the -- we knew the Welsh Government,
 11 we knew the politicians. So through the All-Wales
 12 Advisory Group that I sat on, I made a case for --
 13 there were less than ten -- I think it was between six
 14 and ten people in Wales at the time who needed the
 15 treatment. And, basically, we just appealed to the
 16 Commissioners to: please can you fund that is
 17 treatment, because if they don't have it, they're
 18 going to die anyway.
 19 So this was prior to NICE approval.
 20 Going back -- I'm sorry, I've missed a bit
 21 because the important bit was that Professor Thursz
 22 said in his email -- and it is documented, it's in my
 23 evidence -- that there were all sorts of obstacles
 24 being put in the way by NHS England, as to why they
 25 shouldn't fund the treatment. And Professor Thursz

185

1 said they were inventing the obstacles, he said, as
 2 they went along then. And he blamed the Chief
 3 Pharmacist. I probably better -- can I say his name?
 4 **MS FRASER BUTLIN:** Absolutely.
 5 **MS KELLY:** Malcolm Qualie, so he was the pharmacist who
 6 was preventing that happening. Professor Thursz and
 7 the hepatologists took great exception to it, Matthew
 8 Cramp was involved, the hepatologist from Plymouth,
 9 and they were the experts, they were the specialists.
 10 They were the doctors. They were saying what needed
 11 to happen. And this was being contested by the NHS
 12 Commissioners and a pharmacist who knew nothing about
 13 hepatology, nothing about liver disease, and they
 14 would have the final say.
 15 So the decision was basically just on funding.
 16 It was nothing to do with clinical need.
 17 **MS FRASER BUTLIN:** Can I take you back to Wales --
 18 **MS KELLY:** Yes.
 19 **MS FRASER BUTLIN:** -- and what you did in relation to the
 20 Welsh Government.
 21 **MS KELLY:** Yeah, so then we went to Welsh Government,
 22 obviously I brought this up at the All-Wales Advisory
 23 Group, and basically we were able to get an interim
 24 commissioning policy for the severely ill, and that
 25 was quite early. That was in the summer --

186

1 **MS FRASER BUTLIN:** 2 July 2014.
 2 **MS KELLY:** Yeah. So I resigned from the Society and we
 3 just did it as our own group then, and we got
 4 an interim commissioning policy, and out of the --
 5 there were six patients, but two of them went on to
 6 have liver transplants and they're still alive. So
 7 they had the treatment, and whereas we'd known so many
 8 in our group then that had died because they couldn't
 9 clear the treatment, and once they had a transplant,
 10 the tumours came back with greater force than ever
 11 before. This was a chance of life for these people.
 12 **MS FRASER BUTLIN:** I should say we've had a response from
 13 Malcolm Qualie, which will be published on our website
 14 in due course, he rejects the contention that
 15 NHS England were inventing the process of making
 16 direct acting anti-virals available to patients and
 17 rejecting the contention that NHS England was creating
 18 hurdles to their access.
 19 I just want to pick up one other matter which,
 20 Lynne, you've been very involved in, and Simon, in
 21 relation to achieving a coordinated approach to
 22 access -- to medical records. Lynne --
 23 **MS KELLY:** Sorry, can I just say one -- I'm sorry to
 24 interrupt, but we then did get -- even though we that
 25 the interim commissioning policy, we then had it

187

1 rolled out for the whole of Wales. So everybody,
 2 within that year, regardless of how advanced their
 3 liver disease was, through the blood-borne viral
 4 action plan, everybody was treated and that was in
 5 conjunction with the hepatologists in Wales. And,
 6 basically, they treated everybody and there was no
 7 waiting list. So we didn't have any of the problems
 8 that they had in England with accessing treatments or
 9 having to show that they had cirrhosis before they
 10 were given the treatment. Sorry.
 11 **MS FRASER BUTLIN:** In relation to access to medical
 12 records for the purposes of the Inquiry, you worked to
 13 achieve a coordinated approach to that, didn't you?
 14 **MS KELLY:** Yes.
 15 **MS FRASER BUTLIN:** The end result was a single email
 16 address that patients could email for their medical
 17 records.
 18 **MS KELLY:** Yeah.
 19 **MS FRASER BUTLIN:** Then it's right, isn't it, that you
 20 wrote to all the chief executive officers of the Welsh
 21 Health Boards --
 22 **MS KELLY:** Yes.
 23 **MS FRASER BUTLIN:** -- asking for a concerted approach
 24 to --
 25 **MS KELLY:** Yes, and they all agreed to do that and they

188

1 were really helpful. And, you know, the records
2 office in the -- in Cardiff they had one person who
3 coordinated everything. So if people needed their
4 medical notes, they could email this one person, and
5 she would make it her job then to make sure that all
6 those notes were put together to save, you know,
7 distress to patients then, and their families.

8 **MS FRASER BUTLIN:** Simon, you've worked similarly with the
9 Belfast Trust meeting them on a number of occasions,
10 to agree an approach to accessing medical records.

11 **MR HAMILTON:** Yes, that's correct. This really stemmed
12 from a problem with my brother Nigel when he sought
13 records initially, he had difficulty accessing them
14 and, in fairness, the Trust came back. We talked to
15 our legal team, Watkins & Gunn, who were extremely
16 helpful with this process and they accompanied us to
17 several meetings with the Trust. Those were positive
18 meetings. In fairness, we felt that the Trust was
19 very willing to cooperate and help and I think the
20 background to that is because of the changes in the
21 management of records over a long period of time,
22 we're talking about 30, maybe 40 years, it was
23 an "industrial task", to quote the Trust, finding that
24 information, and accessing it.

25 I have to say, we had number of meetings, and

189

1 for Haemophilia Scotland remains a formidable
2 challenge. What can you tell us about that in terms
3 of the position?

4 **MR WRIGHT:** Well, I take my hat off to my colleagues here.
5 Simon has no support in terms of employees and nor
6 does Lynne, so I stand in awe. Because we're
7 fortunate to have two members of staff. I'm afraid it
8 I was a bit grumpy in my written statement in terms of
9 the demands that this Inquiry has made on us because,
10 obviously, it's taken a lot of effort, and we're now
11 in a position in Scotland where, in order to secure
12 the continuing employment of our chief executive and
13 our engagement officer, we basically have to do it on
14 a funded basis.

15 I have long experience of this. Advocacy is
16 a desperately difficult thing to get funded. Support,
17 family events, Lynne's run family events, as has Simon
18 in Northern Ireland. But in the initial years, when
19 we became established, we were in the fortunate
20 position to employ Dan Farthing. He previously worked
21 with The Haemophilia Society and had huge experience
22 of the issues involved, and has given a written
23 statement.

24 And for the first three years we got £100,000
25 a year from Government. That then came down to 60,000

191

1 those meetings potentially could have been ongoing,
2 but without the very useful method in the sense that
3 we had a contact from the legal team who worked with
4 a contact from the Trust, and that's expedited the
5 process of accessing materials, and we were very
6 impressed that some of Nigel's records, which
7 initially couldn't be found, dating back to
8 handwritten records in a particular kind of log book,
9 they were found somewhere in the archives of one of
10 the buildings where all the records were being kept,
11 and I think that facilitated the expeditious
12 identification of records across the Belfast Trust and
13 further afield for other sufferers within Northern
14 Ireland.

15 Yes, so that was a good experience and
16 a positive one. And I think an observation I would
17 have made from some of the public local meetings which
18 were held during the Public Inquiry, that individuals
19 who hadn't -- who had worked on their own who had gone
20 independent, as it were, struggled to find records or
21 to access them as easily.

22 **MS FRASER BUTLIN:** The final substantive topic before we
23 deal with just a couple of matters, and it's
24 relatively brief.

25 Bill, you've said in your statement that funding

190

1 and to 50,000, and in recent times it has been 25,000.
2 Now, you can't pay two salaries on £25,000. So yes,
3 please, I remember badgering Lynne and indeed Simon
4 about -- in awe of this, you guys need to get some
5 money out of this, because you can't go on like this.

6 **MS FRASER BUTLIN:** Lynne, what's your experience?

7 **MS KELLY:** Well, our concern as a group, as I say we're
8 all volunteers. We didn't want it to curtail our
9 campaigning, because we thought if we were having
10 funding from Welsh Government, we might be restricted
11 on how much we could campaign for a Public Inquiry,
12 whereas we were sort of able to say what we wanted at
13 meetings, and we could challenge them. So
14 I understand the difficulties, and I suppose -- I'm
15 the chair, you know, and I run it from home but are
16 trustees will all have other jobs as well, and this is
17 a full-time job for me, but it's worth it to get
18 justice for everybody.

19 So it's not top of our priority list at the
20 moment, because we want to make -- we want the Inquiry
21 to report.

22 **MS FRASER BUTLIN:** Simon, any views?

23 **MR HAMILTON:** Well, we're a small organisation. We're all
24 volunteers as well. So that resonates very much with
25 me what Lynne was saying, and I do appreciate Bill's

192

1 help and guidance when we were starting up. It's been
2 very useful to be able to pick up the phone and get
3 ideas from others with more experience.

4 It's just around funding, the reality of funding
5 is it would enable us to provide better services,
6 better advocacy and more help to those that we are
7 trying to serve. And I think that is the reality. We
8 will always be a small organisation with a very small
9 turnover but all of that money goes back into events
10 and guidance, and we have good relationships with the
11 clinic, and we can draw on experts from there and be
12 given a little guidance. We have regular meetings
13 with the consultant Dr Benson on an annual basis to
14 discuss issues and needs, and to share ideas, and to
15 give our feedback to him.

16 But we are really -- we would appreciate
17 a little more understanding from the Department and
18 I'm fairly confident with my own general experience of
19 life that we would not be incumbent on the Department
20 if we were given some support. It was difficult
21 enough to actually find access to a room. This
22 meeting today is taking place from my place of work in
23 the boardroom, and that's where we've held our
24 meetings, by and large, because it was virtually
25 impossible to access anywhere else.

193

1 influence over what we're doing. And we support the
2 families but I think we run it very much as a basic
3 charity. We do a lot of advocacy work for people of
4 all ages with haemophilia.

5 We've also, strangely enough, we've also made
6 friends with lots of transfusion families and victims
7 as well. But as regards -- the Public Inquiry has to
8 be the most urgent thing now for us, rather than
9 funding.

10 **MR WRIGHT:** The point being, in relation to what Lynne is
11 saying, our integrity is such, as trustees of
12 a charity, that we would not be influenced by that
13 pharmaceutical firm if we were to run an event such as
14 Lynne is talking about. And it's very specific to
15 that particular event.

16 The other matter, and unfortunately, Dan has
17 a sore experience of this, the regulations around
18 pharmaceutical funding are tightening, are becoming
19 tighter and tighter.

20 **MS FRASER BUTLIN:** Final two questions. When you reflect
21 on your campaign work, the three of you, and that of
22 those you know in the community, why, in your view,
23 have efforts in the campaign been resisted in the ways
24 we have spoken of over the time?

25 **MS KELLY:** I think there's a deliberate attempt to cover

195

1 In all of those numerous buildings that are
2 empty and vacant in the evenings, within the three
3 hospital services which are within the vicinity of
4 Belfast, we found it difficult to -- to believe that
5 we couldn't access anywhere. But we're happy to go it
6 alone. We're happy to do it our way, if that's the
7 way it has to be done, and we will continue to do
8 that.

9 But, there's no doubt about it, additional
10 funding would make a big difference to the kind of
11 service and the kind of information and the benefits
12 to the people we are trying to serve.

13 **MR WRIGHT:** Could I just pick up Lynne's point because
14 I think it's a very important point here, about who
15 pays, because this is an issue that's arisen in
16 relation to pharmaceutical funding, as well. I think
17 we've possibly all had -- for specific events, had far
18 more money for specific events.

19 **MS KELLY:** We've had it -- if we done -- like, we do
20 children's events, so we'd ask for funding for
21 a one-off weekend because, obviously, as a charity we
22 rely on donations, and for us to raise £10,000 to take
23 all the children in Wales on a weekend, that's a lot
24 of money for us, so we usually -- we ask pharma. We
25 don't always get it but we ask for it, but it has no

194

1 up what happened. The government doesn't want to get
2 to the truth. And so, whichever way you attack it,
3 there are just obstacles in the way and the progress
4 is blocked, there are falsehoods about the events that
5 happened, and that just gets repeated and repeated and
6 repeated by successive governments because, as I think
7 was Bill said earlier, the civil servants don't
8 change. Those civil servants are in post for a number
9 of years. And the civil servants, you know, they have
10 that mantra. They invent that mantra. We saw it with
11 the self-sufficiency, the Department of Health report
12 on self-sufficiency.

13 So basically we had the Archer Inquiry, 2007.
14 In 2006 the Department of Health, they published
15 a report. It's not named. It's just the Department
16 of Health and blood products and self-sufficiency in
17 the UK from 1971 to -- or 1973 to 1991. And in that
18 are basically all the falsehoods that the Government
19 has supported over the years. And that's repeated in
20 the House of Lords and it's repeated in correspondence
21 to victims. When people write to their MPs, you get
22 a standard letter from the Department of Health saying
23 that there was no fault, everything was done, this
24 report has been issued and basically, you know, it was
25 an accident. And it's not an accident.

196

1 **MS FRASER BUTLIN:** Bill, Simon?
 2 **MR HAMILTON:** Yeah, if I could, I think inevitably
 3 Government, and the structures in the Government, ie,
 4 the Civil Service, have forgotten their calling. And
 5 their calling is to serve honourably and honestly.
 6 And I think they have neglected that charge.
 7 I think as a consequence they have forgotten
 8 that we depend on them, and therefore their chief
 9 responsibility is to look after us properly. And when
 10 that doesn't happen, and it cannot -- it may not
 11 happen for a number of reasons, it is their
 12 responsibility then paternally and maternally to
 13 accept that they must do things to make that
 14 different.
 15 The key fact, really, is, it is not the
 16 responsibility of Government -- and it shouldn't be,
 17 of a moral Government -- to defend the past when the
 18 past is wrong. Their responsibility is to address the
 19 future and provide a resolution and a solution in the
 20 future.
 21 The only people who are capable of doing that
 22 are Government ministers in the highest parts of
 23 office. They are responsible, they take the knock.
 24 They are responsible for making the decisions. And
 25 they should take those decisions and accept that it is

197

1 I really hope that we get to the bottom of -- get into
 2 places we've never been able to get at in this story.
 3 We've at least had the advantage in Scotland of the
 4 15-year rule. What about the 30-year rule? What
 5 about the 50-year rule that might be exerted upon all
 6 of this?
 7 So yes, I agree. I think Government doesn't --
 8 we had a duty of candour in Scotland that was
 9 introduced after -- the idea started to flourish after
 10 2007. We gave evidence because we had felt the whole
 11 cover-up thing needs to stop. Let's open things up.
 12 Unfortunately that doesn't apply strategically, it
 13 only applies in cases in clinical circumstances.
 14 Sorry, I've just got cramp.
 15 **SIR BRIAN LANGSTAFF:** If you want to stand up, that's
 16 fine.
 17 **MR WRIGHT:** Sorry, sir. Oh dear.
 18 **MS KELLY:** Bill, I would say that from my experience, and
 19 I think yours is the same, it's the civil servants.
 20 The governments change but the civil servants remain.
 21 And, you know, it's rotten. With regard to -- it's
 22 rotten to the core.
 23 **MR WRIGHT:** I'd say, sir, that -- you know, Lynne, the
 24 number of times you must have travelled backwards and
 25 forwards between Cardiff and London, and Simon and

199

1 perfectly all right to say something was done
 2 incorrectly and wrongly in the past and to address it
 3 about for the future. That is doing their job as we
 4 expect them to do it. And that's all that I could say
 5 on the matter.
 6 **MS FRASER BUTLIN:** Bill?
 7 **MR WRIGHT:** Yes. Government. Ha!
 8 If ever there was evidence of Government, of us
 9 scaring them, having harmed us, having not looked
 10 after people and allowed people to die through NHS
 11 treatment, it's the issue of Crown immunity.
 12 Now, my understanding is that some bright spark
 13 somewhere in Government sought to exert this on us.
 14 We're not soldiers. We're people that were harmed.
 15 So my understanding is that, legally, it could never
 16 actually have been applied to us. But what worries me
 17 here is that they were scared of us. They'd done
 18 something to us. That they didn't like. Somebody,
 19 some bright spark somewhere came up with this idea,
 20 so: "Let's dampen this down, let's defend ourselves
 21 against these people". Like Susan Deacon did in the
 22 early days of the Scottish Parliament. "Let's fight
 23 them in the courts. Let's do everything we can to
 24 stop this."
 25 So I welcome the tenacity of this Inquiry. And

198

1 I haven't done that, we live in the outer Celtic
 2 reaches rather than the closer Celtic reaches. But
 3 for me, these people are a waste of time, you know.
 4 I think we do want -- Government is going to
 5 have to take some action as a result of this Inquiry,
 6 and the Inquiry -- the words "we're investigating
 7 a cover-up", thank you, I think that is what needs to
 8 happen. The only problem is it's 10, 20, 30 years too
 9 late.
 10 **MS KELLY:** And I think also for us, you know, it's very
 11 difficult to get meetings with ministers. It's only
 12 that, you know, I was fortunate, through Della, who
 13 lost her son, and Lynne, who is Baroness, that we were
 14 able to get access to those meetings, and she was able
 15 to then ask questions in the House of Lords about --
 16 you know, like, the 10-year rule as the reason for the
 17 destruction of Lord Owen's papers, and Lynne was able
 18 to get it confirmed that -- by Lord Prior of
 19 Brampton -- that there is no 10-year rule. So, you
 20 know, they're just lies.
 21 The Department of Health self-sufficiency
 22 report, that's now been withdrawn. And that's down to
 23 Lynne opening the doors for her and I to go to the
 24 meetings. It just wouldn't have happened. And to
 25 challenge those key officials in the blood policy

200

1 unit, like Rowena Jecock, who, over the years, must
2 have seen all of the people in Wales, all the
3 campaigners in Wales that have died, and made false
4 promises to them. And ignored them. You know, it's
5 just -- it's disgusting.

6 And yet they're in positions of authority, and
7 they block. They block and they block and they block
8 because it's all about money and just covering it all
9 up.

10 **MR WRIGHT:** Counsel, can I make one further observation
11 about this point?

12 It's not just a failure in Government, and
13 governance. The Parliamentary process, if you look at
14 what's happened in Westminster, we've had umpteen
15 Health Committee examinations of this matter in
16 Scotland. Has the Westminster Parliament Health
17 Committee ever seriously looked at this matter in all
18 the decades it's happened?

19 **MS FRASER BUTLIN:** Sir, those are the questions I have for
20 the panel. I'm conscious that we need some time for
21 the recognised legal representatives to indicate if
22 they have any further questions. I wonder if we might
23 take a short break for me to be able to do that.

24 **SIR BRIAN LANGSTAFF:** Well, yes. How long do you think we
25 might need?

201

1 know, that should be done without question. They
2 shouldn't have to wait on waiting lists and -- you
3 know, they need to have priority access as well.

4 Obviously the numbers are very small, but that
5 definitely needs to be -- that needs to happen. And
6 they shouldn't be treated as, you know, secondary
7 infected. They are primary infected. And they've
8 suffered equally.

9 **MS FRASER BUTLIN:** Bill, Simon, do you want to add
10 anything to that?

11 **MR HAMILTON:** I agree with Lynne. I think there are
12 issues that need to be addressed to ensure that they
13 are given a very fair and supportive and compassionate
14 treatment, and that they are not left feeling isolated
15 in any way. Or secondary, or less important in any
16 way.

17 I know from a number of experiences that all
18 sufferers have had within the bleeding community, in
19 terms of even dental care going back to the old days,
20 we were treated quite harshly and we were treated with
21 deep suspicion. I think those days have gone. I
22 trust they have for good. I know practice is much
23 better. But I think it is really important,
24 remembering how I felt at times, when I was being
25 faced with treatment and by people who didn't

203

1 **MS FRASER BUTLIN:** Twenty minutes.

2 **SIR BRIAN LANGSTAFF:** Shall we then say quarter past five,
3 no earlier than.

4 **MS FRASER BUTLIN:** Thank you, sir.

5 **SIR BRIAN LANGSTAFF:** But be ready for quarter past five,
6 if you please.

7 **(4.54 pm)**

8 **(A short break)**

9 **(5.15 pm)**

10 **MS FRASER BUTLIN:** Thank you, sir.

11 I've got three -- or we just need to make
12 sure -- there he is. Simon has joined us as well.

13 I've got three questions from recognised legal
14 representatives and then six matters raised by your
15 own representatives.

16 If we start with those raised by the recognised
17 legal representatives of other Core Participants. In
18 relation to HIV-infected partners, so
19 non-haemophiliacs, and the access to care and
20 treatment that they have, what support and advocacy is
21 provided and what's needed for HIV-infected partners
22 of haemophiliacs in your view?

23 **MS KELLY:** Well, I -- we would be lobbying for equal
24 access for partners as well, because, depending on
25 where they choose to go for their HIV treatment, you

202

1 understand my circumstances, I think it's really
2 important that we ensure that they are properly
3 facilitated and supported and that they are clear that
4 they get that treatment and support in the same
5 compassionate way.

6 **MS KELLY:** And also, can I just add something? I think
7 the point that Simon raises about dentistry and HIV,
8 particularly with the HIV drugs and the impact on --
9 you know, on their teeth, they definitely need to have
10 priority. Because, aside from the stigma and the
11 difficulty finding a dentist, you know, this is an
12 impact of a treatment that they've been given and they
13 need to have partners as well -- as well as -- you
14 know, as well as the infected.

15 **MR WRIGHT:** Could I ask you to repeat the question,
16 please?

17 **MS FRASER BUTLIN:** Of course. What support and advocacy
18 is provided and what's needed for HIV-infected
19 partners of haemophiliacs?

20 **MR WRIGHT:** Ah. Um, well, I am familiar with cases in
21 England. I'm not aware of particular cases in
22 Scotland, but in relation to the "should" word,
23 I completely agree.

24 **MS FRASER BUTLIN:** Linked to that, in relation to
25 potentially infected families, in your campaigning

204

1 work, have any of you been aware of any discussion
2 about a look-back extending to potentially infected
3 family members?

4 **MS KELLY:** No.

5 **MR WRIGHT:** No.

6 **MR HAMILTON:** No --

7 **MS KELLY:** Which is -- sorry -- which is ridiculous,
8 because obviously at the time, when people didn't know
9 they were infected, obviously the family members could
10 have been infected. We know obviously some partners
11 were tested, but that does need to happen, definitely.

12 **MR HAMILTON:** Yeah, when we've been talking in previous
13 times about these sorts of situations and scenarios,
14 people have reflected on that and asked the question,
15 but I can't say for sure that that has actually been
16 practised.

17 **MR WRIGHT:** Are you just considering HIV here?

18 **MS FRASER BUTLIN:** No, I think the question relates to
19 both HIV and hepatitis C.

20 **MR WRIGHT:** Well, through personal experience, after I was
21 diagnosed, we had two children and my wife was never
22 tested. And it got to the stage that, when our
23 daughter became a teenager, we were in a perilous
24 position. The problem is insurance, because it would
25 have wiped us out, financially, if Rosie had lost her

205

1 I was, because she didn't who I was every time I wrote
2 to her.

3 **MS FRASER BUTLIN:** It was quite specific about the
4 financial review, thank you, Bill.

5 **MS KELLY:** Sorry.

6 **MS FRASER BUTLIN:** Lynne, I've been asked to ask about two
7 matters, one is, I think, more of a point of
8 information arising from your statement than
9 a particular question, you note in your statement that
10 your grandfather was a haemophiliac who lived until he
11 was 76 and your great-uncle, also a haemophiliac,
12 lived until he was 92.

13 **MS KELLY:** Yes.

14 **MS FRASER BUTLIN:** Is that right?

15 **MS KELLY:** So my grandfather he worked underground, and in
16 later life he worked on the railways, and he had seven
17 children. And his brother -- also, his brother --
18 actually, he worked -- he was a civil servant and he
19 became the Mayor of Pontypridd, and he lived until he
20 was, I think he was 91 or 92, but yeah, whatever I've
21 said in my statement, yes. So it demonstrates that,
22 you know, the fact that it said to us -- I've gone to
23 lots of meetings in the Department of Health and
24 they've said "Oh, all the haemophiliacs would have
25 died at 23", I think is the number they quote. Well,

207

1 job or her income. So it's a very dangerous place to
2 be. And I think, like other parents, I would have
3 found it impossible to live with myself if my son and
4 daughter had been infected.

5 **MS FRASER BUTLIN:** Bill, another question I've been asked
6 to ask. You referred to the financial review and the
7 presentation from Jan Barlow. What was it about the
8 presentation that convinced you that you wanted
9 nothing to do with the Alliance House organisations?

10 **MR WRIGHT:** Um ... she wasn't the only presentation we
11 had. We had lots of different presentations, but
12 I don't know if it just simply lacked enthusiasm.
13 We'd had bad experiences. Our membership, during the
14 process, had had bad experiences, and I just don't
15 think she was able to answer the questions in response
16 to the feedback that we'd had from members of both the
17 Scottish Infected Blood Forum and of Haemophilia
18 Scotland.

19 **MS KELLY:** And I would add that I've had correspondence
20 many times with Jan Barlow and it's never amounted to
21 anything at all and, every time I've contacted her,
22 she would ask for confirmation of who I was, even
23 though I would copy the person that had asked me to
24 resolve a problem into the email to her, and there'd
25 be maybe two or three emails just confirming who

206

1 that's just not true, because our family are living
2 proof and I know other families in Wales where the
3 grandfather, you know, lived, with interventions, but
4 a relatively normal life. And, you know, they had
5 children and yet it was the next generation then, the
6 generation, like my generation, my cousins.

7 **MS FRASER BUTLIN:** In terms of support you've received,
8 Lynne, I understand you've had quite a lot of support
9 from the Irish Haemophilia Society. Again, is that
10 right?

11 **MS KELLY:** Yeah. So it was in 2015 -- well, when I was
12 a trustee, I first met Brian O'Mahony, who's the -- at
13 the time I think he was -- I think he was the chief
14 executive at the time of the Irish Haemophilia
15 Society. And he was also involved in the World
16 Federation and the European Haemophilia Consortium.
17 And as a trustee, I went to two conferences; and Brian
18 basically, you know, presented on advocacy in action.
19 And that's where -- I looked at their society and I
20 could see that they'd got the settlement in Ireland,
21 you know, and it seemed to be the best one that was on
22 offer.

23 And basically, he highlighted all the areas of
24 advocacy. He went through his campaign and how they
25 got it, and, you know, I replicated a lot of that in

208

1 our campaign. But basically Brian is himself
2 a haemophiliac and also with family members as well.
3 I would say that when Lord Morris was alive,
4 Lord Morris would go and ask Brian O'Mahony's advice
5 about things, and there will be examples of that in
6 Hansard where he's asked Brian O'Mahony to -- you
7 know, for advice or to ask for further information
8 about the Irish scheme. And I just feel that the
9 Irish Haemophilia Society in Southern Ireland, you
10 know, it's an exemplar charity, and it's a really good
11 example of how a charity can work. It doesn't need to
12 be infected blood in one area and younger families in
13 the other area. I think it needs to -- it's
14 a generational thing. And I just feel that Brian
15 should be asked to give evidence to the Inquiry,
16 because he really does set a very good example of
17 a successful society.

18 **MR WRIGHT:** Could I just support what Lynne is saying in
19 terms of the Irish Haemophilia Society being an
20 exemplar. We look at it enviously, because -- the
21 qualification that I'll put on that in relation to
22 funding is it received, since the Lindsay Inquiry huge
23 Government funding.

24 **MS FRASER BUTLIN:** Bill, I've been asked to look at
25 a document, WITN2287021, a meeting from

209

1 **MR WRIGHT:** Well, if I can just take a moment to remind --
2 go into my mental filing cabinet here.

3 The context for this was that, at the time, I'd
4 been working in the world of the environment where we
5 talked about indicators, and the precautionary
6 principle. And by then, I had really hooked onto the
7 whole thing about ALT testing, and the reason for that
8 was the confidence that the days after I was
9 infected -- the total confidence in 1986 that my
10 raised ALT levels were confirmation of my own
11 infection, and that led me to be thinking about, well,
12 hang on a minute here, they were able to confirm for
13 me. So the donors, one of those donors in those
14 thousands of blood donations that led to my infection,
15 one donor somewhere must also have had raised ALT
16 levels and had been infected.

17 And that raised for me the whole issue about
18 screening, and that then, during the questioning,
19 during this session, it came out from Brian
20 McClelland -- and I remember this quite vividly, he
21 talked about raised ALT levels and his words were,
22 "Well, we wouldn't have been able to eliminate someone
23 because of possible false-positives, because", his
24 words were, "they'd had a good drink in them the night
25 before". In other words, alcohol raised ALT levels.

211

1 25 November 1999, a meeting with senior
2 representatives of the Scottish National Blood
3 Transfusion Service in Edinburgh.

4 **MR WRIGHT:** Yeah.

5 **MS FRASER BUTLIN:** I think you did attend. I think your
6 name has been redacted out of an abundance of caution
7 or an error on our part, but you were at that meeting,
8 weren't you, Bill?

9 **MR WRIGHT:** I certainly was.

10 **MS FRASER BUTLIN:** What was the purpose of the meeting?

11 **MR WRIGHT:** It followed -- I'm just looking at the timing
12 of this, actually. We were already making -- this was
13 in the very early days of the Scottish Parliament. We
14 were making representations to ministers by then. And
15 I think one thing that Susan Deacon did do, and
16 I suspect it was probably her that arranged this, in
17 that she, I suspect, instructed these very senior
18 people from the Scottish National Blood Transfusion
19 Service to meet with many of us, and for them to
20 explain what had happened from their particular
21 perspective, but also for us to be able to ask
22 questions.

23 **MS FRASER BUTLIN:** What did you learn about the
24 possibility of ALT testing as a surrogate test for
25 hepatitis C?

210

1 Subsequently, of course, we were able to find
2 out that gamma GT is an indication of raised -- of
3 alcohol. But what also came out of that was that the
4 main consideration appeared to have been, within the
5 Scottish National Blood Transfusion Service, was
6 volume, in terms of blood donations. They didn't want
7 to scare the donors, and that became very evident
8 during this particular meeting.

9 **MS FRASER BUTLIN:** What impression did you have of the way
10 in which the SNBTS conducted the meeting?

11 **MR WRIGHT:** [Laughs]

12 Um ... I think, yeah, a bit defensive. A bit
13 patronising. Particularly the chairman, Angus
14 Macmillan Douglas, who we later came across again when
15 we appeared in front of the Health Committee.

16 **MS FRASER BUTLIN:** We spoke about the petition that was
17 proposed, and we spoke about it as being one of the
18 Scottish Infected Blood Forum. It was in fact
19 proposed by the Scottish Haemophilia Groups Forum.

20 **MR WRIGHT:** That's correct.

21 **MS FRASER BUTLIN:** Can you tell us briefly about what the
22 difference between the two groups is?

23 **MR WRIGHT:** The Scottish Infected Blood Forum was formed
24 much later. The Scottish Haemophilia Groups Forum
25 was, in effect, an amalgamation of the local groups of

212

1 The Haemophilia Society in Scotland.
2 I moved back to Scotland in 1996, and I was
3 buttonholed and introduced to members of the Tayside
4 group by a couple who lived close by in Perth and
5 unfortunately neither are -- they're no longer with
6 us.

7 And it was very much led by the late
8 Philip Dolan, and he was tenacious. He could be
9 a very difficult man at times, Philip, but he was
10 tenacious.

11 And so the difference is it kind of petered out.
12 It was a Scottish committee that was -- London felt
13 they needed, to reinvigorate matters of the Scottish
14 Office, and appointed.

15 Latterly Philip identified that there was --
16 people who had had blood transfusions were really not
17 provided for in Scotland and it was a separate
18 charity. But we worked very, very closely with them.
19 And I must emphasise the importance of that particular
20 charity that -- who are our close partners. We have
21 joint meetings with -- every, I don't know, three
22 months or whatever.

23 And they did two things in particular that were
24 really useful. Robert, on Tuesday, referred to a bit
25 of artistic work that he did -- well, the SIBF

213

1 frankly meant that we didn't ... we didn't get to
2 throw some of the accusations at Government that I've
3 just thrown today, frankly, and bring it -- or,
4 another way of putting it might be, to bring evidence
5 to that particular inquiry.

6 Philip in particular was deeply frustrated. He
7 spent 20 years of his life and he was turned down.
8 I was put forward, and equally was turned down.

9 **MS FRASER BUTLIN:** Finally, when we -- we've heard talk
10 a lot about Nothing About Us Without Us.

11 **MR WRIGHT:** Yes.

12 **MS FRASER BUTLIN:** In that context, what access -- and
13 it's really a question for all three of you -- what
14 access do you think that patients should have to
15 medical information about them?

16 **MR HAMILTON:** I think it's fundamentally important to
17 understand. I mean, what we're talking about is
18 a trust relationship, what we're looking at now is
19 a breakdown of trust. And, therefore, there needs to
20 be a balance in how that information is shared. But
21 it needs to be shared.

22 It comes as a rather a surprise to find that one
23 might have spent ten years being observed with
24 a potential illness that one wasn't being informed
25 about and then afterwards being assured, in my case,

215

1 sponsored a similar exercise but they also then --
2 I think they were funded by Scottish Government to
3 conduct a scoping exercise, which in many ways was --
4 it came out around the same time as the Penrose
5 Report. The bit of artistic work that was done -- and
6 I'm sorry, I'm a bit tired and can't remember the
7 complete detail -- it was important because it gave
8 the opportunity to people who wanted to appear and
9 tell their stories in a way that Lord Penrose hadn't
10 allowed.

11 **MS FRASER BUTLIN:** Before we come back to the Penrose,
12 which -- I have another question to raise with you.

13 Just to be clear, the Scottish Infected Blood Forum is
14 for those who either have been infected because of
15 a bleeding disorder or because of a transfusion. It's
16 both groups.

17 **MR WRIGHT:** Yes, we have a crossover, and there's members
18 in both. I mean, we have people who have come to us
19 in Haemophilia Scotland who had transfusions.

20 **MS FRASER BUTLIN:** In relation to the Penrose, how many
21 campaigners were asked to give oral evidence?

22 **MR WRIGHT:** None.

23 **MS FRASER BUTLIN:** And what was the impact on the infected
24 and affected community of that decision?

25 **MR WRIGHT:** Well, in line with the terms of reference, it

214

1 that I definitely had stage 2 hepatitis -- cirrhosis
2 of the liver. So those things come as a surprise.

3 I think building relationships on trust is
4 fundamentally important and that breakdown in trust is
5 something which I think has to be restored, and has to
6 be restored in such a way that it won't be broken
7 again.

8 Perhaps regulation is a way of ensuring that
9 happens, by standardising practice, professional
10 practice, but I think there needs to be
11 an understanding and an acceptance that there's
12 a certain risk in that process and there needs to be
13 some protection around that risk for those who share
14 that information.

15 **MS FRASER BUTLIN:** Lynne, Bill, do you want to add
16 anything?

17 **MS KELLY:** Yeah, I think obviously, you know, it should be
18 transparent and I think it shouldn't just be something
19 that Government says is going to happen. I think it
20 should actually happen. It's one thing when ministers
21 say, in the Lords, you know -- I think one of the
22 phrases is, you know -- I think again it was Earl Howe
23 said this "The absence of patients in the development
24 of services is often a -- or is always a reason for
25 their failure", and that would be in Hansard. And

216

1 yet, at the same time, they're restricting services
2 and they're -- it's not being based on clinical need.
3 It's being based on how much the Government can
4 afford.

5 **MR WRIGHT:** Sorry, I'm going to ask you to repeat the
6 question.

7 **MS FRASER BUTLIN:** Absolutely. In relation to -- we've
8 heard lots about Nothing About Us Without Us. In
9 relation to the provision of medical information, what
10 access do you think patients should have to medical
11 information about them?

12 **MR WRIGHT:** Well, I'm going to chuck something out there.
13 I believe there's a strong case, and we've discussed
14 this within Haemophilia Scotland, for a duty that each
15 time there's a medical document of any significance
16 produced, a legal duty to provide a copy of that to
17 the patient.

18 I'll draw an analogy here. The two most private
19 things our life are our health circumstances and our
20 financial circumstances. Can you imagine going to
21 a bank and them saying "You're fine", they don't tell
22 you what your bank balance is, they don't tell you
23 what the ins and outs are in your account. That's the
24 situation that we face to this day. And I've had --
25 I say this from experience as a patient, which is

217

1 the question of the duty of candour. Yes, the
2 Scottish Government has done good stuff on that. In
3 2018 we gave evidence to some of the MSPs on the
4 Health Committee about it because we felt it was
5 important, it's part of the lessons being learned, but
6 it's not at a strategic level, and this goes back to
7 the question of cover-up.

8 **MS FRASER BUTLIN:** I'm just going to look behind me.
9 Sir, do you have any matters to raise?

10 **Questions from SIR BRIAN LANGSTAFF**

11 **SIR BRIAN LANGSTAFF:** Yes. The first couple of questions
12 for you, if I may, Bill. Let me just press you
13 a little bit further on the question that was asked
14 about why Jan Barlow's presentation was so
15 unpersuasive. The reasons you've given are that, in
16 effect, it was lacklustre and that she couldn't answer
17 questions that were then asked. Now, that's very much
18 a reflection of one person, their reaction. What you
19 were considering, I take it, was the future structure
20 of the health -- the arrangements for paying money to
21 those who had been infected and affected.

22 What was it about the AHOs that led you to think
23 that they were not the right vehicle to do that?

24 **MR WRIGHT:** Well, the question of accountability, sir.
25 You've received evidence on the AH from some of the

219

1 a very mixed experience.

2 I remember one time I had an endoscopy. At the
3 end of the endoscopy, the nurse took me through, sat
4 me down, gave me a sandwich and said, "Right, I want
5 you to sit here and listen to me and here's two pieces
6 of paper I want to take away of with you to explain
7 what's just happened and what the results are".

8 To this day -- I mean, I recently had a bit of
9 a scare, a bit of a chest scare. I had a chest X-ray
10 and blood samples and I had to ring my own surgery to
11 get the results. So I'm throwing out that -- that out
12 there. I understand there will be a great wailing and
13 gnashing of teeth because I've actually spoken to
14 an administrator within the haemophilia world in
15 Scotland, quite a senior individual, and the reaction
16 was "Wow, there's clearly a cost to that". But can
17 you just imagine a bank manager saying -- can you
18 imagine if you went for private healthcare -- we pay
19 taxes -- can you imagine them saying, "Well, no, we're
20 not giving you any paperwork to follow it up."

21 And if you look at this disaster and medical
22 records going missing, then that has been one of the
23 key issues in all of this, throughout the evidence
24 that the Inquiry has received.

25 The second point I want to make about this is

218

1 trustees of the AHOs. I have some experience of
2 charity governance, and much larger charities than
3 ours, with tens of thousands of acres of land, 40, 50
4 employees, and the question of -- the impression I've
5 received from that evidence, which is consistent with
6 the impression we received at the time with
7 Jan Barlow, was that, in effect, they were like NDPBs,
8 but the Government was able to say that's their
9 decision.

10 I remember in particular there was one bit of
11 evidence about them not going out to fundraise.
12 Charities have to go out and fundraise. But they were
13 reliant -- their only source of funding was the
14 Government. So, in effect, they were NDPBs but it was
15 convenient for Government.

16 Now, one of the questions we were asked during
17 the financial review was "Which model do you want to
18 arrive at?" and the Minister was open minded about
19 that. But we reached the conclusion that
20 accountability was important. And the Minister
21 supported us in that. In fact, she left a legacy, and
22 there are some views in Scotland that maybe it needs
23 to be a bit arm's length, but the legacy was, as
24 I said earlier, we can go back and pin these guys down
25 about the way that those -- that the Scottish scheme

220

1 is being operated.

2 **SIR BRIAN LANGSTAFF:** Thank you.

3 The second question is also about the review of

4 financial arrangements in 2016, when you told us that

5 Scottish Government came to you and said, "Well, we'll

6 go with a median wage."

7 **MR WRIGHT:** Yes.

8 **SIR BRIAN LANGSTAFF:** 27,000. Was there any discussion in

9 that meeting that you can recall about the question of

10 whether any account should be taken of the spouses or

11 the partners or the carers who may have sacrificed

12 their own earnings in order to care for the person who

13 was the primary, in this sense, beneficiary?

14 **MR WRIGHT:** I'm grateful you raised that, sir, because the

15 legal definition under the Act in two thousand and ...

16 oh, sorry, wrong Act. The legal definition that --

17 after the Ross Report and the Skipton Fund was formed,

18 used the term "definition", where we started

19 discussions with Scottish Government about that very

20 matter.

21 This is 2021. My wife is not my dependant. My

22 god, if I was to suggest that ...

23 And similarly with partners.

24 With sons and daughters who were children, it

25 has proven advantageous on occasions in order for

221

1 never been compensated. And worst of all, with

2 parents who'd lost children.

3 So that we didn't -- and that's one of my

4 biggest regrets, but balancing the time imperative

5 that we -- we'd press Government on at that point.

6 And certainly I feel -- and I'm sure colleagues would

7 agree -- that's something that needs close examination

8 now.

9 **SIR BRIAN LANGSTAFF:** The next is really to you, Simon.

10 It's -- you were explaining that the ideal, in terms

11 of future funding arrangements in respect of any form

12 of support, whether ex gratia or whether compensation

13 or for those who have suffered, should be paid for out

14 of the HM Government funds, central funds, and

15 I understood you to be saying essentially there ought

16 to be central funding but local management. Have

17 I got it right?

18 **MR WRIGHT:** [Laughs] -- (overspeaking) --

19 **MR HAMILTON:** -- (overspeaking) --

20 **SIR BRIAN LANGSTAFF:** This is for Simon, so let him go

21 first, then you have your chance for the constitution.

22 **MR HAMILTON:** I think, first of all, I would like to be

23 clear that I believe that central Government has the

24 responsibility because, going back pre-devolution,

25 this is a problem prior to devolution, and therefore

223

1 financial support to be continued for them. But

2 that is a matter that needs to be examined pretty

3 closely.

4 **SIR BRIAN LANGSTAFF:** The point I was perhaps asking about

5 was, suppose that a partner has lost part of the job

6 that he or she may have done, they may be working

7 part-time, ten hours a week, instead of full-time,

8 38 hours a week. They may have had various other

9 expenses which come with that.

10 The person who has been infected has no income,

11 because they can't work -- at least, little income,

12 because of their infection. They may be attributed

13 27,000, and that may add 15, 20,000 to what they

14 already earn. But the partner has already lost, and

15 part of the overall cost to that household is the loss

16 of his or her income.

17 **MR WRIGHT:** At that point during your deliberations, that

18 particular point you're talking about in terms of

19 carer, rather than being dependent, being a carer,

20 which is what I think, sir, you're getting at --

21 **SIR BRIAN LANGSTAFF:** It is. It's the costs of caring.

22 **MR WRIGHT:** Yes. In other words, if you draw an analogy

23 with litigation in terms of settling litigation care

24 costs, no, that -- that was something probably

25 missed -- and similarly with adult children who'd

222

1 it's about the responsibility and accountability of

2 that.

3 The other issue is that effectively, there

4 are -- it depends on the nature of devolved Government

5 and the relationship with the United Kingdom

6 Government, in terms of how monies are separated,

7 divided, awarded, provided, in general practice.

8 I know the reality of the situation in

9 Northern Ireland is that if Northern Ireland were to

10 be given the responsibility and our Minister of Health

11 has said he would be listening, and responding

12 positively to the -- if I understand him correctly,

13 responding positively to any recommendations coming

14 out of the Inquiry, the reality is that no matter how

15 well intentioned he is, he would not be able to

16 provide the recommendation to its -- to any level,

17 because the recommendation I would anticipate, if

18 there were one, would be so significant and

19 substantial, or substantive, that the current budget

20 would be inadequate to meet it, and therefore it could

21 not be achieved.

22 And under those circumstances, I think the

23 responsibility has to fall with central Government and

24 the Treasury.

25 How it is finally arranged is not as big an

224

1 issue for me, to be honest with you, and I think for
2 other -- for other victims and other recipients, that
3 wouldn't be as significant an issue, but I can
4 understand -- and I can almost hear Bill saying that,
5 for him, it would be. And I understand, because of
6 the differences in Government, from where we are at
7 the moment, our Government would be looking to central
8 Government to provide them with something which then
9 they would be passing on.

10 **SIR BRIAN LANGSTAFF:** So, for Simon, it doesn't
11 particularly matter where those sums are administered.
12 Bill, and then Lynne, what about Scotland and Wales?
13 What's your view?

14 **MR WRIGHT:** Well, Bruce yesterday raised a question of
15 what's this money for, in terms of the treatment of
16 people with haemophilia. And he, you know, he made
17 some pretty strong assertions that obviously the
18 Inquiry will look at.

19 I think this is -- we've given this a lot of
20 thought, because we get into a whole constitutional
21 wrangle about a post-devolution Government and
22 a pre-devolution -- when the disaster really all
23 commenced -- we're still living the disaster, but the
24 disaster commenced prior to devolution. I've
25 consulted with legal colleagues about this, and it

225

1 people in the group that say, "Well, I don't need that
2 support, I don't need the welfare advice. I don't
3 need all of that, I would prefer it -- I would prefer
4 to have financial recompense for that rather than the
5 scheme, the all singing and dancing scheme". But
6 I think that would be -- I couldn't answer that until
7 we've spoken to everybody about that.

8 **SIR BRIAN LANGSTAFF:** So you're arguing for a local
9 solution, even if it is to accept central management?

10 **MS KELLY:** Not really. You know, I think we have to
11 have -- we have to have this -- the facility where
12 there's face-to-face contact and, you know, financial
13 support -- sorry, psychological support. But I think
14 it just has to be all funded centrally. So -- because
15 obviously in Wales, we have the scheme, and we have
16 the -- it's based in South Wales but for the people in
17 North Wales, that's four or five hours away. So it
18 does have a -- you know, a problem of logistics.

19 So in South Wales it's all close by, but for the
20 people in North Wales, that's not the case.

21 **MR WRIGHT:** Sir, having had the impertinence to bat this
22 back to you, could I ask that there is a further
23 consideration here. The schemes tend to operate on
24 a payment monthly, and that is important. And that
25 was something we considered during the financial

227

1 goes back to what was the will of Parliament at the
2 time that devolution took place, in terms of -- in
3 terms of -- and I know the Inquiries Act doesn't allow
4 us to look at liability but, in many senses, Scottish
5 Government has inherited the liabilities of the
6 Scottish Office.

7 But until this Inquiry examines those issues
8 of -- and says -- I'm sorry, sir, I'm putting this
9 back in your plate, to actually look at what went on
10 within Government, I don't think we can answer that
11 question.

12 **SIR BRIAN LANGSTAFF:** So you ask for simple funding but
13 leave it up to me to decide who administers it.

14 **MR WRIGHT:** [Laughs]

15 **SIR BRIAN LANGSTAFF:** Simon says he doesn't mind. Lynne,
16 do you have a position?

17 **MS KELLY:** Well, I believe the funding needs to come from
18 central Government. Obviously we -- in Wales, we've
19 worked hard to get this holistic approach but, that
20 said, there are people in our group who don't use that
21 anyway. So I think it'll be a question that we put
22 out to our members in our next discussions about how
23 they would feel, you know, if it was centrally funded.

24 I think the features of our scheme, I think, you
25 know, are good, and they work, but then there are

226

1 review.

2 One thing we never did during the financial
3 review in Scotland was present the opportunity to then
4 convert that off into a one-off payment, such as
5 happens in Ireland.

6 There's a middle house here, because one-off
7 payments, in terms of compensation, there was
8 additional money paid at that time and, therefore,
9 I had a discussion at senior level about this in terms
10 of whether it's easier for Government to pay a great
11 big -- a whole lot of money at once or to spread it
12 out over the years. So there is a consideration here
13 about, not only enhancement of the schemes on
14 a monthly basis or yearly basis but also in terms of
15 a capital payment.

16 **MR HAMILTON:** Sir Brian, forgive me, may I make one other
17 point?

18 I think in the context of the experience we've
19 had in Northern Ireland, with a great sense of
20 insecurity around the continuation of Government,
21 without punctuated breaks that last up to three years,
22 if a recommendation came forward, and it was -- it was
23 the responsibility of devolved Government to deal with
24 that and Government wasn't functioning, effectively,
25 the experience of the last three years indicates that

228

1 we would be waiting, and that is something which would
2 be totally against the spirit and the principle of
3 a conclusive arrangement. So that influences me in
4 a way that my colleagues wouldn't be influenced,
5 I think.

6 **SIR BRIAN LANGSTAFF:** Well, that's all that I have to ask.
7 Thank you very much.

8 **MS FRASER BUTLIN:** I think each of you wanted to say
9 something to close.

10 Simon, would you like to start?

11 **Statement by SIMON HAMILTON**

12 **MR HAMILTON:** Yes, thank you very much. I just prepared
13 something because I had several thoughts on this, but
14 I will be very brief. And it answers your question
15 originally, sir, in relation to my early negative
16 conclusion, and thank you for giving me the chance to
17 say something.

18 I was critical of the progress of Government in
19 the conclusion of my campaign statement.

20 I highlighted the obfuscations, strategies of delay,
21 verbal assurances, endless meetings and
22 correspondences which encouraged me to wait patiently
23 while the big cogs of Government and the bureaucracies
24 of Government ground slowly. But time doesn't wait
25 while the process animates itself. Throughout this

229

1 justification for defending the past, when you can
2 correct the future.

3 As I now review the situation after much
4 campaigning and much disappointment, I actually have
5 some hope. I've seen that light has been shone and
6 process has responded, and issues long fought for have
7 been hard won, but won nevertheless. Parity, whatever
8 that means, is being achieved. And there is an
9 acknowledgement that there is a moral obligation on
10 Government to clean up the human debris trail by
11 redeeming itself from the horror of the past and the
12 pain of the present. What is only left is the future.

13 Victims in Northern Ireland have tasted the
14 sweetness of acknowledgement and compassion.

15 Only because we have a Health Minister in
16 Robin Swann who accepted that he should address what
17 others have failed to do, and in so doing, he has
18 proven that when Government accepts its moral
19 responsibility, it fulfils its duty to its citizens.

20 What we need is what we have always needed:
21 central Government acknowledging its responsibility
22 and acting swiftly, as you once, Sir Brian, requested.

23 So I will continue as one with the endurance and
24 determination to run for miles if I need to, because
25 I stand ... I stand in a line with all other victims,

231

1 period of frustration and stress, people were and are
2 despairing and dying, lives were and are
3 deteriorating.

4 Uncovering the facts about personal harm and
5 injury is a painstaking process. This process is
6 greatly magnified when it is a question of how
7 Government deals with the health and wellbeing of
8 those of us who innocently and haplessly trusted the
9 State to care for us. Both medical and Government
10 bureaucratic decisions have turned the infected and
11 affected blood community into victims.

12 We trusted our health practitioners and we ended
13 up as victims. We trusted Government on two previous
14 inquiries, and we ended up as victims. This cannot
15 happen again. I've spent the last six years of
16 campaigning metaphorically screaming out that delays
17 are not the way to resolve the wrongs of the past. In
18 fact, the chorus from many campaigners is the same:
19 there's only one practical way to clean up the human
20 trail of emotional and physical debris that lies at
21 the Government's feet; that is to acknowledge its
22 existence, and to acknowledge that it needs to be put
23 right.

24 As I said to the Right Honourable
25 David Lidington in 2019, there's no moral

230

1 whether looking ahead or looking back, looking to the
2 left or looking to the right. We cannot give up on
3 ourselves.

4 Thank you.

5 [Applause]

6 **MS FRASER BUTLIN:** Lynne?

7 **Statement by LYNNE KELLY**

8 **MS KELLY:** I feel privileged to be here today, giving
9 evidence to the Inquiry on behalf of Haemophilia Wales
10 and the people we represent. The campaign to bring
11 this disaster into the public domain has succeeded
12 because of the continued efforts of victims and
13 campaigners against the orchestrated and deliberate
14 attempts by successive governments and others to
15 conceal the truth.

16 This campaign has truly been fought on the
17 shoulders of giants. They fought the lack of
18 transparency, accountability and willingness to engage
19 for over 30 years, and we will not forget them, or
20 their perseverance.

21 We have heard in this Inquiry from those in
22 positions of responsibility at the time who cannot
23 remember, did not keep records or trouble themselves
24 to understand or accurately recall the details that
25 led to the deaths of over 3,000 people in the UK.

232

1 The lack of transparency, accountability and
2 willingness to come to terms with the past to prevent
3 this happening again continues.

4 There remains an unwillingness of some to
5 properly engage with key individuals and campaigners
6 still excluded from decision-making forums. There
7 still exists a lack of transparency of funding
8 sources, to quote the Welsh Health Minister's
9 evidence, where, like the medical records, "money
10 appears from the back of the sofa."

11 And there is still the lack of accountability,
12 where families -- sorry, there is still a lack of
13 accountability, where people responsible retire to
14 enjoy the benefits denied to the infected and their
15 families.

16 Victims and families will never forget what
17 happened or the response of those who should have had
18 their interests at the centre of their duties. If
19 they ever thought Government was their friend, they
20 now understand it is not.

21 We hope the Inquiry will finally get to the
22 truth about what happened and ensure that victims and
23 families receive the compensation and support needed
24 to allow them to live what is left of their lives in
25 the dignity they're entitled to.

233

1 but, my God, we're resolute".

2 After that, a widow phoned me and talked to me
3 privately. I continue to do that and I'm sure Lynne
4 has a similar experience, and Simon as well. She was
5 really struggling because what was important to her
6 was the need to be believed.

7 She felt that all her power had been removed
8 and, because of that removal of power and not being
9 believed, she felt the need to be able to trust -- the
10 thing she really wanted was to be able to trust again,
11 and this is important because this disaster, because
12 of the financial implications, and the health impacts,
13 has removed choices.

14 She revealed her sense of vulnerability to me.
15 And we've talked about Nothing About Us Without Us,
16 and I hope that we may look at this process in the
17 future. But I go back to how I got involved in all of
18 this, and Robert, on Tuesday, talked about some names,
19 some first names.

20 For me the equivalent names are John and Pat,
21 Philip, brothers Dave and Ian, and also another John.
22 But then, there were the men, and they are largely
23 men -- there are some women but there were the men who
24 were the husbands and the fathers that I never met.
25 Dave, Davy, Peter, Tom, Billy, I'm sorry to the widows

235

1 Thank you.

2 [Applause]

3 **MS FRASER BUTLIN:** Bill?

4 **Statement by WILLIAM WRIGHT**

5 **MR WRIGHT:** I've got a great big long list of wants, duty
6 and -- documents have talked about duty of candour.
7 Pharmaceutical hazard fund, in other words we
8 stop nationalising the losses while pharmaceuticals
9 make vast profits in the cases where people have been
10 the subject of trials.

11 There's an ongoing situation in Scotland with
12 regard to Patient Safety Commissioner, and I remain,
13 and I really do hope, that the Inquiry can look at
14 what happened in public health terms here because, to
15 me, there was a public health disaster and the public
16 health officials were nowhere to be seen throughout
17 this process. So they were the missing bit of the
18 jigsaw that previous inquiries simply haven't
19 looked at.

20 However, I'd like to bring this much closer to
21 home for me. When we met on Saturday, I was chairing
22 the meeting of -- joint meeting of the Scottish
23 Infected Blood Forum and Haemophilia Scotland and
24 said, "Folks, how are you all feeling about this?" and
25 the message came over "We're exhausted, we're weary

234

1 whose names I've not included because the list goes on
2 and on.

3 And, finally, the wee boys. We need to have
4 a memorial. Bruce talked about it yesterday, I agree
5 and Robert illustrated what can be done, thanks to the
6 Birchgrove Group.

7 We need to mark this in time and, yes, we must
8 provide for people, but we must never ever forget, and
9 one of the main ambitions I have in Scotland -- we
10 have in Scotland, and these people who do these things
11 that raise money for this memorial keep us going and
12 they're a tremendous inspiration.

13 So it's for those people that I think we need to
14 continue to act and to continue to be resolute. Thank
15 you.

16 [Applause]

17 **SIR BRIAN LANGSTAFF:** You may have wondered, perhaps
18 others may have wondered, why today we have chosen to
19 have the three of you as a panel. I think those who
20 are listening will be left in no doubt that in your
21 very different ways, you have expressed much of the
22 same feelings, given much of the same evidence, though
23 with regional variations, as appropriate to
24 devolution.

25 I suspect that in this way, by having the three

236

1 of you together, you have allowed the voices that you
 2 have said need to be heard to be expressed, if not
 3 directly to the Inquiry, through you, because each of
 4 you represents a body, and it is important to hear the
 5 representatives, the heads of those bodies, talking to
 6 us on their behalf, as well as on your own individual
 7 side.

8 The impact of what has happened, on you and on
 9 others, but essentially what you've been giving
 10 evidence directed to, within our terms of reference,
 11 is the impact on you, on those you represent, on
 12 others that you know of, and the appropriateness of
 13 the Government response. And it's varied and the
 14 expression of it is varied. I think few of us will
 15 ever forget your emphatic oratory, Bill, and the way
 16 in which you've left us in no doubt as to your strong
 17 feelings on matters of principle, and your championing
 18 of the individual at the heart of it all, whoever that
 19 individual may be.

20 Simon, you've expressed yourself in, well,
 21 rather different terms, but very eloquently. You
 22 described yourself, for instance, in terms that Bill
 23 wouldn't I think have used today, as "less than
 24 enamoured", on one occasion, by a Government response.
 25 I think he might have put it rather differently.

237

1 And it has been, I hope, as worthwhile for you
 2 as it has for us.

3 But also, I think you've expressed a collective
 4 sense of having been wronged, and a collective desire
 5 for accountability. And for a continuing voice. I'd
 6 like to thank you for that, for being here to do it
 7 for being prepared to put up with the difficulties of
 8 having a panel, having to be quiet at times when you
 9 might have wanted to speak, and being conscious of the
 10 fact that you have taken different approaches
 11 reflecting your different areas but giving each of
 12 them value in the very different ways.

13 It's been a new experience for us to do it this
 14 way, but I think it's been worth it. Thank you.

15 [Applause]

16 Tomorrow?

17 **MS FRASER BUTLIN:** Tomorrow we have Jason Evans giving
 18 evidence.

19 **SIR BRIAN LANGSTAFF:** Ten o'clock. So ten o'clock
 20 tomorrow.

21 **(6.13 pm)**

22 **(Adjourned until 10.00 am the following day)**
 23
 24
 25

239

1 And you, Lynne, have always been mindful of the
 2 fact that you speak for a community, and you need to
 3 be sure that the community are properly reflected in
 4 what you say because they are a wide and diverse
 5 group.

6 But I've heard from each of you, I think, and
 7 I think you've expressed your own campaigning -- if
 8 I can call it that, to use a word Bill doesn't like --
 9 in terms of that you've shown us that you -- it's
 10 rather quieter perhaps, the evidence you've given,
 11 than Bill, but there is -- I've seen a steely
 12 determination running through your persistence in
 13 asking questions and waiting for the answers.

14 But each of you, I think, has drawn attention to
 15 the need for compassion, openness, the need to avoid
 16 delay. On that, by the way, if I can just say, I'm
 17 sorry that because of the need to avoid delay which
 18 you've each touched on repeatedly, that there may have
 19 been pressures put upon you by the Inquiry to respond.
 20 It's inevitable and is one of the reasons I thank you
 21 for being prepared to give up your time, not simply in
 22 being here today, which goodness knows that's enough
 23 of an effort, particularly from Scotland these days,
 24 and not being as well as you might be, but also
 25 preparation beforehand, which takes a lot of effort.

238

I N D E X

1		
2		
3	SIMON HAMILTON, affirmed	2
4	LYNNE KELLY, sworn	2
5	WILLIAM WRIGHT, affirmed	2
6	Questions by MS FRASER BUTLIN	3
7	Questions from SIR BRIAN LANGSTAFF	219
8	Statement by SIMON HAMILTON	229
9	Statement by LYNNE KELLY	232
10	Statement by WILLIAM WRIGHT	234

240

<p>MR HAMILTON: [74] 1/5 1/7 1/10 1/18 2/1 2/6 2/8 3/9 3/14 4/5 4/8 4/11 5/4 6/19 6/24 7/3 51/19 86/22 87/3 88/15 88/18 126/11 126/15 128/11 128/19 128/22 129/10 130/15 130/17 131/8 131/13 131/24 132/9 132/14 133/8 133/19 134/5 134/8 134/12 134/17 135/8 135/23 136/3 136/5 137/14 138/7 138/11 140/7 143/19 145/13 145/20 145/23 147/1 147/5 147/14 147/23 147/25 148/3 149/4 153/19 154/7 163/17 178/1 189/11 192/23 197/2 203/11 205/6 205/12 215/16 223/19 223/22 228/16 229/12</p> <p>MR WRIGHT: [155] 7/10 7/13 7/20 7/24 8/3 8/12 8/15 8/21 9/8 9/10 9/13 10/14 10/17 10/22 11/3 12/25 19/25 22/7 22/14 22/21 22/24 23/24 24/2 24/22 26/7 27/13 27/16 27/19 29/21 29/25 30/6 31/3 32/11 32/16 32/21 33/16 34/1 35/9 36/18 36/21 37/1 37/20 37/24 38/1 38/12 39/12 39/16 39/20 40/18 40/22 41/3 42/12 42/17 42/19 43/1 43/8 43/15 45/17 48/18 48/21 49/9 49/21 62/17 62/23 63/19 63/22 64/4 66/25 67/3 69/5 69/16 69/19 69/22 70/16 72/9 72/12 74/17 77/17 77/21 90/10 90/16 90/21 95/3 95/5 95/10 96/22 96/24 97/1 97/5 98/3 98/9 99/22 101/5 103/1 103/3 103/6 103/16 103/22 104/1 148/8 148/14 148/16 150/17 152/20 152/22 152/25 153/4 153/6 155/14 155/22 156/17 159/2 161/1 162/25 163/14 175/9 176/21</p>	<p>177/14 191/4 194/13 195/10 198/7 199/17 199/23 201/10 204/15 204/20 205/5 205/17 205/20 206/10 209/18 210/4 210/9 210/11 211/1 212/11 212/20 212/23 214/17 214/22 214/25 215/11 217/5 217/12 219/24 221/7 221/14 222/17 222/22 223/18 225/14 226/14 227/21 234/5</p> <p>MS FRASER BUTLIN: [291] MS KELLY: [113] 13/13 14/12 15/3 15/9 15/22 15/25 16/3 16/20 17/5 18/2 18/4 52/2 52/5 53/10 55/2 57/12 58/14 58/17 59/8 59/11 59/19 60/22 70/15 72/8 72/11 79/7 80/18 80/22 81/2 82/8 82/10 82/14 82/17 83/22 83/24 84/20 85/11 85/15 85/17 86/10 89/15 89/21 91/9 93/20 94/6 106/1 109/7 109/9 109/11 112/12 112/15 114/8 114/12 115/6 116/5 116/14 116/18 117/17 118/3 121/8 122/19 123/2 123/22 125/12 126/4 150/3 153/21 160/25 161/2 165/6 168/1 168/3 171/1 171/4 171/6 172/3 172/6 172/10 172/20 174/18 180/6 183/16 183/22 184/24 185/2 185/5 186/5 186/18 186/21 187/2 187/23 188/14 188/18 188/22 188/25 192/7 194/19 195/25 199/18 200/10 202/23 204/6 205/4 205/7 206/19 207/5 207/13 207/15 208/11 216/17 226/17 227/10 232/8</p> <p>RACHEL: [1] 156/19 SIR BRIAN LANGSTAFF: [59] 1/3 1/6 1/9 1/17 1/19 2/2 2/7 2/9 2/15 4/1 8/6 8/9 8/13 8/19 15/5 17/1 27/18 32/15 32/20 41/4 42/14 42/18 49/7 51/3 51/10</p>	<p>51/15 51/18 77/16 77/19 90/14 90/17 90/20 90/25 148/12 148/15 148/22 152/24 153/3 153/5 183/14 183/17 199/15 201/24 202/2 202/5 219/11 221/2 221/8 222/4 222/21 223/9 223/20 225/10 226/12 226/15 227/8 229/6 236/17 239/19</p> <p>' '20 [2] 133/20 134/3 '91 [1] 162/14 'advising [1] 23/10 'immense [1] 29/13 'inclination [1] 29/17 'look [1] 46/5 'look-back [1] 46/5 'that [1] 157/4 'The [1] 131/19 'there [1] 73/25 'unsympathetic [1] 29/17</p> <p>- -- and [1] 97/24</p> <p>0 0.1 [1] 157/23 029 [2] 152/20 152/20 051 [1] 95/13</p> <p>1 1 November 2011 [1] 167/4 1.03 [1] 142/23 1.03 million [1] 142/12 1.3 [1] 146/15 1.3 million [1] 149/22 1.50 [1] 90/24 1/stage [1] 104/2 10 [1] 200/8 10 June 2021 [1] 1/1 10,000 [5] 38/23 92/4 100/8 117/22 194/22 10-year [2] 200/16 200/19 10.00 [2] 1/2 239/22 100 [3] 157/23 157/25 181/16 100 per [1] 161/18 100,000 [3] 157/19 157/23 191/24 10th February 2000 [1] 155/5 11.20 [1] 51/12 11.50 [1] 51/14 12 [3] 12/6 51/11</p>	<p>65/15 12 million [2] 11/17 70/4 12.47 [1] 90/22 13 [2] 158/21 159/11 13 February 2020 [1] 142/4 13 years [1] 12/6 14 [3] 38/18 65/15 68/10 14 years [1] 49/13 14th November 2011 [1] 52/1 15 [1] 222/13 15 years [4] 28/19 153/12 159/23 160/21 15-year [2] 29/9 199/4 16 June 2006 [1] 45/22 17 [1] 78/25 18 [1] 25/10 18 April [1] 47/10 19 [1] 138/12 1970s [1] 29/11 1971 [1] 196/17 1973 [1] 196/17 1986 [2] 26/9 211/9 1989 [1] 13/14 1990s [1] 28/9 1991 [7] 29/11 157/7 157/16 157/21 161/3 161/5 196/17 1996 [1] 213/2 1997 [1] 7/9 1997/98 [1] 14/8 1998 [2] 7/9 127/2 1999 [11] 12/3 14/12 15/11 19/5 30/6 32/7 33/18 34/21 40/1 150/23 210/1 1s [5] 100/9 100/23 107/7 174/23 175/6</p> <p>2 2 July 2014 [1] 187/1 20 [5] 35/12 49/13 63/11 158/21 200/8 20 million [1] 152/13 20 years [1] 215/7 20,000 [1] 222/13 200 [1] 2/4 2000 [10] 24/24 29/23 29/25 30/1 32/7 33/11 33/18 40/2 155/5 159/7 2001 [4] 15/12 29/4 35/8 153/8 2002 [1] 153/8 2003 [3] 15/19 15/20 39/9 2005 [4] 11/12 45/13 48/24 50/1</p>	<p>2006 [4] 45/13 45/22 175/12 196/14 2007 [7] 9/1 30/7 43/24 48/20 165/3 196/13 199/10 2008 [1] 50/10 2009 [1] 51/25 2010 [6] 7/21 9/9 16/3 18/7 79/24 80/17 2011 [18] 9/11 10/18 16/12 18/1 52/1 52/12 62/7 62/13 79/24 80/6 121/9 121/17 122/1 123/13 165/11 165/12 165/18 167/4 2012 [3] 10/19 11/6 62/19 2013 [6] 62/19 62/20 79/1 82/9 105/21 180/22 2013/14 [1] 38/18 2014 [6] 16/2 16/13 17/3 63/21 105/21 187/1 2015 [9] 40/6 67/9 67/18 69/14 92/2 126/10 157/4 174/20 208/11 2016 [10] 44/8 92/2 96/2 101/2 114/7 115/11 116/10 152/13 156/24 221/4 2017 [7] 4/4 29/1 83/17 83/23 85/13 102/25 127/3 2018 [2] 158/16 219/3 2019 [4] 18/15 134/7 138/12 230/25 2020 [4] 138/12 140/2 142/4 145/15 2021 [3] 1/1 158/1 221/21 20m [2] 29/6 153/10 21 [1] 35/13 21st January 2016 [1] 115/11 22 January 2019 [1] 134/7 23 [1] 207/25 23 November 2017 [1] 85/13 24 [1] 11/13 25 [2] 77/24 157/3 25 January 2017 [1] 83/23 25 March 2015 [1] 69/14 25 March 2020 [1] 145/15 25 million [5] 76/24 77/8 77/25 78/2 78/18 25 November 1999 [1] 210/1</p>	<p>25,000 [2] 192/1 192/2 25th [1] 77/4 26th [1] 77/4 26th March 2015 [1] 40/6 27 January [1] 142/13 27,000 [3] 100/6 221/8 222/13 29 August [1] 39/8 2s [1] 107/7</p> <p>3 3,000 people [1] 232/25 3.10 [1] 148/17 3.35 [1] 148/19 3.39 [1] 148/21 30 [3] 107/3 157/25 189/22 30 years [3] 83/12 200/8 232/19 30-year [1] 199/4 300 [1] 2/4 300 people [1] 108/18 33 [1] 158/18 33 million [1] 149/22 34 [1] 49/14 36 [2] 158/19 159/24 36 could [1] 159/22 38 hours [1] 222/8</p> <p>4 4,000 [1] 142/15 4.54 [1] 202/7 40 [2] 107/3 220/3 40 years [1] 189/22 40,000 [1] 38/24 400 [2] 29/10 153/10 45 million [1] 149/22</p> <p>5 5.15 [1] 202/9 50 [2] 100/18 220/3 50,000 [2] 42/2 192/1 50-year [1] 199/5 55 million [2] 134/14 135/7</p> <p>6 6 July [1] 117/15 6 July 2016 [1] 116/10 6.13 [1] 239/21 60,000 [1] 191/25 69 [1] 158/16 69 names [1] 159/20</p> <p>7 75 [1] 100/19 76 [1] 207/11</p>
---	--	---	--	--	---

8	178/15	208/18	225/11	95/25 105/13 105/13	agreed [9] 85/17
8th [1] 165/18	accessible [1] 63/1	actions [3] 43/1 156/6	administering [2]	115/14 115/18 119/6	100/6 102/15 102/15
9	accessing [5] 188/8	157/10	110/21 144/22	121/25 122/3 129/17	154/16 172/4 172/15
9 February 2016 [1]	189/10 189/13 189/24	active [6] 6/13 7/4 7/7	administers [1]	130/4 131/20 142/19	182/2 188/25
101/2	190/5	45/15 49/20 174/25	226/13	145/18 176/2 214/24	agreement [3] 138/2
91 [1] 207/20	accident [2] 196/25	actively [2] 10/8	administration [1]	219/21 230/11	138/16 176/8
92 [2] 207/12 207/20	196/25	16/14	30/8	affecting [4] 53/20	agreements [2]
96,000 [1] 168/23	accidents [1] 178/24	activities [3] 5/13	administrative [1]	54/15 80/3 105/14	138/20 139/8
96,369 [1] 167/19	accommodation [2]	13/20 13/21	31/15	affects [1] 104/19	agricultural [1] 1/16
97 [1] 35/15	66/17 130/6	actually [60] 8/7 9/23	administrator [1]	affirmed [4] 2/12 2/14	ah [4] 99/22 107/21
98 [3] 14/8 35/15 36/4	accompanied [1]	11/20 12/1 18/8 24/14	218/14	240/3 240/5	204/20 219/25
A	189/16	25/18 26/14 30/12	administrators [2]	afford [2] 162/3 217/4	ahead [4] 89/25
AA [2] 30/18 37/11	account [4] 74/6	34/8 37/2 38/15 38/16	110/21 111/18	afraid [5] 37/9 90/8	126/14 176/21 232/1
Aberdeen [1] 97/7	160/17 217/23 221/10	39/24 44/10 50/2	admission [2] 174/12	98/19 148/9 191/7	AHOs [2] 219/22
able [36] 12/18 12/22	accountability [9]	53/24 56/10 58/25	175/3	after [39] 15/20 29/23	220/1
26/1 31/24 39/21	151/9 219/24 220/20	61/19 63/4 63/4 63/11	admit [1] 41/13	30/3 32/25 35/6 49/22	aid [1] 41/25
39/22 40/15 50/5 73/4	224/1 232/18 233/1	64/25 65/2 65/14 71/1	admitted [1] 57/3	58/5 61/25 62/22	Aileen [1] 32/21
74/19 84/3 94/12	233/11 233/13 239/5	71/22 72/21 76/17	adopted [1] 117/3	63/24 83/11 85/19	aim [1] 88/23
94/13 105/12 131/11	accountable [1]	88/18 93/6 93/9 96/18	adult [2] 107/5 222/25	88/13 89/11 94/25	aims [3] 5/2 12/23
153/23 161/6 182/17	151/22	97/10 99/22 102/2	adults [1] 5/15	95/16 98/19 101/9	17/3
183/24 186/23 192/12	accounts [1] 101/11	102/8 104/24 129/13	advanced [3] 55/16	102/12 119/21 125/22	air [2] 136/19 162/7
193/2 199/2 200/14	accurately [1] 232/24	135/17 136/19 150/24	70/1 188/2	126/12 136/8 161/5	airport [1] 136/9
200/14 200/17 201/23	accusation [1] 160/3	159/17 160/1 164/1	advantage [2] 151/9	164/11 165/4 167/17	alarmed [1] 24/16
206/15 210/21 211/12	accusations [1] 215/2	164/17 175/25 177/17	199/3	172/20 172/20 180/24	albeit [1] 64/8
211/22 212/1 220/8	achieve [2] 147/11	183/1 183/5 193/21	advantageous [1]	197/9 198/10 199/9	alcohol [3] 57/24
224/15 235/9 235/10	188/13	198/16 205/15 207/18	221/25	199/9 205/20 211/8	211/25 212/3
about [253]	achieved [5] 43/3	210/12 216/20 218/13	advantages [1] 149/1	221/17 231/3 235/2	Alex [3] 62/20 63/12
absence [2] 53/12	88/23 175/15 224/21	226/9 231/4	advice [18] 11/15	afternoon [4] 50/7	67/25
216/23	231/8	add [13] 44/24 47/3	33/12 36/1 92/5 92/14	69/14 74/11 76/9	Alice [3] 50/13 69/9
absolute [3] 21/15	achieving [1] 187/21	48/10 49/13 89/15	92/17 93/25 111/6	afterwards [3] 2/21	96/16
160/12 173/17	acknowledge [5]	160/25 163/16 183/3	114/19 116/5 119/3	72/19 215/25	Alistair [2] 118/9
absolutely [7] 20/22	30/11 136/22 178/7	203/9 204/6 206/19	120/12 156/7 156/12	again [41] 8/19 15/4	118/11
128/16 148/12 162/25	230/21 230/22	216/15 222/13	159/7 209/4 209/7	21/4 27/11 48/18	alive [5] 157/22
178/1 186/4 217/7	acknowledged [2]	added [1] 100/8	227/2	61/18 82/3 85/8 85/21	158/11 158/21 187/6
abundance [2] 144/16	129/23 139/23	addition [1] 98/6	advise [4] 92/8	85/22 90/4 107/14	209/3
210/6	acknowledgement [5]	additional [13] 38/24	114/16 117/7 121/1	111/10 111/19 113/22	all [152] 5/5 8/24 9/2
accede [1] 64/20	80/14 80/25 149/16	67/10 74/14 125/11	advised [2] 70/24	114/18 118/9 119/13	12/11 16/8 16/8 17/6
accept [10] 3/14	231/9 231/14	125/14 137/9 137/12	95/20	119/21 120/6 125/12	17/16 18/23 24/5
46/17 74/4 75/15 88/8	acknowledges [1]	143/14 150/6 167/19	advisers [3] 120/20	125/25 127/8 136/13	24/13 27/1 35/17
101/15 136/21 197/13	26/22	177/23 194/9 228/8	122/12 138/25	145/24 148/10 161/21	42/12 44/21 52/16
197/25 227/9	acknowledging [1]	address [17] 16/16	Advisory [4] 18/23	162/11 163/17 166/21	53/25 54/8 55/19
acceptance [1]	231/21	56/3 79/13 79/16	123/15 185/12 186/22	173/13 174/21 183/16	57/23 60/2 60/13 61/4
216/11	acquired [1] 157/15	101/3 103/20 107/16	advocacy [16] 5/23	184/1 208/9 212/14	61/23 73/19 74/18
accepted [3] 105/15	acquitted [1] 38/15	132/19 142/17 143/4	13/6 13/7 17/6 19/7	216/7 216/22 230/15	75/22 77/3 77/4 77/13
105/17 231/16	acres [1] 220/3	143/10 164/2 181/12	45/16 49/20 62/8	233/3 235/10	78/3 79/19 79/21 80/2
accepting [1] 43/17	across [21] 10/4	188/16 197/18 198/2	147/21 191/15 193/6	against [8] 41/18	83/2 83/16 83/25 84/1
accepts [1] 231/18	16/17 25/1 25/7 43/7	231/16	195/3 202/20 204/17	41/21 109/8 140/19	84/2 84/11 84/13 85/5
access [33] 1/11	87/11 89/8 99/1 118/6	addressed [8] 88/3	208/18 208/24	140/24 198/21 229/2	85/22 86/18 86/22
55/12 55/13 61/14	118/23 134/25 135/4	101/3 125/21 136/23	advocate [2] 4/19	232/13	87/4 88/14 88/18 89/3
61/16 85/2 86/11	141/7 143/7 147/12	137/22 137/22 159/3	140/25	age [1] 20/17	89/24 90/11 91/17
87/13 113/18 122/4	166/17 170/21 177/2	203/12	advocates [1] 5/5	aged [1] 75/19	92/11 93/1 97/13
125/24 168/6 170/16	178/13 190/12 212/14	addressing [3] 139/19	advocating [4] 6/14	agenda [1] 54/11	99/14 102/17 105/1
170/18 179/15 180/3	act [12] 11/12 11/21	139/24 142/25	43/6 87/7 138/21	ages [2] 17/6 195/4	105/21 107/10 107/16
181/11 182/11 185/4	30/12 34/18 34/19	adequacy [1] 36/1	affair [3] 9/4 23/17	ago [6] 22/8 46/25	108/4 109/11 109/12
187/18 187/22 188/11	72/20 74/8 150/19	adequate [1] 114/6	41/11	48/8 49/12 59/5	109/25 110/6 111/14
190/21 193/21 193/25	221/15 221/16 226/3	Adjoined [1] 239/22	affairs [1] 152/17	agree [14] 3/2 82/4	111/20 112/5 112/21
194/5 200/14 202/19	236/14	90/23	affected [33] 5/24	95/22 150/3 150/3	113/14 118/7 120/2
202/24 203/3 215/12	acted [1] 31/15	adjusted [1] 2/25	5/24 17/12 18/20	150/17 162/25 180/16	120/14 123/15 125/14
215/14 217/10	acting [3] 140/16	administer [2] 2/9	19/21 29/6 36/24	189/10 199/7 203/11	129/13 131/20 131/22
accessibility [1]	187/16 231/22	2/10	41/25 42/10 65/5	204/23 223/7 236/4	137/8 138/17 143/4
	action [6] 29/18 164/6	administered [1]	65/11 69/2 73/20		145/10 145/14 148/24
	175/13 188/4 200/5		84/25 86/25 92/12		150/5 150/25 155/7

A	168/17 168/18 178/11 182/5 185/10 210/12 222/14 222/14 also [70] 6/1 7/14 11/12 17/3 17/8 17/22 17/24 21/8 27/3 27/25 28/14 32/5 32/8 35/22 36/11 41/24 42/8 44/2 44/5 44/7 44/24 45/14 48/6 48/9 49/10 49/19 49/22 66/7 70/7 76/23 82/11 87/1 100/22 120/11 128/13 130/24 131/5 131/16 136/6 136/7 145/25 146/21 147/2 154/24 156/6 163/20 164/21 167/3 171/9 174/15 175/22 176/16 178/24 195/5 195/5 200/10 204/6 207/11 207/17 208/15 209/2 210/21 211/15 212/3 214/1 221/3 228/14 235/21 238/24 239/3 ALT [6] 210/24 211/7 211/10 211/15 211/21 211/25 although [2] 27/8 131/21 Alun [1] 82/12 always [22] 4/12 14/13 17/14 53/16 57/6 66/3 79/7 81/19 81/22 81/24 106/4 123/24 130/8 161/2 173/2 175/23 184/9 193/8 194/25 216/24 231/20 238/1 am [14] 1/2 3/11 36/19 51/7 51/12 51/14 89/17 95/11 117/7 121/6 148/8 177/9 204/20 239/22 amalgamation [1] 212/25 ambitions [1] 236/9 amid [1] 11/8 amount [2] 78/8 162/5 amounted [2] 146/14 206/20 amounts [2] 31/11 140/20 an absolute [1] 173/17 an acceptance [1] 216/11 an acknowledgement [1] 80/14 an additional [2] 67/10 137/9 an administrator [1]	218/14 an agreement [1] 138/16 an announcement [3] 80/6 81/14 81/22 an annual [1] 193/13 an approach [1] 189/10 an argument [1] 169/25 an assumption [1] 163/24 an easy [1] 168/24 an effort [1] 238/23 an enabling [1] 65/23 an endoscopy [1] 218/2 an enhanced [1] 125/3 an environmental [1] 20/2 an error [1] 210/7 an impartial [1] 24/20 an inclusive [1] 76/13 an independent [2] 12/5 22/10 an indication [1] 212/2 an inquiry [5] 21/14 43/23 43/25 63/25 64/1 an insult [1] 81/10 an interim [2] 186/23 187/4 an intransigent [1] 44/14 an investigation [1] 23/20 an MSP [1] 45/5 an observation [1] 190/16 an operation [1] 162/19 an opportunity [1] 81/24 an understanding [1] 216/11 analogous [1] 36/15 analogy [2] 217/18 222/22 analysis [3] 31/1 37/17 158/19 Andrew [2] 30/10 43/24 Andrew Kerr [2] 30/10 43/24 Andy [1] 45/24 anecdotes [1] 179/10 anger [2] 88/20 88/20 Anglocentric [1] 132/17 angry [3] 71/3 172/14	173/11 Angus [1] 212/13 animates [1] 229/25 Anna [1] 89/18 annotation [2] 155/15 155/19 annotations [1] 155/19 announce [1] 81/17 announced [8] 39/9 78/2 78/14 123/14 126/13 142/12 145/16 168/8 announcement [16] 39/11 39/14 74/12 77/12 80/6 81/14 81/15 81/22 82/2 86/12 94/25 114/22 167/3 167/24 168/14 168/24 announcements [4] 76/5 76/5 117/1 147/13 annoyed [1] 77/6 annual [2] 143/9 193/13 anonymised [1] 8/2 anonymity [2] 65/4 68/14 anonymous [2] 30/17 37/11 another [22] 6/11 18/16 18/17 50/4 57/5 68/7 70/25 72/21 80/4 80/20 82/22 87/23 101/9 110/22 113/25 122/10 141/22 141/22 206/5 214/12 215/4 235/21 answer [17] 51/3 77/9 77/10 81/5 87/3 87/20 90/1 92/9 107/13 118/16 131/2 141/3 184/25 206/15 219/16 226/10 227/6 answers [4] 37/14 56/14 229/13 238/13 anti [1] 187/16 anti-virals [1] 187/16 anticipate [1] 224/17 Antoniw [2] 18/16 83/1 anxiety [1] 127/17 any [83] 14/17 18/21 25/17 26/3 27/4 27/8 32/4 37/12 40/12 40/15 41/13 42/14 42/23 46/17 47/11 47/16 47/18 48/5 50/25 53/18 55/4 56/3 59/9 59/13 60/18 61/12 75/16 80/7 82/1	82/19 83/8 86/5 88/1 88/2 90/1 91/6 91/6 92/18 92/21 93/4 95/10 97/17 98/7 106/1 111/18 111/25 114/2 119/4 121/20 123/17 124/1 125/17 128/7 128/8 130/8 131/5 133/12 133/14 143/13 149/8 153/16 153/23 156/12 170/14 172/24 179/9 179/23 181/3 188/7 192/22 201/22 203/15 203/15 205/1 205/1 217/15 218/20 219/9 221/8 221/10 223/11 224/13 224/16 anybody [12] 14/22 18/19 19/1 88/25 92/7 113/5 119/17 122/4 125/6 125/8 126/4 135/12 anyone [4] 42/23 93/4 141/24 179/6 anything [13] 67/1 87/24 93/9 101/6 107/19 113/23 126/23 141/17 163/15 184/9 203/10 206/21 216/16 anyway [8] 18/12 83/9 108/4 111/19 118/8 136/24 185/18 226/21 anywhere [3] 171/20 193/25 194/5 apart [1] 184/3 apologise [3] 76/16 78/20 90/17 apologising [3] 76/17 76/20 76/22 apology [1] 114/20 apparent [1] 166/8 appeal [1] 93/21 appealed [1] 185/15 appeals [2] 120/23 120/24 appear [2] 49/6 214/8 appeared [9] 33/3 49/14 65/9 65/10 88/9 101/1 102/21 212/4 212/15 appears [2] 31/3 233/10 appetite [1] 52/20 APPG [6] 78/25 79/4 89/16 110/15 126/19 131/8 Applause [4] 232/5 234/2 236/16 239/15 applicants [1] 125/15 applied [2] 114/11 198/16	applies [1] 199/13 apply [5] 16/9 106/6 115/16 125/9 199/12 appointed [8] 7/24 42/3 121/17 142/1 142/3 170/7 172/19 213/14 appointing [1] 173/12 appointment [2] 59/1 170/5 appointments [2] 170/19 177/3 appreciate [4] 27/9 117/5 192/25 193/16 appreciated [1] 116/23 approach [14] 23/20 40/4 40/5 74/21 109/20 122/13 122/17 130/18 143/23 187/21 188/13 188/23 189/10 226/19 approachable [1] 124/16 approached [1] 9/15 approaches [1] 239/10 appropriate [3] 166/23 173/24 236/23 appropriateness [1] 237/12 approval [3] 181/11 184/11 185/19 approximately [2] 157/19 157/23 April [5] 47/10 48/20 62/20 79/1 96/2 April 2007 [1] 48/20 April 2013 [2] 62/20 79/1 April 2016 [1] 96/2 Archer [9] 51/22 52/5 52/8 59/22 60/20 62/3 79/9 82/20 196/13 archives [1] 190/9 are [140] 1/9 2/3 2/19 2/19 3/5 3/12 3/17 3/22 5/3 13/1 13/3 15/4 15/5 17/4 18/6 18/19 18/25 23/11 23/11 25/7 28/5 32/15 35/16 35/22 39/5 44/15 44/17 44/20 55/25 57/18 60/16 61/24 64/17 65/3 66/14 68/13 73/20 77/16 78/5 80/12 87/10 90/15 94/4 95/9 97/9 101/10 102/10 105/12 105/13 110/14 110/23 113/11 115/24 120/21 122/7 124/15
----------	---	---	--	--	---

<p>A</p> <p>are... [84] 125/21 126/5 130/3 131/22 141/12 143/12 144/14 149/11 150/9 150/14 157/22 157/23 158/24 161/22 162/1 163/5 164/11 166/4 166/8 169/1 169/10 170/2 172/23 172/23 172/25 174/6 175/24 176/10 177/5 177/5 178/17 179/10 181/9 192/15 193/6 193/16 194/1 194/3 194/12 195/18 195/18 196/3 196/4 196/8 196/18 197/21 197/22 197/23 197/24 200/3 201/19 203/4 203/7 203/11 203/13 203/14 204/2 204/3 205/17 208/1 213/5 213/20 217/19 217/23 218/7 219/15 220/22 224/4 224/6 225/6 225/11 226/20 226/25 226/25 230/1 230/2 230/17 234/24 235/20 235/22 235/23 236/20 238/3 238/4</p> <p>area [3] 165/7 209/12 209/13</p> <p>areas [4] 143/13 185/6 208/23 239/11</p> <p>aren't [4] 18/22 161/6 162/12 174/8</p> <p>argue [1] 162/2</p> <p>arguing [2] 55/9 227/8</p> <p>argument [2] 145/4 169/25</p> <p>arisen [2] 178/20 194/15</p> <p>arising [4] 36/2 94/5 167/4 207/8</p> <p>arm's [2] 130/19 220/23</p> <p>arm's length [2] 130/19 220/23</p> <p>arms [1] 21/18</p> <p>arose [1] 65/25</p> <p>around [31] 6/21 14/19 15/8 25/10 60/6 65/25 72/3 84/1 85/20 100/5 100/7 100/21 104/14 133/23 134/24 137/6 137/18 137/19 144/11 149/11 153/8 153/10 157/25 160/18 169/3 178/8 193/4 195/17 214/4 216/13 228/20</p>	<p>arrange [1] 145/6</p> <p>arranged [2] 210/16 224/25</p> <p>arrangement [3] 145/2 151/21 229/3</p> <p>arrangements [6] 117/13 138/20 154/17 219/20 221/4 223/11</p> <p>arrive [1] 220/18</p> <p>arrived [3] 77/9 98/16 100/5</p> <p>article [2] 28/23 29/3</p> <p>artistic [2] 213/25 214/5</p> <p>as [260]</p> <p>ascites [1] 55/18</p> <p>aside [1] 204/10</p> <p>ask [26] 45/19 47/20 64/2 98/6 148/24 156/19 162/17 165/14 167/2 172/24 183/5 194/20 194/24 194/25 200/15 204/15 206/6 206/22 207/6 209/4 209/7 210/21 217/5 226/12 227/22 229/6</p> <p>asked [50] 2/24 23/11 23/12 44/3 49/6 57/15 66/10 73/7 73/12 77/7 91/3 104/1 104/2 104/13 110/9 111/13 112/21 113/2 113/7 115/14 117/23 118/11 118/16 124/11 132/12 151/16 151/20 156/1 157/9 158/5 158/8 159/8 159/9 159/14 172/1 180/7 180/9 181/23 183/24 205/14 206/5 206/23 207/6 209/6 209/15 209/24 214/21 219/13 219/17 220/16</p> <p>asking [12] 22/16 55/13 83/10 92/8 106/3 135/6 171/21 179/13 185/1 188/23 222/4 238/13</p> <p>asks [1] 140/10</p> <p>aspects [1] 140/8</p> <p>assemblies [3] 87/11 144/20 145/6</p> <p>assembly [20] 15/10 15/15 17/10 17/11 17/14 18/5 79/12 83/3 83/24 84/1 84/2 85/10 107/4 124/14 129/12 140/16 144/12 171/20 171/21 172/1</p> <p>assertions [1] 225/17</p> <p>assess [3] 105/4 125/2 157/13</p>	<p>assessing [1] 110/22</p> <p>assessment [9] 73/23 97/22 97/24 98/1 103/21 103/25 104/16 104/18 124/23</p> <p>assist [1] 155/10</p> <p>assistance [8] 19/20 35/25 36/6 36/11 36/14 92/1 93/18 137/12</p> <p>associate [1] 178/5</p> <p>associated [1] 151/2</p> <p>assumed [1] 114/12</p> <p>assumption [2] 163/24 163/25</p> <p>assurance [1] 85/1</p> <p>assurances [1] 229/21</p> <p>assured [1] 215/25</p> <p>attack [1] 196/2</p> <p>attempt [7] 8/25 26/11 48/24 49/22 109/2 162/8 195/25</p> <p>attempts [2] 26/10 232/14</p> <p>attend [4] 65/2 180/8 180/9 210/5</p> <p>attendance [1] 155/16</p> <p>attended [10] 51/24 51/25 59/20 60/7 79/6 79/7 89/18 109/11 110/15 134/9</p> <p>attending [3] 54/10 64/21 175/6</p> <p>attention [2] 158/23 238/14</p> <p>attitude [3] 40/4 152/15 163/1</p> <p>attributable [1] 57/4</p> <p>attributed [1] 222/12</p> <p>August [3] 39/8 116/11 156/24</p> <p>August 2016 [1] 156/24</p> <p>authority [1] 201/6</p> <p>automatic [1] 128/8</p> <p>available [3] 165/20 177/8 187/16</p> <p>average [1] 100/5</p> <p>avoid [8] 48/22 49/3 152/5 164/4 173/18 173/22 238/15 238/17</p> <p>avoided [4] 20/19 74/1 75/13 108/5</p> <p>avoiding [1] 96/3</p> <p>awarded [2] 36/6 224/7</p> <p>aware [14] 20/12 41/20 63/25 84/18 89/6 141/1 144/14 144/15 156/2 175/17 177/9 178/12 204/21</p>	<p>205/1</p> <p>awareness [3] 87/14 89/5 137/18</p> <p>away [13] 3/13 12/8 12/20 41/24 42/8 61/3 71/22 73/2 77/13 83/5 90/5 159/17 227/17</p> <p>awe [2] 191/6 192/4</p> <p>awkward [1] 71/7</p> <p>B</p> <p>baby [1] 75/20</p> <p>back [89] 10/12 19/5 25/5 27/13 33/13 39/16 39/17 46/12 49/4 49/7 49/16 51/17 57/8 58/24 62/5 67/11 67/11 71/4 71/9 71/15 78/7 86/17 90/9 90/18 91/24 97/13 102/12 105/3 105/11 109/16 111/15 112/20 113/9 119/19 120/8 121/14 122/8 125/1 125/24 127/4 128/14 128/16 129/11 134/2 136/10 138/15 139/11 143/25 144/25 145/7 150/22 151/1 152/14 154/22 154/25 156/8 161/12 163/17 164/4 171/17 175/8 176/22 176/23 182/9 183/2 183/20 184/7 184/9 185/1 185/8 185/20 186/17 187/10 189/14 190/7 193/9 203/19 205/2 213/2 214/11 219/6 220/24 223/24 226/1 226/9 227/22 232/1 233/10 235/17</p> <p>back' [1] 46/5</p> <p>backbench [4] 45/1 79/23 80/20 84/8</p> <p>backed [3] 43/2 43/4 152/1</p> <p>background [6] 7/15 113/24 165/17 183/6 183/23 189/20</p> <p>backwards [2] 66/17 199/24</p> <p>bad [6] 34/4 67/14 70/3 102/5 206/13 206/14</p> <p>badgering [1] 192/3</p> <p>badly [1] 123/11</p> <p>baggage [1] 34/22</p> <p>balance [3] 26/23 215/20 217/22</p> <p>balanced [1] 48/1</p> <p>balancing [1] 223/4</p> <p>Bangor [1] 165/1</p>	<p>bank [4] 101/11 217/21 217/22 218/17</p> <p>Barlow [4] 98/17 206/7 206/20 220/7</p> <p>Barlow's [1] 219/14</p> <p>Baroness [1] 200/13</p> <p>barrister [1] 92/8</p> <p>barristers [3] 92/7 92/15 92/19</p> <p>based [5] 100/4 158/15 217/2 217/3 227/16</p> <p>basic [2] 115/18 195/2</p> <p>basically [57] 14/3 15/9 16/8 17/16 17/19 18/18 53/14 53/25 54/16 55/2 55/16 57/2 59/3 60/23 83/6 85/23 95/20 106/1 106/6 110/22 113/5 114/12 117/21 118/4 118/18 121/11 123/18 123/22 124/6 169/8 169/18 169/22 171/16 172/10 172/13 173/1 173/4 173/10 180/8 180/23 181/9 181/14 182/3 183/1 184/4 184/15 185/15 186/15 186/23 188/6 191/13 196/13 196/18 196/24 208/18 208/23 209/1</p> <p>basis [12] 36/7 50/23 103/13 105/14 143/16 149/17 167/20 176/25 191/14 193/13 228/14 228/14</p> <p>bat [1] 227/21</p> <p>battle [4] 83/16 125/22 139/24 152/6</p> <p>battling [1] 144/14</p> <p>BBC [1] 71/23</p> <p>be [285]</p> <p>bear [6] 88/3 102/19 128/2 149/21 158/1 159/12</p> <p>bearing [1] 24/2</p> <p>beaten [1] 89/12</p> <p>became [15] 9/11 9/14 18/5 30/12 34/21 40/3 47/4 48/11 58/6 63/20 141/14 191/19 205/23 207/19 212/7</p> <p>because [213] 1/12 1/15 3/11 4/21 5/18 6/1 6/4 9/13 11/4 11/15 12/9 14/15 15/23 16/13 17/10 18/9 18/14 20/23 21/8 21/21 28/18 29/11 29/18 37/6 40/25 45/8</p>	<p>50/3 54/14 54/22 55/2 55/14 55/23 56/19 57/12 58/2 59/21 60/11 60/14 60/23 61/16 61/20 63/11 65/17 67/9 67/13 67/19 68/4 70/11 71/5 71/9 71/11 72/15 75/4 75/4 75/20 75/23 75/25 76/23 77/6 79/21 81/11 81/22 83/5 83/8 84/22 84/24 86/1 89/15 92/9 93/4 93/10 93/15 93/24 94/11 94/17 95/14 95/15 98/16 99/7 99/12 100/1 100/13 101/19 101/20 102/5 102/9 102/11 102/21 104/1 104/7 104/18 106/19 106/21 107/2 108/11 108/15 109/1 110/4 110/24 114/19 116/5 118/20 119/5 119/9 120/2 121/2 121/23 123/3 123/12 124/5 124/9 125/18 126/1 126/5 127/15 128/12 129/2 136/20 137/5 137/15 139/21 144/9 144/23 146/4 150/5 152/1 153/12 153/24 159/8 160/4 161/21 162/1 162/25 164/2 168/16 168/17 169/1 169/12 170/4 170/11 171/10 171/12 172/10 173/7 173/18 174/3 174/14 174/16 175/5 176/9 176/16 176/18 180/6 181/1 181/15 182/2 182/16 183/5 184/2 184/8 185/17 185/21 187/8 189/20 191/6 191/9 192/5 192/9 192/20 193/24 194/13 194/15 194/21 196/6 199/10 201/8 202/24 204/10 205/8 205/24 207/1 208/1 209/16 209/20 211/23 211/23 214/7 214/14 214/15 218/13 219/4 221/14 222/11 222/12 223/24 224/17 225/5 225/20 227/14 228/6 229/13 231/15 231/24 232/12 234/14 235/5 235/8 235/11 235/11 236/1 237/3 238/4 238/17</p> <p>become [7] 20/3 44/6</p>
--	--	--	---	---	---

B	214/14 218/22 219/21 222/10 223/1 231/5 231/7 232/16 234/9 235/7 237/9 238/1 238/19 239/1 239/4 239/13 239/14 before [38] 3/7 3/15 24/7 32/2 47/9 47/20 49/15 50/5 50/23 58/18 58/18 77/6 78/24 90/11 91/2 96/2 98/11 101/1 102/21 115/2 116/12 119/16 139/1 140/2 141/24 148/6 155/14 157/6 159/23 167/2 168/19 169/25 180/1 187/11 188/9 190/22 211/25 214/11 beforehand [2] 89/25 238/25 begging [1] 150/10 beginning [5] 58/17 83/3 91/9 129/3 178/4 behalf [7] 14/5 74/3 75/14 139/3 172/16 232/9 237/6 behemoth [1] 24/12 behind [5] 25/10 38/17 127/17 133/25 219/8 beholden [1] 108/25 being [71] 3/12 4/18 6/5 9/7 18/22 20/21 23/11 23/12 39/5 40/19 41/14 44/13 55/15 55/15 57/3 65/2 65/18 73/16 81/11 84/18 88/4 95/7 95/7 97/17 103/24 109/5 111/12 125/19 130/19 130/20 130/20 132/12 133/14 133/25 135/11 135/19 135/20 137/21 137/21 137/22 146/6 160/13 163/21 172/13 173/23 175/2 184/6 185/24 186/11 190/10 195/10 203/24 209/19 212/17 215/23 215/24 215/25 217/2 217/3 219/5 221/1 222/19 222/19 231/8 235/8 238/21 238/22 238/24 239/6 239/7 239/9 Belfast [6] 6/17 177/24 178/7 189/9 190/12 194/4 belief [1] 88/2 believe [21] 8/1 8/1 32/14 32/17 36/8 36/11 47/10 50/24	53/8 56/1 102/9 106/21 115/25 149/14 149/15 151/13 177/16 194/4 217/13 223/23 226/17 believed [2] 235/6 235/9 believes [2] 27/7 28/16 Ben [3] 53/12 180/13 183/4 Ben Cole [3] 53/12 180/13 183/4 bench [1] 33/3 beneficiaries [9] 110/13 119/9 119/12 129/25 142/13 143/1 143/11 147/8 147/12 beneficiary [1] 221/13 benefit [8] 14/17 47/19 82/22 83/7 88/1 137/9 170/14 176/3 benefits [10] 39/20 111/5 119/2 120/12 120/20 122/15 175/22 178/17 194/11 233/14 Benson [3] 164/13 177/22 193/13 bereaved [4] 17/22 112/3 122/4 147/10 Bernard [3] 16/22 184/12 184/22 best [7] 4/24 67/15 107/18 142/24 143/10 173/9 208/21 bet [2] 76/18 105/7 better [23] 4/19 15/10 16/9 28/5 76/19 76/21 80/7 81/23 89/9 107/19 108/3 108/14 115/19 116/1 118/19 125/1 146/4 170/10 183/14 186/3 193/5 193/6 203/23 between [32] 2/19 3/4 9/17 16/5 22/12 29/11 30/6 31/7 31/20 31/21 33/10 40/5 56/15 67/7 67/17 77/4 85/5 87/22 100/16 101/14 101/16 104/19 118/4 134/22 142/15 152/6 169/25 176/9 177/9 185/13 199/25 212/22 beyond [3] 2/2 137/15 154/19 big [18] 11/8 31/5 44/15 59/21 64/19 75/24 81/16 83/14 83/24 97/23 104/6 104/25 141/4 194/10 224/25 228/11 229/23	234/5 bigger [5] 144/8 164/1 164/3 164/3 164/3 biggest [2] 11/9 223/4 bill [58] 1/20 7/4 13/8 13/10 19/6 19/23 22/1 26/6 26/16 29/19 37/18 38/7 38/11 39/8 39/18 41/7 47/21 48/15 53/25 62/5 65/7 68/24 73/21 78/20 81/10 84/15 84/17 87/5 88/19 90/8 94/24 134/18 139/11 141/8 154/25 158/23 160/25 172/11 178/2 190/25 196/7 197/1 198/6 199/18 203/9 206/5 207/4 209/24 210/8 216/15 219/12 225/4 225/12 234/3 237/15 237/22 238/8 238/11 Bill Wright [2] 1/20 73/21 Bill's [2] 50/17 192/25 Billy [1] 235/25 Bio [1] 25/10 Birchgrove [1] 236/6 Birmingham [1] 61/20 bit [44] 7/14 33/24 35/3 38/18 38/20 54/13 61/3 61/3 62/3 63/8 65/14 71/7 76/13 77/6 91/4 92/1 93/10 96/1 99/17 101/13 101/16 101/16 105/25 118/9 118/15 119/24 121/4 172/25 175/10 180/17 185/20 185/21 191/8 212/12 212/12 213/24 214/5 214/6 218/8 218/9 219/13 220/10 220/23 234/17 blamed [1] 186/2 bleeding [19] 5/6 5/14 5/17 8/21 9/22 9/24 13/5 17/6 18/24 123/16 166/2 166/25 167/8 167/15 167/21 176/12 177/12 203/18 214/15 bleeds [1] 178/23 block [7] 126/15 127/9 127/10 201/7 201/7 201/7 201/7 blocked [2] 185/6 196/4 blockers [1] 150/7 blood [97] 4/20 5/25 6/3 6/6 6/15 16/7 17/13 17/21 18/1 18/20 19/9 19/18 22/5	23/19 25/9 25/21 26/25 28/25 29/11 36/2 36/2 41/15 46/19 46/20 47/4 47/13 47/13 48/9 48/11 53/11 53/18 55/12 57/13 60/25 61/7 76/20 79/4 89/8 89/9 103/8 103/10 105/8 109/15 109/18 111/7 112/2 112/2 114/10 115/11 120/9 120/22 121/21 122/1 122/6 124/13 137/19 142/14 142/20 155/11 157/6 157/15 157/21 159/16 162/16 162/21 164/10 165/21 165/22 170/10 170/17 176/6 176/14 177/5 177/12 178/21 179/4 179/14 181/3 181/7 182/13 188/3 196/16 200/25 206/17 209/12 210/2 210/18 211/14 212/5 212/6 212/18 212/23 213/16 214/13 218/10 230/11 234/23 blood-borne [1] 188/3 bloody [2] 27/17 151/10 blueprint [2] 132/20 132/21 board [6] 166/10 169/16 170/1 172/12 184/10 184/10 boardroom [2] 1/12 193/23 Boards [1] 188/21 bodies [2] 130/8 237/5 body [7] 20/5 20/9 31/16 64/9 104/9 136/20 237/4 bono [1] 103/13 book [1] 190/8 border [1] 34/13 Borders [1] 64/20 born [2] 13/14 14/7 borne [2] 156/5 188/3 borrowed [1] 120/4 both [16] 7/13 13/10 17/20 37/3 43/20 134/20 136/10 150/17 159/4 171/24 185/6 205/19 206/16 214/16 214/18 230/9 bottom [13] 23/15 27/15 31/9 31/19 35/3 41/2 73/15 80/11 98/22 132/5 142/8 153/6 199/1	boy [1] 67/5 boys [2] 16/4 236/3 Brampton [1] 200/19 branch [1] 4/12 break [14] 12/8 51/9 51/11 51/13 90/12 90/14 99/12 105/9 148/7 148/8 148/13 148/18 201/23 202/8 breakdown [2] 215/19 216/4 breaks [2] 2/22 228/21 breakthrough [5] 58/25 75/24 83/19 86/1 86/6 breath [1] 136/19 brewing [1] 23/16 Brian [13] 1/5 134/22 208/12 208/17 209/1 209/4 209/6 209/14 211/19 219/10 228/16 231/22 240/7 Brian O'Mahony [2] 208/12 209/6 Brian O'Mahony's [1] 209/4 bridge [1] 16/5 brief [2] 190/24 229/14 briefed [4] 82/18 89/22 89/24 91/18 briefing [5] 10/3 10/10 69/7 75/7 77/23 briefs [1] 62/20 briefly [3] 43/13 87/20 212/21 bright [4] 8/16 8/22 198/12 198/19 bring [13] 18/24 47/18 73/4 84/12 84/14 124/1 147/22 148/8 159/25 215/3 215/4 232/10 234/20 bringing [1] 137/18 British [1] 34/10 broadband [1] 66/14 broader [7] 69/1 84/25 132/15 164/15 164/15 179/2 179/2 broadly [1] 11/1 broke [1] 12/20 broken [2] 127/3 216/6 brother [6] 179/18 179/19 182/4 189/12 207/17 207/17 brothers [3] 14/22 101/22 235/21 brought [7] 8/3 8/16 57/6 97/13 120/1 138/16 186/22
----------	---	--	---	---	--

<p>B</p> <p>Bruce [17] 12/12 33/1 45/6 50/13 69/9 75/2 75/20 76/7 76/7 95/10 96/15 100/11 100/16 100/19 104/7 225/14 236/4</p> <p>budget [6] 144/7 146/17 150/5 150/15 152/14 224/19</p> <p>build [4] 41/23 43/6 98/12 151/12</p> <p>building [2] 63/6 216/3</p> <p>buildings [2] 190/10 194/1</p> <p>built [1] 100/21</p> <p>bullet [1] 26/17</p> <p>bunch [2] 71/3 96/13</p> <p>bureaucracies [1] 229/23</p> <p>bureaucratic [2] 124/21 230/10</p> <p>Burt [2] 118/10 118/11</p> <p>business [5] 1/10 79/23 80/20 84/8 100/1</p> <p>but [301]</p> <p>BUTLIN [2] 3/6 240/6</p> <p>buttonholed [1] 213/3</p> <p>buying [1] 41/3</p> <p>by [126] 1/14 1/19 3/6 3/17 4/24 9/5 9/15 14/6 15/13 16/3 17/13 19/21 21/18 22/3 26/3 27/4 29/6 29/8 29/24 30/3 30/14 30/15 30/23 34/24 35/17 36/17 37/10 40/17 42/3 44/13 47/9 53/13 53/14 53/16 55/17 56/19 56/20 59/16 61/3 63/15 64/23 68/15 70/17 73/20 73/21 74/1 75/13 78/19 80/5 82/18 83/21 87/1 88/8 89/25 93/13 94/25 95/2 103/2 105/17 108/16 108/19 109/13 109/14 110/9 114/21 115/15 121/25 127/6 131/25 135/19 135/21 137/10 138/16 141/12 141/12 142/17 142/19 142/19 150/7 151/20 157/8 158/19 159/4 165/21 166/12 166/14 167/9 167/12 172/23 176/2 178/7 180/8 182/22</p>	<p>183/4 183/18 185/24 186/11 193/24 195/12 196/6 200/18 202/14 202/16 203/25 210/14 211/6 212/19 213/4 213/4 213/7 214/2 216/9 227/19 229/11 231/10 232/7 232/14 234/4 236/25 237/24 238/16 238/19 240/6 240/8 240/9 240/10</p> <p>C</p> <p>cabinet [2] 34/25 211/2</p> <p>Cairngorms [2] 20/3 21/9</p> <p>Cairns [1] 82/12</p> <p>calculated [1] 39/1</p> <p>calculations [1] 135/16</p> <p>call [6] 46/2 100/24 116/3 133/17 179/13 238/8</p> <p>called [9] 20/5 24/15 34/8 45/4 112/10 123/15 170/3 174/6 175/8</p> <p>calling [5] 19/14 22/3 160/11 197/4 197/5</p> <p>calls [4] 11/7 83/13 86/15 106/2</p> <p>came [55] 7/23 11/2 11/22 13/12 14/9 14/12 37/11 37/16 50/10 59/23 63/12 64/9 66/11 67/5 67/8 67/9 69/13 72/6 72/8 78/7 89/23 92/23 95/17 97/15 97/18 97/21 98/25 100/17 104/17 104/25 106/14 111/15 112/24 113/8 113/16 119/1 121/14 133/21 134/16 134/21 152/13 168/14 180/6 180/10 187/10 189/14 191/25 198/19 211/19 212/3 212/14 214/4 221/5 228/22 234/25</p> <p>Cameron [6] 76/14 76/22 77/5 78/1 98/11 114/21</p> <p>Cameron's [1] 77/22</p> <p>campaign [20] 13/18 15/17 16/15 17/8 82/7 86/8 119/10 134/10 135/1 135/3 135/22 143/20 192/11 195/21 195/23 208/24 209/1 229/19 232/10 232/16</p> <p>campaigned [1] 54/21</p>	<p>campaigner [2] 7/4 7/6</p> <p>campaigners [11] 10/4 14/20 56/10 122/21 122/22 183/22 201/3 214/21 230/18 232/13 233/5</p> <p>campaigning [24] 6/21 13/8 13/12 13/23 14/8 14/19 15/8 20/2 20/3 62/9 86/9 87/7 91/8 112/1 126/9 147/21 164/22 171/2 180/1 192/9 204/25 230/16 231/4 238/7</p> <p>Campbell [3] 159/13 159/17 159/20</p> <p>Campbell Tait [1] 159/17</p> <p>can [180] 2/16 2/17 2/18 2/21 3/7 3/8 3/9 4/2 4/9 5/2 7/6 7/21 7/25 8/8 8/10 11/1 12/23 13/11 14/21 14/24 17/3 18/24 19/1 19/1 19/1 19/13 22/14 23/3 25/6 26/17 27/13 27/21 27/24 28/22 29/2 29/22 32/10 32/13 32/20 33/24 35/11 35/14 38/6 38/13 38/21 39/6 40/24 41/1 42/14 43/12 45/18 45/22 47/22 48/18 49/4 51/21 53/6 57/15 57/15 62/11 66/13 69/20 73/9 73/11 73/16 73/18 74/17 77/17 78/24 79/2 79/3 80/11 84/17 85/16 88/16 90/10 91/6 92/24 95/8 96/18 98/4 98/6 99/14 101/8 101/12 103/17 105/20 105/24 108/19 108/24 111/23 112/4 112/4 115/3 115/9 116/3 116/12 116/14 116/15 117/11 118/2 118/19 121/24 122/4 122/13 122/24 123/17 123/17 125/7 125/9 126/8 127/24 128/11 128/17 129/21 131/15 132/5 133/18 136/4 138/6 142/2 142/6 142/8 143/6 145/11 145/14 148/5 148/8 148/24 152/3 155/7 155/8 156/21 156/24 157/20 158/24 160/21 160/25</p>	<p>164/20 165/13 165/17 166/4 172/24 174/4 179/9 179/11 181/23 183/7 183/8 183/15 183/16 183/18 184/25 185/16 186/3 186/17 187/23 191/2 193/11 198/23 201/10 204/6 209/11 211/1 212/21 217/3 217/20 218/16 218/17 218/19 220/24 221/9 225/3 225/4 226/10 231/1 234/13 236/5 238/8 238/16</p> <p>can't [17] 49/3 56/15 58/9 93/14 100/10 103/11 110/12 112/6 119/15 144/13 160/18 179/11 192/2 192/5 205/15 214/6 222/11</p> <p>cancer [5] 99/15 120/19 174/13 179/19 182/6</p> <p>candour [3] 199/8 219/1 234/6</p> <p>cannot [14] 12/17 27/6 28/15 42/20 46/17 47/16 68/15 74/1 75/13 154/8 197/10 230/14 232/2 232/22</p> <p>canvassing [1] 87/7</p> <p>capable [1] 197/21</p> <p>capacity [1] 10/7</p> <p>capital [1] 228/15</p> <p>carcinoma [1] 104/6</p> <p>Cardiff [17] 92/7 92/15 120/19 164/25 165/7 165/9 166/10 166/19 167/1 169/15 169/17 170/1 170/7 170/8 170/21 189/2 199/25</p> <p>care [30] 37/6 52/9 56/21 57/1 60/3 60/14 60/17 61/25 79/16 106/9 106/10 163/20 165/4 165/11 167/9 170/2 171/11 171/13 173/21 173/22 173/25 175/11 176/1 179/3 179/3 202/19 203/19 221/12 222/23 230/9</p> <p>careful [1] 101/20</p> <p>carefully [3] 47/8 131/25 135/11</p> <p>carer [2] 222/19 222/19</p> <p>carers [1] 221/11</p> <p>caring [1] 222/21</p> <p>Carolyn [1] 45/4</p> <p>Carolyn Leckie [1]</p>	<p>45/4</p> <p>carpet [2] 57/23 61/1</p> <p>carried [3] 4/18 15/16 146/16</p> <p>carries [3] 74/5 157/12 157/17</p> <p>Carroll [1] 184/12</p> <p>carry [6] 14/10 95/23 115/21 166/5 166/11 166/20</p> <p>Carwyn [2] 82/13 115/15</p> <p>case [15] 25/15 35/16 39/24 41/18 41/21 73/25 75/12 153/9 169/16 179/21 183/9 185/12 215/25 217/13 227/20</p> <p>cases [10] 27/6 28/15 102/18 140/19 176/2 177/6 199/13 204/20 204/21 234/9</p> <p>catch [1] 171/14</p> <p>category [5] 6/4 122/23 122/25 123/21 124/7</p> <p>catering [1] 66/16</p> <p>cause [2] 57/7 93/4</p> <p>caused [3] 86/12 119/8 142/17</p> <p>causes [3] 47/12 51/1 150/6</p> <p>causing [2] 21/2 41/5</p> <p>caution [1] 210/6</p> <p>Celtic [2] 200/1 200/2</p> <p>cent [2] 100/18 161/18</p> <p>central [19] 88/6 95/7 95/8 96/21 96/25 129/14 144/16 149/7 149/9 156/10 159/6 223/14 223/16 223/23 224/23 225/7 226/18 227/9 231/21</p> <p>centrally [2] 226/23 227/14</p> <p>centre [8] 26/3 27/4 61/21 121/24 122/8 164/13 177/24 233/18</p> <p>centres [5] 12/13 55/25 121/18 125/16 161/17</p> <p>certain [6] 41/22 87/1 99/1 146/12 159/3 216/12</p> <p>certainly [13] 7/1 7/3 26/12 51/10 74/4 75/15 144/12 164/9 175/17 178/3 179/5 210/9 223/6</p> <p>certificate [1] 57/16</p> <p>cetera [2] 5/7 39/2</p>	<p>chair [19] 4/3 9/11 9/15 10/18 17/2 18/14 18/15 18/17 30/21 53/6 53/10 62/12 64/23 68/15 104/24 119/13 180/8 180/13 192/15</p> <p>chaired [6] 36/17 42/3 53/13 95/2 103/2 183/4</p> <p>chairing [1] 234/21</p> <p>chairman [1] 212/13</p> <p>chairmanship [1] 165/25</p> <p>challenge [5] 89/6 116/7 191/2 192/13 200/25</p> <p>challenged [1] 73/14</p> <p>challenging [1] 184/22</p> <p>chamber [1] 75/18</p> <p>championing [1] 237/17</p> <p>chance [4] 174/3 187/11 223/21 229/16</p> <p>change [6] 30/6 84/15 84/15 147/22 196/8 199/20</p> <p>changed [2] 91/14 127/8</p> <p>changes [3] 128/7 128/8 189/20</p> <p>changing [1] 127/16</p> <p>channel [1] 6/10</p> <p>chapter [2] 73/5 73/6</p> <p>characterisation [1] 50/19</p> <p>characterises [2] 163/1 163/3</p> <p>characteristic [1] 44/12</p> <p>charge [3] 60/17 92/22 197/6</p> <p>charitable [3] 5/13 5/21 12/10</p> <p>charities [3] 13/2 220/2 220/12</p> <p>charity [23] 4/17 5/1 12/5 15/18 20/2 67/18 92/5 108/20 111/20 111/21 113/10 119/14 121/1 122/16 151/18 194/21 195/3 195/12 209/10 209/11 213/18 213/20 220/2</p> <p>chat [1] 1/7</p> <p>check [3] 2/15 32/18 48/18</p> <p>checked [2] 75/4 75/10</p> <p>chest [2] 218/9 218/9</p> <p>CHI [1] 158/19</p>
--	--	---	--	--	--

C	clause [1] 41/23 clean [2] 230/19 231/10 clear [16] 24/19 47/1 97/19 99/5 100/22 110/7 130/8 136/15 137/1 164/16 164/19 172/20 187/9 204/3 214/13 223/23 cleared [2] 174/24 181/18 cleared the [1] 174/24 clearest [1] 36/7 clearly [5] 33/8 36/14 64/10 152/9 218/16 clinic [5] 161/16 170/19 174/21 174/22 193/11 clinical [24] 36/1 54/21 59/16 97/20 97/21 98/2 99/13 99/13 102/25 103/18 103/21 104/4 104/4 104/12 104/17 104/22 126/3 154/23 166/6 166/7 180/2 186/16 199/13 217/2 clinicians [9] 52/7 55/22 59/25 104/17 168/10 169/4 171/6 171/16 173/5 CLO [1] 156/12 close [8] 101/17 123/23 177/9 213/4 213/20 223/7 227/19 229/9 closely [3] 23/13 213/18 222/3 closer [2] 200/2 234/20 closing [1] 147/25 co [2] 100/8 176/10 co-infected [1] 100/8 co-morbidities [1] 176/10 cogs [1] 229/23 cohort [11] 52/25 56/25 57/24 60/25 87/17 87/17 126/7 161/14 161/20 161/23 181/3 coincided [1] 48/21 Cole [3] 53/12 180/13 183/4 collaboration [1] 171/23 collaboratively [2] 123/25 168/9 collapse [5] 8/24 49/1 49/23 50/3 140/5 collapsed [1] 127/4 colleague [1] 134/19	colleagues [8] 133/22 141/5 143/20 154/17 191/4 223/6 225/25 229/4 collective [2] 239/3 239/4 collectively [1] 41/18 Colne [1] 80/16 Colonsay [2] 66/12 66/14 colour [3] 30/8 34/15 67/3 coloured [1] 64/5 colours [1] 34/12 column [2] 73/11 73/15 combination [1] 71/6 combined [1] 106/8 come [64] 1/20 6/25 10/12 17/9 17/15 19/23 20/8 21/25 26/12 28/18 31/2 33/11 36/5 49/6 54/20 56/4 56/12 56/24 58/21 63/23 67/4 68/3 70/19 72/13 77/8 78/14 86/17 87/6 88/8 88/20 90/18 91/24 98/18 99/25 101/24 107/25 112/6 119/15 119/17 119/18 119/19 123/17 127/7 128/16 134/2 149/6 149/14 150/4 150/5 153/14 154/4 154/11 176/8 178/22 179/23 182/17 183/5 183/25 214/11 214/18 216/2 222/9 226/17 233/2 comes [9] 49/14 76/4 90/8 123/8 128/5 144/25 153/17 163/17 215/22 comfort [1] 90/12 coming [13] 28/2 54/1 56/9 64/6 89/6 90/6 99/5 106/7 113/17 151/6 151/10 175/19 224/13 commenced [2] 225/23 225/24 commend [1] 147/16 comment [3] 135/14 154/7 154/20 comments [3] 73/21 74/22 132/7 Commission [1] 60/16 commissioned [3] 38/13 38/14 156/23 Commissioner [1] 234/12	Commissioners [6] 170/1 171/10 171/11 172/12 185/16 186/12 commissioning [4] 97/4 186/24 187/4 187/25 commit [1] 115/25 commitment [5] 95/23 139/14 145/25 146/2 165/23 commitments [4] 139/9 144/1 146/7 146/8 committed [2] 144/3 147/17 committee [42] 7/22 9/7 9/12 9/13 9/16 9/18 10/19 12/4 16/3 20/7 20/13 21/11 21/12 21/18 21/20 21/22 21/24 22/1 35/8 35/11 36/22 36/25 37/5 43/16 43/21 43/22 43/24 44/5 46/2 47/9 62/12 63/13 80/20 101/2 101/5 102/23 170/4 201/15 201/17 212/15 213/12 219/4 common [1] 39/2 Commons [1] 79/5 communicate [3] 126/17 127/12 147/8 communication [2] 46/13 81/23 community [25] 16/7 16/16 36/24 37/22 42/11 53/21 69/2 69/4 86/25 107/1 109/3 110/4 119/6 126/21 127/14 164/10 175/16 179/5 182/13 195/22 203/18 214/24 230/11 238/2 238/3 community's [1] 116/23 company [1] 1/11 compared [2] 39/25 55/25 compassion [5] 44/18 139/12 139/13 231/14 238/15 compassionate [3] 139/10 203/13 204/5 compensate [1] 162/6 compensated [2] 91/13 223/1 compensation [11] 22/4 26/21 29/13 39/1 108/10 108/11 153/10 154/18 223/12 228/7 233/23	compensatory [1] 145/2 complete [3] 20/13 115/14 214/7 completely [7] 9/16 16/13 49/2 89/24 98/17 126/6 204/23 complex [2] 167/8 176/10 comprehensive [2] 167/9 173/22 comprising [1] 52/7 conceal [1] 232/15 concern [12] 52/14 61/12 109/10 109/13 121/13 164/14 168/6 168/13 169/12 169/13 170/24 192/7 concerned [4] 34/7 35/22 86/10 117/5 concerns [18] 18/11 22/22 23/22 35/17 109/18 112/14 122/25 124/20 128/2 129/8 145/22 145/23 149/5 158/24 161/3 166/4 168/2 171/9 concerted [1] 188/23 concluded [2] 48/4 96/1 conclusion [7] 41/19 131/3 150/25 159/5 220/19 229/16 229/19 conclusions [3] 25/2 35/10 35/14 conclusive [1] 229/3 concur [1] 147/14 condition [2] 21/11 59/25 conduct [2] 64/15 214/3 conducted [3] 24/20 159/23 212/10 conference [8] 70/12 70/16 70/24 71/12 75/5 77/11 182/13 184/5 conferences [1] 208/17 confess [1] 66/7 confidence [6] 23/7 141/15 164/9 173/3 211/8 211/9 confident [1] 193/18 confirm [2] 7/1 211/12 confirmation [2] 206/22 211/10 confirmed [4] 80/16 117/8 156/10 200/18 confirming [1] 206/25 conflicting [2] 11/22 98/25	confusion [1] 86/12 conjunction [1] 188/5 connection [1] 1/16 connections [2] 62/15 66/14 Conor [1] 137/23 conscious [5] 94/21 96/3 101/20 201/20 239/9 consequence [10] 4/23 6/11 121/19 126/16 134/21 135/13 140/21 159/6 175/4 197/7 consequences [2] 46/10 46/11 consider [4] 19/19 142/24 157/9 165/11 considerable [3] 22/22 34/10 147/7 considerably [1] 147/16 consideration [8] 32/5 35/24 87/25 143/5 143/13 212/4 227/23 228/12 considered [6] 24/1 35/20 42/18 47/8 167/11 227/25 considering [4] 130/23 154/18 205/17 219/19 considers [1] 26/20 consistency [1] 36/13 consistent [1] 220/5 Consortium [1] 208/16 constituency [4] 14/2 87/12 126/17 129/12 constituent [2] 2/5 3/4 constituents [4] 17/12 80/4 84/3 84/11 constitution [3] 12/10 12/25 223/21 constitutional [1] 225/20 constraints [1] 154/14 construct [1] 47/1 constructed [1] 100/7 constructive [2] 76/2 97/14 consultant [9] 28/4 55/13 124/3 166/23 168/6 170/16 173/25 174/19 193/13 consultants [3] 104/20 104/25 160/10 consultation [33] 74/7 81/4 93/14 93/17 97/3 114/9 114/11
----------	--	---	--	---	--

<p>C</p> <p>consultation... [26] 114/14 115/1 115/3 115/5 115/11 115/15 116/3 118/8 118/15 119/8 119/19 120/6 120/10 126/12 128/1 130/5 130/13 131/5 131/19 131/21 132/8 132/12 133/7 141/22 141/23 141/23</p> <p>consultations [3] 85/19 116/24 118/1</p> <p>consulted [3] 110/5 153/25 225/25</p> <p>consuming [1] 46/23</p> <p>contact [16] 33/14 60/12 71/1 89/4 92/23 102/1 120/17 123/23 125/18 137/13 156/2 159/19 179/24 190/3 190/4 227/12</p> <p>contacted [5] 13/25 113/6 139/1 181/20 206/21</p> <p>contained [1] 167/22</p> <p>contaminated [19] 17/13 17/21 17/25 18/20 19/18 29/11 41/14 55/12 79/4 89/9 121/25 137/19 142/20 164/10 164/15 178/21 179/4 179/4 181/7</p> <p>contention [2] 187/14 187/17</p> <p>contest [1] 24/22</p> <p>contested [1] 186/11</p> <p>context [9] 69/24 87/10 95/14 95/16 157/10 177/24 211/3 215/12 228/18</p> <p>continuation [1] 228/20</p> <p>continue [10] 37/8 117/9 130/10 130/23 131/1 194/7 231/23 235/3 236/14 236/14</p> <p>continued [2] 222/1 232/12</p> <p>continues [5] 103/12 147/10 178/16 179/16 233/3</p> <p>continuing [2] 191/12 239/5</p> <p>contracted [3] 19/18 22/4 46/8</p> <p>contrast [3] 40/5 44/20 44/22</p> <p>contribute [1] 93/15</p> <p>contribution [4] 133/6 133/13 139/3 139/4</p>	<p>contributions [2] 80/12 80/13</p> <p>contributory [1] 140/1</p> <p>control [3] 34/3 130/20 151/4</p> <p>controlled [1] 42/5</p> <p>controversy [1] 23/16</p> <p>convenient [1] 220/15</p> <p>conversation [2] 33/1 136/10</p> <p>conversations [1] 137/10</p> <p>convert [1] 228/4</p> <p>conveying [1] 116/23</p> <p>convinced [2] 24/21 206/8</p> <p>Cooke [1] 113/15</p> <p>cooperate [1] 189/19</p> <p>coordinated [3] 187/21 188/13 189/3</p> <p>copied [1] 25/7</p> <p>copies [1] 25/1</p> <p>copy [8] 24/24 40/25 47/22 75/6 124/10 131/16 206/23 217/16</p> <p>core [10] 10/7 50/11 63/20 68/8 70/1 70/20 96/20 149/10 199/22 202/17</p> <p>corner [1] 137/7</p> <p>correct [17] 4/5 7/3 7/20 10/22 22/7 23/24 34/15 35/1 35/9 62/17 67/20 73/23 103/22 165/7 189/11 212/20 231/2</p> <p>correctly [2] 21/19 224/12</p> <p>correspondence [3] 142/10 196/20 206/19</p> <p>correspondences [2] 134/22 229/22</p> <p>cost [6] 135/16 144/6 153/10 162/6 218/16 222/15</p> <p>costs [5] 47/17 130/7 143/15 222/21 222/24</p> <p>could [89] 4/24 5/12 8/5 10/15 16/5 17/17 19/11 23/2 25/17 25/21 26/15 35/25 38/10 41/2 42/1 45/20 50/6 56/23 71/10 79/1 80/10 81/9 87/4 89/15 92/8 92/18 92/21 98/8 106/6 106/6 107/19 107/22 108/24 109/22 112/17 113/8 116/19 117/22 117/23 119/18 124/17 124/19 124/19 124/25 125/2 125/16 126/2 127/22 129/19</p>	<p>131/7 133/10 134/6 137/6 139/20 141/24 142/7 150/19 152/25 154/11 154/13 155/2 155/3 155/6 155/14 158/19 159/10 159/22 167/2 168/21 170/15 175/18 182/25 184/18 188/16 189/4 190/1 192/11 192/13 194/13 197/2 198/4 198/15 204/15 205/9 208/20 209/18 213/8 224/20 227/22</p> <p>couldn't [28] 11/11 11/18 40/6 56/1 61/8 61/14 81/5 81/6 85/4 90/1 99/18 102/8 106/1 113/18 119/12 120/16 120/16 158/10 162/2 162/3 168/18 180/8 181/1 187/8 190/7 194/5 219/16 227/6</p> <p>counsel [5] 66/9 68/12 68/12 175/9 201/10</p> <p>counselling [6] 5/11 111/2 111/3 166/16 167/14 167/20</p> <p>country [3] 64/19 93/16 123/5</p> <p>couple [10] 9/2 78/23 127/9 136/14 149/17 165/13 177/4 190/23 213/4 219/11</p> <p>course [18] 10/14 16/25 38/1 41/24 50/10 50/18 54/9 76/1 116/15 118/7 121/7 129/11 147/13 148/2 182/20 187/14 204/17 212/1</p> <p>courses [1] 112/20</p> <p>court [2] 29/18 156/6</p> <p>courts [7] 27/20 28/20 43/18 74/23 74/23 74/25 198/23</p> <p>cousin [2] 52/14 58/7</p> <p>cousins [2] 13/17 208/6</p> <p>Coveny [1] 138/17</p> <p>cover [8] 11/5 38/25 163/3 163/4 195/25 199/11 200/7 219/7 163/4 199/11 219/7</p> <p>cover-up [4] 163/3</p> <p>covered [2] 52/21 56/20</p> <p>covering [1] 201/8</p> <p>cramp [2] 186/8 199/14</p>	<p>crazy [1] 93/10</p> <p>create [1] 29/12</p> <p>creating [1] 187/17</p> <p>CRGs [1] 60/15</p> <p>critical [5] 44/7 45/8 147/4 170/6 229/18</p> <p>criticise [1] 23/12</p> <p>criticisms [3] 3/17 3/21 16/23</p> <p>cross [11] 15/12 17/10 17/25 18/9 18/10 18/13 82/23 106/14 109/12 168/22 171/18</p> <p>crossover [1] 214/17</p> <p>CrowdJustice [1] 93/21</p> <p>Crown [1] 198/11</p> <p>culmination [1] 49/1</p> <p>culture [1] 39/25</p> <p>cured [2] 175/7 175/8</p> <p>current [5] 117/9 130/1 130/2 146/5 224/19</p> <p>currently [1] 154/8</p> <p>curtail [1] 192/8</p> <p>cut [3] 161/3 161/5 162/14</p> <p>cut-off [3] 161/3 161/5 162/14</p> <p>Cymru [1] 15/13</p>	<p>206/4</p> <p>daughters [1] 221/24</p> <p>Dave [2] 235/21 235/25</p> <p>David [13] 76/14 77/5 78/1 98/11 103/2 104/23 114/21 134/11 134/23 135/10 144/10 145/4 230/25</p> <p>David Cameron [4] 76/14 77/5 78/1 98/11</p> <p>David Lidington [5] 134/11 134/23 135/10 145/4 230/25</p> <p>Davy [1] 235/25</p> <p>day [30] 12/19 50/6 53/14 67/8 67/13 67/16 69/22 69/23 73/7 75/1 77/12 94/25 95/16 96/2 98/11 98/14 101/17 102/22 105/14 105/14 133/9 133/12 140/3 170/12 170/12 179/13 182/14 217/24 218/8 239/22</p> <p>day-to-day [1] 170/12</p> <p>days [11] 33/2 66/11 112/25 154/15 163/11 198/22 203/19 203/21 210/13 211/8 238/23</p> <p>Deacon [18] 21/14 22/9 22/12 22/15 23/5 29/15 29/23 30/2 30/9 32/3 33/20 40/1 40/5 152/15 153/7 160/6 198/21 210/15</p> <p>Deacon's [1] 74/22</p> <p>dead [2] 61/4 152/2</p> <p>deadline [1] 96/10</p> <p>deaf [1] 54/8</p> <p>deal [15] 8/3 23/19 27/6 27/24 28/15 34/3 47/5 56/25 66/21 71/25 108/3 154/13 171/5 190/23 228/23</p> <p>dealing [2] 41/11 178/19</p> <p>deals [1] 230/7</p> <p>dealt [2] 136/23 163/22</p> <p>dear [2] 65/13 199/17</p> <p>death [4] 57/7 57/8 57/9 57/16</p> <p>deaths [3] 57/3 57/21 232/25</p> <p>debate [10] 32/6 33/20 79/23 80/1 80/17 80/21 83/24 84/8 96/5 106/16</p> <p>debates [2] 84/7 162/4</p> <p>debris [2] 230/20</p>	<p>231/10</p> <p>debts [2] 119/25 120/3</p> <p>decades [1] 201/18</p> <p>December [2] 4/4 180/22</p> <p>December 2013 [1] 180/22</p> <p>December 2017 [1] 4/4</p> <p>decency [1] 77/13</p> <p>decide [3] 42/4 128/10 226/13</p> <p>decided [8] 16/7 59/15 70/23 71/1 71/25 98/19 117/25 124/8</p> <p>decimated [1] 84/13</p> <p>decision [11] 12/8 46/2 48/3 132/16 140/18 141/24 152/1 186/15 214/24 220/9 233/6</p> <p>decision-making [2] 132/16 233/6</p> <p>decisions [8] 34/16 129/14 140/19 140/23 160/4 197/24 197/25 230/10</p> <p>declaration [1] 105/19</p> <p>declassified [1] 29/4</p> <p>decompensating [3] 173/23 174/10 181/22</p> <p>dedicated [2] 170/9 178/9</p> <p>deep [2] 160/16 203/21</p> <p>deeply [3] 110/9 160/15 215/6</p> <p>defend [2] 197/17 198/20</p> <p>defending [2] 29/16 231/1</p> <p>defensive [1] 212/12</p> <p>definitely [7] 98/20 144/18 154/3 203/5 204/9 205/11 216/1</p> <p>definition [3] 221/15 221/16 221/18</p> <p>degree [2] 34/10 68/14</p> <p>delay [8] 35/23 81/22 101/6 129/4 174/15 229/20 238/16 238/17</p> <p>delayed [1] 148/20</p> <p>delaying [1] 141/21</p> <p>delays [1] 230/16</p> <p>deliberate [3] 28/11 195/25 232/13</p> <p>deliberately [5] 26/4 27/5 27/24 28/6 28/12</p> <p>deliberations [1]</p>
---	--	--	---	---	--

<p>D</p> <p>deliberations... [1] 222/17</p> <p>delighted [1] 85/25</p> <p>delivered [3] 133/15 154/18 179/20</p> <p>delivering [3] 47/15 48/13 139/9</p> <p>delivery [1] 167/12</p> <p>Della [1] 200/12</p> <p>demand [1] 26/2</p> <p>demands [1] 191/9</p> <p>democratic [1] 9/20</p> <p>Democrats [1] 44/25</p> <p>demonstrated [1] 181/14</p> <p>demonstrates [1] 207/21</p> <p>denied [4] 41/24 61/16 184/6 233/14</p> <p>dental [1] 203/19</p> <p>dentist [1] 204/11</p> <p>dentistry [1] 204/7</p> <p>dentists [1] 60/2</p> <p>deny [2] 41/16 90/5</p> <p>departed [1] 65/13</p> <p>department [46] 23/18 52/8 53/5 53/6 53/15 53/16 54/6 55/3 56/2 57/5 88/5 88/7 92/2 94/13 94/15 113/6 113/9 114/13 115/10 117/8 118/14 128/6 128/23 129/9 129/15 129/19 132/18 132/24 133/3 136/1 137/11 140/12 142/12 150/7 151/25 161/10 161/24 180/11 193/17 193/19 196/11 196/14 196/15 196/22 200/21 207/23</p> <p>departmental [9] 22/13 22/19 22/23 23/7 23/8 23/23 24/23 25/8 35/6</p> <p>depend [4] 46/23 48/7 49/10 197/8</p> <p>dependant [1] 221/21</p> <p>dependent [1] 222/19</p> <p>dependents [1] 165/22</p> <p>depending [1] 202/24</p> <p>depends [1] 224/4</p> <p>Deputy [7] 18/14 32/21 32/23 32/24 44/6 160/7 171/8</p> <p>derisory [1] 41/12</p> <p>derived [2] 14/3 149/10</p> <p>described [5] 86/19</p>	<p>86/20 86/23 95/6 237/22</p> <p>deserve [1] 150/16</p> <p>deserved [1] 173/20</p> <p>designed [1] 20/9</p> <p>desire [2] 4/19 239/4</p> <p>despairing [2] 141/15 230/2</p> <p>desperate [3] 54/2 56/9 109/2</p> <p>desperately [1] 191/16</p> <p>despite [1] 73/23</p> <p>destruction [1] 200/17</p> <p>detail [5] 6/25 10/13 107/7 107/23 214/7</p> <p>detailed [1] 47/1</p> <p>details [4] 8/9 8/10 107/10 232/24</p> <p>deteriorating [1] 230/3</p> <p>determination [2] 231/24 238/12</p> <p>determine [1] 37/13</p> <p>determined [1] 117/14</p> <p>determining [1] 160/3</p> <p>devastating [1] 50/21</p> <p>develop [2] 25/25 38/24</p> <p>developed [4] 102/5 102/6 179/19 182/6</p> <p>developing [1] 67/18</p> <p>development [1] 216/23</p> <p>devolution [23] 12/3 12/18 14/9 14/12 32/24 33/22 34/8 34/10 34/23 34/25 39/17 86/9 86/10 144/19 149/8 150/23 223/24 223/25 225/21 225/22 225/24 226/2 236/24</p> <p>devolve [1] 144/11</p> <p>devolved [19] 11/13 60/13 81/19 87/11 114/24 116/6 123/5 128/5 144/12 144/19 144/20 145/5 149/1 149/13 149/25 151/12 154/5 224/4 228/23</p> <p>diagnosed [3] 16/6 55/16 205/21</p> <p>diagnosis [2] 102/5 167/13</p> <p>dialogue [2] 76/2 76/2</p> <p>Diana [1] 89/25</p> <p>did [81] 13/19 16/10 16/12 19/23 28/7 30/12 36/23 42/23</p>	<p>43/13 55/1 59/20 67/3 71/20 71/22 72/5 72/11 82/15 86/8 86/24 88/18 92/8 97/8 97/11 97/22 102/15 109/9 111/14 113/3 113/21 114/10 115/4 118/10 118/11 119/19 119/20 120/5 120/13 121/5 121/8 122/1 126/15 126/18 129/10 129/10 130/21 132/9 132/13 133/5 136/3 137/7 137/12 138/5 138/24 138/24 146/2 146/3 154/6 159/15 160/9 162/1 168/2 169/2 174/19 180/4 183/4 184/9 184/23 185/3 185/5 186/19 187/3 187/24 198/21 210/5 210/15 210/23 212/9 213/23 213/25 228/2 232/23</p> <p>didn't [84] 1/13 10/8 22/6 22/23 24/1 27/22 28/10 28/12 28/13 50/11 50/24 52/11 55/5 56/3 56/11 57/18 58/5 59/2 60/24 61/11 64/20 65/6 65/15 65/18 65/19 68/2 71/16 74/12 75/21 76/7 76/17 82/19 87/21 88/11 88/24 92/6 92/13 92/18 93/24 97/22 98/20 99/8 99/11 100/19 100/22 106/20 106/21 107/18 110/7 110/10 111/9 111/15 111/15 113/15 114/12 114/19 114/24 118/25 119/4 120/2 120/6 121/18 135/11 137/5 137/5 160/22 170/24 171/13 182/4 182/5 183/9 184/15 184/16 188/7 188/13 192/8 198/18 203/25 205/8 207/1 212/6 215/1 215/1 223/3</p> <p>die [6] 159/7 162/9 174/13 182/3 185/18 198/10</p> <p>died [17] 16/4 52/15 58/1 58/4 68/6 83/25 158/12 158/22 159/11 159/12 168/18 168/19 168/20 182/5 187/8 201/3 207/25</p> <p>dies [1] 61/2</p>	<p>difference [6] 39/25 87/21 129/25 194/10 212/22 213/11</p> <p>differences [2] 3/3 225/6</p> <p>different [30] 3/4 5/13 25/22 30/8 34/12 34/17 40/9 40/10 40/12 43/19 44/12 66/6 74/15 80/10 91/16 91/21 91/23 94/23 109/14 154/19 164/20 175/11 182/22 197/14 206/11 236/21 237/21 239/10 239/11 239/12</p> <p>differently [3] 60/15 176/18 237/25</p> <p>difficult [19] 14/13 47/1 48/3 49/18 49/21 68/23 68/23 103/20 106/19 106/25 114/1 161/21 162/17 179/15 191/16 193/20 194/4 200/11 213/9</p> <p>difficulties [9] 15/7 33/22 103/23 105/23 105/25 124/4 140/4 192/14 239/7</p> <p>difficulties' [1] 29/14</p> <p>difficulty [7] 41/6 123/9 140/23 173/2 180/25 189/13 204/11</p> <p>dignity [1] 233/25</p> <p>dilemma [1] 114/15</p> <p>ding [1] 152/6</p> <p>direct [7] 88/4 125/18 127/2 127/5 127/6 129/2 187/16</p> <p>directed [1] 237/10</p> <p>direction [4] 31/23 88/6 133/2 173/5</p> <p>directly [5] 78/9 118/21 133/15 151/22 237/3</p> <p>Director [1] 165/25</p> <p>directors [4] 26/4 27/4 33/10 156/7</p> <p>disadvantages [1] 149/2</p> <p>disappointed [1] 50/19</p> <p>disappointment [3] 73/19 73/24 231/4</p> <p>disaster [7] 218/21 225/22 225/23 225/24 232/11 234/15 235/11</p> <p>disciplinary [3] 121/12 125/18 169/7</p> <p>discomfort [1] 148/9</p> <p>discretionary [2] 130/6 130/8</p>	<p>discriminate [1] 85/5</p> <p>discuss [5] 78/9 154/2 155/9 172/7 193/14</p> <p>discussed [7] 33/13 47/9 103/24 117/16 143/17 150/24 217/13</p> <p>discussing [1] 126/21</p> <p>discussion [5] 59/14 126/23 205/1 221/8 228/9</p> <p>discussions [5] 2/19 20/24 22/11 221/19 226/22</p> <p>disease [6] 55/16 57/4 57/22 174/6 186/13 188/3</p> <p>disgrace [1] 160/12</p> <p>disgusting [2] 117/23 201/5</p> <p>disillusioned [2] 16/13 141/14</p> <p>disinterested [1] 58/20</p> <p>disinterested in [1] 58/20</p> <p>disorder [2] 5/25 214/15</p> <p>disorders [16] 5/14 5/17 8/21 9/22 9/24 13/5 17/7 18/24 123/16 166/2 166/25 167/8 167/15 167/21 176/13 177/13</p> <p>dissolved [1] 180/16</p> <p>distance [1] 127/6</p> <p>distinguish [1] 56/15</p> <p>distress [1] 189/7</p> <p>distressed [1] 141/14</p> <p>disturbance [1] 178/22</p> <p>disturbed [1] 160/16</p> <p>diverse [2] 167/10 238/4</p> <p>diversion [2] 47/15 48/13</p> <p>divide [1] 107/1</p> <p>divided [3] 110/10 146/18 224/7</p> <p>divisive [1] 108/16</p> <p>do [103] 3/3 3/16 3/23 6/12 12/7 14/9 14/11 15/10 16/8 19/4 32/10 33/5 41/6 46/10 47/10 49/8 53/18 54/19 57/17 61/5 62/21 69/1 70/5 70/6 70/23 70/25 71/19 72/15 77/1 78/2 78/7 81/8 81/13 86/4 89/2 93/11 94/1 94/6 98/9 98/10 104/18 108/20 109/25 111/14</p>	<p>115/16 115/17 116/8 117/15 118/19 122/14 122/16 124/9 125/16 132/7 134/15 138/8 140/13 146/11 149/15 150/2 151/17 151/20 151/22 152/18 153/16 155/14 156/15 160/20 162/13 162/23 170/12 184/11 185/9 186/16 188/25 191/13 192/25 194/6 194/7 194/19 195/3 197/13 198/4 198/23 200/4 201/23 201/24 203/9 206/9 210/15 215/14 216/15 217/10 219/9 219/23 220/17 226/16 231/17 234/13 235/3 236/10 239/6 239/13</p> <p>doctor [2] 57/9 169/14</p> <p>doctor's [1] 181/24</p> <p>doctors [11] 28/13 55/4 55/4 55/20 61/5 123/23 125/13 169/11 169/19 169/20 186/10</p> <p>document [25] 11/25 38/2 38/6 38/8 38/17 38/18 47/20 80/9 80/10 80/11 80/13 130/12 130/13 133/10 138/2 138/2 138/16 138/16 138/18 139/2 139/8 156/19 158/25 209/25 217/15</p> <p>document in [2] 38/18 158/25</p> <p>documentation [2] 31/25 95/13</p> <p>documented [4] 57/12 79/20 169/21 185/22</p> <p>documents [10] 13/1 29/8 45/18 64/10 66/10 155/1 156/20 158/24 165/14 234/6</p> <p>Dodds [2] 126/14 129/5</p> <p>does [12] 35/20 41/13 51/3 77/8 103/12 125/20 128/8 170/20 191/6 205/11 209/16 227/18</p> <p>doesn't [13] 23/7 51/6 113/23 196/1 197/10 199/7 199/12 209/11 225/10 226/3 226/15 229/24 238/8</p> <p>doing [18] 1/14 79/13 80/24 93/25 110/1 110/22 115/25 117/20 133/22 133/23 144/3</p>
--	---	--	--	--	--

<p>D</p> <p>doing... [7] 154/1 168/25 174/16 195/1 197/21 198/3 231/17</p> <p>Dolan [5] 20/15 20/16 30/17 36/20 213/8</p> <p>domain [1] 232/11</p> <p>domestic [1] 26/2</p> <p>don't [61] 2/23 3/1 3/12 8/1 24/10 28/6 32/14 32/17 38/13 53/8 57/6 59/22 60/15 70/24 77/2 78/20 90/17 93/8 97/10 104/16 104/18 111/3 111/24 111/25 113/5 117/11 123/4 125/5 125/8 125/17 125/24 126/1 133/12 149/3 150/13 150/15 154/3 159/11 161/12 161/25 162/14 162/20 162/23 164/18 169/9 174/25 177/7 183/11 185/17 194/25 196/7 206/12 206/14 213/21 217/21 217/22 226/10 226/20 227/1 227/2 227/2</p> <p>donation [1] 85/7</p> <p>donations [3] 194/22 211/14 212/6</p> <p>done [25] 19/7 19/8 54/5 54/8 60/22 74/13 81/11 98/11 117/24 118/22 119/16 124/13 124/20 135/16 194/7 194/19 196/23 198/1 198/17 200/1 203/1 214/5 219/2 222/6 236/5</p> <p>dong [1] 152/6</p> <p>donor [1] 211/15</p> <p>donors [3] 211/13 211/13 212/7</p> <p>door [2] 94/18 151/6</p> <p>doors [2] 94/12 200/23</p> <p>dose [1] 26/8</p> <p>doubt [4] 140/10 194/9 236/20 237/16</p> <p>doubts [1] 147/21</p> <p>Douglas [1] 212/14</p> <p>down [36] 15/21 16/8 20/17 21/9 29/7 38/21 41/2 41/5 43/2 43/4 46/21 64/19 66/1 72/16 75/23 79/14 89/12 98/20 99/18 99/24 105/9 131/15 135/14 151/11 151/11 152/7 152/25 156/13</p>	<p>173/11 191/25 198/20 200/22 215/7 215/8 218/4 220/24</p> <p>Doyle [2] 110/15 134/11</p> <p>dozen [1] 68/10</p> <p>Dr [7] 32/21 83/2 164/13 171/7 174/20 177/22 193/13</p> <p>Dr Aileen Keel [1] 32/21</p> <p>Dr Benson [3] 164/13 177/22 193/13</p> <p>Dr Chris Jones [1] 171/7</p> <p>Dr Dai Lloyd [1] 83/2</p> <p>Dr Srivastava [1] 174/20</p> <p>dragged [1] 9/2</p> <p>Drakeford [1] 115/16</p> <p>drama [1] 71/7</p> <p>dramatic [1] 67/4</p> <p>draw [5] 69/1 158/23 193/11 217/18 222/22</p> <p>drawing [1] 64/11</p> <p>drawn [4] 3/25 10/4 63/17 238/14</p> <p>dreadful [2] 71/14 73/20</p> <p>drew [3] 7/18 44/21 68/9</p> <p>drift [1] 96/3</p> <p>drink [1] 211/24</p> <p>driver [1] 5/9</p> <p>drop [1] 61/3</p> <p>drugs [4] 57/24 181/15 184/6 204/8</p> <p>drying [1] 25/23</p> <p>due [8] 4/12 16/25 40/13 50/18 78/9 147/13 183/12 187/14</p> <p>Dundee [1] 97/7</p> <p>DUP [3] 126/13 126/16 127/10</p> <p>during [39] 2/22 28/2 33/20 40/2 43/5 43/16 45/9 50/13 50/15 50/20 54/9 68/5 95/15 97/20 98/17 102/6 103/20 104/15 112/18 120/10 127/8 127/8 140/15 141/19 151/16 155/20 159/12 160/6 165/23 174/22 190/18 206/13 211/18 211/19 212/8 220/16 222/17 227/25 228/2</p> <p>Dusheiko [1] 180/23</p> <p>duties [2] 170/13 233/18</p> <p>duty [7] 199/8 217/14 217/16 219/1 231/19</p>	<p>234/5 234/6</p> <p>dying [10] 20/25 20/25 52/16 54/3 55/14 57/2 57/13 68/5 101/18 230/2</p> <p>dynamic [2] 7/25 8/15</p> <p>dynamics [1] 24/4</p> <p>E</p> <p>each [16] 1/22 55/6 61/2 68/13 68/16 68/18 89/14 92/4 93/2 217/14 229/8 237/3 238/6 238/14 238/18 239/11</p> <p>Earl [2] 84/21 216/22</p> <p>Earl Howe [2] 84/21 216/22</p> <p>earlier [12] 44/3 102/3 131/24 133/1 134/4 138/24 139/11 172/8 179/8 196/7 202/3 220/24</p> <p>earliest [1] 21/6</p> <p>early [15] 13/18 15/13 33/2 43/22 112/25 151/2 154/15 154/15 163/11 181/11 182/11 186/25 198/22 210/13 229/15</p> <p>earn [1] 222/14</p> <p>earnings [1] 221/12</p> <p>ears [1] 54/9</p> <p>earth [1] 160/3</p> <p>easier [4] 151/12 159/24 185/8 228/10</p> <p>easily [2] 25/21 190/21</p> <p>easy [4] 61/22 144/17 161/19 168/24</p> <p>Edinburgh [4] 31/7 76/15 97/8 210/3</p> <p>Education [1] 34/25</p> <p>Edwina [2] 81/25 123/13</p> <p>effect [11] 12/6 12/15 31/15 58/3 59/17 99/7 151/24 212/25 219/16 220/7 220/14</p> <p>effective [3] 5/19 147/21 167/7</p> <p>effectively [12] 12/8 24/12 43/19 49/23 50/1 127/5 128/12 128/23 130/19 144/9 224/3 228/24</p> <p>effects [1] 25/19</p> <p>efficacy [1] 46/5</p> <p>effort [7] 47/15 48/13 160/22 160/22 191/10 238/23 238/25</p> <p>efforts [3] 47/17</p>	<p>195/23 232/12</p> <p>either [10] 23/10 23/12 27/22 47/11 50/25 100/18 115/17 141/18 177/5 214/14</p> <p>elected [2] 16/11 34/2</p> <p>electing [1] 18/17</p> <p>election [1] 18/16</p> <p>element [5] 27/24 32/9 99/14 99/20 152/4</p> <p>elements [1] 38/21</p> <p>eligibility [1] 147/9</p> <p>eliminate [1] 211/22</p> <p>eliminated [1] 25/13</p> <p>elimination [1] 124/14</p> <p>eloquently [1] 237/21</p> <p>else [12] 14/23 22/3 41/4 67/1 88/25 90/15 94/6 129/6 135/12 141/18 150/9 193/25</p> <p>elsewhere [1] 4/18</p> <p>email [10] 66/19 180/10 181/12 181/20 184/11 185/22 188/15 188/16 189/4 206/24</p> <p>emailed [3] 181/12 181/13 182/8</p> <p>emails [4] 169/9 169/10 182/10 206/25</p> <p>embarrassing [2] 90/12 148/10</p> <p>emergency [4] 170/13 173/17 174/12 175/2</p> <p>emotional [1] 230/20</p> <p>emphasise [2] 12/17 213/19</p> <p>emphatic [1] 237/15</p> <p>employ [1] 191/20</p> <p>employees [2] 191/5 220/4</p> <p>employment [1] 191/12</p> <p>empty [1] 194/2</p> <p>enable [1] 193/5</p> <p>enabled [1] 138/18</p> <p>enabling [1] 65/23</p> <p>enamoured [2] 128/22 237/24</p> <p>encounter [1] 137/8</p> <p>encourage [1] 89/5</p> <p>encouraged [2] 130/13 229/22</p> <p>encouragement [1] 137/4</p> <p>encouraging [2] 79/11 136/18</p> <p>end [17] 37/7 48/24 50/1 54/22 68/1 98/14 103/15 130/12 133/9 133/12 135/15 139/8 143/3 145/3 169/2</p>	<p>188/15 218/3</p> <p>ended [4] 75/7 75/20 230/12 230/14</p> <p>endless [1] 229/21</p> <p>endoscopies [2] 61/13 61/14</p> <p>endoscopy [2] 218/2 218/3</p> <p>endurance [1] 231/23</p> <p>endured [1] 142/19</p> <p>enduring [2] 87/18 87/18</p> <p>energetic [2] 8/22 20/16</p> <p>energy [3] 8/4 8/16 8/23</p> <p>engage [11] 11/11 11/19 77/1 78/11 106/20 110/19 114/16 118/21 119/12 232/18 233/5</p> <p>engaged [2] 11/20 50/10</p> <p>engagement [1] 191/13</p> <p>engaging [1] 16/15</p> <p>England [41] 25/11 53/24 56/1 70/20 87/15 87/16 88/7 93/14 110/11 115/11 115/13 115/17 116/4 117/2 117/21 118/10 123/8 123/10 124/4 124/5 124/9 124/10 128/7 128/25 131/22 132/2 132/18 133/3 142/17 144/25 145/17 154/10 161/11 181/15 182/15 183/22 185/24 187/15 187/17 188/8 204/21</p> <p>English [10] 115/4 116/3 123/2 123/8 126/12 127/25 132/12 132/21 139/15 143/8</p> <p>enhanced [1] 125/3</p> <p>enhancement [1] 228/13</p> <p>enjoy [1] 233/14</p> <p>enlightened [1] 178/18</p> <p>enormous [1] 49/24</p> <p>enough [6] 12/17 109/21 139/7 193/21 195/5 238/22</p> <p>enquiry [3] 23/7 23/8 92/19</p> <p>ensure [5] 102/11 166/23 203/12 204/2 233/22</p> <p>ensuring [2] 23/20 216/8</p>	<p>entails [1] 164/17</p> <p>enthusiasm [1] 206/12</p> <p>enthusiastic [1] 24/7</p> <p>entirely [2] 10/20 150/3</p> <p>entitled [3] 62/1 108/11 233/25</p> <p>entity [1] 10/21</p> <p>enviously [1] 209/20</p> <p>environment [3] 19/3 20/5 211/4</p> <p>environmental [1] 20/2</p> <p>epidemiologist [1] 104/24</p> <p>episode [3] 77/18 163/1 163/2</p> <p>equal [1] 202/23</p> <p>equally [2] 203/8 215/8</p> <p>equipment [1] 25/23</p> <p>equivalence [1] 137/20</p> <p>equivalent [2] 119/20 235/20</p> <p>error [1] 210/7</p> <p>essential [1] 132/3</p> <p>essentially [2] 223/15 237/9</p> <p>established [19] 7/23 9/7 10/20 11/2 15/11 15/18 16/2 16/19 18/13 36/23 49/15 51/24 95/7 146/19 157/8 165/10 165/24 177/23 191/19</p> <p>establishing [1] 31/4</p> <p>establishment [1] 31/5</p> <p>estimated [2] 157/14 157/17</p> <p>et [2] 5/7 39/2</p> <p>et cetera [2] 5/7 39/2</p> <p>European [1] 208/16</p> <p>Evans [1] 239/17</p> <p>even [17] 22/15 58/5 73/19 118/16 120/7 121/13 125/19 126/6 129/15 149/18 174/24 179/14 181/1 187/24 203/19 206/22 227/9</p> <p>evenings [1] 194/2</p> <p>event [2] 195/13 195/15</p> <p>events [13] 9/25 46/24 48/3 48/7 49/11 73/20 191/17 191/17 193/9 194/17 194/18 194/20 196/4</p> <p>eventually [5] 50/3 83/17 147/22 174/19</p>
--	---	---	--	---	---

(70) doing... - eventually

<p>E</p> <p>eventually... [1] 175/13</p> <p>ever [11] 59/9 69/22 89/23 161/13 162/16 187/10 198/8 201/17 233/19 236/8 237/15</p> <p>every [4] 81/13 206/21 207/1 213/21</p> <p>everybody [19] 60/3 63/7 91/18 108/12 108/12 112/1 118/6 118/13 124/2 124/2 162/12 162/15 168/4 182/23 188/1 188/4 188/6 192/18 227/7</p> <p>everyone [8] 2/25 78/15 78/15 80/15 93/18 153/3 157/5 175/14</p> <p>everything [6] 40/9 65/8 135/11 189/3 196/23 198/23</p> <p>evidence [54] 2/23 3/15 6/16 13/9 21/21 26/3 26/8 26/12 27/4 28/19 31/22 32/8 35/8 35/20 39/8 47/11 48/5 50/23 50/25 54/22 54/23 64/9 65/3 68/24 75/3 77/19 105/19 112/18 125/6 128/13 138/11 146/13 146/22 146/24 147/15 159/5 182/10 185/23 198/8 199/10 209/15 214/21 215/4 218/23 219/3 219/25 220/5 220/11 232/9 233/9 236/22 237/10 238/10 239/18</p> <p>evident [1] 212/7</p> <p>ex [2] 129/24 223/12</p> <p>ex gratia [1] 223/12</p> <p>ex-gratia [1] 129/24</p> <p>exactly [3] 98/10 138/9 174/2</p> <p>examination [2] 155/10 223/7</p> <p>examinations [1] 201/15</p> <p>examine [1] 104/2</p> <p>examined [1] 222/2</p> <p>examines [1] 226/7</p> <p>examining [1] 65/22</p> <p>example [7] 28/3 37/5 64/16 67/21 145/5 209/11 209/16</p> <p>examples [2] 111/19 209/5</p> <p>except [1] 61/10</p> <p>exception [1] 186/7</p>	<p>exchange [1] 60/6</p> <p>excluded [2] 59/14 233/6</p> <p>Excuse [1] 165/8</p> <p>executive [18] 24/15 24/18 29/5 29/16 29/24 30/4 30/23 38/12 41/10 41/19 41/20 41/24 97/5 103/6 157/1 188/20 191/12 208/14</p> <p>exemplar [2] 209/10 209/20</p> <p>exercise [21] 27/3 33/13 46/5 46/12 46/23 78/14 81/16 95/11 96/12 96/18 97/3 97/15 97/19 98/23 116/16 156/4 159/22 160/20 161/12 214/1 214/3</p> <p>exert [1] 198/13</p> <p>exerted [1] 199/5</p> <p>exhausted [4] 75/19 76/8 141/23 234/25</p> <p>exhausting [2] 64/4 64/4</p> <p>exhaustion [1] 66/24</p> <p>exhibited [1] 28/24</p> <p>existed [1] 62/15</p> <p>existence [2] 40/13 230/22</p> <p>existing [1] 129/23</p> <p>exists [1] 233/7</p> <p>expect [2] 93/15 198/4</p> <p>expectation [3] 87/22 88/11 88/12</p> <p>expectations [3] 36/23 37/21 52/4</p> <p>expected [1] 65/21</p> <p>expecting [4] 2/4 37/22 39/10 54/5</p> <p>expedited [1] 190/4</p> <p>expeditious [1] 190/11</p> <p>expenses [1] 222/9</p> <p>expensive [1] 92/16</p> <p>experience [35] 8/21 21/8 34/4 52/15 53/4 66/1 66/8 68/25 69/3 73/4 91/5 97/25 100/15 141/9 161/9 172/23 175/11 179/25 181/6 190/15 191/15 191/21 192/6 193/3 193/18 195/17 199/18 205/20 217/25 218/1 220/1 228/18 228/25 235/4 239/13</p> <p>experienced [3] 49/24 49/25 140/15</p>	<p>experiences [16] 37/7 37/9 40/10 40/11 40/12 66/6 79/18 106/8 106/11 106/16 106/17 168/5 169/22 203/17 206/13 206/14</p> <p>experiencing [2] 60/4 66/7</p> <p>expert [2] 36/16 42/3</p> <p>expertise [1] 8/3</p> <p>experts [5] 59/24 121/2 172/23 186/9 193/11</p> <p>explain [6] 76/17 80/13 119/14 141/11 210/20 218/6</p> <p>explained [4] 93/2 146/9 146/12 156/3</p> <p>explaining [1] 223/10</p> <p>exploit [1] 137/14</p> <p>explore [2] 91/3 140/3</p> <p>exploring [1] 35/19</p> <p>express [1] 131/20</p> <p>expressed [5] 236/21 237/2 237/20 238/7 239/3</p> <p>expression [2] 39/22 237/14</p> <p>expressions [2] 26/24 27/16</p> <p>extended [1] 177/1</p> <p>extending [1] 205/2</p> <p>extent [4] 86/24 99/1 157/13 159/3</p> <p>extra [2] 76/23 78/2</p> <p>extraordinary [1] 63/10</p> <p>extremely [3] 21/21 44/20 189/15</p> <p>eyes [1] 75/23</p> <p>eyeservice [1] 135/12</p> <p>F</p> <p>face [6] 72/16 97/12 97/12 217/24 227/12 227/12</p> <p>face-to-face [2] 97/12 227/12</p> <p>faced [3] 91/7 140/4 203/25</p> <p>facilitated [3] 137/16 190/11 204/3</p> <p>facility [1] 227/11</p> <p>facing [3] 33/23 44/23 74/20</p> <p>fact [33] 10/1 20/6 31/11 34/13 36/13 45/2 57/8 58/3 61/8 72/9 75/10 83/10 91/10 105/22 113/14 130/24 132/6 143/19 144/6 146/21 155/6</p>	<p>160/19 161/3 168/22 177/3 178/10 197/15 207/22 212/18 220/21 230/18 238/2 239/10</p> <p>factor [4] 13/24 14/4 14/6 31/18</p> <p>Factor VIII [3] 13/24 14/4 14/6</p> <p>facts [1] 230/4</p> <p>factual [1] 156/3</p> <p>failed [3] 27/3 89/7 231/17</p> <p>failing [1] 174/9</p> <p>failure [3] 57/5 201/12 216/25</p> <p>fair [6] 49/17 74/16 78/8 135/17 139/10 203/13</p> <p>fairly [2] 161/19 193/18</p> <p>fairness [5] 24/17 36/9 144/2 189/14 189/18</p> <p>faith [1] 141/15</p> <p>fall [2] 6/14 224/23</p> <p>false [2] 201/3 211/23 211/23</p> <p>falsehoods [2] 196/4 196/18</p> <p>familiar [3] 63/8 134/20 204/20</p> <p>families [31] 5/15 5/23 9/22 16/6 17/22 17/23 18/12 57/18 74/8 85/22 95/25 112/3 112/3 121/23 122/4 122/7 143/21 176/3 177/6 177/19 178/22 189/7 195/2 195/6 204/25 208/2 209/12 233/12 233/15 233/16 233/23</p> <p>family [19] 13/16 52/16 53/3 57/14 58/3 61/2 61/2 101/21 101/22 102/2 120/4 122/3 179/3 191/17 191/17 205/3 205/9 208/1 209/2</p> <p>family's [1] 13/21</p> <p>fan [1] 7/6</p> <p>far [7] 4/11 26/13 35/20 86/10 133/10 175/17 194/17</p> <p>Farthing [2] 30/22 191/20</p> <p>fatal [1] 41/15</p> <p>fathers [1] 235/24</p> <p>fatigue [1] 49/24</p> <p>fault [9] 3/19 35/19 35/23 36/6 82/21</p>	<p>91/11 91/22 134/4 196/23</p> <p>favour [3] 83/18 123/21 181/22</p> <p>fear [1] 141/21</p> <p>feared [2] 29/5 29/10</p> <p>features [1] 226/24</p> <p>February [6] 33/11 63/21 101/2 142/4 155/5 159/7</p> <p>February 2000 [2] 33/11 159/7</p> <p>February 2014 [1] 63/21</p> <p>fed [6] 37/1 37/10 49/2 98/17 109/18 125/4</p> <p>Federation [1] 208/16</p> <p>feedback [3] 122/11 193/15 206/16</p> <p>feeding [1] 20/10</p> <p>feel [15] 3/11 19/3 65/18 78/13 82/19 99/20 100/12 122/13 150/10 174/23 209/8 209/14 223/6 226/23 232/8</p> <p>feeling [9] 39/13 52/23 83/4 85/23 89/11 118/24 128/21 203/14 234/24</p> <p>feelings [3] 73/18 236/22 237/17</p> <p>feels [1] 78/16</p> <p>feet [3] 39/22 78/5 230/21</p> <p>fell [1] 54/8</p> <p>fellow [1] 130/21</p> <p>felt [59] 4/14 4/20 4/23 6/1 14/15 15/9 15/13 16/5 16/13 30/19 52/16 52/25 53/19 54/7 54/13 56/8 57/21 59/3 60/11 61/8 61/11 65/23 66/9 66/20 67/2 67/24 74/19 87/23 88/20 88/20 88/21 88/25 89/2 93/7 96/21 106/19 107/15 107/17 109/20 111/11 111/12 112/8 120/5 124/18 124/24 127/11 135/17 168/23 169/15 171/10 173/19 185/6 189/18 199/10 203/24 213/12 219/4 235/7 235/9</p> <p>few [9] 9/18 30/3 46/21 66/11 118/3 139/1 139/22 182/18 237/14</p> <p>FibroScans [1] 82/4</p>	<p>field [2] 132/15 176/7</p> <p>fight [2] 28/20 198/22</p> <p>figure [13] 32/11 32/15 77/8 100/9 100/9 134/14 134/15 134/16 135/7 135/19 135/20 135/21 162/7</p> <p>figures [5] 21/23 100/3 102/18 161/20 162/5</p> <p>filing [1] 211/2</p> <p>fill [2] 125/7 170/11</p> <p>filling [2] 71/8 146/1</p> <p>final [8] 15/1 47/7 67/7 67/9 178/12 186/14 190/22 195/20</p> <p>finalised [1] 146/6</p> <p>finally [6] 12/7 139/18 215/9 224/25 233/21 236/3</p> <p>finance [11] 44/9 45/11 59/14 136/2 136/8 137/11 137/17 137/23 140/20 149/11 152/12</p> <p>finances [1] 149/20</p> <p>financial [64] 6/22 19/20 32/5 35/24 36/5 36/17 38/21 39/7 41/12 44/8 52/18 59/6 67/22 74/10 74/13 78/21 81/7 83/8 86/18 89/14 90/8 91/2 92/3 93/18 94/21 95/2 95/15 95/24 98/4 98/7 98/18 101/13 102/11 102/22 106/10 114/3 114/6 115/19 118/19 122/20 126/10 130/2 135/18 136/25 140/23 142/18 143/3 143/7 148/6 148/23 148/25 151/17 152/12 206/6 207/4 217/20 220/17 221/4 222/1 227/4 227/12 227/25 228/2 235/12</p> <p>financially [1] 205/25</p> <p>financials [1] 104/15</p> <p>find [21] 3/1 27/3 28/9 34/15 54/9 92/6 113/8 113/11 122/7 149/20 159/24 160/19 161/19 161/25 162/8 162/22 162/23 190/20 193/21 212/1 215/22</p> <p>finding [2] 189/23 204/11</p> <p>findings [6] 23/6 25/6 25/8 37/5 37/13 74/6</p> <p>fine [4] 8/13 116/16 199/16 217/21</p>
---	--	---	--	---	---

<p>F</p> <p>finish [12] 79/15 85/20 98/4 121/10 145/11 148/6 165/10 165/24 166/13 169/5 172/5 172/17</p> <p>fire [1] 39/23</p> <p>firm [1] 195/13</p> <p>firmly [1] 151/13</p> <p>first [37] 2/10 13/13 13/24 15/12 19/8 24/5 26/19 38/19 43/22 44/7 45/11 45/19 45/23 45/24 51/25 63/12 72/12 74/17 75/8 76/18 87/4 88/18 92/17 93/3 95/1 95/19 118/16 127/24 142/23 153/19 158/25 191/24 208/12 219/11 223/21 223/22 235/19</p> <p>Firstly [1] 154/22</p> <p>fiscal [1] 144/23</p> <p>five [5] 148/13 148/15 202/2 202/5 227/17</p> <p>flatter [1] 133/8</p> <p>flourish [1] 199/9</p> <p>fobbed [1] 172/13</p> <p>focus [6] 9/20 35/19 46/5 53/20 103/17 184/25</p> <p>focused [1] 118/18</p> <p>folk [1] 179/23</p> <p>Folks [1] 234/24</p> <p>follow [8] 76/5 132/17 132/21 146/5 156/12 159/10 159/14 218/20</p> <p>follow-up [1] 159/14</p> <p>followed [2] 40/17 210/11</p> <p>following [9] 8/25 51/22 69/23 74/19 116/11 142/9 142/11 158/1 239/22</p> <p>force [4] 67/11 74/22 74/23 187/10</p> <p>forced [2] 68/14 107/24</p> <p>forces [1] 79/10</p> <p>forefront [1] 127/20</p> <p>forget [6] 67/5 69/22 232/19 233/16 236/8 237/15</p> <p>forgive [2] 135/5 228/16</p> <p>forgotten [3] 123/19 197/4 197/7</p> <p>form [5] 4/21 9/15 125/3 136/25 223/11</p> <p>formal [1] 19/9</p> <p>formally [1] 145/16</p>	<p>formation [2] 6/22 7/2</p> <p>formed [7] 4/10 4/17 6/7 19/7 24/3 212/23 221/17</p> <p>former [1] 63/2</p> <p>formidable [1] 191/1</p> <p>forth [4] 9/23 50/8 98/14 99/16</p> <p>fortuitous [1] 94/8</p> <p>fortunate [4] 44/5 191/7 191/19 200/12</p> <p>forum [22] 3/2 7/12 7/16 7/18 12/2 19/9 20/9 21/3 50/12 60/4 60/18 97/10 103/8 103/10 105/8 206/17 212/18 212/19 212/23 212/24 214/13 234/23</p> <p>forums [1] 233/6</p> <p>forward [16] 1/20 22/6 64/9 71/10 74/9 106/7 107/9 113/17 138/19 143/6 145/1 148/8 168/13 174/4 215/8 228/22</p> <p>forwards [3] 66/17 102/24 199/25</p> <p>fought [4] 99/22 231/6 232/16 232/17</p> <p>found [19] 11/7 25/12 27/19 41/17 53/5 130/20 136/18 141/4 141/5 141/6 141/20 144/10 148/9 159/20 184/13 190/7 190/9 194/4 206/3</p> <p>founded [1] 4/4</p> <p>four [12] 13/16 26/10 50/4 101/9 102/3 121/16 148/13 148/15 164/25 169/2 181/18 227/17</p> <p>four years [1] 50/4</p> <p>fourth [3] 8/25 48/25 49/22</p> <p>frame [1] 33/17</p> <p>Francis [1] 76/3</p> <p>Frank [2] 30/16 37/11</p> <p>Frank Maguire [1] 30/16</p> <p>frankly [8] 9/14 37/15 49/2 67/10 151/1 177/6 215/1 215/3</p> <p>FRASER [2] 3/6 240/6</p> <p>fray [1] 62/8</p> <p>free [4] 92/22 180/3 180/21 180/24</p> <p>Freedom [1] 158/4</p> <p>freeze [1] 25/23</p> <p>freeze-drying [1] 25/23</p> <p>fresh [2] 24/5 136/19</p>	<p>friend [3] 94/9 94/19 233/19</p> <p>friendly [1] 182/23</p> <p>friends [2] 143/21 195/6</p> <p>from [207] 1/14 2/4 3/13 3/25 4/20 6/6 7/18 10/4 11/22 12/12 13/10 14/17 15/13 15/17 16/22 17/9 19/18 22/5 24/18 24/20 25/7 26/8 26/18 28/19 29/4 29/20 29/23 30/1 30/2 31/16 32/6 34/23 36/2 37/11 38/9 40/1 41/1 42/6 42/23 43/3 43/10 45/15 45/18 45/24 47/15 48/13 49/19 52/12 52/17 53/4 53/23 53/24 55/23 56/14 56/25 57/22 59/6 61/9 61/10 61/21 62/4 64/7 64/8 64/19 66/8 67/25 68/10 70/4 70/19 74/19 75/7 77/8 77/10 77/11 79/8 80/2 80/9 80/15 83/5 83/7 84/17 88/1 88/6 88/6 91/9 93/4 93/23 94/5 97/19 98/12 99/2 99/11 100/17 104/4 105/18 111/21 112/24 113/9 114/2 116/5 116/5 116/11 116/22 120/4 122/18 126/19 127/6 129/18 131/6 131/10 132/15 132/19 132/22 132/24 133/3 133/6 133/17 133/19 134/10 134/16 135/3 135/9 137/4 138/13 138/25 140/2 140/8 143/20 146/20 146/25 149/2 149/6 149/10 149/14 150/4 150/14 152/13 153/14 153/17 153/21 154/4 154/12 155/12 156/17 158/15 159/1 160/10 165/2 165/3 167/5 171/24 175/19 176/7 176/8 177/1 177/17 177/22 180/21 180/23 181/3 181/5 182/12 182/18 184/3 184/21 186/8 187/2 187/12 189/12 190/3 190/4 190/17 191/25 192/10 192/15 193/3 193/11 193/17 193/22 196/17 196/22 199/18 202/13 203/17</p>	<p>204/10 206/7 206/16 207/8 208/9 209/25 210/18 210/20 211/19 217/25 219/10 219/25 220/5 225/6 226/17 230/18 231/11 232/21 233/6 233/10 238/6 238/23 240/7</p> <p>front [11] 2/16 12/2 21/5 21/12 33/3 71/5 71/21 89/16 155/15 159/21 212/15</p> <p>fruitful [1] 35/21</p> <p>frustrated [2] 67/19 215/6</p> <p>frustration [3] 69/5 73/19 230/1</p> <p>fulfils [1] 231/19</p> <p>full [10] 1/24 24/25 46/3 46/18 46/22 101/15 127/5 142/22 192/17 222/7</p> <p>full-time [1] 222/7</p> <p>fuller [1] 48/16</p> <p>fully [1] 127/4</p> <p>functioning [2] 54/25 228/24</p> <p>fund [18] 31/6 31/11 31/15 39/10 40/17 110/21 112/10 112/11 113/4 117/9 170/4 176/23 182/14 182/19 185/16 185/25 221/17 234/7</p> <p>fundamentally [7] 4/22 5/4 5/9 5/22 144/1 215/16 216/4</p> <p>funded [8] 64/25 65/2 108/19 191/14 191/16 214/2 226/23 227/14</p> <p>funding [29] 56/7 103/14 109/1 143/2 143/3 146/5 146/19 167/20 168/14 169/24 170/15 186/15 190/25 192/10 193/4 193/4 194/10 194/16 194/20 195/9 195/18 209/22 209/23 220/13 223/11 223/16 226/12 226/17 233/7</p> <p>fundraise [2] 220/11 220/12</p> <p>fundraising [2] 14/18 15/7</p> <p>funds [3] 93/20 223/14 223/14</p> <p>funny [1] 75/2</p> <p>further [21] 29/7 35/16 35/22 38/20 46/21 74/13 87/24 94/4 132/15 136/14</p>	<p>146/3 146/16 147/13 156/13 174/17 190/13 201/10 201/22 209/7 219/13 227/22</p> <p>fuss [1] 59/21</p> <p>future [19] 29/13 41/17 47/6 47/14 48/6 51/2 117/13 130/11 130/23 143/14 156/6 197/19 197/20 198/3 219/19 223/11 231/2 231/12 235/17</p> <p>G</p> <p>gain [1] 45/7</p> <p>gained [1] 137/4</p> <p>Galbraith [2] 34/20 34/24</p> <p>gallery [1] 32/7</p> <p>game [1] 125/1</p> <p>gamma [1] 212/2</p> <p>gap [1] 16/5</p> <p>gaps [6] 57/1 60/3 79/16 166/7 166/12 166/14</p> <p>garden [1] 63/5</p> <p>garner [1] 133/11</p> <p>gastroenterologist [4] 170/25 172/18 173/13 173/14</p> <p>gastroenterology [3] 169/6 170/13 173/15</p> <p>gather [2] 133/11 144/24</p> <p>gathered [5] 52/17 53/4 79/18 82/23 105/23</p> <p>gathering [5] 69/15 69/21 79/10 132/14 156/4</p> <p>gave [18] 1/11 6/16 12/12 21/21 33/21 35/8 66/20 69/10 75/6 86/13 159/5 173/5 181/12 181/13 199/10 214/7 218/4 219/3</p> <p>general [15] 5/17 26/20 58/5 66/3 92/19 130/18 141/7 145/15 150/12 170/12 170/25 173/15 178/21 193/18 224/7</p> <p>generalist [1] 170/25</p> <p>generally [4] 65/22 66/2 126/20 162/20</p> <p>generation [3] 208/5 208/6 208/6</p> <p>generational [1] 209/14</p> <p>generations [1] 13/15</p> <p>generous [1] 88/22</p> <p>Geoffrey [1] 79/25</p>	<p>gesture [1] 149/25</p> <p>get [88] 9/1 14/6 20/19 24/8 31/25 32/2 35/2 37/19 42/23 50/5 50/6 54/3 54/4 54/11 55/1 56/7 61/14 65/15 65/19 71/23 72/5 72/15 73/2 79/19 82/15 87/25 87/25 92/14 92/17 93/22 94/14 99/8 101/6 101/7 101/11 106/1 107/10 107/23 108/1 109/2 109/3 111/9 112/20 114/2 115/2 116/12 118/25 120/16 122/11 125/3 127/13 128/25 130/4 150/15 153/12 163/9 170/19 173/2 173/9 174/3 174/19 175/18 180/4 181/1 182/5 184/10 184/14 186/23 187/24 191/16 192/4 192/17 193/2 194/25 196/1 196/21 199/1 199/1 199/2 200/11 200/14 200/18 204/4 215/1 218/11 225/20 226/19 233/21</p> <p>Getting [5] 82/13 85/13 85/24 116/10 116/22</p> <p>gets [3] 63/7 95/10 196/5</p> <p>getting [12] 20/14 21/12 26/11 65/1 92/10 93/23 99/11 101/16 107/6 119/4 120/23 222/20</p> <p>giants [1] 232/17</p> <p>give [16] 2/24 23/7 28/2 50/2 77/24 88/11 98/24 105/3 106/22 137/12 152/18 193/15 209/15 214/21 232/2 238/21</p> <p>given [21] 23/16 26/8 57/25 70/1 81/17 89/10 106/5 117/12 140/5 143/5 188/10 191/22 193/12 193/20 203/13 204/12 219/15 224/10 225/19 236/22 238/10</p> <p>gives [1] 173/3</p> <p>giving [10] 2/23 21/16 68/22 77/19 218/20 229/16 232/8 237/9 239/11 239/17</p> <p>Glasgow [1] 97/7</p> <p>glean [1] 40/15</p>
---	--	--	--	--	---

<p>G</p> <p>gloves [1] 58/10</p> <p>gnashing [1] 218/13</p> <p>go [74] 3/24 12/6 19/5 21/5 27/13 27/21 28/23 29/2 37/23 38/10 49/4 54/14 54/19 60/11 61/21 63/10 64/25 72/4 73/9 73/15 74/24 76/8 79/21 87/23 90/11 93/24 97/23 97/24 98/20 105/6 105/21 110/6 110/7 113/3 116/15 121/6 121/24 122/8 124/6 124/19 125/14 126/14 132/5 137/3 138/4 151/6 152/22 153/20 155/13 156/21 157/20 158/13 159/14 160/19 162/4 162/13 171/13 171/17 174/2 174/9 177/7 179/13 180/18 192/5 194/5 200/23 202/25 209/4 211/2 220/12 220/24 221/6 223/20 235/17</p> <p>goal [1] 93/22</p> <p>god [4] 27/13 101/19 221/22 235/1</p> <p>goes [8] 12/19 144/24 162/11 176/22 193/9 219/6 226/1 236/1</p> <p>going [76] 1/14 10/12 14/16 21/25 27/19 31/2 31/7 31/20 32/4 32/18 37/18 48/22 49/7 52/11 52/12 54/7 54/20 59/2 68/2 68/19 70/3 72/2 75/9 77/21 78/21 79/9 81/21 81/24 83/7 86/5 86/17 90/15 92/16 96/13 100/12 101/10 103/14 105/5 105/9 107/11 109/16 111/16 114/17 114/23 117/19 128/16 132/13 132/16 133/6 135/15 138/9 141/21 143/6 151/1 152/14 153/25 162/5 169/9 172/11 178/10 180/10 180/18 182/3 185/18 185/20 200/4 203/19 216/19 217/5 217/12 217/20 218/22 219/8 220/11 223/24 236/11</p> <p>Goldberg [1] 103/2</p> <p>golf [1] 50/8</p> <p>gone [10] 71/13 104/5</p>	<p>110/18 112/13 113/6 150/13 152/3 190/19 203/21 207/22</p> <p>good [40] 1/5 1/6 1/12 2/17 15/14 18/8 30/24 34/4 51/9 55/23 60/6 69/10 73/3 78/17 86/11 86/11 87/3 96/14 96/18 111/4 111/22 118/20 118/23 120/23 121/3 122/12 124/15 141/17 147/21 164/12 173/7 179/20 190/15 193/10 203/22 209/10 209/16 211/24 219/2 226/25</p> <p>goodness [2] 90/17 238/22</p> <p>goodwill [4] 12/11 12/12 12/13 12/21</p> <p>got [75] 8/23 12/20 15/15 17/16 23/1 24/5 24/9 24/13 24/13 24/24 30/23 31/9 31/19 35/10 43/1 44/23 44/24 49/2 58/9 63/11 63/14 63/14 67/20 70/8 71/3 71/4 71/6 77/6 77/9 82/9 90/11 94/15 98/16 99/14 99/15 99/20 101/24 102/12 105/7 107/4 111/6 116/10 119/14 121/3 125/17 127/3 129/18 132/24 143/25 152/24 153/24 155/17 159/21 160/9 161/2 162/14 164/12 168/5 171/20 171/25 175/10 175/22 182/10 183/6 187/3 191/24 199/14 202/11 202/13 205/22 208/20 208/25 223/17 234/5 235/17</p> <p>governance [4] 9/5 13/1 201/13 220/2</p> <p>government [175] 11/17 12/14 21/13 23/8 24/4 24/11 31/8 31/16 31/25 33/10 34/2 34/5 34/11 37/3 42/24 44/4 44/14 58/15 58/19 58/23 62/21 71/10 74/1 74/3 74/19 75/9 75/13 75/14 76/3 77/1 78/10 78/17 80/5 81/3 81/8 81/12 81/16 81/23 81/25 82/1 82/18 83/13 83/18 84/12 84/20 85/21 86/2 86/3 86/14 88/6 88/24 89/2</p>	<p>90/5 91/10 91/14 91/15 91/20 93/11 98/13 98/15 99/11 100/5 100/18 101/14 101/15 105/15 105/17 108/19 109/1 109/19 113/6 115/25 116/7 116/8 118/5 118/17 118/22 120/5 125/1 127/9 129/14 133/9 133/16 134/24 138/14 138/15 139/18 141/7 143/25 143/25 144/17 149/7 149/8 149/9 149/15 151/13 151/14 152/6 152/7 154/8 154/10 154/14 156/18 156/22 157/4 157/9 159/10 161/25 163/12 164/16 167/19 168/13 168/25 169/24 171/7 184/14 185/4 185/10 186/20 186/21 191/25 192/10 196/1 196/18 197/3 197/3 197/16 197/17 197/22 198/7 198/8 198/13 199/7 200/4 201/12 209/23 214/2 215/2 216/19 217/3 219/2 220/8 220/14 220/15 221/5 221/19 223/5 223/14 223/23 224/4 224/6 224/23 225/6 225/7 225/8 225/21 226/5 226/10 226/18 228/10 228/20 228/23 228/24 229/18 229/23 229/24 230/7 230/9 230/13 231/10 231/18 231/21 233/19 237/13 237/24</p> <p>Government's [6] 73/13 96/4 105/5 163/1 177/15 230/21</p> <p>governments [5] 31/21 154/5 196/6 199/20 232/14</p> <p>governments' [1] 11/14</p> <p>GP [2] 125/25 125/25</p> <p>grabbed [3] 71/20 71/21 75/22</p> <p>gradually [1] 63/17</p> <p>grandfather [4] 13/14 207/10 207/15 208/3</p> <p>grant [1] 106/4</p> <p>grants [2] 110/24 110/25</p> <p>grateful [2] 169/1 221/14</p> <p>gratia [2] 129/24 223/12</p>	<p>Gray [3] 135/25 136/5 136/14</p> <p>great [14] 8/3 34/3 63/9 88/10 88/12 89/11 96/14 111/3 186/7 207/11 218/12 228/10 228/19 234/5</p> <p>great-uncle [1] 207/11</p> <p>greater [4] 127/10 147/11 164/14 187/10</p> <p>greatly [1] 230/6</p> <p>grew [2] 17/19 17/19</p> <p>grim [1] 67/13</p> <p>gritty [1] 118/25</p> <p>ground [2] 98/12 229/24</p> <p>grounds [2] 91/13 139/21</p> <p>group [114] 4/7 4/24 4/25 6/7 10/3 10/3 10/9 13/19 14/15 14/15 14/20 15/12 16/2 17/10 17/19 17/25 18/3 18/9 18/13 18/18 18/23 36/16 36/20 42/3 52/7 52/8 57/19 59/22 59/23 60/1 61/23 68/8 69/7 69/8 76/9 79/15 79/17 79/21 82/23 85/20 92/11 92/25 93/3 93/6 95/4 98/8 99/20 102/25 103/21 103/24 106/15 106/23 107/9 108/6 108/12 108/17 109/12 109/13 111/13 111/13 111/23 111/24 112/21 118/7 118/24 119/11 121/10 123/14 123/15 124/3 124/8 124/15 134/18 135/1 143/21 153/25 156/23 157/8 158/8 158/18 159/13 160/20 164/16 165/10 165/24 166/13 166/15 167/11 168/4 168/22 169/5 169/19 169/21 170/13 170/17 171/18 172/5 172/14 172/17 173/19 174/7 182/18 182/25 184/6 185/12 186/23 187/3 187/8 192/7 213/4 226/20 227/1 236/6 238/5</p> <p>grouped [2] 57/23 106/9</p> <p>groups [24] 5/14 7/12 7/15 7/18 7/19 12/2 21/3 50/12 59/17 110/6 111/25 112/1</p>	<p>134/10 135/3 135/22 143/20 143/21 167/12 168/4 212/19 212/22 212/24 212/25 214/16</p> <p>grown [1] 174/13</p> <p>grumpy [3] 42/12 75/19 191/8</p> <p>GT [1] 212/2</p> <p>guess [1] 50/14</p> <p>guidance [5] 5/11 128/25 193/1 193/10 193/12</p> <p>guide [1] 88/6</p> <p>guidelines [1] 106/5</p> <p>guiding [1] 129/15</p> <p>Gunn [3] 92/24 92/25 189/15</p> <p>guy [3] 7/14 70/23 71/17</p> <p>guys [3] 34/22 192/4 220/24</p>	<p>169/7 169/11 169/14 169/19 170/2 170/9 171/11 171/12 173/16 174/21 175/16 177/1 177/8 177/16 177/17 179/5 180/7 180/15 183/2 184/7 185/8 191/1 191/21 195/4 206/17 208/9 208/14 208/16 209/9 209/19 212/19 212/24 213/1 214/19 217/14 218/14 225/16 232/9 234/23</p> <p>haemophilic [5] 13/15 159/18 207/10 207/11 209/2</p> <p>haemophilic [19] 5/5 17/13 17/21 26/25 41/13 41/16 41/21 42/1 87/13 89/7 121/24 129/17 164/10 164/13 178/23 202/19 202/22 204/19 207/24</p> <p>haemophilic [1] 41/23</p> <p>half [4] 42/7 67/7 68/3 68/17</p> <p>hall [1] 63/9</p> <p>HAMILTON [6] 2/12 131/11 132/24 229/11 240/3 240/8</p> <p>hand [6] 38/22 39/3 41/11 41/16 73/11 108/24</p> <p>hands [3] 23/18 23/20 99/10</p> <p>handwriting [2] 132/6 155/16</p> <p>handwritten [2] 155/15 190/8</p> <p>hang [3] 49/13 75/17 211/12</p> <p>Hansard [2] 209/6 216/25</p> <p>haplessly [1] 230/8</p> <p>happen [23] 20/11 60/9 63/6 64/14 80/25 93/12 100/12 132/2 145/7 146/11 161/14 169/18 170/21 174/11 186/11 197/10 197/11 200/8 203/5 205/11 216/19 216/20 230/15</p> <p>happened [42] 20/23 20/24 28/3 38/17 58/7 61/19 69/20 69/25 76/10 76/12 80/14 93/2 93/12 95/15 102/20 105/11 108/9 113/8 113/19 113/24 116/13 118/3 119/16 122/6 136/9 138/10</p>
---	--	--	--	--	--

H	222/10 222/10 222/14 223/23 224/11 224/23 226/5 227/14 231/5 231/6 231/17 232/11 232/16 235/4 235/13 237/8 238/14 239/1 239/2	147/2 147/10 147/17 147/17 149/19 159/10 169/16 173/14 173/15 173/16 174/18 174/18 174/20 174/21 180/9 181/2 181/9 181/12 181/13 181/20 182/1 182/3 182/4 182/5 182/9 182/10 182/12 182/13 182/14 182/17 183/22 183/23 184/22 184/23 186/1 186/2 186/5 187/14 189/12 189/13 191/20 202/12 207/10 207/12 207/15 207/16 207/16 207/18 207/18 207/18 207/19 207/19 207/20 208/13 208/13 208/15 208/23 208/24 209/16 211/20 213/8 213/8 213/9 213/25 215/6 215/7 222/6 224/11 224/15 224/15 225/16 225/16 226/15 231/16 231/17 237/25	133/3 141/17 143/22 144/22 150/5 150/8 151/25 152/14 158/16 160/4 160/5 161/10 161/24 163/23 164/13 165/19 166/10 169/16 170/1 170/3 171/22 172/2 172/12 178/8 179/21 180/12 188/21 196/11 196/14 196/16 196/22 200/21 201/15 201/16 207/23 212/15 217/19 219/4 219/20 224/10 230/7 230/12 231/15 233/8 234/14 234/15 234/16 235/12	26/9 27/6 37/7 38/25 41/9 46/4 46/8 46/14 46/19 47/5 48/12 57/16 57/20 99/9 104/5 114/4 117/7 124/14 155/12 161/12 161/19 162/12 165/21 175/14 180/12 181/5 181/8 184/3 205/19 210/25 216/1	162/25 163/7 164/13 173/14 175/10 175/19 176/5 177/14 191/4 194/14 198/17 205/17 211/2 211/12 217/18 218/5 227/23 228/6 228/12 232/8 234/14 238/22 239/6
happened... [16] 142/5 156/8 159/9 160/14 176/19 196/1 196/5 200/24 201/14 201/18 210/20 218/7 233/17 233/22 234/14 237/8	hasn't [1] 175/23 hasten [1] 44/24 hat [1] 191/4 hate [2] 39/22 105/2 haunted [2] 159/2 159/8	Health's [1] 132/25 healthcare [5] 85/2 149/10 163/23 167/10 218/18	hepatitis C [28] 19/17 21/2 22/5 25/13 26/9 37/7 38/25 41/9 46/4 46/8 46/14 46/19 47/5 48/12 57/16 57/20 114/4 124/14 155/12 161/12 161/19 165/21 175/14 181/5 181/8 184/3 205/19 210/25	here's [3] 71/17 76/23 218/5	
happening [14] 24/5 51/21 53/22 57/14 57/17 81/1 114/20 141/2 161/10 163/12 170/22 182/19 186/6 233/3	have [312] haven't [7] 67/20 100/13 153/24 178/11 179/9 200/1 234/18	Health's [1] 132/25 healthcare [5] 85/2 149/10 163/23 167/10 218/18	hepatologist [8] 165/8 170/7 171/3 174/1 174/19 174/20 182/1 186/8	Hermon [1] 131/6 Higgins [5] 109/6 110/8 110/18 110/19 111/16	
happens [5] 123/4 132/2 161/13 216/9 228/5	having [30] 1/7 20/7 39/14 49/24 56/16 81/6 82/12 82/22 87/5 96/5 105/24 107/17 107/20 119/15 124/5 125/13 138/14 138/15 139/21 173/2 180/25 188/9 192/9 198/9 198/9 227/21 236/25 239/4 239/8 239/8	heard [18] 13/9 20/21 75/1 80/2 81/12 83/6 105/18 111/12 112/23 113/17 146/24 177/22 178/11 215/9 217/8 232/21 237/2 238/6	hepatologists [8] 60/1 104/21 124/15 165/4 180/21 181/10 186/7 188/5	high [1] 150/24 higher [1] 125/9 highest [1] 197/22	
happy [6] 12/9 58/19 65/7 179/10 194/5 194/6	hazard [1] 234/7	hearing [3] 67/10 67/10 67/12	hepatology [22] 52/19 52/19 55/12 55/14 59/1 121/14 165/1 165/4 166/9 166/18 166/20 166/24 167/25 168/6 170/17 171/5 174/17 175/12 175/18 175/22 179/8 186/13	highlight [4] 3/16 9/23 81/6 127/13	
hard [12] 12/21 20/19 45/6 65/17 70/9 99/22 100/20 101/5 101/19 151/10 226/19 231/7	HCV [4] 19/21 157/5 157/14 157/24	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	hearing [3] 67/10 67/10 67/12	highlighted [3] 142/10 208/23 229/20	
harder [1] 126/5	HCV [1] 157/7	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	hear [6] 3/8 118/5 138/24 162/4 225/4 237/4	him [23] 50/23 58/9 71/17 77/7 93/1	
hardship [2] 84/9 142/18	HDs [1] 156/11	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	hear [6] 3/8 118/5 138/24 162/4 225/4 237/4	highlighted [3] 142/10 208/23 229/20	
harm [4] 26/22 27/2 36/10 230/4	he [167] 20/19 27/7 28/7 28/10 28/11 28/16 30/12 30/12 30/19 33/1 34/21 34/21 34/24 44/8 44/10 44/11 44/14 44/21 45/25 46/6 46/12 47/25 49/14 49/15 49/16 50/18 50/22 50/23 51/3 51/4 51/6 51/18 51/20 56/12 56/13 63/2 63/12 64/21 65/25 66/3 67/15 68/15 71/16 73/23 75/3 75/21 76/17 76/17 76/23 79/24 85/17 85/17 85/25 97/5 97/6 97/7 97/11 97/12 101/19 101/21 102/11 103/11 103/12 103/12 123/6 123/7 123/8 123/9 123/10 124/3 124/4 127/24 131/18 133/2 133/20 135/13 135/13 135/14 139/22 142/4 145/24 145/25 145/25 146/1 146/1 146/2 146/3 146/9 146/11 146/12 146/13	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	himself [4] 66/21 146/25 147/17 209/1
harm [4] 26/22 27/2 36/10 230/4	he [167] 20/19 27/7 28/7 28/10 28/11 28/16 30/12 30/12 30/19 33/1 34/21 34/21 34/24 44/8 44/10 44/11 44/14 44/21 45/25 46/6 46/12 47/25 49/14 49/15 49/16 50/18 50/22 50/23 51/3 51/4 51/6 51/18 51/20 56/12 56/13 63/2 63/12 64/21 65/25 66/3 67/15 68/15 71/16 73/23 75/3 75/21 76/17 76/17 76/23 79/24 85/17 85/17 85/25 97/5 97/6 97/7 97/11 97/12 101/19 101/21 102/11 103/11 103/12 103/12 123/6 123/7 123/8 123/9 123/10 124/3 124/4 127/24 131/18 133/2 133/20 135/13 135/13 135/14 139/22 142/4 145/24 145/25 145/25 146/1 146/1 146/2 146/3 146/9 146/11 146/12 146/13	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	himself [4] 66/21 146/25 147/17 209/1	
harm [4] 26/22 27/2 36/10 230/4	he [167] 20/19 27/7 28/7 28/10 28/11 28/16 30/12 30/12 30/19 33/1 34/21 34/21 34/24 44/8 44/10 44/11 44/14 44/21 45/25 46/6 46/12 47/25 49/14 49/15 49/16 50/18 50/22 50/23 51/3 51/4 51/6 51/18 51/20 56/12 56/13 63/2 63/12 64/21 65/25 66/3 67/15 68/15 71/16 73/23 75/3 75/21 76/17 76/17 76/23 79/24 85/17 85/17 85/25 97/5 97/6 97/7 97/11 97/12 101/19 101/21 102/11 103/11 103/12 103/12 123/6 123/7 123/8 123/9 123/10 124/3 124/4 127/24 131/18 133/2 133/20 135/13 135/13 135/14 139/22 142/4 145/24 145/25 145/25 146/1 146/1 146/2 146/3 146/9 146/11 146/12 146/13	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	himself [4] 66/21 146/25 147/17 209/1	
harm [4] 26/22 27/2 36/10 230/4	he [167] 20/19 27/7 28/7 28/10 28/11 28/16 30/12 30/12 30/19 33/1 34/21 34/21 34/24 44/8 44/10 44/11 44/14 44/21 45/25 46/6 46/12 47/25 49/14 49/15 49/16 50/18 50/22 50/23 51/3 51/4 51/6 51/18 51/20 56/12 56/13 63/2 63/12 64/21 65/25 66/3 67/15 68/15 71/16 73/23 75/3 75/21 76/17 76/17 76/23 79/24 85/17 85/17 85/25 97/5 97/6 97/7 97/11 97/12 101/19 101/21 102/11 103/11 103/12 103/12 123/6 123/7 123/8 123/9 123/10 124/3 124/4 127/24 131/18 133/2 133/20 135/13 135/13 135/14 139/22 142/4 145/24 145/25 145/25 146/1 146/1 146/2 146/3 146/9 146/11 146/12 146/13	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	himself [4] 66/21 146/25 147/17 209/1	
harm [4] 26/22 27/2 36/10 230/4	he [167] 20/19 27/7 28/7 28/10 28/11 28/16 30/12 30/12 30/19 33/1 34/21 34/21 34/24 44/8 44/10 44/11 44/14 44/21 45/25 46/6 46/12 47/25 49/14 49/15 49/16 50/18 50/22 50/23 51/3 51/4 51/6 51/18 51/20 56/12 56/13 63/2 63/12 64/21 65/25 66/3 67/15 68/15 71/16 73/23 75/3 75/21 76/17 76/17 76/23 79/24 85/17 85/17 85/25 97/5 97/6 97/7 97/11 97/12 101/19 101/21 102/11 103/11 103/12 103/12 123/6 123/7 123/8 123/9 123/10 124/3 124/4 127/24 131/18 133/2 133/20 135/13 135/13 135/14 139/22 142/4 145/24 145/25 145/25 146/1 146/1 146/2 146/3 146/9 146/11 146/12 146/13	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	himself [4] 66/21 146/25 147/17 209/1	
harm [4] 26/22 27/2 36/10 230/4	he [167] 20/19 27/7 28/7 28/10 28/11 28/16 30/12 30/12 30/19 33/1 34/21 34/21 34/24 44/8 44/10 44/11 44/14 44/21 45/25 46/6 46/12 47/25 49/14 49/15 49/16 50/18 50/22 50/23 51/3 51/4 51/6 51/18 51/20 56/12 56/13 63/2 63/12 64/21 65/25 66/3 67/15 68/15 71/16 73/23 75/3 75/21 76/17 76/17 76/23 79/24 85/17 85/17 85/25 97/5 97/6 97/7 97/11 97/12 101/19 101/21 102/11 103/11 103/12 103/12 123/6 123/7 123/8 123/9 123/10 124/3 124/4 127/24 131/18 133/2 133/20 135/13 135/13 135/14 139/22 142/4 145/24 145/25 145/25 146/1 146/1 146/2 146/3 146/9 146/11 146/12 146/13	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	himself [4] 66/21 146/25 147/17 209/1	
harm [4] 26/22 27/2 36/10 230/4	he [167] 20/19 27/7 28/7 28/10 28/11 28/16 30/12 30/12 30/19 33/1 34/21 34/21 34/24 44/8 44/10 44/11 44/14 44/21 45/25 46/6 46/12 47/25 49/14 49/15 49/16 50/18 50/22 50/23 51/3 51/4 51/6 51/18 51/20 56/12 56/13 63/2 63/12 64/21 65/25 66/3 67/15 68/15 71/16 73/23 75/3 75/21 76/17 76/17 76/23 79/24 85/17 85/17 85/25 97/5 97/6 97/7 97/11 97/12 101/19 101/21 102/11 103/11 103/12 103/12 123/6 123/7 123/8 123/9 123/10 124/3 124/4 127/24 131/18 133/2 133/20 135/13 135/13 135/14 139/22 142/4 145/24 145/25 145/25 146/1 146/1 146/2 146/3 146/9 146/11 146/12 146/13	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	himself [4] 66/21 146/25 147/17 209/1	
harm [4] 26/22 27/2 36/10 230/4	he [167] 20/19 27/7 28/7 28/10 28/11 28/16 30/12 30/12 30/19 33/1 34/21 34/21 34/24 44/8 44/10 44/11 44/14 44/21 45/25 46/6 46/12 47/25 49/14 49/15 49/16 50/18 50/22 50/23 51/3 51/4 51/6 51/18 51/20 56/12 56/13 63/2 63/12 64/21 65/25 66/3 67/15 68/15 71/16 73/23 75/3 75/21 76/17 76/17 76/23 79/24 85/17 85/17 85/25 97/5 97/6 97/7 97/11 97/12 101/19 101/21 102/11 103/11 103/12 103/12 123/6 123/7 123/8 123/9 123/10 124/3 124/4 127/24 131/18 133/2 133/20 135/13 135/13 135/14 139/22 142/4 145/24 145/25 145/25 146/1 146/1 146/2 146/3 146/9 146/11 146/12 146/13	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	himself [4] 66/21 146/25 147/17 209/1	
harm [4] 26/22 27/2 36/10 230/4	he [167] 20/19 27/7 28/7 28/10 28/11 28/16 30/12 30/12 30/19 33/1 34/21 34/21 34/24 44/8 44/10 44/11 44/14 44/21 45/25 46/6 46/12 47/25 49/14 49/15 49/16 50/18 50/22 50/23 51/3 51/4 51/6 51/18 51/20 56/12 56/13 63/2 63/12 64/21 65/25 66/3 67/15 68/15 71/16 73/23 75/3 75/21 76/17 76/17 76/23 79/24 85/17 85/17 85/25 97/5 97/6 97/7 97/11 97/12 101/19 101/21 102/11 103/11 103/12 103/12 123/6 123/7 123/8 123/9 123/10 124/3 124/4 127/24 131/18 133/2 133/20 135/13 135/13 135/14 139/22 142/4 145/24 145/25 145/25 146/1 146/1 146/2 146/3 146/9 146/11 146/12 146/13	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	himself [4] 66/21 146/25 147/17 209/1	
harm [4] 26/22 27/2 36/10 230/4	he [167] 20/19 27/7 28/7 28/10 28/11 28/16 30/12 30/12 30/19 33/1 34/21 34/21 34/24 44/8 44/10 44/11 44/14 44/21 45/25 46/6 46/12 47/25 49/14 49/15 49/16 50/18 50/22 50/23 51/3 51/4 51/6 51/18 51/20 56/12 56/13 63/2 63/12 64/21 65/25 66/3 67/15 68/15 71/16 73/23 75/3 75/21 76/17 76/17 76/23 79/24 85/17 85/17 85/25 97/5 97/6 97/7 97/11 97/12 101/19 101/21 102/11 103/11 103/12 103/12 123/6 123/7 123/8 123/9 123/10 124/3 124/4 127/24 131/18 133/2 133/20 135/13 135/13 135/14 139/22 142/4 145/24 145/25 145/25 146/1 146/1 146/2 146/3 146/9 146/11 146/12 146/13	he'd [10] 56/12 79/23 89/23 101/22 101/23 102/5 102/6 102/6 102/9 123/9	he		

H	138/9 142/24 143/5 150/22 154/15 154/17 158/9 158/9 158/11 158/11 159/12 161/25 164/16 183/25 184/5 188/2 192/11 201/24 203/24 208/24 209/11 214/20 215/20 217/3 224/6 224/14 224/25 226/22 230/6 234/24 235/17 How's [1] 77/9 Howe [4] 84/17 84/21 85/3 216/22 however [16] 6/1 9/2 28/7 33/7 36/2 70/7 71/9 71/25 72/1 73/20 104/10 128/4 130/7 131/18 139/7 234/20 howling [3] 75/20 75/21 76/8 HRI [1] 127/4 huge [8] 39/20 65/10 66/10 86/6 125/22 176/3 191/21 209/22 hugged [1] 75/22 human [2] 230/19 231/10 hundreds [1] 77/13 Hunt [1] 85/18 hurdles [1] 187/18 hurt [1] 142/17 husbands [1] 235/24	60/7 109/11 I believe [6] 8/1 149/14 149/15 177/16 217/13 226/17 I brought [1] 186/22 I can [23] 3/9 4/2 14/21 38/13 62/11 73/18 77/17 78/24 92/24 96/18 101/12 111/23 116/3 126/8 164/20 179/9 179/11 181/23 211/1 225/3 225/4 238/8 238/16 I can't [6] 49/3 100/10 103/11 144/13 179/11 205/15 I cannot [4] 12/17 42/20 46/17 47/16 I certainly [3] 74/4 75/15 210/9 I completely [1] 204/23 I contacted [2] 113/6 181/20 I contest [1] 24/22 I continue [1] 235/3 I could [3] 50/6 87/4 197/2 I couldn't [2] 102/8 227/6 I decided [1] 16/7 I definitely [1] 216/1 I did [17] 13/19 16/10 16/12 59/20 71/20 72/11 88/18 102/15 109/9 113/21 126/15 126/18 136/3 138/24 138/24 184/9 185/5 I didn't [10] 1/13 10/8 50/11 52/11 55/5 56/11 75/21 76/7 92/18 183/9 I do [4] 3/16 47/10 57/17 192/25 I don't [18] 8/1 28/6 32/14 32/17 38/13 53/8 113/5 123/4 133/12 149/3 154/3 161/12 169/9 183/11 206/12 213/21 226/10 227/1 I emailed [3] 181/12 181/13 182/8 I ended [1] 75/20 I feel [4] 78/13 100/12 223/6 232/8 I felt [13] 16/5 52/16 52/25 59/3 60/11 61/8 88/20 88/20 88/21 88/25 89/2 111/12 203/24 I firmly [1] 151/13	I first [1] 208/12 I found [4] 53/5 130/20 136/18 141/20 I gained [1] 137/4 I gathered [1] 79/18 I get [1] 122/11 I go [1] 235/17 I got [5] 49/2 102/12 132/24 223/17 235/17 I grabbed [1] 71/20 I guess [1] 50/14 I had [13] 48/25 50/2 66/1 75/18 78/4 179/13 180/17 211/6 218/2 218/9 218/10 228/9 229/13 I happen [1] 63/6 I happened [1] 136/9 I hasten [1] 44/24 I hate [2] 39/22 105/2 I have [19] 12/7 20/18 20/18 22/15 48/4 63/1 66/7 97/24 128/12 142/7 143/24 160/15 189/25 191/15 201/19 214/12 220/1 229/6 236/9 I haven't [3] 67/20 100/13 200/1 I heard [1] 75/1 I highlighted [1] 229/20 I hope [5] 12/18 76/3 179/21 235/16 239/1 I include [1] 176/2 I joined [1] 16/11 I just [32] 2/18 8/17 16/13 22/14 51/16 53/19 54/13 56/1 56/8 57/21 60/9 61/10 74/17 89/15 92/19 98/4 112/8 140/3 148/5 154/7 155/14 184/25 185/7 187/19 187/23 194/13 204/6 206/14 209/8 209/14 209/18 229/12 I knew [5] 53/1 66/15 75/24 128/23 183/23 I know [9] 40/10 57/19 134/17 168/10 170/22 203/17 208/2 224/8 226/3 I later [1] 27/19 I learned [1] 77/10 I listened [1] 88/19 I live [1] 1/15 I look [1] 3/10 I looked [1] 208/19 I made [4] 59/20 64/13 71/11 74/22 I make [3] 3/7 201/10	228/16 I may [5] 33/6 33/6 37/1 148/1 219/12 I mean [9] 37/12 40/8 42/18 68/20 77/21 153/7 214/18 215/17 218/8 I met [4] 13/25 18/7 53/23 94/10 I might [2] 90/12 112/23 I moved [1] 213/2 I must [1] 213/19 I name [2] 7/25 32/13 I need [3] 101/19 165/7 231/24 I needed [1] 142/23 I never [1] 77/9 I now [1] 231/3 I obviously [2] 79/21 180/24 I okay [1] 121/6 I owe [1] 105/10 I pay [1] 69/6 I physically [1] 8/24 I presented [1] 31/1 I probably [1] 186/3 I raised [1] 59/11 I realise [1] 160/2 I really [2] 199/1 234/13 I received [1] 146/20 I recently [1] 218/8 I recruited [1] 9/18 I refer [1] 95/14 I remain [1] 234/12 I remember [11] 58/22 72/18 75/17 96/5 100/2 100/10 100/16 102/8 192/3 211/20 218/2 I replicated [1] 208/25 I reported [3] 183/1 183/2 184/7 I rescue [1] 71/19 I resigned [2] 185/7 187/2 I respected [1] 137/15 I right [1] 36/19 I run [2] 111/21 192/15 I said [13] 59/21 72/23 78/4 78/8 92/18 92/21 100/19 102/13 110/23 131/24 184/13 220/24 230/24 I saw [2] 88/19 180/10 I say [12] 53/7 53/21 80/5 84/17 125/12 139/21 172/21 175/4 183/7 186/3 192/7 217/25	I see [2] 150/25 176/3 I sent [1] 184/11 I set [1] 69/24 I should [6] 16/21 38/4 45/23 89/3 183/3 187/12 I sometimes [1] 95/12 I sort [1] 185/5 I spoke [1] 180/23 I stand [4] 78/19 191/6 231/25 231/25 I start [1] 3/7 I started [2] 50/7 71/24 I stop [1] 90/10 I strongly [1] 59/19 I submitted [1] 146/22 I suffered [1] 49/24 I suggested [1] 64/16 I support [1] 175/9 I suppose [3] 86/15 173/11 192/14 I suspect [3] 210/16 210/17 236/25 I take [3] 8/8 186/17 191/4 I talked [1] 30/22 I thank [1] 238/20 I then [1] 110/19 I think [157] 1/3 1/23 8/9 8/19 11/5 11/13 14/21 16/1 21/4 24/2 24/16 30/18 31/13 35/12 34/1 34/14 35/3 32/8 37/1 37/14 41/4 42/17 43/10 43/20 44/12 44/20 60/19 61/3 63/11 65/12 65/14 67/6 67/24 70/13 71/15 71/22 72/6 72/25 75/3 77/20 81/25 82/11 86/10 87/20 87/23 89/17 89/25 91/9 93/5 99/6 99/19 100/17 100/24 102/19 102/21 104/7 105/9 110/20 112/18 117/17 117/20 117/25 118/3 126/10 128/6 133/8 143/17 144/8 146/15 148/3 149/5 149/10 152/4 152/15 154/7 155/19 156/24 159/20 162/20 163/6 163/17 164/24 170/21 176/5 176/22 178/1 178/3 178/6 178/25 182/10 183/14 185/13 189/19 190/11 190/16 193/7 194/14 194/16 195/2 195/25 196/6 197/2 197/6 197/7
----------	--	--	---	--	--

I	222/4 229/18 234/21	191/7 192/14 193/18	111/3 113/7 114/16	33/22 48/17 64/3	including [3] 62/20
I think... [53] 199/7	I wasn't [3] 13/17 41/3	201/20 204/21 210/11	115/21 116/2 116/19	65/15 66/23 67/2	92/4 167/13
199/19 200/4 200/7	50/11	214/6 214/6 217/5	117/2 117/19 121/23	68/25 69/1 86/9	inclusive [1] 76/13
200/10 203/11 203/21	I welcome [1] 198/25	217/12 218/11 219/8	121/23 121/24 124/12	102/16 204/8 204/12	income [4] 206/1
203/23 204/1 204/6	I welcomed [1] 143/1	221/14 223/6 226/8	124/18 124/23 125/19	214/23 237/8 237/11	222/10 222/11 222/16
205/18 206/2 207/7	I went [8] 9/17 52/10	226/8 235/3 235/25	126/8 127/6 127/22	124/18 124/24	incorrectly [1] 198/2
207/20 207/25 208/13	52/22 159/8 180/20	238/16	128/3 128/17 129/19	impacted [3] 123/11	increase [3] 108/15
209/13 210/5 210/5	183/3 183/25 208/17	I've [50] 11/25 13/9	129/21 131/7 131/25	124/18 124/24	143/14 154/10
210/15 212/12 214/2	I wept [1] 75/23	26/8 26/17 31/9 31/19	132/5 132/17 132/20	impacts [2] 141/19	increased [1] 147/9
215/16 216/3 216/5	I were [1] 66/16	31/24 32/25 33/8 43/2	132/20 134/2 140/10	235/12	incredibly [1] 20/16
216/10 216/17 216/18	I will [6] 13/7 28/7	71/6 76/13 87/6 91/3	140/11 142/2 142/6	impartial [1] 24/20	incumbent [1] 193/19
216/19 216/21 222/20	I will [6] 67/5 149/4 229/14	100/13 101/7 105/7	145/2 145/3 145/11	imperative [2] 99/7	incurred [1] 120/3
223/22 224/22 225/1	231/23	110/20 123/18 124/13	146/8 148/1 149/18	223/4	indeed [10] 18/21
225/19 226/21 226/24	I won't [2] 14/22 148/4	135/5 138/11 148/9	151/2 152/22 152/25	Imperato [1] 92/25	22/14 26/13 27/1
226/24 227/6 227/10	201/22	149/5 150/24 154/1	153/2 153/6 155/2	impertinence [1]	88/18 129/10 132/9
227/13 228/18 229/5	I wonder [2] 51/9	161/2 161/11 185/20	155/3 155/13 155/17	227/21	143/19 143/19 192/3
229/8 236/19 237/14	201/22	199/14 202/11 202/13	156/21 156/24 157/20	implement [2] 74/8	independent [5] 12/5
237/23 237/25 238/6	I worked [1] 20/1	206/5 206/19 206/21	158/1 158/13 159/10	117/19	19/16 22/10 35/17
238/7 238/14 239/3	I would [29] 31/23	207/6 207/20 207/22	159/22 162/1 162/21	implementation [2]	190/20
239/14	42/19 49/3 49/5 69/5	209/24 215/2 217/24	162/22 163/23 164/20	158/6 172/8	indicate [2] 137/23
I thought [9] 10/9	82/17 87/12 89/21	218/13 220/4 225/24	165/15 166/5 166/11	implemented [7]	201/21
16/9 33/5 52/5 53/21	106/13 110/6 139/5	230/15 231/5 234/5	167/5 170/6 170/8	31/10 37/15 37/25	indicated [3] 13/9
71/19 73/22 180/18	139/20 147/14 147/16	236/1 238/6 238/11	170/8 170/15 172/24	39/4 39/5 79/10	101/15 104/7
184/1	152/10 153/21 164/8	I, [1] 100/16	173/25 174/2 174/5	172/17	indicates [3] 45/25
I to [2] 28/5 200/23	164/14 178/5 184/9	I, between [1] 100/16	175/17 182/3 183/12	implications [3] 29/18	128/13 228/25
I took [1] 61/17	190/16 199/18 206/2	Ian [2] 95/2 235/21	183/15 183/17 183/17	117/2 235/12	indication [1] 212/2
I totally [1] 3/14	206/19 206/23 209/3	idea [16] 18/9 20/7	184/8 185/17 189/3	importance [5] 12/17	indicative [5] 131/25
I turn [1] 51/21	223/22 224/17 227/3	20/11 21/14 44/11	192/9 193/20 194/6	35/4 137/13 139/19	132/1 132/23 133/1
I understand [7] 4/11	I wouldn't [1] 112/17	76/19 76/21 96/4	194/19 195/13 197/2	213/19	163/3
85/12 192/14 208/8	I wrote [4] 22/16 77/3	104/25 124/17 126/16	198/8 199/15 201/13	important [31] 3/5 6/2	indicators [1] 211/5
218/12 224/12 225/5	92/7 207/1	140/25 140/25 182/24	201/21 201/22 202/6	10/9 26/20 31/13	indigenous [1] 5/20
I understood [1]	I'd [28] 1/24 13/25	198/19 199/9	202/16 205/25 206/3	54/23 57/10 72/15	individual [9] 10/6
223/15	26/7 35/2 48/22 49/14	ideal [1] 223/10	206/12 211/1 218/18	73/6 96/1 97/9 98/24	27/6 28/15 66/4 69/6
I voiced [1] 110/14	49/25 49/25 52/17	ideas [3] 78/18 193/3	218/21 219/12 221/22	102/17 102/19 126/25	218/15 237/6 237/18
I want [20] 19/5 24/25	53/3 54/14 54/15	193/14	222/22 224/9 224/12	175/1 180/11 185/21	237/19
35/14 45/13 45/19	64/11 65/20 71/13	identification [1]	224/17 226/23 227/9	194/14 203/15 203/23	individually [2] 7/13
64/2 78/22 80/8 89/13	77/6 103/8 106/13	190/12	228/22 231/24 233/18	204/2 214/7 215/16	41/18
90/7 94/20 98/1	110/6 133/22 145/9	identified [5] 159/16	237/2 238/7 238/16	216/4 219/5 220/20	individuals [13] 3/18
102/24 152/5 154/21	152/11 180/14 184/13	166/12 166/14 176/4	110/16 112/8 169/18	227/24 235/5 235/11	5/20 36/9 45/8 50/21
156/19 165/13 218/4	199/23 211/3 234/20	213/15	171/16 171/19 173/10	237/4	143/12 157/14 158/9
218/6 218/25	239/5	identify [4] 25/16	201/4	importantly [1]	161/22 165/20 178/25
I wanted [3] 50/1 90/6	I'll [12] 3/24 28/2 41/6	68/16 156/8 179/11	ILIT0000660 [1] 40/24	144/21	190/18 233/5
101/11	41/7 69/22 87/3 99/25	ie [4] 137/20 138/22	ill [5] 9/14 21/1 58/23	impossible [4] 11/16	industrial [1] 189/23
I was [60] 7/3 9/14	147/25 150/17 165/14	157/13 197/3	130/7 186/24	107/8 193/25 206/3	inevitable [2] 3/16
10/8 13/18 16/11	209/21 217/18	if [178] 1/20 2/19 2/22	ill health [2] 21/1	impressed [1] 190/6	238/20
19/25 20/12 21/8 26/9	I'm [79] 1/10 1/10 3/10	3/1 3/13 4/2 4/15 5/20	130/7	impression [3] 212/9	infectably [1] 197/2
28/8 30/21 44/5 48/24	3/12 3/13 12/18 15/3	7/6 10/15 18/9 18/21	illness [1] 215/24	220/4 220/6	infected [103] 5/24
50/5 50/10 50/14	23/3 27/25 32/18 37/9	23/1 25/4 28/22 28/23	illogical [1] 154/13	improve [1] 95/24	6/3 6/6 6/15 16/7
54/10 55/9 64/22	37/12 39/18 42/20	29/2 33/12 35/1 35/11	illustrate [2] 12/19	119/20	17/21 18/20 19/9
66/12 70/15 73/20	49/5 63/8 65/11 66/7	35/18 37/14 38/6	101/12	improving [3] 47/15	19/22 26/9 26/25 28/8
75/2 75/4 75/10 75/18	68/19 69/11 70/23	38/10 38/13 38/19	illustrated [1] 236/5	48/13 176/17	30/19 31/17 36/24
75/19 76/8 76/15 77/3	75/5 76/25 77/15 78/3	39/6 40/24 41/22 44/9	illustrates [1] 152/16	inactivity [2] 4/13	42/10 47/4 48/12 53/1
79/16 101/5 102/3	78/20 84/18 87/5 90/8	45/20 46/14 47/22	imagine [5] 66/13	4/22	53/18 56/19 56/19
111/11 128/22 129/2	90/10 93/6 94/4 94/21	47/24 49/5 49/13	217/20 218/17 218/18	inadequate [2] 115/24	56/20 57/13 58/6
135/6 142/22 178/2	95/13 98/18 101/20	49/14 49/15 51/9	218/19	224/20	60/25 61/7 65/5 65/11
180/6 180/7 180/17	103/14 112/7 123/20	52/25 54/6 55/9 55/20	immediate [2] 95/23	inadvertent [1] 27/2	69/2 78/12 86/24 89/8
184/8 185/1 185/6	129/4 129/5 138/9	73/15 78/24 79/2 87/4	142/16	include [3] 52/9 147/9	92/12 100/8 103/8
191/8 200/12 203/24	144/14 144/14 144/15	87/24 87/24 94/4 94/6	immunity [1] 198/11	176/2	103/10 105/8 109/15
205/20 206/22 207/1	145/13 152/2 152/15	96/18 97/23 100/10	impact [16] 12/22	included [9] 59/6 83/8	109/18 110/3 110/4
207/1 208/11 211/8	153/3 160/15 160/23	101/12 103/11 107/2		83/11 84/25 106/24	111/7 111/8 112/2
213/2 215/8 221/22	160/23 163/14 173/1	107/21 107/25 108/23		107/13 121/21 135/2	114/10 115/11 115/18
	175/17 178/12 180/18			236/1	120/8 120/22 121/21
	183/12 185/20 187/23				

<p>I</p> <p>infected... [52] 121/25 122/3 122/6 123/7 124/12 125/7 129/17 142/13 142/14 142/19 143/9 143/12 155/25 157/14 157/24 161/5 162/1 164/10 164/15 165/20 170/10 170/17 181/3 181/6 182/12 182/22 182/25 202/18 202/21 203/7 203/7 204/14 204/18 204/25 205/2 205/9 205/10 206/4 206/17 209/12 211/9 211/16 212/18 212/23 214/13 214/14 214/23 219/21 222/10 230/10 233/14 234/23</p> <p>infection [14] 28/10 46/3 46/18 47/12 51/1 56/16 85/5 123/6 157/15 161/18 173/20 211/11 211/14 222/12</p> <p>infections [1] 19/17</p> <p>infects [1] 104/8</p> <p>inferences [1] 3/24</p> <p>influence [4] 31/5 113/10 127/11 195/1</p> <p>influenced [2] 195/12 229/4</p> <p>influences [1] 229/3</p> <p>information [25] 13/4 17/5 47/11 50/23 50/25 105/23 114/2 132/15 133/11 155/10 156/4 156/5 158/4 158/15 161/17 181/13 189/24 194/11 207/8 209/7 215/15 215/20 216/14 217/9 217/11</p> <p>informed [3] 131/9 163/25 215/24</p> <p>inherited [12] 17/6 18/23 123/15 166/1 166/25 167/8 167/15 167/21 176/12 177/12 177/12 226/5</p> <p>initial [2] 38/23 191/18</p> <p>initially [9] 9/20 18/4 43/20 69/9 82/17 136/24 176/24 189/13 190/7</p> <p>initiative [2] 56/6 56/6</p> <p>injury [1] 230/5</p> <p>innocent [1] 41/22</p> <p>innocently [1] 230/8</p> <p>input [9] 65/19 69/10 110/5 121/12 138/5 166/24 169/7 181/3</p>	<p>181/5</p> <p>inquiries [8] 11/9 11/12 11/14 67/3 89/7 226/3 230/14 234/18</p> <p>inquiry [139] 5/8 6/3 6/17 6/18 10/6 10/7 11/4 11/7 11/9 11/18 11/20 11/21 11/23 19/16 20/18 21/14 22/10 22/13 22/19 22/23 23/23 24/23 25/8 25/8 26/13 26/14 28/2 30/5 31/23 31/24 35/2 35/7 35/17 35/22 37/13 38/4 43/23 43/25 46/3 46/16 46/18 46/22 47/3 47/10 48/2 48/4 48/8 50/9 50/24 51/22 62/6 62/10 62/11 63/17 63/25 63/25 64/1 64/2 64/3 64/7 64/8 64/10 64/15 64/22 64/23 65/1 65/17 66/9 68/2 69/11 70/4 70/18 73/12 73/13 74/20 78/23 80/24 82/6 82/7 82/16 82/17 82/20 82/21 82/22 83/14 83/18 84/6 85/9 85/14 85/18 86/8 86/15 87/2 88/13 88/16 91/5 91/8 91/25 93/22 101/9 105/18 113/17 118/13 136/6 144/9 146/24 155/20 157/3 157/11 159/15 164/5 177/24 178/4 178/6 178/20 179/6 188/12 190/18 191/9 192/11 192/20 195/7 196/13 198/25 200/5 200/6 209/15 209/22 215/5 218/24 224/14 225/18 226/7 232/9 232/21 233/21 234/13 237/3 238/19</p> <p>ins [1] 217/23</p> <p>insecurity [1] 228/20</p> <p>inside [1] 174/8</p> <p>insight [1] 40/15</p> <p>insofar [2] 3/5 86/11</p> <p>inspiration [1] 236/12</p> <p>instance [3] 68/6 92/17 237/22</p> <p>instead [1] 222/7</p> <p>instigated [1] 79/23</p> <p>instruct [1] 68/12</p> <p>instructed [2] 69/8 210/17</p> <p>instructions [1] 66/11</p> <p>instrument [1] 129/15</p> <p>instrumental [1]</p>	<p>114/5</p> <p>insult [3] 78/4 78/19 81/10</p> <p>insulting [1] 130/21</p> <p>insurance [1] 205/24</p> <p>integrity [2] 44/18 195/11</p> <p>intelligent [1] 8/16</p> <p>intended [3] 59/23 62/21 142/16</p> <p>intent [1] 28/6</p> <p>intention [1] 9/19</p> <p>intentioned [1] 224/15</p> <p>interaction [1] 87/14</p> <p>interactions [2] 22/9 63/23</p> <p>interest [2] 90/4 93/4</p> <p>interested [4] 59/4 74/24 108/7 151/25</p> <p>interested in [2] 108/7 151/25</p> <p>interesting [2] 104/15 144/5</p> <p>interestingly [1] 139/7</p> <p>interests [3] 24/17 108/21 233/18</p> <p>interferon [7] 8/25 26/10 48/25 49/22 180/3 180/21 181/19</p> <p>interferon-free [2] 180/3 180/21</p> <p>interim [6] 142/13 142/15 146/13 186/23 187/4 187/25</p> <p>internal [3] 22/19 23/22 46/14</p> <p>interpreted [1] 139/20</p> <p>interrupt [1] 187/24</p> <p>intervention [1] 171/19</p> <p>interventions [1] 208/3</p> <p>interview [1] 177/18</p> <p>intimate [1] 100/15</p> <p>into [45] 17/16 19/16 20/6 20/11 28/10 32/12 35/17 37/1 40/16 46/3 46/18 48/2 48/22 55/10 63/17 63/25 69/10 92/23 94/22 96/4 101/6 101/11 107/6 107/10 107/23 107/24 109/19 110/5 110/7 125/4 138/5 140/3 143/13 166/24 169/25 179/20 179/24 193/9 199/1 206/24 211/2 225/20 228/4 230/11 232/11</p> <p>intransigence [1]</p>	<p>20/14</p> <p>intransigent [1] 44/14</p> <p>intrigued [1] 34/7</p> <p>introduce [2] 84/20 85/4</p> <p>introduced [2] 199/9 213/3</p> <p>introducing [1] 32/11</p> <p>introduction [2] 1/22 122/22</p> <p>invent [1] 196/10</p> <p>inventing [2] 186/1 187/15</p> <p>Inverness [1] 97/7</p> <p>investigate [2] 23/11 38/16</p> <p>investigated [1] 158/17</p> <p>investigating [2] 35/23 200/6</p> <p>investigation [5] 23/20 28/10 30/14 156/13 160/17</p> <p>invite [1] 91/3</p> <p>invited [6] 58/20 98/17 119/7 119/17 131/23 135/1</p> <p>involve [4] 13/4 13/4 13/5 23/9</p> <p>involved [36] 6/21 7/2 9/1 10/6 13/12 13/17 13/18 17/24 18/18 19/25 20/4 23/10 32/22 33/7 33/9 33/12 47/18 47/19 50/12 58/15 69/7 69/9 83/2 96/11 96/24 96/25 109/17 111/11 134/18 177/18 180/3 186/8 187/20 191/22 208/15 235/17</p> <p>involvement [10] 6/24 7/7 9/4 10/16 11/14 13/13 33/9 45/15 97/2 177/25</p> <p>involves [2] 26/23 167/8</p> <p>involving [1] 153/9</p> <p>Ireland [59] 4/3 4/10 4/20 5/1 5/3 5/18 6/9 6/23 40/11 60/13 86/25 87/12 87/16 88/4 89/4 91/12 91/16 126/22 126/24 127/14 128/4 128/9 128/15 128/24 132/3 133/6 133/16 133/21 133/24 135/24 136/7 138/14 138/18 139/6 139/18 140/9 140/16 143/15 144/7 144/13 144/24 145/12 145/16 146/18</p>	<p>146/24 149/21 154/9 154/24 164/8 177/22 190/14 191/18 208/20 209/9 224/9 224/9 228/5 228/19 231/13</p> <p>Ireland's [1] 136/1</p> <p>Irish [10] 4/6 84/23 88/14 107/15 107/21 208/9 208/14 209/8 209/9 209/19</p> <p>is: [1] 160/9</p> <p>is: where [1] 160/9</p> <p>Island [1] 66/12</p> <p>Isle [2] 66/14 102/3</p> <p>isn't [11] 6/20 16/1 49/17 55/8 124/10 126/4 144/16 144/16 162/12 165/3 188/19</p> <p>isolated [1] 203/14</p> <p>issue [42] 42/25 50/21 52/24 55/21 55/21 57/6 57/20 58/13 66/9 89/1 89/1 91/3 101/3 103/21 104/7 106/8 106/12 110/3 113/13 119/13 126/24 134/15 139/12 139/19 139/23 141/3 143/6 144/8 144/19 152/9 154/3 159/2 160/5 162/11 163/18 168/21 194/15 198/11 211/17 224/3 225/1 225/3</p> <p>issued [3] 92/3 118/14 196/24</p> <p>issues [82] 4/20 5/8 5/16 6/2 6/21 7/8 9/21 14/18 16/16 17/18 18/11 18/21 18/22 18/24 19/2 32/9 35/23 36/7 52/9 52/16 52/21 53/19 53/20 54/15 54/15 54/21 54/21 60/18 60/24 61/13 65/25 66/22 79/13 80/3 81/6 81/7 82/3 87/1 88/2 89/5 89/9 94/20 103/14 103/20 103/24 107/16 107/20 111/10 120/10 120/14 123/18 124/1 126/20 126/21 127/13 133/23 134/24 135/18 136/16 136/22 137/19 137/19 137/20 138/21 139/25 143/4 144/11 149/9 149/11 154/21 167/11 169/3 178/8 178/21 179/7 180/2 191/22 193/14 203/12 218/23 226/7 231/6</p>	<p>it'll [2] 174/11 226/21</p> <p>it's [138] 2/25 3/16 6/20 8/13 8/13 8/19 11/20 16/1 19/3 19/12 19/13 21/6 23/3 24/2 25/3 30/24 31/13 32/17 32/19 35/12 35/13 38/8 39/18 40/25 40/25 41/11 41/12 41/22 48/20 49/17 53/8 54/23 56/10 56/20 56/21 59/13 61/19 63/6 75/1 75/3 79/1 79/3 80/9 80/15 100/14 102/19 104/8 105/14 107/25 113/22 113/25 122/9 122/9 125/5 126/5 131/25 140/7 144/17 146/6 149/12 150/11 151/10 151/11 152/23 154/12 154/15 156/25 157/17 159/2 159/8 160/11 160/12 160/23 162/5 162/9 162/17 165/3 166/6 170/21 170/22 174/12 174/25 175/16 176/11 176/13 179/15 185/22 188/19 190/23 191/10 192/17 192/19 193/1 193/4 194/14 195/14 196/15 196/15 196/20 196/25 198/11 199/19 199/21 199/21 200/8 200/10 200/11 201/4 201/5 201/8 201/12 201/18 204/1 206/1 206/20 209/10 209/10 209/13 214/15 215/13 215/16 216/20 217/2 217/3 219/5 219/6 222/21 223/10 224/1 227/16 227/19 228/10 236/13 237/13 238/9 238/20 239/13 239/14</p> <p>item [1] 54/17</p> <p>its [20] 4/17 11/18 41/22 64/8 64/10 74/1 75/13 88/23 93/16 128/24 128/25 149/16 154/9 174/11 224/16 230/21 231/18 231/19 231/19 231/21</p> <p>itself [7] 4/25 62/25 64/2 131/2 179/8 229/25 231/11</p> <p>ITV [1] 71/23</p>
<p>J</p> <p>Jackie [2] 110/15 134/11</p>					

J	133/19 138/17 Julian Smith MP [1] 133/18 Julian Smith's [1] 138/25 Julie [9] 13/25 14/5 18/4 18/7 18/13 83/1 83/15 172/2 172/15 Julie Morgan [3] 83/1 83/15 172/2 July [3] 116/10 117/15 187/1 jump [1] 124/6 jumping [1] 85/6 June [3] 1/1 45/22 165/12 June 2011 [1] 165/12 junior [2] 70/22 72/24 just [210] 1/7 1/23 2/15 2/18 7/1 8/10 8/13 8/17 8/17 10/15 11/1 12/23 15/6 16/13 16/15 17/19 18/16 22/1 22/1 22/10 22/14 24/10 26/18 27/19 32/3 32/18 33/17 34/2 37/4 37/10 37/18 38/19 38/20 39/14 42/14 47/24 48/18 50/9 51/16 52/14 52/20 53/19 54/13 54/16 54/23 55/12 56/1 56/8 56/14 57/2 57/7 57/21 57/22 57/23 59/5 59/13 59/14 60/8 60/9 61/10 67/14 71/8 71/17 74/17 77/2 77/24 78/2 78/18 78/24 80/8 80/23 81/8 81/12 82/5 83/12 84/13 85/8 86/7 87/23 89/12 89/15 89/23 89/24 90/4 90/5 91/20 92/13 92/19 93/2 93/18 94/1 94/16 94/17 96/13 96/20 98/4 101/21 102/18 103/17 106/7 106/10 106/13 106/19 107/15 108/2 108/5 109/2 109/24 109/25 110/8 110/12 110/13 110/16 111/1 111/19 112/8 113/19 113/24 114/1 115/2 117/17 117/23 118/18 119/17 122/2 122/7 123/11 124/9 125/4 125/5 128/17 140/3 148/5 148/23 150/10 150/11 152/16 154/7 155/14 158/13 160/18 160/25 162/2	162/6 162/9 162/15 162/15 163/5 163/14 167/17 168/23 171/13 171/17 171/25 172/7 172/13 173/14 174/13 175/6 175/7 176/15 177/3 177/20 178/19 180/1 183/8 183/8 184/15 184/25 185/6 185/7 185/15 186/15 187/3 187/19 187/23 190/23 193/4 194/13 196/3 196/5 196/15 199/14 200/20 200/24 201/5 201/8 201/12 202/11 204/6 205/17 206/12 206/14 206/25 208/1 209/8 209/14 209/18 210/11 211/1 214/13 215/3 216/18 218/7 218/17 219/8 219/12 227/14 229/12 238/16 justice [3] 44/17 108/10 192/18 justification [3] 47/17 48/2 231/1	72/1 75/24 79/19 83/3 84/2 84/11 86/5 92/9 101/24 106/21 106/23 107/11 107/12 107/18 108/12 108/12 108/13 111/23 113/5 118/7 118/7 123/9 124/4 128/23 169/12 169/23 172/21 181/16 183/23 185/10 185/10 185/11 186/12 knock [2] 99/18 197/23 know [254] know, [1] 53/1 know, UK-wide [1] 53/1 knowing [4] 52/3 58/1 58/1 163/21 knowledge [1] 164/12 known [4] 18/6 112/24 114/17 187/7 knows [1] 238/22	lateral [1] 137/2 latest [1] 41/9 Latterly [1] 213/15 laughs [6] 40/22 42/17 44/17 212/11 223/18 226/14 law [1] 39/2 lawsuit [1] 159/25 lawyers [6] 92/15 114/25 116/5 160/3 160/5 160/11 lead [9] 29/13 47/13 48/5 48/23 49/25 51/1 85/6 169/6 176/6 lead-up [2] 48/23 49/25 leader [1] 126/13 leading [4] 26/9 119/10 180/21 182/1 leaning [1] 65/4 learn [2] 21/2 210/23 learned [7] 45/9 64/7 64/11 77/10 164/5 164/6 219/5 least [6] 2/4 42/2 50/5 160/21 199/3 222/11 leave [6] 8/9 8/9 23/17 75/18 180/1 226/13 Leckie [1] 45/4 led [12] 9/3 11/4 15/13 30/15 31/4 80/4 83/15 211/11 211/14 213/7 219/22 232/25 left [19] 38/22 58/2 101/10 110/14 111/18 127/17 133/25 141/24 145/4 145/5 154/5 165/5 203/14 220/21 231/12 232/2 233/24 236/20 237/16 left-hand [1] 38/22 legacies [1] 112/15 legacy [3] 113/4 220/21 220/23 legal [22] 34/17 41/13 41/17 41/21 41/25 92/5 92/14 92/17 93/25 114/18 140/19 156/10 159/6 189/15 190/3 201/21 202/13 202/17 217/16 221/15 221/16 225/25 legally [2] 92/9 198/15 Leggett [1] 103/7 legs [1] 76/15 length [2] 130/19 220/23 lengthy [1] 106/4 less [8] 31/12 42/7 87/13 95/11 128/22 185/13 203/15 237/23	lessons [6] 47/14 48/6 51/2 164/5 164/6 219/5 let [9] 1/23 2/15 99/23 105/4 134/2 153/7 177/14 219/12 223/20 let's [23] 21/17 28/21 74/23 74/24 77/24 90/14 90/18 96/6 96/6 98/15 100/24 101/6 101/7 101/21 105/3 105/6 134/4 163/8 198/20 198/20 198/22 198/23 199/11 letter [36] 23/1 23/4 23/15 25/1 26/15 27/12 29/20 29/23 30/1 32/4 41/7 42/9 42/22 43/3 45/23 46/1 47/7 47/23 48/15 48/16 61/17 64/12 77/3 77/5 116/10 116/12 126/3 127/25 128/20 131/6 131/10 131/16 132/23 142/4 146/20 196/22 letters [4] 62/9 82/12 88/17 128/13 leukaemia [1] 102/7 level [5] 115/18 150/25 219/6 224/16 228/9 levels [4] 211/10 211/16 211/21 211/25 Lewis [1] 14/21 LHBs [1] 166/22 liabilities [1] 226/5 liability [2] 150/20 226/4 liaison [1] 177/9 Liberal [1] 44/25 Lidington [6] 134/11 134/23 135/10 144/10 145/4 230/25 lie [1] 160/9 lies [2] 200/20 230/20 life [19] 20/1 37/7 42/8 48/23 85/1 140/9 156/23 157/8 158/7 158/18 159/13 160/20 163/10 187/11 193/19 207/16 208/4 215/7 217/19 lift [1] 75/23 lifted [1] 139/2 light [3] 4/15 28/2 231/5 like [59] 3/13 4/15 5/20 19/2 26/24 35/2 43/17 44/16 44/24 50/13 59/12 63/8 66/9 66/20 68/10 69/9
		K Keel [1] 32/21 keen [4] 64/21 64/22 98/22 130/3 keep [6] 56/14 66/3 108/17 127/19 232/23 236/11 keeping [2] 141/12 141/13 Kelly [5] 1/20 2/13 232/7 240/4 240/9 kept [6] 91/10 91/15 91/19 130/19 130/20 190/10 Kerr [6] 30/10 43/24 45/24 49/4 49/6 50/16 key [7] 32/11 82/25 145/1 197/15 200/25 218/23 233/5 kicking [1] 104/14 killer [1] 174/6 kind [8] 8/23 47/6 67/24 92/21 190/8 194/10 194/11 213/11 kindly [2] 1/11 182/2 King's [1] 176/23 Kingdom [5] 2/5 3/5 134/25 135/4 224/5 Kings [2] 182/14 182/19 knew [45] 18/10 18/11 53/1 53/20 55/14 55/24 66/15 68/18 68/20 70/2 70/7 71/9	L labelled [1] 119/9 Laboratory [1] 25/11 Labour [1] 45/1 lack [12] 3/25 4/14 52/18 52/18 90/4 166/16 166/18 232/17 233/1 233/7 233/11 233/12 lacked [1] 206/12 lacklustre [1] 219/16 Lady [2] 131/8 132/9 Lady Sylvia [1] 132/9 laid [1] 147/18 land [1] 220/3 LANGSTAFF [2] 219/10 240/7 large [6] 17/15 18/25 88/8 106/23 126/15 193/24 largely [1] 235/22 larger [1] 220/2 last [12] 26/18 47/24 49/8 59/20 60/7 109/2 120/2 149/17 177/4 228/21 228/25 230/15 lasting [1] 58/3 late [9] 20/15 28/9 30/15 30/16 34/23 168/17 174/12 200/9 213/7 Lately [1] 87/6 later [15] 2/18 12/21 27/19 28/19 29/20 30/21 33/15 37/16 40/3 48/24 59/15 160/21 207/16 212/14 212/24		

L	187/6 188/3 216/2 lives [7] 46/10 123/6 129/25 160/1 184/18 230/2 233/24 living [4] 42/1 157/14 208/1 225/23 Liz [1] 184/12 Liz Carroll [1] 184/12 Lloyd [2] 83/2 83/3 lobbied [2] 14/5 109/8 lobby [4] 63/5 86/13 181/10 182/11 lobbying [13] 15/10 38/18 84/22 126/9 138/22 143/23 171/17 172/16 180/3 181/15 184/14 185/4 202/23 local [10] 4/12 4/17 4/24 4/25 7/19 66/18 190/17 212/25 223/16 227/8 log [1] 190/8 logical [1] 41/19 logistics [1] 227/18 London [9] 14/16 20/15 20/17 39/16 76/16 76/23 181/25 199/25 213/12 long [10] 10/23 36/10 66/10 90/10 97/25 189/21 191/15 201/24 231/6 234/5 long-term [1] 36/10 longer [2] 18/14 213/5 longevity [1] 146/9 look [56] 3/10 25/3 29/17 30/24 30/25 33/12 33/13 35/11 38/6 38/15 38/19 43/15 44/9 45/18 46/12 47/22 47/24 55/6 60/8 65/24 66/4 68/1 91/2 98/13 98/15 98/15 104/10 104/13 115/3 119/5 119/14 151/2 153/2 153/6 154/22 154/25 155/17 156/19 159/15 159/17 161/12 165/13 167/3 184/13 197/9 201/13 205/2 209/20 209/24 218/21 219/8 225/18 226/4 226/9 234/13 235/16 look-back [5] 33/13 46/12 154/22 154/25 161/12 looked [14] 11/12 38/5 48/16 61/25 102/12 107/14 125/3 128/24 164/11 168/25 198/9 201/17 208/19	234/19 looked at [3] 38/5 48/16 234/19 looking [22] 3/11 3/13 14/3 22/24 58/4 65/12 67/21 70/5 84/24 90/3 92/20 154/10 155/4 156/8 173/6 210/11 215/18 225/7 232/1 232/1 232/1 232/2 looks [1] 3/13 lord [26] 11/23 30/15 30/25 31/10 36/17 37/4 37/14 38/15 38/22 39/6 39/14 42/4 42/7 64/20 65/4 65/24 66/20 67/11 67/14 85/3 94/14 200/17 200/18 209/3 209/4 214/9 Lord Howe [1] 85/3 Lord Morris [2] 209/3 209/4 lord Penrose [4] 65/24 67/11 67/14 214/9 Lord Penrose's [1] 11/23 Lord Prior [2] 94/14 200/18 Lord Ross [9] 30/15 30/25 36/17 37/4 37/14 38/22 39/6 39/14 42/4 Lord Ross's [2] 31/10 38/15 Lords [6] 84/16 84/22 85/3 196/20 200/15 216/21 losing [1] 141/15 loss [1] 222/15 losses [1] 234/8 lost [10] 60/12 107/6 140/21 159/19 177/7 200/13 205/25 222/5 222/14 223/2 lot [36] 2/3 7/8 8/16 8/22 9/14 12/11 18/10 20/6 37/10 37/14 58/12 59/11 69/5 79/7 87/21 88/9 107/2 119/25 130/21 133/21 137/4 138/11 139/4 151/11 154/23 159/23 164/21 191/10 194/23 195/3 208/8 208/25 215/10 225/19 228/11 238/25 Lothian [1] 177/2 lots [14] 10/12 18/11 59/12 61/3 106/11 106/11 110/15 141/1	155/18 174/6 195/6 206/11 207/23 217/8 loud [1] 97/18 loved [4] 50/22 58/4 108/9 177/7 low [1] 41/10 Lowe [2] 155/24 159/4 luck [1] 94/1 Ludlam [4] 28/4 156/6 159/1 159/4 lump [2] 38/23 38/24 lunch [3] 90/11 90/14 105/10 luncheon [1] 90/23 Lyle [1] 63/2 Lynne [61] 1/20 2/13 11/5 13/9 51/21 57/11 70/13 72/7 73/3 78/22 78/24 79/6 82/6 87/5 91/2 105/20 134/19 141/8 144/15 150/17 151/18 153/16 153/19 153/20 154/16 160/24 162/25 163/6 164/21 167/2 175/9 176/5 176/13 178/2 180/2 184/25 187/20 187/22 191/6 192/3 192/6 192/25 195/10 195/14 199/23 200/13 200/17 200/23 203/11 207/6 208/8 209/18 216/15 225/12 226/15 232/6 232/7 235/3 238/1 240/4 240/9 Lynne Kelly [3] 1/20 2/13 240/4 Lynne's [6] 16/23 40/11 163/11 175/20 191/17 194/13	146/7 146/13 150/9 152/1 155/20 165/19 165/23 167/18 167/24 168/22 169/16 172/13 177/4 178/10 185/12 190/17 191/9 195/5 201/3 225/16 magic [1] 24/10 magnificent [1] 63/6 magnified [1] 230/6 Maguire [1] 30/16 main [9] 10/10 11/24 14/20 118/12 127/19 166/14 167/22 212/4 236/9 mainly [3] 13/19 17/9 35/19 maintain [1] 15/24 maintaining [1] 114/5 major [4] 46/22 48/9 58/25 106/7 majority [2] 24/6 127/10 make [46] 3/7 8/18 12/22 46/25 51/16 59/21 62/25 71/2 71/24 81/4 81/21 82/1 89/4 100/22 110/6 120/13 122/1 122/5 123/25 125/4 133/9 133/13 140/18 141/24 142/24 143/24 145/6 146/2 149/25 154/7 156/2 160/21 160/22 161/2 162/8 172/16 189/5 189/5 192/20 194/10 197/13 201/10 202/11 218/25 228/16 234/9 makes [3] 18/3 25/2 164/18 making [12] 29/10 41/12 114/1 132/16 135/14 140/23 147/13 187/15 197/24 210/12 210/14 233/6 Malcolm [8] 30/9 30/11 31/3 31/20 32/2 42/6 186/5 187/13 Malcolm Chisholm [5] 30/9 30/11 31/3 31/20 42/6 Malcolm Chisholm's [1] 32/2 male [1] 159/18 man [4] 20/16 101/18 182/3 213/9 manage [1] 154/11 managed [4] 14/6 25/25 60/14 160/20 management [8] 7/22 9/7 10/18 62/12 167/7	189/21 223/16 227/9 manager [4] 103/8 103/12 105/8 218/17 managing [1] 144/21 manner [1] 24/20 Manson [3] 16/22 184/12 184/22 mantra [3] 91/21 196/10 196/10 many [34] 11/3 15/15 20/22 42/7 46/10 53/3 53/23 55/14 61/24 80/12 83/6 101/10 115/20 116/18 126/17 129/2 129/25 129/25 139/5 141/13 158/9 158/10 158/11 158/12 161/25 174/8 184/19 187/7 206/20 210/19 214/3 214/20 226/4 230/18 map [1] 10/15 March [10] 35/8 40/6 67/9 67/18 69/14 76/6 78/15 145/15 157/3 165/18 March 2001 [1] 35/8 March 2011 [1] 165/18 March 2015 [1] 67/9 March 25 [1] 157/3 Margaret [2] 44/25 129/7 Margaret Ritchie [1] 129/7 mark [3] 115/15 146/9 236/7 marked [1] 39/3 marking [1] 22/25 Mary [2] 2/10 2/11 Mary's [1] 181/25 massive [4] 57/1 86/1 93/5 162/5 materials [1] 190/5 materially [1] 197/12 matter [22] 23/17 36/8 40/4 50/20 66/15 74/10 103/18 104/8 128/3 128/5 128/10 149/1 149/25 187/19 195/16 198/5 201/15 201/17 221/20 222/2 224/14 225/11 matters [12] 23/10 51/8 65/22 78/23 101/8 166/4 190/23 202/14 207/7 213/13 219/9 237/17 Matthew [1] 186/7 Maureen [1] 72/24 Maureen Watt [1] 72/24
----------	---	--	--	---	---

M	182/22 231/8	110/15 110/16 112/6 118/4 119/8 119/15 135/25 136/14 137/16 141/1 161/11 169/22 172/15 180/15 181/4 189/17 189/18 189/25 190/1 190/17 192/13 193/12 193/24 200/11 200/14 200/24 207/23 213/21 229/21	middle [2] 75/19 228/6 might [31] 2/24 8/6 11/5 11/5 21/4 33/23 33/23 41/21 69/24 72/25 87/25 87/25 90/12 112/23 149/2 153/10 154/18 156/5 159/25 162/19 175/9 178/11 192/10 199/5 201/22 201/25 215/4 215/23 237/25 238/24 239/9	minutes [3] 43/15 54/10 202/1 misidentified [1] 33/6 mislead [2] 26/4 27/5 misled [2] 27/8 28/17 misreading [1] 134/1 missed [4] 54/12 76/13 185/20 222/25 missing [2] 218/22 234/17 mistake [1] 164/2 misunderstanding [2] 99/25 100/25 mixed [2] 117/5 218/1 MLA [3] 131/11 132/24 142/5 Mm [1] 45/17 model [2] 4/15 220/17 moderately [1] 105/13 moment [24] 2/11 7/1 8/8 8/11 22/1 22/8 27/18 34/1 34/14 37/18 59/5 63/24 78/6 78/21 86/18 98/2 100/10 102/9 128/17 145/11 153/22 192/20 211/1 225/7 moments [1] 12/20 monetary [1] 146/17 money [53] 12/9 13/22 14/16 14/16 14/17 31/14 37/4 59/14 77/2 78/18 81/17 101/7 101/7 101/11 106/1 106/7 109/21 110/7 110/9 110/18 111/17 111/18 113/3 113/11 119/4 119/24 120/2 120/3 140/10 144/15 149/6 149/14 150/4 150/8 150/10 150/14 151/6 153/14 153/14 154/4 163/8 169/23 192/5 193/9 194/18 194/24 201/8 219/20 225/15 228/8 228/11 233/9 236/11 monies [3] 109/5 154/15 224/6 monitor [2] 82/4 181/25 monitored [7] 55/15 125/19 170/20 173/21 174/1 174/24 181/1 monitoring [10] 52/19 82/3 125/23 142/11 142/25 170/9 170/10 175/1 179/16 179/16 monthly [2] 227/24 228/14 months [4] 25/10	66/21 102/3 213/22 moods [1] 67/15 moral [12] 74/1 75/13 88/25 89/1 91/13 139/21 139/23 139/23 197/17 230/25 231/9 231/18 morally [3] 81/12 81/12 149/7 morals [1] 74/24 moratorium [1] 139/2 morbidities [1] 176/10 more [37] 33/24 40/6 46/25 47/20 48/8 49/11 65/14 68/17 82/5 82/23 82/24 82/24 82/24 84/25 89/6 91/4 92/1 109/19 114/1 114/1 116/8 117/23 119/2 119/24 120/13 124/18 124/24 127/18 147/15 161/21 165/2 172/25 193/3 193/6 193/17 194/18 207/7 Morgan [5] 14/1 18/4 83/1 83/15 172/2 morning [8] 1/5 1/6 1/19 69/25 70/9 70/12 70/14 91/4 Morris [2] 209/3 209/4 mortgage [1] 85/1 most [12] 42/1 64/17 87/23 103/20 109/11 113/3 155/24 162/9 162/21 166/8 195/8 217/18 mother [1] 16/4 mother's [1] 13/21 mothers [1] 14/2 motion [3] 84/5 84/14 84/21 mouths [1] 95/19 move [14] 51/8 54/16 71/10 74/19 89/13 90/7 94/20 102/24 112/19 137/8 138/19 140/2 154/21 164/20 moved [6] 99/2 136/7 146/23 147/6 147/16 213/2 movement [2] 20/20 178/7 moving [5] 101/12 136/21 138/13 145/1 184/14 MP [5] 14/1 18/4 94/11 131/6 133/18 MPs [18] 13/25 20/20 79/5 79/8 79/12 79/22 80/2 80/16 84/9 84/10
Maxwellisation [1] 67/6 may [29] 1/3 3/20 11/22 19/5 23/8 33/6 33/6 33/11 37/1 130/22 142/18 143/9 144/24 148/1 174/9 197/10 219/12 221/11 222/6 222/6 222/8 222/12 222/13 228/16 235/16 236/17 236/18 237/19 238/18 May 1999 [1] 19/5 maybe [14] 72/6 96/14 99/6 99/8 107/3 108/1 124/17 138/3 152/25 168/19 174/7 189/22 206/25 220/22 Mayor [1] 207/19 McCartney [1] 80/15 McClelland [1] 211/20 me [93] 1/11 1/23 2/15 3/8 8/23 9/1 9/2 14/10 16/8 22/17 28/3 28/7 28/8 28/10 34/7 34/7 35/1 42/14 43/3 48/4 50/4 50/15 52/14 54/19 60/9 61/10 71/16 72/20 72/22 75/22 75/22 78/1 78/7 89/16 102/2 102/4 102/8 102/10 102/13 110/23 116/14 135/5 137/5 139/1 139/2 146/21 150/22 152/18 153/7 158/1 159/2 159/8 160/8 161/3 165/8 177/14 179/13 179/14 181/2 181/4 181/12 181/13 181/20 182/9 183/5 183/24 192/17 192/25 198/16 200/3 201/23 206/23 211/11 211/13 211/17 218/3 218/4 218/4 218/5 219/8 219/12 225/1 226/13 228/16 229/3 229/16 229/22 234/15 234/21 235/2 235/2 235/14 235/20 mean [14] 29/16 37/12 40/8 42/18 68/20 77/21 78/18 128/8 153/7 165/7 170/18 214/18 215/17 218/8 meaningless [2] 149/24 149/24 means [6] 128/6 161/6 164/6 181/8	meant [11] 52/6 52/9 59/23 60/5 60/5 80/6 116/16 129/5 139/17 139/17 215/1 meantime [1] 101/18 measure [1] 142/16 mechanism [6] 122/23 123/1 123/21 124/7 140/14 146/10 mechanisms [2] 133/4 144/22 media [3] 64/24 70/11 72/1 median [3] 100/4 100/6 221/6 medical [22] 26/22 27/2 32/22 32/23 32/25 125/6 160/7 165/25 171/8 171/24 187/22 188/11 188/16 189/4 189/10 215/15 217/9 217/10 217/15 218/21 230/9 233/9 meet [11] 22/16 27/22 68/11 72/13 76/9 136/9 136/13 145/25 146/2 210/19 224/20 meeting [69] 12/1 21/4 33/9 53/10 53/17 56/12 58/22 58/24 59/20 60/7 60/10 78/25 79/6 89/17 89/18 89/23 93/13 94/14 107/2 107/3 107/8 108/23 111/23 112/22 116/9 116/11 116/13 116/13 117/15 134/9 134/11 134/19 134/19 134/21 135/2 135/9 135/15 136/9 136/12 142/3 142/6 143/18 154/2 155/4 155/7 155/9 160/7 172/7 173/1 180/9 180/11 180/13 180/19 180/24 180/25 183/24 184/3 184/4 189/9 193/22 209/25 210/1 210/7 210/10 212/8 212/10 221/9 234/22 234/22 meetings [59] 9/3 13/21 17/14 17/15 18/19 18/25 18/25 33/7 52/4 52/10 52/20 53/5 53/23 54/2 54/3 56/5 58/11 58/16 58/21 58/21 59/10 61/18 82/12 82/25 83/7 94/10 106/14 106/15 107/25 109/12	member [9] 7/11 18/5 36/19 37/11 52/16 61/2 70/22 124/3 172/1 members [24] 12/4 14/19 16/3 17/11 18/6 79/12 84/2 84/2 85/2 93/8 111/22 129/11 150/12 154/2 169/5 171/21 191/7 205/3 205/9 206/16 209/2 213/3 214/17 226/22 membership [1] 206/13 memorable [1] 63/4 memorial [2] 236/4 236/11 memory [2] 95/12 116/16 men [4] 5/15 235/22 235/23 235/23 mental [4] 50/2 141/17 178/8 211/2 mention [3] 2/18 8/14 14/22 mentioned [5] 8/6 22/8 75/3 164/23 183/11 Mervyn [1] 142/5 message [2] 132/1 234/25 messages [6] 37/3 73/2 97/14 98/25 99/5 117/6 met [19] 13/25 14/5 18/7 22/15 53/23 53/24 56/10 85/12 85/21 89/23 94/9 94/10 143/21 146/1 180/14 182/21 208/12 234/21 235/24 metaphorically [1] 230/16 method [1] 190/2 Michael [4] 92/25 93/13 93/13 94/2 Michael Imperato [1] 92/25 Mick [2] 18/15 83/1 Mick Antoniw [1] 83/1 mid [1] 102/25 mid-2017 [1] 102/25			

<p>M</p> <p>MPs... [8] 88/14 89/4 89/21 126/16 126/17 126/22 127/10 196/21</p> <p>Mr [11] 45/24 49/4 49/6 50/16 51/4 76/22 95/22 129/5 144/2 146/7 146/25</p> <p>Mr Andy [1] 45/24</p> <p>Mr Cameron [1] 76/22</p> <p>Mr Dodds [1] 129/5</p> <p>Mr Kerr [3] 49/4 49/6 50/16</p> <p>Mr Swann [3] 144/2 146/7 146/25</p> <p>Mr Wright [1] 51/4</p> <p>Mr Wright's [1] 95/22</p> <p>Mrs [3] 156/3 156/10 156/15</p> <p>Mrs Towers [3] 156/3 156/10 156/15</p> <p>MS [2] 3/6 240/6</p> <p>MSP [4] 44/6 45/5 63/1 63/2</p> <p>MSPs [14] 24/6 24/9 39/24 40/2 43/10 44/13 45/2 45/3 62/10 63/3 63/11 63/14 63/24 219/3</p> <p>much [39] 2/21 9/20 15/17 31/12 52/23 55/6 64/5 64/7 65/4 81/15 81/17 82/5 84/24 112/3 121/4 135/12 135/15 145/9 146/4 147/15 150/22 165/2 169/15 192/11 192/24 195/2 203/22 212/24 213/7 217/3 219/17 220/2 229/7 229/12 231/3 231/4 234/20 236/21 236/22</p> <p>multi [3] 121/12 125/18 169/7</p> <p>multi-disciplinary [1] 169/7</p> <p>Murphy [1] 137/24</p> <p>must [14] 71/14 144/9 144/19 145/23 149/14 149/15 166/25 197/13 199/24 201/1 211/15 213/19 236/7 236/8</p> <p>my [113] 3/12 6/24 8/25 9/1 10/23 12/2 12/8 13/13 13/13 13/14 13/16 13/23 14/1 14/7 14/8 16/12 18/4 19/25 21/5 28/4 28/10 31/13 34/8 35/1 44/5 48/23 49/1 49/23 50/1 50/3 50/14 52/14</p>	<p>52/23 53/2 54/14 58/7 60/23 64/13 65/7 66/2 66/16 67/3 71/24 72/21 75/6 75/7 75/23 76/15 76/18 78/5 94/9 94/19 95/12 101/18 111/11 111/21 126/16 130/21 133/22 134/1 134/4 139/3 139/3 140/8 142/12 147/25 149/5 150/22 150/25 151/8 152/8 155/16 159/5 161/9 161/24 169/10 175/25 179/18 179/18 179/23 182/10 184/1 185/22 189/12 191/4 191/4 191/8 193/18 193/22 198/12 198/15 199/18 204/1 205/21 206/3 207/15 207/21 208/6 208/6 211/2 211/9 211/10 211/14 215/25 218/10 221/21 221/21 221/21 223/3 229/4 229/15 229/19 235/1</p> <p>myself [8] 103/6 132/1 133/8 148/9 159/18 179/12 182/18 206/3</p>	<p>224/4</p> <p>navigate [1] 132/11</p> <p>NDNA [1] 138/15</p> <p>NDPBs [2] 220/7 220/14</p> <p>near [2] 177/7 181/16</p> <p>nearby [1] 177/6</p> <p>nearly [1] 161/18</p> <p>necessarily [9] 26/23 64/8 67/20 71/16 130/10 130/23 133/13 143/10 175/23</p> <p>necessary [2] 156/1 156/14</p> <p>need [60] 1/22 3/16 12/5 21/5 42/19 43/15 46/17 72/3 78/20 82/19 95/12 96/8 96/8 101/19 110/23 115/1 125/6 125/20 125/23 126/1 134/24 136/16 136/22 143/13 151/6 151/14 160/17 161/14 164/12 165/7 172/22 178/19 184/13 186/16 192/4 201/20 201/25 202/11 203/3 203/12 204/9 204/13 205/11 209/11 217/2 227/1 227/2 227/3 231/20 231/24 235/6 235/9 236/3 236/7 236/13 237/2 238/2 238/15 238/15 238/17</p> <p>needed [22] 11/19 20/11 43/18 47/5 52/24 93/25 116/7 119/2 119/2 120/7 121/4 142/23 168/15 169/15 185/14 186/10 189/3 202/21 204/18 213/13 231/20 233/23</p> <p>needing [1] 125/11</p> <p>needs [33] 6/14 13/21 15/1 16/6 16/7 89/6 130/24 130/24 130/25 139/25 143/1 143/5 143/10 146/2 149/6 150/8 164/6 176/10 193/14 199/11 200/7 203/5 203/5 209/13 215/19 215/21 216/10 216/12 220/22 222/2 223/7 226/17 230/22</p> <p>negative [2] 141/19 229/15</p> <p>neglected [1] 197/6</p> <p>negligent [1] 26/22</p> <p>negotiated [1] 138/20</p> <p>Neil [3] 62/21 63/12 67/25</p> <p>neither [3] 170/4</p>	<p>172/12 213/5</p> <p>network [4] 176/12 176/13 176/15 177/13</p> <p>networking [1] 171/17</p> <p>neutrally [2] 183/15 183/17</p> <p>never [32] 22/15 24/6 31/9 31/19 31/24 54/10 59/11 67/5 67/22 69/22 77/9 83/7 86/2 94/13 105/2 105/5 109/22 119/16 119/16 145/6 162/9 168/21 171/25 198/15 199/2 205/21 206/20 223/1 228/2 233/16 235/24 236/8</p> <p>nevertheless [5] 27/7 28/16 31/19 138/4 231/7</p> <p>new [22] 20/8 24/5 24/7 24/14 34/21 41/10 47/11 48/5 50/25 62/24 73/5 113/25 117/18 125/22 138/2 138/2 138/2 138/15 150/20 172/2 180/21 239/13</p> <p>newly [2] 16/6 29/4</p> <p>newly-declassified [1] 29/4</p> <p>news [3] 28/23 67/14 70/3</p> <p>newspaper [1] 41/8</p> <p>next [23] 19/12 20/23 23/3 27/21 30/2 38/10 46/15 54/17 73/7 76/10 76/12 80/20 108/3 110/17 118/15 154/1 154/2 156/19 158/13 182/14 208/5 223/9 226/22</p> <p>NHS [20] 26/21 36/10 41/15 46/4 46/9 46/19 47/12 56/20 150/15 163/9 165/21 165/25 176/9 181/15 182/15 185/24 186/11 187/15 187/17 198/10</p> <p>NHS England [5] 181/15 182/15 185/24 187/15 187/17</p> <p>NI [1] 142/14</p> <p>nice [4] 124/16 124/20 181/11 185/19</p> <p>Nicola [5] 43/11 44/3 64/12 69/17 73/12</p> <p>Nicola Sturgeon [1] 73/12</p> <p>Nigel [2] 126/14 189/12</p> <p>Nigel's [1] 190/6</p>	<p>nigh [1] 11/16</p> <p>night [5] 71/23 77/3 77/4 77/4 211/24</p> <p>nightmare [1] 66/20</p> <p>nitty [1] 118/25</p> <p>nitty-gritty [1] 118/25</p> <p>no [80] 1/10 1/22 3/14 3/14 3/19 3/24 12/9 12/9 12/10 12/10 16/15 18/14 21/15 21/15 25/5 25/16 26/3 28/18 36/6 39/12 40/18 41/4 51/6 53/19 57/25 58/24 59/22 60/18 77/10 82/21 82/21 90/2 90/17 91/11 91/22 91/22 91/25 98/9 99/22 100/1 106/7 110/5 111/1 113/10 115/19 121/18 126/4 137/14 138/14 145/14 162/8 165/4 169/23 172/10 172/11 175/4 177/14 181/2 182/12 182/24 184/2 188/6 191/5 194/9 194/25 196/23 200/19 202/3 205/4 205/5 205/6 205/18 213/5 218/19 222/10 222/24 224/14 230/25 236/20 237/16</p> <p>nobody [7] 60/9 61/10 95/10 96/21 126/2 170/11 180/16</p> <p>noises [1] 173/11</p> <p>non [7] 14/3 26/22 143/2 145/18 177/16 181/17 202/19</p> <p>non-affected [1] 145/18</p> <p>non-haemophilia [1] 177/16</p> <p>non-haemophiliacs [1] 202/19</p> <p>non-negligent [1] 26/22</p> <p>non-plasma [1] 14/3</p> <p>non-responders [1] 181/17</p> <p>none [2] 119/5 214/22</p> <p>nor [2] 172/12 191/5</p> <p>normal [2] 5/13 208/4</p> <p>north [3] 34/13 227/17 227/20</p> <p>Northern [56] 4/3 4/6 4/10 4/19 5/1 5/3 5/18 6/9 6/23 40/11 60/13 86/25 87/12 87/16 88/3 88/14 89/4 126/22 126/24 127/14 128/4 128/9 128/15</p>	<p>128/24 132/3 133/6 133/16 133/21 133/24 135/24 136/1 136/7 138/13 139/6 139/18 140/9 140/16 143/15 144/7 144/13 144/24 145/12 145/16 146/18 146/24 149/21 154/9 154/24 164/8 177/21 190/13 191/18 224/9 224/9 228/19 231/13</p> <p>Northern Ireland [1] 224/9</p> <p>not [146] 1/10 3/10 3/11 3/20 7/5 12/9 20/21 21/16 23/17 24/21 25/17 26/21 28/7 28/11 28/13 31/10 32/4 32/19 33/6 34/2 35/16 35/20 37/10 41/13 42/5 43/2 43/17 46/11 47/3 47/10 48/10 53/25 55/12 56/20 56/21 59/13 61/24 63/8 63/14 63/25 64/8 64/17 68/13 69/11 74/24 75/3 78/10 78/18 84/18 86/22 88/22 88/23 88/24 89/24 90/10 96/7 97/17 97/22 101/6 101/6 104/5 104/8 105/3 105/3 105/14 108/19 108/25 114/16 114/17 115/16 115/17 121/2 125/19 126/6 126/22 128/8 130/10 130/23 131/11 141/12 141/17 142/22 143/4 143/9 145/14 149/12 149/22 149/22 149/23 153/3 157/7 158/19 159/14 159/15 159/22 159/24 159/25 160/19 161/23 162/17 162/22 163/5 163/8 170/21 173/23 175/8 175/8 178/19 179/10 183/12 185/8 192/19 193/19 195/12 196/15 196/25 197/10 197/15 198/9 198/14 201/12 203/14 204/21 208/1 213/16 217/2 218/20 219/6 219/23 220/11 221/21 224/15 224/21 224/25 227/10 227/20 228/13 230/17 232/19 232/23 233/20 235/8 236/1 237/2 238/21 238/24</p> <p>not 23 million [1]</p>
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(81) MPs... - not 23 million

<p>N</p> <p>not 23 million... [1] 149/23</p> <p>note [9] 3/24 33/19 33/19 131/18 144/9 155/4 155/9 155/15 207/9</p> <p>noted [4] 43/9 128/2 135/9 166/6</p> <p>notes [5] 27/3 135/14 161/16 189/4 189/6</p> <p>nothing [15] 12/20 39/4 61/4 81/2 81/2 119/22 168/1 169/17 186/12 186/13 186/16 206/9 215/10 217/8 235/15</p> <p>noting [1] 147/6</p> <p>November [4] 52/1 85/13 167/4 210/1</p> <p>now [47] 1/3 1/22 2/9 2/18 11/20 18/6 28/1 42/4 44/19 47/6 51/9 59/22 64/18 82/6 87/10 90/14 94/11 94/20 96/3 98/13 104/21 117/8 123/6 129/4 138/1 139/21 146/4 147/20 151/24 159/12 160/2 164/24 174/25 175/16 176/24 184/14 191/10 192/2 195/8 198/12 200/22 215/18 219/17 220/16 223/8 231/3 233/20</p> <p>nowhere [4] 20/15 24/11 86/4 234/16</p> <p>number [30] 7/5 46/7 65/10 66/21 116/25 121/13 126/18 130/25 134/9 134/10 134/22 135/3 137/16 140/19 143/12 152/18 159/11 166/4 166/6 167/18 168/6 168/12 169/12 189/9 189/25 196/8 197/11 199/24 203/17 207/25</p> <p>number 1 [1] 121/13</p> <p>number 8 [1] 166/6</p> <p>number one [2] 168/12 169/12</p> <p>numbers [4] 157/14 163/5 164/16 203/4</p> <p>numerous [1] 194/1</p> <p>nurse [5] 58/4 58/8 104/23 166/24 218/3</p> <p>nurses [1] 169/7</p>	<p>239/19</p> <p>O'Mahony [2] 208/12 209/6</p> <p>O'Mahony's [1] 209/4</p> <p>oath [2] 2/10 27/25</p> <p>obfuscations [2] 141/20 229/20</p> <p>objected [1] 59/19</p> <p>objectives [5] 5/3 5/21 5/22 12/24 17/4</p> <p>obligation [1] 231/9</p> <p>observation [3] 95/22 190/16 201/10</p> <p>observed [2] 5/18 215/23</p> <p>observing [1] 32/6</p> <p>obsession [2] 175/10 176/1</p> <p>obstacles [4] 91/7 185/23 186/1 196/3</p> <p>obtain [1] 25/24</p> <p>obvious [2] 39/18 79/8</p> <p>obviously [69] 6/4 14/15 15/16 17/11 18/7 29/19 38/4 52/15 52/18 52/22 55/24 57/17 57/19 60/13 61/6 73/18 79/21 82/18 82/25 83/15 84/3 84/10 84/22 85/25 86/14 89/15 90/2 91/12 91/17 92/11 92/17 94/17 98/25 106/9 106/10 106/13 106/25 107/11 109/17 116/6 119/3 123/5 123/22 124/22 125/4 125/9 125/15 135/1 154/1 163/20 168/3 168/9 169/2 169/4 171/20 173/4 180/24 182/21 186/22 191/10 194/21 203/4 205/8 205/9 205/10 216/17 225/17 226/18 227/15</p> <p>occasion [2] 143/23 237/24</p> <p>occasions [3] 46/7 189/9 221/25</p> <p>occur [1] 178/24</p> <p>occurred [1] 144/3</p> <p>October [5] 24/24 29/23 29/25 30/1 67/17</p> <p>October 2000 [4] 24/24 29/23 29/25 30/1</p> <p>off [26] 7/8 54/12 80/7 96/21 97/17 98/4 100/9 115/19 115/20</p>	<p>117/18 117/22 119/25 120/3 137/6 148/6 148/23 161/3 161/5 162/14 172/13 175/7 191/4 194/21 228/4 228/4 228/6</p> <p>offended [1] 110/9</p> <p>offer [9] 41/12 42/5 91/25 95/25 119/20 122/12 157/5 162/15 208/22</p> <p>offered [2] 162/12 178/13</p> <p>office [14] 1/10 13/2 24/13 34/6 34/11 34/16 34/20 35/5 156/10 156/17 189/2 197/23 213/14 226/6</p> <p>Office's [1] 159/6</p> <p>officer [8] 7/25 32/22 32/24 32/25 136/5 160/7 171/8 191/13</p> <p>officers [1] 188/20</p> <p>official [3] 42/15 95/18 113/7</p> <p>officials [7] 23/9 55/3 58/16 113/23 118/22 200/25 234/16</p> <p>often [5] 26/23 125/19 150/7 174/11 216/24</p> <p>oh [23] 15/3 27/13 54/17 55/7 58/8 77/24 96/7 108/2 111/1 112/22 123/20 125/25 135/8 144/18 150/8 150/14 153/4 173/1 182/24 183/7 199/17 207/24 221/16</p> <p>okay [12] 8/15 8/19 13/13 17/5 31/3 33/16 37/20 94/7 98/3 103/16 121/6 185/5</p> <p>old [3] 77/7 81/2 203/19</p> <p>older [2] 5/15 112/24</p> <p>omitted [1] 52/12</p> <p>once [12] 25/25 93/7 107/6 114/20 114/20 127/18 143/25 146/15 148/9 187/9 228/11 231/22</p> <p>one [125] 11/9 11/24 12/3 19/8 21/6 25/5 26/7 34/6 34/22 37/5 37/18 39/20 41/11 43/2 44/16 45/2 47/20 56/10 58/4 58/22 60/10 61/17 62/20 63/4 63/12 63/13 63/13 64/13 65/20 66/13 70/3 71/20 75/16 80/11 80/13</p>	<p>83/1 87/4 89/19 89/21 91/3 93/2 97/11 97/11 97/15 98/9 99/5 99/6 100/9 101/19 101/21 103/4 103/17 103/19 104/24 104/25 108/9 110/16 111/10 111/19 113/22 115/19 117/22 118/12 118/12 123/2 124/22 132/25 138/25 141/4 143/20 151/16 151/19 152/10 160/13 162/13 162/20 165/9 167/22 168/6 168/12 169/12 172/11 172/14 176/4 176/16 180/9 181/21 182/2 183/6 183/22 187/19 187/23 189/2 189/4 190/9 190/16 194/21 201/10 207/7 208/21 209/12 210/15 211/13 211/15 212/17 215/22 215/24 216/20 216/21 218/2 218/22 219/18 220/10 220/16 223/3 224/18 228/2 228/4 228/6 228/16 230/19 231/23 236/9 237/24 238/20</p> <p>one-off [2] 117/22 228/6</p> <p>one-to-one [1] 97/11</p> <p>ones [2] 50/22 177/7</p> <p>ongoing [4] 96/7 125/23 190/1 234/11</p> <p>only [36] 21/11 35/23 41/19 42/5 60/10 63/14 65/12 92/1 92/4 92/9 92/10 93/13 115/12 115/13 116/4 126/22 127/7 127/7 131/22 135/14 159/14 170/15 177/2 179/9 179/13 184/19 197/21 199/13 200/8 200/11 206/10 220/13 228/13 230/19 231/12 231/15</p> <p>onto [2] 57/8 211/6</p> <p>onus [1] 57/8</p> <p>onwards [1] 93/23</p> <p>open [11] 18/19 21/18 23/8 23/21 24/19 58/10 62/25 94/12 148/5 199/11 220/18</p> <p>opened [1] 94/18</p> <p>opening [1] 200/23</p> <p>openly [2] 122/14 147/8</p> <p>openness [1] 238/15</p> <p>operate [1] 227/23</p> <p>operated [1] 221/1</p> <p>operation [2] 144/23</p>	<p>162/19</p> <p>opinion [5] 49/16 55/14 60/23 161/24 168/7</p> <p>opportunity [10] 3/20 20/12 21/10 72/9 81/24 118/21 131/19 136/13 214/8 228/3</p> <p>opposite [1] 98/10</p> <p>opposition [5] 24/9 40/2 43/12 44/13 45/10</p> <p>or [124] 2/4 3/11 18/5 18/20 18/20 23/13 23/18 27/7 27/23 28/11 28/16 30/18 30/18 31/4 33/19 41/18 43/18 46/11 46/25 47/5 47/6 47/11 47/13 47/18 48/2 48/5 48/8 49/11 50/4 50/12 50/13 50/13 50/25 51/1 53/18 53/18 56/6 57/4 57/15 58/16 59/14 63/9 65/5 65/15 67/23 69/1 79/24 81/5 84/14 87/7 87/7 89/5 92/12 94/14 98/7 100/11 100/19 102/18 102/18 105/13 107/3 108/1 108/15 112/2 112/20 115/18 120/3 121/25 122/21 135/13 137/12 139/8 139/13 141/11 141/17 142/19 149/19 151/21 156/13 159/25 162/15 162/22 163/8 165/21 165/22 170/10 171/7 176/25 177/6 178/15 179/3 181/17 181/18 188/8 190/20 196/17 202/11 203/15 203/15 206/1 206/25 207/20 209/7 210/7 213/22 214/15 215/3 216/24 221/10 221/11 222/6 222/16 223/12 223/13 224/19 227/17 228/11 228/14 232/1 232/2 232/19 232/23 232/24 233/17</p> <p>oral [1] 214/21</p> <p>oratory [1] 237/15</p> <p>orchestrated [1] 232/13</p> <p>order [9] 5/10 25/24 65/23 68/9 128/25 146/11 191/11 221/12 221/25</p> <p>ordering [1] 30/14</p> <p>organ [1] 85/6</p> <p>organisation [5]</p>	<p>63/16 96/16 103/10 192/23 193/8</p> <p>organisations [3] 3/18 98/21 206/9</p> <p>organised [4] 63/3 70/11 72/5 72/12</p> <p>original [2] 100/17 126/16</p> <p>originally [1] 229/15</p> <p>OSCR [1] 13/2</p> <p>other [75] 1/22 5/19 12/20 14/2 19/17 23/13 24/10 25/2 36/6 36/17 38/5 41/16 51/8 53/2 53/3 55/6 56/5 56/6 56/17 68/13 68/15 68/16 68/18 86/5 93/7 94/8 97/8 101/24 104/8 110/1 111/25 111/25 112/22 113/13 114/22 126/19 128/13 130/2 136/12 137/7 139/5 140/8 140/12 141/3 143/12 143/20 147/11 151/5 152/10 160/8 169/5 173/2 177/15 179/7 179/13 181/8 184/2 187/19 190/13 192/16 195/16 202/17 206/2 208/2 209/13 211/25 222/8 222/22 224/3 225/2 225/2 225/2 228/16 231/25 234/7</p> <p>others [15] 35/18 72/2 87/9 126/23 138/5 139/23 150/2 179/22 182/18 193/3 231/17 232/14 236/18 237/9 237/12</p> <p>otherwise [2] 41/22 48/2</p> <p>ought [1] 223/15</p> <p>our [135] 1/10 1/11 1/16 5/22 9/19 9/20 11/10 12/2 12/25 13/1 14/5 16/3 16/16 17/9 17/14 17/19 18/10 18/19 18/23 18/24 18/25 20/20 30/22 37/17 38/12 44/11 46/8 47/3 48/9 48/11 50/17 55/8 55/22 55/24 59/13 60/14 60/18 61/21 64/5 64/17 66/9 68/22 79/10 84/1 86/13 86/15 88/5 93/2 96/16 97/5 99/3 103/9 106/23 108/12 108/17 108/21 109/13 109/18 111/13 111/13 111/16</p>
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<p>O</p> <p>our... [74] 111/22 111/22 111/24 114/25 116/5 116/7 118/24 119/10 119/11 123/2 124/3 128/10 129/15 132/18 133/2 133/15 138/15 143/1 143/10 143/23 143/25 144/23 153/21 153/25 154/2 154/2 158/23 163/19 168/4 168/22 169/2 170/13 171/20 172/16 173/4 173/19 174/7 174/19 176/12 181/1 181/21 182/2 182/18 184/6 187/3 187/8 187/13 189/15 191/12 191/13 192/7 192/8 192/19 193/15 193/23 194/6 195/11 205/22 206/13 208/1 209/1 210/7 213/20 217/19 217/19 217/19 224/10 225/7 226/20 226/22 226/22 226/24 230/12 237/10</p> <p>ours [1] 220/3</p> <p>ourselves [10] 5/4 5/7 5/9 5/10 9/19 11/8 96/9 185/9 198/20 232/3</p> <p>out [81] 1/10 4/18 8/10 10/15 12/25 16/18 19/1 22/14 24/11 27/19 28/9 28/19 29/5 52/25 60/21 60/22 67/5 67/8 67/9 69/13 73/25 75/12 75/23 78/15 86/25 88/20 89/7 93/21 95/17 95/23 97/6 97/15 100/14 101/24 106/1 113/8 113/11 118/16 119/1 119/19 120/8 121/14 124/25 140/10 147/18 150/5 151/6 153/8 154/2 155/14 155/24 159/25 161/25 162/7 162/13 164/1 170/14 171/13 175/19 178/20 180/15 187/4 188/1 192/5 205/25 210/6 211/19 212/2 212/3 213/11 214/4 217/12 218/11 218/11 220/11 220/12 223/13 224/14 226/22 228/12 230/16</p> <p>outcome [1] 164/24</p> <p>outcomes [1] 62/3</p>	<p>outer [1] 200/1</p> <p>outline [1] 12/23</p> <p>outlined [1] 149/5</p> <p>outs [1] 217/23</p> <p>outside [3] 17/7 146/21 182/7</p> <p>outstanding [1] 105/7</p> <p>outwardly [1] 174/7</p> <p>over [29] 7/5 23/16 28/25 29/2 53/12 56/17 73/3 79/25 91/18 113/10 116/25 128/24 141/13 142/21 146/9 146/14 154/1 157/20 164/21 166/5 189/21 195/1 195/24 196/19 201/1 228/12 232/19 232/25 234/25</p> <p>overall [1] 222/15</p> <p>overestimate [1] 162/7</p> <p>overlooked [1] 152/11</p> <p>overspeaking [7] 83/21 93/19 116/18 138/7 174/17 223/18 223/19</p> <p>owe [1] 105/10</p> <p>Owen [1] 79/22</p> <p>Owen's [1] 200/17</p> <p>own [26] 3/19 4/17 11/18 12/2 13/11 22/25 44/5 53/2 58/7 66/2 68/25 93/16 116/7 129/15 133/15 146/12 184/1 187/3 190/19 193/18 202/15 211/10 218/10 221/12 237/6 238/7</p> <p>ownership [1] 78/16</p>	<p>115/7 116/19 127/23 142/7 155/6 158/3 167/4</p> <p>page 20 [1] 35/12</p> <p>page 21 [1] 35/13</p> <p>page 3 [2] 25/4 28/23</p> <p>page 4 [1] 115/21</p> <p>page 5 [7] 46/14 79/1 80/10 152/23 155/3 155/13 166/11</p> <p>page 6 [1] 156/25</p> <p>page 8 [1] 166/20</p> <p>page 9 [1] 139/9</p> <p>paid [4] 38/14 103/11 223/13 228/8</p> <p>pain [2] 38/25 231/12</p> <p>painstaking [1] 230/5</p> <p>pair [1] 41/3</p> <p>palliative [1] 37/6</p> <p>pandemic [1] 178/14</p> <p>panel [10] 2/19 3/1 124/12 124/17 145/10 148/5 177/18 201/20 236/19 239/8</p> <p>paper [3] 33/4 131/22 218/6</p> <p>papers [2] 29/4 200/17</p> <p>paperwork [1] 218/20</p> <p>paragraph [20] 23/4 26/18 27/14 27/21 36/4 45/23 45/24 47/7 47/24 49/4 49/7 49/8 92/20 115/22 116/21 117/4 131/17 155/18 155/23 167/6</p> <p>paragraph 9 [1] 155/18</p> <p>paragraph 98 [1] 36/4</p> <p>paragraphs [5] 35/15 46/21 116/21 127/24 129/22</p> <p>paragraphs 97 [1] 35/15</p> <p>parameters [1] 98/7</p> <p>parents [6] 5/15 107/4 107/6 119/7 206/2 223/2</p> <p>parity [14] 133/24 134/15 136/16 136/25 137/19 137/20 138/3 138/9 138/10 138/22 139/15 141/1 147/11 231/7</p> <p>Park [1] 20/4</p> <p>Parliament [40] 10/1 17/12 18/7 19/6 19/14 19/14 20/8 20/10 21/7 21/17 21/22 24/3 24/6 30/14 33/3 34/18 39/21 40/8 40/14 42/24 44/15 45/4 45/6</p>	<p>62/24 62/25 63/5 63/9 73/8 74/12 80/2 86/12 106/17 108/1 128/4 150/21 150/21 198/22 201/16 210/13 226/1</p> <p>Parliament's [2] 21/20 101/2</p> <p>Parliamentarians [1] 24/7</p> <p>Parliamentary [4] 44/10 62/19 162/4 201/13</p> <p>part [36] 2/17 6/7 10/24 24/10 27/11 30/14 54/23 62/14 65/5 77/19 79/16 95/4 97/2 106/23 117/14 120/21 121/11 123/12 126/6 131/16 132/7 140/14 143/23 144/21 148/24 149/15 151/24 161/23 171/12 171/14 177/16 210/7 219/5 222/5 222/7 222/15</p> <p>part-time [1] 222/7</p> <p>partially [1] 139/20</p> <p>Participant [3] 10/7 50/11 63/20</p> <p>Participants [4] 68/8 70/1 70/20 202/17</p> <p>particular [32] 25/18 43/10 44/1 46/4 58/22 64/6 68/6 77/18 91/7 95/18 97/15 99/24 103/17 110/2 112/9 116/21 119/18 136/8 155/1 176/7 190/8 195/15 204/21 207/9 210/20 212/8 213/19 213/23 215/5 215/6 220/10 222/18</p> <p>particularly [18] 1/12 10/5 16/17 24/16 37/8 45/8 66/15 73/21 109/13 158/25 161/13 166/18 169/14 181/17 204/8 212/13 225/11 238/23</p> <p>parties [4] 126/19 129/12 138/17 138/19</p> <p>partly [1] 159/3</p> <p>partner [4] 96/16 103/9 222/5 222/14</p> <p>partners [10] 83/11 202/18 202/21 202/24 204/13 204/19 205/10 213/20 221/11 221/23</p> <p>parts [6] 2/5 3/4 104/9 175/14 177/10 197/22</p> <p>party [17] 15/12 17/10 17/25 18/9 18/10 18/13 40/1 45/2 79/21</p>	<p>82/23 101/6 106/15 109/12 109/12 110/6 112/21 171/18</p> <p>pass [1] 33/18</p> <p>passed [4] 21/19 34/18 150/19 178/11</p> <p>passing [3] 33/4 33/19 225/9</p> <p>passionate [1] 77/17</p> <p>passionately [1] 100/13</p> <p>past [10] 23/9 197/17 197/18 198/2 202/2 202/5 230/17 231/1 231/11 233/2</p> <p>pat [2] 177/15 235/20</p> <p>paternally [1] 197/12</p> <p>pathetic [1] 26/11</p> <p>patience [1] 86/20</p> <p>patient [22] 27/7 27/8 28/16 52/1 79/18 103/4 104/19 162/16 162/17 166/3 167/12 168/3 168/5 168/11 169/20 169/21 172/24 176/9 179/3 217/17 217/25 234/12</p> <p>patiently [1] 229/22</p> <p>patients [49] 25/20 26/4 27/5 29/10 46/13 46/18 47/13 47/19 52/7 52/17 55/24 58/23 59/18 59/24 61/7 61/21 61/24 74/7 104/16 105/1 121/13 123/17 131/22 155/24 156/9 156/13 158/16 158/18 161/16 166/24 167/7 170/10 170/11 170/14 172/21 173/17 173/19 174/3 174/21 181/1 181/21 182/2 187/5 187/16 188/16 189/7 215/14 216/23 217/10</p> <p>patients' [2] 106/11 169/12</p> <p>patronising [2] 27/17 212/13</p> <p>pattern [1] 81/20</p> <p>Paul [1] 14/21</p> <p>pause [8] 8/5 8/17 14/24 51/7 140/3 183/8 183/10 183/19</p> <p>paused [1] 14/25</p> <p>pausing [2] 80/8 86/7</p> <p>pay [13] 26/21 63/1 69/6 103/13 140/10 154/8 162/2 171/12 181/15 182/15 192/2 218/18 228/10</p> <p>paying [4] 29/5</p>	<p>119/24 120/3 219/20</p> <p>payment [15] 117/22 119/21 125/3 125/9 127/15 129/16 130/3 133/24 137/21 142/14 144/11 146/14 227/24 228/4 228/15</p> <p>payments [14] 31/16 100/23 117/9 130/6 130/9 142/13 142/16 143/9 143/11 145/17 145/18 147/9 154/11 228/7</p> <p>payouts [2] 29/1 29/10</p> <p>pays [2] 152/10 194/15</p> <p>PE185 [1] 27/23</p> <p>PE45 [3] 19/10 21/6 27/23</p> <p>Peatty [1] 183/5</p> <p>Penrose [36] 10/6 11/3 26/13 50/9 62/6 62/22 63/24 64/3 64/7 64/15 64/20 65/4 65/24 66/20 67/11 67/14 67/23 71/20 73/12 73/13 74/20 78/25 86/23 87/2 88/13 89/11 95/1 95/16 155/20 157/3 158/7 159/15 214/4 214/9 214/11 214/20</p> <p>Penrose's [1] 11/23</p> <p>people [225] 2/3 3/20 4/19 6/9 6/14 9/14 9/18 9/21 10/10 12/12 13/5 15/23 17/6 17/15 17/16 19/17 19/20 19/22 20/25 21/1 27/1 29/6 37/7 44/23 44/24 46/10 50/13 53/2 53/3 53/23 54/2 54/16 55/11 55/19 56/9 56/14 56/17 56/25 57/2 57/24 58/1 58/1 61/3 61/14 63/10 64/17 65/3 65/11 68/5 68/11 68/20 69/9 70/19 71/3 71/7 71/8 71/8 71/15 72/1 72/3 72/14 72/16 76/4 77/2 77/2 77/23 78/3 78/5 78/11 78/11 79/11 79/22 80/6 81/5 81/7 81/10 83/6 83/25 85/1 85/6 87/17 87/20 87/23 88/8 88/23 89/8 90/2 92/12 93/6 93/7 95/25 96/11 96/23 97/2 97/6 97/10 97/22 98/24 101/10 105/12</p>
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<p>P</p> <p>people... [125] 105/24 106/2 106/5 106/14 106/23 107/2 107/3 107/16 107/20 108/6 108/18 108/21 108/23 110/3 110/8 110/24 112/6 112/22 113/16 114/2 114/16 115/14 117/18 118/12 118/21 119/1 119/10 119/10 119/14 120/14 120/16 121/1 121/19 122/13 124/23 125/2 125/21 126/5 130/1 131/25 132/15 139/5 141/13 150/6 150/9 150/11 150/13 150/14 151/11 152/2 152/3 153/10 157/19 159/6 159/24 160/17 160/18 161/4 161/6 161/25 162/6 162/8 162/9 162/13 162/19 162/21 162/23 163/5 163/6 166/1 167/15 168/17 170/22 171/13 172/23 172/25 173/3 173/3 173/22 174/7 174/13 175/5 176/1 176/14 177/1 177/4 177/18 179/10 181/17 182/20 182/22 184/17 185/14 187/11 189/3 194/12 195/3 196/21 197/21 198/10 198/10 198/14 198/21 200/3 201/2 203/25 205/8 205/14 210/18 213/16 214/8 214/18 225/16 226/20 227/1 227/16 227/20 230/1 232/10 232/25 233/13 234/9 236/8 236/10 236/13</p> <p>people's [4] 66/5 101/11 139/4 163/10</p> <p>per [5] 52/8 100/18 120/9 142/15 161/18</p> <p>perceived [2] 54/13 54/25</p> <p>percentage [1] 100/1 perception [1] 55/1 perfectly [2] 65/6 198/1</p> <p>perhaps [8] 4/16 88/24 138/6 141/6 216/8 222/4 236/17 238/10</p> <p>perilous [1] 205/23 period [24] 4/13 4/22 40/1 40/2 44/7 45/10</p>	<p>45/19 48/23 50/14 50/15 50/20 67/6 67/17 67/19 68/5 117/10 127/8 131/9 140/15 141/13 141/20 146/22 189/21 230/1</p> <p>periods [1] 43/16 permanent [7] 136/1 136/7 137/11 137/17 140/17 143/22 178/10</p> <p>perseverance [1] 232/20</p> <p>persistence [1] 238/12</p> <p>person [14] 122/3 125/17 142/15 151/4 151/5 174/16 181/6 181/7 189/2 189/4 206/23 219/18 221/12 222/10</p> <p>personal [13] 6/17 8/10 13/11 65/16 65/19 66/1 83/6 97/24 102/16 102/17 106/16 205/20 230/4</p> <p>personally [9] 26/8 28/3 48/23 49/18 55/5 67/2 89/3 179/9 184/18</p> <p>perspective [5] 15/17 104/4 149/2 153/21 210/21</p> <p>persuaded [1] 35/16 Perth [1] 213/4 pertinent [1] 140/7 pessimistic [1] 147/20</p> <p>Peter [1] 235/25 petered [3] 60/21 60/22 213/11</p> <p>petition [7] 19/10 19/13 19/23 20/22 22/2 22/2 212/16</p> <p>petitions [13] 20/7 20/13 21/7 21/9 21/11 21/12 21/18 22/6 22/11 22/18 30/13 36/8 43/20</p> <p>pharma [1] 194/24 pharmaceutical [4] 194/16 195/13 195/18 234/7</p> <p>pharmaceuticals [1] 234/8</p> <p>pharmacist [3] 186/3 186/5 186/12</p> <p>phase [1] 74/16 Philip [13] 20/15 20/16 30/17 36/20 37/11 65/13 65/13 69/10 213/8 213/9 213/15 215/6 235/21</p>	<p>Philip Dolan [3] 30/17 36/20 213/8</p> <p>phone [2] 179/13 193/2</p> <p>phoned [3] 102/4 102/8 235/2</p> <p>phrase [1] 112/18 phrases [1] 216/22</p> <p>physical [3] 49/1 50/3 230/20</p> <p>physically [1] 8/24 physios [1] 169/8 physiotherapy [2] 167/14 169/3</p> <p>pick [26] 25/4 28/21 33/15 35/15 38/6 45/13 46/14 62/7 62/11 62/13 78/21 78/24 80/9 94/23 98/1 103/14 126/8 129/21 134/6 142/2 145/9 145/14 172/11 187/19 193/2 194/13</p> <p>picked [3] 55/17 134/3 166/21</p> <p>picking [2] 105/20 176/15</p> <p>picture [3] 47/1 119/5 152/22</p> <p>piece [1] 33/4 pieces [2] 66/4 218/5</p> <p>pilot [1] 176/25</p> <p>pin [2] 151/11 220/24 pinpoint [1] 107/20 pioneered [1] 175/20 pioneering [1] 87/9 PIP [1] 120/24</p> <p>pithily [1] 115/22 pivotal [1] 20/23</p> <p>place [28] 11/10 12/3 22/19 44/8 46/25 47/2 48/8 48/9 49/11 61/23 63/10 70/25 70/25 71/2 72/4 77/12 87/15 103/9 116/25 125/10 141/2 144/1 168/19 175/1 193/22 193/22 206/1 226/2</p> <p>placed [1] 98/7 places [2] 31/24 199/2</p> <p>Plaid [1] 15/13 plan [3] 175/13 176/1 188/4</p> <p>planning [1] 167/12 plans [2] 147/17 175/11</p> <p>plasma [1] 14/3 plate [1] 226/9 play [1] 50/7 playing [1] 135/13 please [42] 1/21 2/11</p>	<p>2/22 3/12 19/11 19/12 25/3 27/14 27/21 35/12 38/10 40/24 41/2 45/21 45/21 46/15 46/15 48/19 49/5 73/9 73/10 103/9 115/7 115/21 116/19 127/22 127/23 129/19 129/22 132/7 142/7 155/2 155/13 158/3 165/15 165/16 166/11 167/4 185/16 192/3 202/6 204/16</p> <p>pleased [1] 117/7 pluck [1] 162/6 Plymouth [1] 186/8 pm [8] 90/22 90/24 148/17 148/19 148/21 202/7 202/9 239/21</p> <p>pocket [1] 101/8 point [71] 10/5 10/8 11/4 11/11 12/4 13/18 16/21 20/25 21/4 22/14 24/9 28/20 29/22 30/2 30/25 31/21 32/7 33/14 42/13 43/12 44/1 44/9 45/2 45/14 49/18 50/5 58/17 62/14 63/15 66/13 74/18 75/18 79/14 80/8 80/16 82/6 83/14 97/16 99/24 100/2 100/6 100/22 100/23 101/4 120/17 132/20 142/23 145/21 150/22 152/11 153/13 153/17 154/12 154/20 155/14 161/8 161/8 162/14 175/19 194/13 194/14 195/10 201/11 204/7 207/7 218/25 222/4 222/17 222/18 223/5 228/17</p> <p>pointed [1] 155/24 points [10] 24/1 25/2 26/17 38/7 47/8 97/16 97/17 145/10 145/15 161/2</p> <p>policy [9] 26/3 27/4 53/11 55/9 56/24 186/24 187/4 187/25 200/25</p> <p>political [7] 30/7 43/7 62/15 87/14 87/14 140/5 140/6 politically [2] 11/15 34/13</p> <p>politician [3] 34/23 75/16 108/2</p> <p>politicians [5] 7/14 15/15 82/25 171/24 185/11</p>	<p>politics [1] 101/7 Pontypridd [1] 207/19 poor [2] 70/21 71/14 Portcullis [2] 134/7 135/2 Portcullis House [2] 134/7 135/2</p> <p>posed [1] 51/4 position [29] 11/8 28/5 39/17 41/22 44/13 50/19 53/2 55/22 62/12 73/13 94/12 99/21 105/18 105/20 107/24 116/2 137/15 137/15 137/23 138/13 138/14 142/22 146/4 184/22 191/3 191/11 191/20 205/24 226/16</p> <p>positions [3] 24/14 201/6 232/22</p> <p>positive [5] 136/11 136/15 137/1 189/17 190/16</p> <p>positively [3] 151/12 224/12 224/13</p> <p>positives [1] 211/23 possibility [1] 210/24 possible [7] 47/17 106/22 126/18 136/17 148/10 148/12 211/23</p> <p>possibly [3] 81/9 154/13 194/17</p> <p>post [11] 34/25 34/25 43/5 156/1 165/5 170/11 173/6 178/4 178/9 196/8 225/21</p> <p>post-devolution [1] 34/25</p> <p>potential [2] 23/16 215/24</p> <p>potentially [5] 23/12 137/24 190/1 204/25 205/2</p> <p>pour [1] 100/14 poverty [1] 119/25 power [7] 116/6 140/18 140/22 151/11 160/9 235/7 235/8</p> <p>powers [2] 60/14 114/24</p> <p>PR [1] 81/16 PRAC [1] 64/10 practical [5] 35/25 36/6 36/11 149/9 230/19</p> <p>practice [5] 60/6 203/22 216/9 216/10 224/7</p> <p>practised [1] 205/16 practitioners [1] 230/12</p>	<p>praise [1] 145/24 pre [7] 34/23 37/13 39/17 157/16 157/21 223/24 225/22</p> <p>pre-1991 [2] 157/16 157/21</p> <p>pre-determine [1] 37/13</p> <p>pre-devolution [3] 34/23 39/17 223/24</p> <p>precautionary [1] 211/5</p> <p>precedent [1] 29/12 predecessors [1] 155/25</p> <p>prefer [3] 110/25 227/3 227/3</p> <p>preparation [1] 238/25</p> <p>prepare [1] 70/10 prepared [3] 229/12 238/21 239/7</p> <p>presence [2] 25/16 64/24</p> <p>present [8] 1/25 54/15 56/5 70/22 98/18 140/3 228/3 231/12</p> <p>presentation [6] 71/24 98/19 206/7 206/8 206/10 219/14</p> <p>presentations [4] 53/16 63/3 180/20 206/11</p> <p>presented [12] 11/25 11/25 20/13 31/1 33/8 70/17 70/17 101/13 101/14 135/20 135/21 208/18</p> <p>presenting [2] 21/8 55/17</p> <p>press [20] 62/10 62/10 64/21 64/24 70/11 70/11 70/16 70/24 71/5 71/8 71/11 72/1 72/14 75/5 77/11 78/10 182/13 184/5 219/12 223/5</p> <p>pressure [2] 48/9 114/6</p> <p>pressures [1] 238/19 pretty [7] 26/11 30/6 64/19 101/5 112/3 222/2 225/17</p> <p>prevarication [1] 141/20</p> <p>prevent [2] 175/2 233/2</p> <p>preventative [1] 163/20</p> <p>preventing [1] 186/6 previous [11] 13/10 27/13 105/18 120/15</p>
--	--	---	---	--	--

<p>P</p> <p>previous... [7] 143/22 165/18 181/4 181/19 205/12 230/13 234/18</p> <p>previously [5] 4/6 62/15 120/21 180/14 191/20</p> <p>Price [2] 110/15 134/11</p> <p>primary [2] 203/7 221/13</p> <p>prime [3] 76/16 77/10 137/22</p> <p>principle [6] 26/21 96/12 100/4 211/6 229/2 237/17</p> <p>principles [5] 39/1 95/6 95/9 96/20 98/6</p> <p>prior [18] 6/22 7/2 22/10 32/24 34/8 34/20 43/24 62/9 94/14 99/13 149/8 149/18 150/23 181/11 185/19 200/18 223/25 225/24</p> <p>priority [9] 56/16 57/25 85/2 130/3 168/16 170/18 192/19 203/3 204/10</p> <p>private [4] 2/22 69/14 217/18 218/18</p> <p>privately [1] 235/3</p> <p>privileged [1] 232/8</p> <p>pro [1] 103/13</p> <p>probably [7] 100/24 128/6 156/25 178/5 186/3 210/16 222/24</p> <p>probity [1] 98/13</p> <p>problem [21] 54/18 55/7 55/8 61/19 93/5 119/3 119/8 119/18 125/20 151/1 157/13 164/1 164/3 164/3 164/4 189/12 200/8 205/24 206/24 223/25 227/18</p> <p>problematic [2] 39/19 68/4</p> <p>problems [9] 47/6 56/4 105/1 141/4 151/18 151/19 163/22 176/4 188/7</p> <p>proceed [1] 137/5</p> <p>Proceedings [1] 148/20</p> <p>process [36] 11/11 12/6 18/17 25/21 30/13 39/5 64/1 76/13 78/11 87/6 87/18 87/19 88/8 106/5 118/9 129/4 132/16</p>	<p>139/25 141/11 144/5 145/3 178/14 178/17 179/15 187/15 189/16 190/5 201/13 206/14 216/12 229/25 230/5 230/5 231/6 234/17 235/16</p> <p>processes [1] 25/23</p> <p>produce [1] 26/2</p> <p>produced [2] 38/9 217/16</p> <p>producing [1] 25/11</p> <p>product [3] 25/12 25/24 26/1</p> <p>products [14] 19/19 25/10 25/19 25/22 26/7 27/1 36/2 41/15 46/20 47/13 112/2 155/12 165/22 196/16</p> <p>profession [2] 34/24 171/24</p> <p>professional [3] 140/8 176/7 216/9</p> <p>professionals [1] 167/10</p> <p>Professor [14] 155/24 156/6 159/1 159/4 159/4 159/13 180/23 181/23 181/24 182/1 182/8 185/21 185/25 186/6</p> <p>Professor Campbell Tait [1] 159/13</p> <p>Professor Dusheiko [1] 180/23</p> <p>Professor Lowe [2] 155/24 159/4</p> <p>Professor Ludlam [3] 156/6 159/1 159/4</p> <p>Professor Thursz [7] 181/23 181/24 182/1 182/8 185/21 185/25 186/6</p> <p>profit [1] 140/11</p> <p>profits [1] 234/9</p> <p>prognostic [1] 163/21</p> <p>progress [9] 40/12 58/24 62/11 93/24 143/24 144/3 172/10 196/3 229/18</p> <p>promises [1] 201/4</p> <p>promote [2] 133/23 140/24</p> <p>promoted [3] 18/14 79/24 178/15</p> <p>proof [1] 208/2</p> <p>proper [1] 76/2</p> <p>properly [5] 109/23 197/9 204/2 233/5 238/3</p> <p>proportion [1] 111/9</p> <p>proportions [1] 105/9</p>	<p>proposal [6] 21/10 21/19 100/17 124/11 124/22 125/2</p> <p>proposals [10] 64/6 76/11 92/3 115/10 115/16 115/17 115/24 117/3 117/19 131/21</p> <p>proposed [4] 115/13 135/17 212/17 212/19</p> <p>prospective [1] 137/1</p> <p>protect [3] 50/1 50/15 141/16</p> <p>protected [1] 164/11</p> <p>protecting [2] 8/13 101/21</p> <p>protection [3] 85/1 158/16 216/13</p> <p>prove [2] 99/14 124/6</p> <p>proven [2] 221/25 231/18</p> <p>provide [15] 5/10 5/23 6/9 6/13 17/5 115/17 130/14 139/14 149/20 193/5 197/19 217/16 224/16 225/8 236/8</p> <p>provided [14] 5/12 6/18 19/21 35/25 50/16 120/11 121/15 146/16 147/2 166/25 202/21 204/18 213/17 224/7</p> <p>providing [8] 13/4 19/19 110/24 111/1 130/5 131/15 167/19 180/5</p> <p>province [1] 178/14</p> <p>proving [2] 123/9 123/10</p> <p>provision [6] 52/19 164/22 165/1 166/7 167/9 217/9</p> <p>proxy [1] 127/7</p> <p>PS [1] 132/6</p> <p>psychological [20] 74/14 110/11 111/5 120/11 121/5 121/6 121/8 121/15 121/20 122/2 164/23 168/15 168/16 175/21 175/24 175/25 177/20 177/23 178/22 227/13</p> <p>psychologically [1] 124/24</p> <p>psychologist [2] 177/17 178/9</p> <p>psychologists [4] 104/21 121/16 164/25 169/2</p> <p>psychology [2] 176/17 176/20</p> <p>public [53] 2/20 5/8 6/3 23/13 32/7 32/15</p>	<p>46/16 46/18 47/10 48/2 50/24 64/22 67/12 72/24 78/23 80/24 82/6 82/7 82/16 82/17 82/20 83/14 83/18 84/6 85/9 85/13 85/18 86/8 86/15 88/16 91/5 91/8 91/25 93/8 93/22 133/10 136/6 150/13 151/4 160/4 160/5 160/13 164/5 178/20 179/6 190/17 190/18 192/11 195/7 232/11 234/14 234/15 234/15</p> <p>publicly [1] 71/6</p> <p>publish [1] 23/6</p> <p>published [12] 3/22 16/25 24/24 29/1 35/7 42/15 50/17 62/22 156/23 157/3 187/13 196/14</p> <p>punch [1] 30/24</p> <p>punctuated [1] 228/21</p> <p>purpose [2] 127/19 210/10</p> <p>purposes [1] 188/12</p> <p>push [4] 90/5 100/20 108/14 182/15</p> <p>pushed [1] 43/18</p> <p>pushing [1] 101/5</p> <p>put [34] 23/2 46/7 47/9 55/10 57/8 57/15 57/15 66/4 89/16 93/21 95/18 95/20 96/4 105/11 108/24 113/24 124/11 129/19 132/6 137/5 142/6 163/19 168/13 168/24 174/4 185/24 189/6 209/21 215/8 226/21 230/22 237/25 238/19 239/7</p> <p>putting [4] 88/22 171/22 215/4 226/8</p>	<p>123/19 132/11 135/7 140/7 140/10 141/3 146/9 154/22 162/16 180/5 203/1 204/15 205/14 205/18 206/5 207/9 214/12 215/13 217/6 219/1 219/7 219/13 219/24 220/4 221/3 221/9 225/14 226/11 226/21 229/14 230/6</p> <p>questioning [1] 211/18</p> <p>questionnaire [1] 115/15</p> <p>questions [33] 3/6 35/19 44/4 45/20 71/8 77/7 81/4 81/5 89/25 90/1 94/4 112/21 125/5 148/5 151/16 159/1 159/4 159/9 171/21 195/20 200/15 201/19 201/22 202/13 206/15 210/22 219/10 219/11 219/17 220/16 238/13 240/6 240/7</p> <p>queue [1] 85/7</p> <p>quick [1] 90/12</p> <p>quickly [2] 26/1 144/4</p> <p>quiet [2] 72/4 239/8</p> <p>quieter [1] 238/10</p> <p>quietly [1] 135/10</p> <p>quite [27] 1/15 2/3 10/7 10/25 17/15 21/19 22/22 48/22 58/23 65/24 66/21 99/8 135/6 137/1 137/8 141/14 144/4 144/10 144/20 150/24 154/23 186/25 203/20 207/3 208/8 211/20 218/15</p> <p>quote [3] 189/23 207/25 233/8</p> <p>quotes [1] 131/16</p>	<p>225/14</p> <p>raises [1] 204/7</p> <p>raising [5] 13/22 14/16 126/20 129/8 136/23</p> <p>ran [3] 5/21 9/25 84/1</p> <p>range [1] 167/11</p> <p>ranging [2] 23/21 142/14</p> <p>rate [2] 161/18 181/16</p> <p>rather [18] 13/8 48/12 66/3 87/16 90/11 129/3 134/3 144/7 152/25 183/18 195/8 200/2 215/22 222/19 227/4 237/21 237/25 238/10</p> <p>ray [1] 218/9</p> <p>re [1] 16/2</p> <p>re-established [1] 16/2</p> <p>reach [1] 48/1</p> <p>reached [3] 11/4 116/4 220/19</p> <p>reaches [2] 200/2 200/2</p> <p>react [2] 71/6 78/2</p> <p>reaction [8] 26/6 27/11 42/15 42/15 42/18 43/1 218/15 219/18</p> <p>read [5] 26/18 29/19 41/7 70/10 131/25</p> <p>reads [1] 155/23</p> <p>ready [1] 202/5</p> <p>real [13] 16/16 21/10 21/11 53/19 57/20 72/16 80/3 81/7 83/19 119/25 125/20 139/16 179/9</p> <p>realisation [2] 33/21 178/25</p> <p>realise [3] 75/21 76/7 160/2</p> <p>realised [1] 140/22</p> <p>reality [18] 10/25 87/22 88/9 128/12 128/23 129/6 129/13 140/7 144/6 144/11 147/15 149/17 154/8 163/24 193/4 193/7 224/8 224/14</p> <p>really [109] 11/18 11/24 24/9 30/20 31/4 31/9 31/23 33/5 35/2 48/21 49/3 49/5 49/14 53/17 54/7 54/14 55/8 56/8 58/20 59/2 59/3 60/7 61/11 62/7 65/17 67/13 68/7 68/19 68/20 69/10 70/3 70/3 71/3 75/1 79/10 80/7</p>
<p>R</p>					
<p>radar [1] 175/7</p> <p>radical [1] 30/6</p> <p>railways [1] 207/16</p> <p>raise [9] 38/7 89/5 155/2 161/8 176/11 194/22 214/12 219/9 236/11</p> <p>raised [25] 16/23 19/3 35/17 36/7 59/9 59/11 93/20 120/10 126/24 128/3 135/19 138/23 167/11 179/7 180/4 202/14 202/16 211/10 211/15 211/17 211/21 211/25 212/2 221/14</p>					

<p>R</p> <p>really... [73] 81/2 81/14 83/12 86/16 91/21 92/1 92/1 93/3 93/25 94/1 97/9 97/14 98/22 99/11 99/18 102/5 104/10 104/15 105/14 106/4 106/20 107/10 107/23 110/8 111/8 111/22 112/23 114/1 114/19 114/24 120/7 120/22 120/25 121/1 121/3 122/15 124/15 125/4 132/14 133/2 138/11 141/25 154/3 154/20 162/15 168/21 168/22 174/25 178/1 178/3 178/18 182/23 184/13 185/6 189/1 189/11 193/16 197/15 199/1 203/23 204/1 209/10 209/16 211/6 213/16 213/24 215/13 223/9 225/22 227/10 234/13 235/5 235/10</p> <p>realm [1] 89/8</p> <p>reason [7] 27/9 60/23 95/14 162/24 200/16 211/7 216/24</p> <p>reasonable [3] 135/18 157/5 179/25</p> <p>reasonably [1] 163/25</p> <p>reasons [7] 11/24 25/14 36/12 98/9 197/11 219/15 238/20</p> <p>reassured [1] 146/21</p> <p>reassures [1] 179/14</p> <p>reassuring [1] 179/17</p> <p>rebuild [1] 62/14</p> <p>recall [4] 32/10 117/16 221/9 232/24</p> <p>recalled [1] 32/6</p> <p>receive [4] 36/11 36/14 145/17 233/23</p> <p>received [19] 3/22 29/10 42/1 47/23 48/15 98/19 127/21 128/21 131/6 133/17 146/20 157/21 158/15 208/7 209/22 218/24 219/25 220/5 220/6</p> <p>receiving [1] 117/6</p> <p>recent [3] 116/25 127/25 192/1</p> <p>recently [5] 146/13 146/20 176/21 177/3 218/8</p> <p>recipient [1] 6/5</p> <p>recipients [2] 6/5 225/2</p>	<p>recognise [1] 71/16</p> <p>recognised [7] 4/25 6/6 89/10 139/13 201/21 202/13 202/16</p> <p>recognising [1] 139/18</p> <p>recognition [2] 36/13 149/16</p> <p>recollect [1] 42/21</p> <p>recollection [3] 33/2 33/18 35/1</p> <p>recollections [3] 46/24 48/7 49/10</p> <p>recombinant [2] 13/24 14/6</p> <p>recommend [2] 92/21 98/8</p> <p>recommendation [12] 51/23 60/20 62/4 70/4 74/9 157/11 158/7 158/18 166/21 224/16 224/17 228/22</p> <p>recommendations [14] 11/21 11/22 31/10 37/23 38/16 40/16 42/2 52/6 79/9 105/16 167/18 167/22 172/17 224/13</p> <p>recommended [5] 38/22 39/7 42/7 79/15 157/4</p> <p>recompense [14] 6/22 30/5 32/5 78/21 86/18 89/14 90/8 91/2 94/21 126/10 148/6 148/24 148/25 227/4</p> <p>reconvene [1] 172/4</p> <p>record [5] 44/10 46/7 57/7 57/7 103/9</p> <p>recorded [2] 57/4 162/10</p> <p>recording [1] 142/5</p> <p>records [17] 28/25 29/8 187/22 188/12 188/17 189/1 189/10 189/13 189/21 190/6 190/8 190/10 190/12 190/20 218/22 232/23 233/9</p> <p>recruited [1] 9/18</p> <p>recurrent [3] 143/2 143/15 167/20</p> <p>red [1] 39/4</p> <p>redact [1] 8/10</p> <p>redacted [13] 8/4 14/22 15/2 32/17 32/19 53/8 65/8 84/19 94/11 94/17 183/9 183/13 210/6</p> <p>redeeming [1] 231/11</p> <p>refer [5] 95/12 95/14 147/25 183/14 183/17</p>	<p>reference [15] 37/2 43/21 52/13 59/17 65/20 65/22 67/21 67/23 95/17 104/12 128/14 129/11 178/6 214/25 237/10</p> <p>references [1] 117/15</p> <p>referred [10] 44/14 45/6 130/13 132/25 138/24 141/8 141/9 173/23 206/6 213/24</p> <p>referring [3] 43/11 95/11 95/13</p> <p>refers [2] 44/11 131/10</p> <p>reflect [1] 195/20</p> <p>reflected [2] 205/14 238/3</p> <p>reflecting [1] 239/11</p> <p>reflection [3] 68/25 99/6 219/18</p> <p>reform [3] 117/1 117/2 143/14</p> <p>Reforming [1] 130/2</p> <p>refusing [2] 22/16 183/25</p> <p>regard [9] 13/23 83/5 95/7 109/21 136/18 158/6 166/9 199/21 234/12</p> <p>regarding [4] 14/18 52/18 61/13 81/7</p> <p>regardless [4] 5/7 131/1 139/17 188/2</p> <p>regards [4] 109/24 122/15 139/12 195/7</p> <p>region [1] 177/2</p> <p>regional [1] 236/23</p> <p>regions [1] 5/19</p> <p>registered [1] 13/1</p> <p>registrants [1] 130/9</p> <p>regret [1] 100/22</p> <p>regrets [1] 223/4</p> <p>regular [5] 79/6 143/9 143/11 170/19 193/12</p> <p>regulation [1] 216/8</p> <p>regulations [1] 195/17</p> <p>Regulator [1] 13/2</p> <p>Reid [2] 31/7 31/20</p> <p>reinforced [1] 97/16</p> <p>reinvigorate [1] 213/13</p> <p>reiterates [1] 50/22</p> <p>rejecting [1] 187/17</p> <p>rejects [1] 187/14</p> <p>relate [1] 61/8</p> <p>related [2] 56/11 179/6</p> <p>relates [4] 97/19 138/12 139/10 205/18</p> <p>relating [7] 5/8 5/14</p>	<p>5/16 6/2 18/21 130/7 149/9</p> <p>relation [45] 15/7 16/22 51/7 66/2 74/14 78/22 78/23 82/15 88/14 98/8 102/20 103/18 104/3 105/21 116/2 126/9 126/24 127/15 133/3 154/17 154/25 156/15 158/25 163/23 175/12 175/21 176/5 177/21 177/25 179/7 180/2 185/4 186/19 187/21 188/11 194/16 195/10 202/18 204/22 204/24 209/21 214/20 217/7 217/9 229/15</p> <p>relationship [6] 14/13 15/14 104/19 173/7 215/18 224/5</p> <p>relationships [3] 151/12 193/10 216/3</p> <p>relative [1] 164/9</p> <p>relatively [4] 55/25 70/21 190/24 208/4</p> <p>relay [5] 82/3 84/3 123/17 124/19 124/25</p> <p>released [1] 29/8</p> <p>relevant [2] 47/12 51/1</p> <p>reliant [1] 220/13</p> <p>reluctance [2] 141/10 141/11</p> <p>reluctant [5] 9/1 37/12 136/21 137/8 140/13</p> <p>reluctantly [1] 88/9</p> <p>rely [1] 194/22</p> <p>relying [2] 81/10 109/1</p> <p>remain [5] 130/1 157/16 157/25 199/20 234/12</p> <p>remainder [1] 142/24</p> <p>remains [4] 130/3 144/12 191/1 233/4</p> <p>remarked [1] 89/22</p> <p>remarks [1] 64/23</p> <p>remember [20] 58/22 72/18 72/21 75/17 96/5 100/2 100/10 100/10 100/16 102/3 102/8 103/11 127/1 160/6 192/3 211/20 214/6 218/2 220/10 232/23</p> <p>remembered [1] 112/25</p> <p>remembering [1] 203/24</p> <p>remind [3] 116/14</p>	<p>128/5 211/1</p> <p>remit [3] 59/6 59/13 128/6</p> <p>removal [1] 235/8</p> <p>removed [2] 235/7 235/13</p> <p>render [1] 25/21</p> <p>renewed [2] 8/22 9/3</p> <p>repeat [4] 26/24 27/16 204/15 217/5</p> <p>repeated [9] 91/16 91/17 91/17 91/20 196/5 196/5 196/6 196/19 196/20</p> <p>repeatedly [1] 238/18</p> <p>replaced [1] 59/16</p> <p>replicated [1] 208/25</p> <p>replicating [2] 4/18 143/8</p> <p>replied [1] 182/9</p> <p>replies [1] 111/14</p> <p>reply [6] 23/25 113/8 127/21 129/18 131/17 131/19</p> <p>report [48] 24/23 24/25 25/7 26/6 26/18 35/6 35/7 36/16 38/5 38/9 39/15 40/16 42/16 43/5 63/24 64/2 64/8 67/4 67/8 68/3 69/13 70/2 70/10 70/16 70/17 74/7 74/19 78/25 88/13 95/1 95/16 99/2 101/13 101/14 105/15 156/22 167/23 172/8 176/22 184/9 185/8 192/21 196/11 196/15 196/24 200/22 214/5 221/17</p> <p>Report in [1] 38/5</p> <p>report's [1] 74/8</p> <p>reported [6] 30/19 58/23 165/12 183/1 183/2 184/7</p> <p>reporting [1] 184/12</p> <p>represent [7] 6/2 17/8 17/20 108/18 112/1 232/10 237/11</p> <p>representation [6] 4/14 4/24 6/13 96/15 182/12 184/2</p> <p>representations [4] 129/8 172/14 172/21 210/14</p> <p>representative [4] 52/1 52/22 130/18 139/4</p> <p>representatives [11] 7/18 103/5 134/10 135/3 168/12 201/21 202/14 202/15 202/17</p>	<p>210/2 237/5</p> <p>represented [3] 74/21 99/1 139/13</p> <p>representing [3] 61/10 108/20 156/11</p> <p>represents [1] 237/4</p> <p>Republic [1] 138/18</p> <p>request [2] 134/23 158/4</p> <p>requested [1] 231/22</p> <p>requests [2] 27/22 30/4</p> <p>required [3] 36/12 146/10 155/10</p> <p>rescue [1] 71/19</p> <p>reserves [1] 110/13</p> <p>resignation [1] 16/12</p> <p>resigned [2] 185/7 187/2</p> <p>resisted [1] 195/23</p> <p>resolute [2] 235/1 236/14</p> <p>resolution [2] 136/16 197/19</p> <p>resolve [6] 60/24 61/22 134/15 168/21 206/24 230/17</p> <p>resolved [3] 18/22 87/1 143/6</p> <p>resonates [1] 192/24</p> <p>respect [6] 32/1 66/5 78/9 144/19 163/6 223/11</p> <p>respect of [2] 163/6 223/11</p> <p>respected [1] 137/15</p> <p>respective [1] 31/21</p> <p>respond [9] 3/21 66/10 66/12 75/9 132/4 132/13 132/19 146/1 238/19</p> <p>respond' [1] 131/23</p> <p>responded [2] 88/5 231/6</p> <p>responders [1] 181/17</p> <p>responding [2] 224/11 224/13</p> <p>response [29] 3/23 3/25 16/22 24/18 24/21 42/23 46/1 50/16 73/16 76/14 82/15 115/4 115/10 115/22 130/16 131/5 131/6 132/23 133/2 147/3 158/13 158/14 180/4 184/21 187/12 206/15 233/17 237/13 237/24</p> <p>responses [2] 3/22 130/14</p> <p>responsibilities [3]</p>
---	---	--	---	---	---

<p>R</p> <p>responsibilities... [3] 117/6 154/9 154/12</p> <p>responsibility [25] 41/14 74/4 75/14 75/15 81/13 91/14 114/23 144/17 149/7 149/12 149/12 163/18 163/19 197/9 197/12 197/16 197/18 223/24 224/1 224/10 224/23 228/23 231/19 231/21 232/22</p> <p>responsibility. [1] 74/2</p> <p>responsible [4] 151/4 197/23 197/24 233/13</p> <p>responsive [4] 133/10 134/24 151/14 151/22</p> <p>responsiveness [1] 151/8</p> <p>rest [4] 10/25 36/23 69/3 119/6</p> <p>restored [2] 216/5 216/6</p> <p>restricted [2] 144/8 192/10</p> <p>restricting [1] 217/1</p> <p>result [9] 36/10 57/13 95/11 121/9 158/17 165/23 178/12 188/15 200/5</p> <p>resultant [1] 25/19</p> <p>resulted [2] 9/6 36/16</p> <p>results [2] 218/7 218/11</p> <p>reticence [1] 108/14</p> <p>reticent [2] 107/23 172/25</p> <p>retire [1] 233/13</p> <p>retrain [1] 112/17</p> <p>returned [2] 62/8 106/3</p> <p>returning [1] 85/8</p> <p>reveal [1] 28/25</p> <p>revealed [1] 235/14</p> <p>revelations [1] 41/9</p> <p>review [44] 9/5 36/1 44/8 74/9 80/5 95/2 95/15 95/24 96/8 96/8 97/20 97/21 97/21 98/2 98/5 98/18 99/13 102/11 102/25 103/18 103/21 104/12 104/15 104/17 104/22 106/9 117/10 117/14 121/10 121/10 121/12 123/13 151/17 152/12 166/1 167/5 167/18 206/6 207/4 220/17 221/3 228/1 228/3 231/3</p>	<p>reviewed [1] 25/19</p> <p>Richard [2] 63/2 63/2</p> <p>rid [1] 175/13</p> <p>ridiculous [1] 205/7</p> <p>right [49] 6/20 9/12 16/1 36/19 39/3 53/10 62/16 65/25 73/11 80/18 89/2 89/17 89/19 93/16 99/8 101/4 109/3 114/8 115/6 117/11 122/13 123/22 124/9 130/4 143/18 144/3 144/20 145/7 155/21 163/11 165/3 168/25 172/9 178/13 180/6 180/18 181/24 184/24 185/5 188/19 198/1 207/14 208/10 218/4 219/23 223/17 230/23 230/24 232/2</p> <p>right-hand [2] 39/3 73/11</p> <p>rightly [2] 67/23 150/16</p> <p>rights [2] 41/17 41/24</p> <p>rigmarole [1] 97/23</p> <p>ring [2] 106/2 218/10</p> <p>rise [1] 23/7</p> <p>risk [3] 1/13 216/12 216/13</p> <p>risks [5] 26/5 26/24 27/5 27/9 36/1</p> <p>Ritchie [1] 129/7</p> <p>road [2] 72/6 98/20</p> <p>roadshow [1] 97/5</p> <p>Robert [4] 76/3 213/24 235/18 236/5</p> <p>Robin [3] 142/3 145/15 231/16</p> <p>Robin Swann [1] 231/16</p> <p>Robinson [1] 79/25</p> <p>Robison [7] 43/11 44/1 69/18 72/18 72/25 74/11 94/25</p> <p>role [6] 5/21 32/3 33/15 137/10 137/17 145/1</p> <p>rolled [1] 188/1</p> <p>room [9] 2/2 12/2 17/16 21/5 64/18 68/11 78/15 107/17 193/21</p> <p>rooms [1] 63/13</p> <p>Rosie [1] 205/25</p> <p>Ross [18] 30/15 30/25 36/17 36/22 37/4 37/5 37/14 38/5 38/9 38/22 39/6 39/14 40/16 42/4 42/7 42/15 43/5 221/17</p>	<p>Ross's [2] 31/10 38/15</p> <p>rotten [2] 199/21 199/22</p> <p>roughly [1] 135/19</p> <p>round [3] 142/11 142/25 148/23</p> <p>roundabout [1] 134/14</p> <p>rounds [2] 146/17 146/17</p> <p>route [2] 56/15 85/5</p> <p>routes [1] 154/19</p> <p>Rowena [2] 53/11 201/1</p> <p>Rowena Jecock [2] 53/11 201/1</p> <p>Royal [1] 180/24</p> <p>Royal Free [1] 180/24</p> <p>rude [1] 3/13</p> <p>rule [12] 2/25 29/9 88/4 127/2 127/5 127/6 129/2 199/4 199/4 199/5 200/16 200/19</p> <p>run [6] 111/21 191/17 192/15 195/2 195/13 231/24</p> <p>running [3] 69/23 114/9 238/12</p> <p>rurally [1] 1/15</p> <p>Russell [1] 113/15</p> <p>Russell-Cooke [1] 113/15</p>	<p>134/14 135/11 136/11 147/20 160/25 167/25 173/12 180/25 181/9 182/9 182/12 182/13 182/14 182/17 182/24 184/13 185/22 186/1 186/1 190/25 196/7 207/21 207/22 207/24 216/23 218/4 220/24 221/5 224/11 226/20 230/24 234/24 237/2</p> <p>Saint [1] 181/25</p> <p>sake [2] 77/22 90/18</p> <p>salaries [1] 192/2</p> <p>Sam [2] 34/20 34/24</p> <p>Sam Galbraith [2] 34/20 34/24</p> <p>same [32] 17/18 24/12 51/4 53/2 53/22 54/1 55/19 57/23 60/13 70/25 71/2 76/15 79/13 81/2 81/20 81/20 84/8 84/11 91/19 91/20 106/17 124/2 145/17 156/20 162/3 199/19 204/4 214/4 217/1 230/18 236/22 236/22</p> <p>samples [1] 218/10</p> <p>sandals [1] 41/3</p> <p>sandwich [1] 218/4</p> <p>sat [6] 30/17 72/20 100/13 135/10 185/12 218/3</p> <p>Saturday [1] 234/21</p> <p>save [3] 160/1 184/18 189/6</p> <p>saving [1] 163/9</p> <p>saw [7] 52/23 61/6 88/19 129/3 180/10 182/8 196/10</p> <p>say [89] 1/24 3/2 3/3 12/7 16/21 19/1 20/18 28/7 38/4 49/17 53/7 53/21 54/17 56/18 59/13 67/1 69/5 69/13 74/15 74/17 80/5 80/24 82/17 84/17 85/3 87/4 87/12 89/16 89/21 91/24 92/24 94/6 96/19 97/6 98/15 101/22 102/10 105/16 108/24 111/23 112/4 112/4 112/5 112/22 122/18 125/12 125/25 138/1 139/20 139/21 143/24 144/18 145/23 146/23 150/8 153/21 153/23 155/19 157/17 172/21 175/4 175/7 179/11 181/23 183/7 183/16 184/23 186/3</p>	<p>186/14 187/12 187/23 189/25 192/7 192/12 198/1 198/4 199/18 199/23 202/2 205/15 209/3 216/21 217/25 220/8 227/1 229/8 229/17 238/4 238/16</p> <p>saying [35] 1/3 15/6 21/15 32/4 49/3 53/25 55/19 56/15 68/18 72/19 76/16 88/19 89/17 91/10 91/15 91/19 100/11 104/18 117/17 163/7 164/18 169/21 175/9 178/2 180/17 186/10 192/25 195/11 196/22 209/18 217/21 218/17 218/19 223/15 225/4</p> <p>says [18] 28/14 29/3 46/6 47/25 78/1 115/9 128/1 128/5 132/1 147/10 147/12 157/2 173/1 176/13 182/11 216/19 226/8 226/15</p> <p>scandal [5] 6/3 6/15 28/25 29/6 160/13</p> <p>scandals [1] 160/14</p> <p>scare [3] 212/7 218/9 218/9</p> <p>scared [1] 198/17</p> <p>scares [1] 160/8</p> <p>scaring [1] 198/9</p> <p>scenario [2] 153/9 173/18</p> <p>scenarios [1] 205/13</p> <p>scene [1] 30/7</p> <p>sceptical [1] 129/3</p> <p>scheme [44] 6/5 22/4 39/10 81/18 83/11 84/25 98/16 100/7 100/21 107/17 107/22 108/3 109/14 109/16 109/18 109/22 111/7 115/13 118/18 120/9 120/14 120/18 120/22 121/22 122/6 123/2 123/8 124/13 125/10 130/7 138/22 139/15 141/1 142/14 143/15 151/23 153/24 181/11 209/8 220/25 226/24 227/5 227/5 227/15</p> <p>schemes [26] 83/9 95/8 95/24 106/20 106/21 107/7 107/11 108/4 108/7 114/23 117/7 123/5 127/15 127/16 127/16 128/7 128/9 129/16 129/24 130/3 130/9 133/24 137/21 143/7 227/23</p>	<p>228/13</p> <p>scientists [1] 25/17</p> <p>SCM [1] 123/10</p> <p>scope [1] 163/21</p> <p>scoping [1] 214/3</p> <p>Scotland [92] 4/16 7/5 7/8 7/19 8/4 8/23 9/25 10/4 10/20 11/2 11/10 12/3 12/5 12/12 12/14 12/24 19/19 20/23 29/9 30/7 30/22 31/17 32/9 32/12 32/22 34/19 38/8 40/13 43/6 44/10 50/24 51/7 53/24 60/12 63/17 64/18 69/2 69/15 70/2 73/22 74/16 75/25 76/18 87/15 94/24 96/17 97/3 103/7 107/12 117/1 150/19 151/10 151/15 152/6 152/12 152/14 154/22 154/24 157/16 157/22 158/16 160/14 161/9 175/10 175/13 175/15 176/12 176/16 176/18 176/19 177/2 191/1 191/11 199/3 199/8 201/16 204/22 206/18 213/1 213/2 213/17 214/19 217/14 218/15 220/22 225/12 228/3 234/11 234/23 236/9 236/10 238/23</p> <p>Scotsman [2] 43/3 75/19</p> <p>Scotsmen [1] 42/12</p> <p>Scottish [103] 7/12 7/15 7/17 7/22 7/22 7/25 9/6 9/16 9/25 10/24 11/17 12/1 12/14 13/2 19/6 19/9 19/14 19/14 20/5 20/9 20/10 21/3 21/13 21/20 23/18 24/3 24/4 24/13 24/15 24/18 25/9 29/5 29/24 30/4 31/16 33/10 34/5 34/6 34/11 34/16 34/20 34/21 35/4 35/5 39/20 40/8 40/14 41/10 42/24 42/24 44/15 45/3 45/3 50/12 62/12 62/23 63/5 69/3 71/10 73/8 74/3 74/12 74/18 75/14 76/20 101/1 103/8 103/10 105/8 105/17 150/21 150/21 151/21 151/24 152/12 156/22 157/4 157/9 163/12 177/11 177/12 177/14 198/22 206/17</p>
--	--	---	---	--	---

S	seeking [9] 43/6 80/24 80/25 82/16 88/17 91/5 122/21 122/22 176/11 seeks [2] 41/16 130/5 seem [1] 56/3 seemed [1] 208/21 seems [3] 62/8 95/17 122/18 seen [11] 45/9 57/1 58/12 93/5 99/13 102/18 182/4 201/2 231/5 234/16 238/11 sees [1] 174/21 self [8] 66/16 105/19 124/23 125/2 196/11 196/12 196/16 200/21 self-assess [1] 125/2 self-assessment [1] 124/23 self-declaration [1] 105/19 self-sufficiency [4] 196/11 196/12 196/16 200/21 semantics [1] 128/11 Senedd [2] 18/6 84/1 senior [9] 32/16 40/3 75/8 136/5 160/10 210/1 210/17 218/15 228/9 sense [16] 4/13 6/8 34/22 60/20 96/9 136/20 137/6 139/16 140/11 149/6 178/5 190/2 221/13 228/19 235/14 239/4 senseless [1] 150/1 senses [2] 11/3 226/4 sensitive [1] 50/20 sent [7] 25/1 47/21 89/24 92/19 154/1 181/20 184/11 separate [6] 10/20 10/25 22/2 55/21 110/20 213/17 separated [2] 146/18 224/6 September [1] 157/7 September 1991 [1] 157/7 sequence [1] 134/4 series [3] 138/19 139/8 155/1 serious [6] 36/9 46/9 148/9 160/2 178/23 178/24 seriously [2] 147/20 201/17 servant [4] 24/13 32/16 75/8 207/18 servants [11] 22/24	23/13 91/18 136/12 137/7 139/1 196/7 196/8 196/9 199/19 199/20 serve [4] 88/25 193/7 194/12 197/5 served [4] 4/24 88/23 88/24 89/9 serves [1] 35/1 service [29] 23/19 24/11 25/9 32/9 48/10 55/10 56/21 76/21 129/1 136/20 140/9 140/17 140/18 141/5 141/6 166/9 171/15 176/17 178/12 179/1 179/1 179/8 179/11 179/20 194/11 197/4 210/3 210/19 212/5 services [21] 47/16 48/14 55/13 60/16 111/1 111/2 164/22 165/19 166/1 166/6 166/8 166/14 167/13 167/14 167/21 168/18 170/3 193/5 194/3 216/24 217/1 session [1] 211/19 set [17] 3/12 5/7 5/10 12/25 40/19 69/24 81/18 95/16 96/6 106/22 107/1 109/19 112/15 120/9 120/18 151/21 209/16 set-up [1] 151/21 sets [1] 95/14 setting [7] 4/25 5/9 40/17 73/25 75/12 87/9 96/9 settle [1] 42/5 settled [1] 72/16 settlement [4] 84/24 107/14 107/15 208/20 settling [1] 222/23 seven [2] 45/3 207/16 several [6] 3/19 33/7 63/3 95/6 189/17 229/13 severe [1] 101/25 severely [2] 105/12 186/24 shall [3] 80/5 90/18 202/2 share [5] 84/16 110/13 139/5 193/14 216/13 shared [2] 215/20 215/21 sharing [1] 126/23 she [99] 8/21 8/21 8/23 14/5 18/5 18/8 18/9 18/11 18/11	18/14 21/15 22/16 23/25 24/1 26/22 26/24 27/3 27/6 27/7 27/8 27/17 27/20 27/22 28/12 28/12 28/14 28/15 28/16 28/18 28/19 32/24 33/3 33/7 33/8 33/9 33/11 33/13 33/13 72/20 72/22 73/14 74/12 76/19 83/15 89/22 89/23 90/1 90/2 94/11 94/12 94/18 102/4 102/8 102/10 102/15 113/7 123/13 129/8 129/10 129/10 131/9 131/10 131/15 131/16 132/6 136/6 136/11 136/11 136/13 136/19 136/25 137/5 137/5 137/6 137/16 137/17 137/22 138/4 149/19 151/25 152/1 156/15 156/17 172/15 189/5 200/14 206/10 206/15 206/22 207/1 210/17 219/16 220/21 222/6 235/4 235/7 235/9 235/10 235/14 She'd [2] 32/23 89/24 she's [3] 8/1 32/14 152/17 Shetland [1] 64/19 shibboleth [1] 99/17 shocked [1] 181/4 Shona [7] 43/11 44/1 69/18 72/18 72/25 74/11 94/25 Shona Robison [7] 43/11 44/1 69/18 72/18 72/25 74/11 94/25 shone [1] 231/5 shop [1] 5/11 short [12] 51/13 143/2 146/14 148/18 156/23 157/8 158/7 158/17 159/13 160/20 201/23 202/8 short-life [1] 156/23 short-term [2] 143/2 146/14 shortly [1] 178/10 shots [1] 160/11 should [47] 2/20 3/24 16/21 22/10 26/21 36/10 38/4 41/17 45/23 56/18 59/25 60/1 60/2 64/14 85/4 89/3 89/9 100/24 115/25 121/16 132/4 137/2 137/3 145/5	148/25 156/4 156/7 156/12 157/10 166/22 171/11 171/14 174/23 183/3 187/12 197/25 203/1 204/22 209/15 215/14 216/17 216/20 217/10 221/10 223/13 231/16 233/17 shoulder [1] 128/24 shoulders [1] 232/17 shouldn't [9] 56/16 60/9 150/4 154/4 185/25 197/16 203/2 203/6 216/18 shout [1] 71/17 shouting [2] 70/21 71/4 show [6] 29/4 29/9 41/9 61/11 169/9 188/9 showing [1] 174/8 shown [1] 238/9 shows [4] 26/14 38/11 160/21 169/10 SIBF [2] 96/16 213/25 SIBSS [1] 151/24 sic [1] 153/9 sickening [1] 56/8 side [8] 38/22 39/3 52/23 55/21 101/24 122/17 122/20 237/7 sight [1] 70/2 sign [1] 42/8 signal [1] 1/12 signals [1] 99/10 signed [1] 40/21 significance [2] 127/11 217/15 significant [12] 21/21 21/23 31/18 47/14 48/6 51/2 129/24 133/14 140/20 166/9 224/18 225/3 significantly [3] 47/3 48/10 143/8 signposting [1] 5/12 signs [1] 41/23 silent [1] 174/6 silly [1] 123/3 silver [1] 44/16 similar [9] 13/3 19/21 24/14 33/1 66/8 69/3 84/7 214/1 235/4 similarly [4] 154/16 189/8 221/23 222/25 Simon [48] 1/4 1/23 2/10 2/12 2/16 3/7 4/2 13/10 51/17 78/22 86/19 126/8 128/17 131/11 132/24 134/1 138/8 145/9 147/19 149/3 150/3 150/17	153/16 154/6 163/13 163/15 177/21 187/20 189/8 191/5 191/17 192/3 192/22 197/1 199/25 202/12 203/9 204/7 223/9 223/20 225/10 226/15 229/10 229/11 235/4 237/20 240/3 240/8 Simon Hamilton [2] 131/11 132/24 Simon's [3] 9/21 13/3 40/10 simple [6] 104/8 125/5 136/24 162/15 164/19 226/12 simply [10] 11/10 23/6 23/25 28/11 41/7 43/15 143/8 206/12 234/18 238/21 since [8] 4/3 17/3 18/1 81/18 83/2 90/15 99/2 209/22 singing [1] 227/5 single [5] 26/8 70/3 120/17 172/7 188/15 sir [48] 1/5 3/15 8/12 15/4 16/21 27/25 28/5 32/18 37/16 41/3 41/7 42/19 49/3 49/16 50/16 51/6 51/7 76/3 76/25 77/15 90/13 90/16 90/19 94/16 134/22 152/15 159/3 160/15 160/23 163/14 183/21 184/21 199/17 199/23 201/19 202/4 202/10 219/9 219/10 219/24 221/14 222/20 226/8 227/21 228/16 229/15 231/22 240/7 Sir Brian [4] 1/5 134/22 228/16 231/22 Sir Chris Wormald [1] 94/16 Sir Robert Francis [1] 76/3 sister [1] 94/10 sit [2] 123/16 218/5 sitting [5] 67/7 72/21 72/23 78/3 135/9 sittings [1] 127/9 situation [20] 42/21 68/7 68/21 87/11 91/15 104/2 104/3 104/11 106/25 127/1 127/18 137/18 140/6 149/16 152/5 156/2 217/24 224/8 231/3 234/11 situations [1] 205/13 six [7] 16/3 65/13 87/8
----------	--	---	--	---	---

S	71/15 78/5 78/16 79/13 87/5 88/1 92/6 92/14 94/21 97/9 97/14 99/21 112/24 119/19 122/7 122/20 122/21 133/22 135/16 135/25 145/21 145/23 146/3 159/8 159/21 162/19 172/14 172/25 174/15 174/16 175/14 176/2 176/24 177/6 178/17 190/6 190/17 192/4 193/20 198/12 198/19 200/5 201/20 205/10 215/2 216/13 219/3 219/25 220/1 220/22 225/17 231/5 233/4 235/18 235/19 235/23	155/6 160/15 160/23 160/23 163/14 165/6 177/12 183/16 184/21 185/2 185/20 187/23 187/23 188/10 199/14 199/17 205/7 207/5 214/6 217/5 221/16 226/8 227/13 233/12 235/25 238/17	specific [10] 54/20 115/1 115/3 135/6 157/10 161/9 194/17 194/18 195/14 207/3 specifically [6] 57/14 104/12 112/16 135/25 170/16 171/5 specification [3] 55/11 56/22 171/15 spectrum [1] 43/7 speech [2] 71/11 75/7 speech [2] 71/11 75/7 spend [1] 135/12 spending [4] 11/17 117/10 117/14 151/5 spent [4] 140/20 215/7 215/23 230/15 spirit [1] 229/2 spoke [13] 62/21 63/12 63/12 84/2 94/24 169/4 173/4 180/23 180/24 182/19 184/5 212/16 212/17 spoken [7] 21/13 53/4 71/1 110/20 195/24 218/13 227/7 sponsored [1] 214/1 sponsoring [1] 136/5 sporadic [1] 127/3 spot [1] 171/22 spouses [1] 221/10 spread [1] 228/11 spreads [1] 141/7 spring [1] 141/22 Srivastava [1] 174/20 staff [4] 12/10 30/23 70/22 191/7 stage [27] 19/8 99/9 99/9 99/23 99/25 100/9 100/23 104/2 104/2 104/11 107/7 107/7 108/15 108/15 109/16 124/19 125/20 125/21 131/12 149/8 174/23 175/6 179/12 181/21 182/6 205/22 216/1 stage 1 [2] 104/11 125/20 stage 1s [3] 107/7 174/23 175/6 stage 2 [2] 99/9 216/1 stage 2s [1] 107/7 stages [1] 128/18 stake [1] 89/1 stalling [1] 140/14 stance [2] 29/24 30/3 stand [6] 78/19 180/16 191/6 199/15 231/25 231/25 standard [1] 196/22 standardising [1] 216/9	standing [1] 4/17 stark [3] 40/7 44/20 44/22 start [22] 3/7 3/15 4/2 14/8 15/10 15/13 52/11 72/17 73/5 74/15 79/2 90/9 93/7 93/20 107/6 125/24 149/3 165/15 172/15 174/2 202/16 229/10 started [19] 13/13 13/23 17/17 50/7 71/24 79/10 83/4 83/13 93/23 94/2 104/14 110/19 114/13 126/9 145/8 171/21 174/20 199/9 221/18 starting [5] 7/8 21/1 100/3 114/6 193/1 State [3] 56/20 133/20 230/9 stated [1] 131/18 statement [38] 16/23 28/24 32/6 33/21 45/15 50/17 60/19 62/18 86/19 86/21 103/19 105/22 114/4 134/2 134/13 147/2 147/3 147/19 147/25 151/2 165/2 165/19 165/23 169/10 183/12 190/25 191/8 191/23 207/8 207/9 207/21 229/11 229/19 232/7 234/4 240/8 240/9 240/10 statements [1] 65/7 states [2] 50/18 147/7 statistics [4] 67/12 102/19 183/6 183/23 stats [1] 159/21 status [3] 12/11 156/9 158/17 statutory [1] 118/13 stay [1] 107/9 staying [6] 32/3 54/24 66/16 82/5 98/21 177/20 steal [1] 148/4 stealing [1] 150/14 steely [1] 238/11 steering [2] 10/2 10/9 stemmed [1] 189/11 step [2] 12/15 95/1 steps [3] 47/5 147/7 157/5 Steven [1] 138/17 stick [2] 151/14 151/17 sticky [1] 71/21 stigma [2] 58/2 204/10	still [27] 24/12 49/15 51/4 64/18 68/5 83/10 99/9 103/12 104/1 105/7 113/11 133/20 144/12 144/14 145/21 147/24 157/22 163/12 170/10 170/14 174/23 187/6 225/23 233/6 233/7 233/11 233/12 stood [1] 60/8 stop [5] 90/6 90/10 198/24 199/11 234/8 stops [1] 151/5 Storey [1] 142/5 stories [13] 61/9 65/16 66/4 72/16 72/17 83/6 84/4 84/8 85/22 87/8 100/14 102/17 214/9 story [15] 6/18 12/18 13/11 28/8 28/14 32/12 32/23 34/4 34/7 35/5 45/9 45/9 66/2 93/8 199/2 straight [1] 28/21 strange [2] 40/25 67/19 strangely [1] 195/5 strategic [1] 219/6 strategically [1] 199/12 strategies [1] 229/20 strategy [2] 61/23 144/10 stream [1] 6/12 street [1] 171/13 strength [3] 82/24 85/23 86/13 stress [2] 150/6 230/1 stretching [1] 64/19 stroke [1] 94/1 strong [8] 83/4 85/23 88/1 96/15 119/11 217/13 225/17 237/16 strongly [4] 44/2 59/19 78/13 138/21 struck [1] 73/21 structure [1] 219/19 structures [1] 197/3 struggled [4] 9/13 31/6 143/24 190/20 struggling [6] 34/14 120/25 121/1 122/16 149/20 235/5 stuck [3] 24/8 24/10 99/9 stuff [5] 30/20 49/2 97/11 97/13 219/2 Sturgeon [5] 43/11 44/3 64/12 69/17 73/12 subject [1] 234/10
----------	---	---	---	---	---

<p>S</p> <p>submission [1] 74/22</p> <p>submissions [2] 33/8 64/13</p> <p>submit [1] 132/7</p> <p>submitted [8] 19/9 19/24 21/7 22/2 22/3 128/12 138/12 146/22</p> <p>subsequent [4] 26/12 43/23 63/13 117/14</p> <p>subsequently [7] 15/20 25/12 30/21 97/20 133/17 146/15 212/1</p> <p>substantial [2] 64/9 224/19</p> <p>substantive [2] 190/22 224/19</p> <p>succeeded [1] 232/11</p> <p>success [1] 181/16</p> <p>successful [2] 176/19 209/17</p> <p>successive [2] 196/6 232/14</p> <p>successor [1] 68/1</p> <p>such [10] 58/2 72/4 85/3 93/5 128/9 169/13 195/11 195/13 216/6 228/4</p> <p>suddenly [1] 174/11</p> <p>Sue [3] 135/25 136/5 136/14</p> <p>Sue Gray [2] 136/5 136/14</p> <p>suffered [5] 27/1 36/9 49/24 203/8 223/13</p> <p>sufferer [1] 179/12</p> <p>sufferers [13] 5/6 5/6 5/16 5/24 6/6 35/25 36/14 127/14 130/21 130/25 134/25 190/13 203/18</p> <p>suffering [4] 4/20 38/25 84/9 179/3</p> <p>sufficiency [4] 196/11 196/12 196/16 200/21</p> <p>sufficient [2] 26/2 143/4</p> <p>suggest [2] 35/21 221/22</p> <p>suggested [3] 43/2 64/16 136/13</p> <p>suggestion [1] 80/19</p> <p>suggestions [3] 40/20 64/14 65/20</p> <p>suit [2] 70/23 71/17</p> <p>suitable [2] 25/25 148/3</p> <p>sum [2] 38/23 38/24</p> <p>summary [3] 13/3 157/1 166/3</p>	<p>summer [1] 186/25</p> <p>sums [1] 225/11</p> <p>sunk [1] 41/10</p> <p>supplied [1] 165/21</p> <p>supply [2] 47/4 48/11</p> <p>support [111] 5/10 5/13 5/23 13/4 17/5 18/10 36/17 43/7 43/10 43/13 43/19 43/25 44/2 44/11 45/7 52/9 52/12 52/18 55/23 59/6 67/22 74/10 74/13 74/14 79/8 81/8 83/8 83/13 85/18 86/2 92/3 95/24 106/3 106/10 109/16 109/18 110/11 111/5 111/7 111/13 114/3 114/6 114/10 118/19 118/19 119/2 120/9 120/11 120/22 121/3 121/5 121/6 121/8 121/15 121/20 121/21 122/2 122/6 122/24 124/13 125/6 125/11 125/23 129/16 129/24 130/2 133/4 134/25 143/7 144/6 144/22 147/12 160/1 161/7 164/23 165/20 166/6 166/8 166/16 166/18 167/13 167/15 167/20 168/15 168/17 168/18 169/11 175/9 175/12 175/21 175/22 175/25 176/24 177/20 177/23 191/5 191/16 193/20 195/1 202/20 204/4 204/17 208/7 208/8 209/18 222/1 223/12 227/2 227/13 227/13 233/23</p> <p>supported [6] 60/9 84/12 86/14 196/19 204/3 220/21</p> <p>supporters [1] 5/5</p> <p>supporting [3] 13/20 44/11 169/20</p> <p>supportive [5] 43/23 45/5 70/8 79/22 203/13</p> <p>suppose [4] 86/15 173/11 192/14 222/5</p> <p>supposed [1] 141/16</p> <p>sure [25] 3/7 3/10 8/18 25/17 39/18 51/16 69/12 90/10 93/6 94/4 122/1 122/5 123/25 129/4 129/5 144/14 153/3 172/16 183/12 189/5 202/12 205/15 223/6 235/3</p>	<p>238/3</p> <p>surface [1] 120/7</p> <p>surgeon [1] 34/24</p> <p>surgery [1] 218/10</p> <p>surprise [2] 215/22 216/2</p> <p>surrogate [1] 210/24</p> <p>surrounding [1] 155/11</p> <p>survey [3] 118/10 118/11 118/17</p> <p>surveys [1] 116/24</p> <p>survivors [1] 173/9</p> <p>Susan [24] 8/3 8/15 9/2 9/17 21/14 22/9 22/12 22/15 23/5 29/15 29/23 30/2 30/9 32/3 33/20 40/1 40/5 74/22 75/22 152/14 153/7 160/6 198/21 210/15</p> <p>Susan Deacon [12] 21/14 22/9 22/12 22/15 23/5 29/15 29/23 30/2 30/9 32/3 33/20 40/1</p> <p>Susan Deacon-type [1] 40/5</p> <p>suspect [3] 210/16 210/17 236/25</p> <p>suspension [1] 140/15</p> <p>suspicion [1] 203/21</p> <p>sustainably [2] 143/5 143/6</p> <p>swallow [1] 105/5</p> <p>Swann [7] 139/22 142/4 144/2 145/15 146/7 146/25 231/16</p> <p>Swansea [2] 164/25 165/8</p> <p>sweep [1] 60/25</p> <p>sweetness [1] 231/14</p> <p>swept [1] 57/22</p> <p>swiftly [1] 231/22</p> <p>Swinney [3] 44/6 44/19 72/25</p> <p>swollen [1] 55/18</p> <p>sworn [2] 2/13 240/4</p> <p>Sylvia [3] 131/6 131/8 132/9</p> <p>Sylvia Hermon MP [1] 131/6</p> <p>sympathises [1] 27/8</p> <p>sympathy [4] 26/25 27/16 46/8 150/15</p> <p>symptoms [1] 174/8</p> <p>system [8] 34/17 113/25 127/3 129/1 130/1 133/15 141/15 144/20</p>	<p>T</p> <p>table [5] 38/20 71/21 72/20 72/22 72/23</p> <p>tactics [1] 141/21</p> <p>tagged [1] 96/14</p> <p>Tait [2] 159/13 159/17</p> <p>take [34] 2/9 8/8 21/17 23/19 24/25 27/18 27/20 41/2 51/9 51/10 53/12 60/18 68/9 74/9 90/14 93/4 102/13 128/17 133/2 134/4 138/8 144/9 148/6 148/12 186/17 191/4 194/22 197/23 197/25 200/5 201/23 211/1 218/6 219/19</p> <p>taken [19] 11/9 29/24 30/3 37/3 41/1 41/5 44/13 53/14 74/21 87/15 95/1 116/25 143/13 147/7 157/10 164/7 191/10 221/10 239/10</p> <p>takes [7] 31/22 62/5 97/25 150/22 157/4 175/1 238/25</p> <p>taking [11] 12/16 30/13 31/24 39/16 39/17 74/6 77/12 78/17 78/17 141/2 193/22</p> <p>talk [11] 2/21 2/23 19/2 66/18 70/10 76/10 100/3 120/16 168/3 173/3 215/9</p> <p>talked [19] 30/22 62/3 72/3 91/4 94/22 100/4 106/15 151/18 160/12 161/11 163/2 189/14 211/5 211/21 234/6 235/2 235/15 235/18 236/4</p> <p>talking [19] 1/24 2/7 5/11 9/21 45/1 45/1 75/5 77/23 97/10 139/11 152/17 154/16 175/20 189/22 195/14 205/12 215/17 222/18 237/5</p> <p>talks [2] 11/13 105/22</p> <p>target [1] 96/6</p> <p>task [11] 9/17 79/15 85/20 121/9 165/10 165/24 166/12 169/5 172/4 172/16 189/23</p> <p>tasted [1] 231/13</p> <p>taxes [2] 144/24 218/19</p> <p>Tayside [1] 213/3</p> <p>team [4] 125/18 167/9</p>	<p>189/15 190/3</p> <p>Teams [1] 178/15</p> <p>tears [1] 100/15</p> <p>technical [1] 25/14</p> <p>technician [1] 1/8</p> <p>technology [1] 1/16</p> <p>teenager [1] 205/23</p> <p>teeth [3] 153/1 204/9 218/13</p> <p>telephone [1] 97/12</p> <p>television [1] 71/23</p> <p>tell [35] 1/23 4/9 5/2 7/21 11/1 13/11 17/3 28/7 28/10 29/22 32/10 33/24 38/11 43/13 68/13 68/19 69/20 72/17 85/16 88/16 91/6 95/8 105/24 116/12 118/2 122/24 125/8 133/18 136/4 158/24 191/2 212/21 214/9 217/21 217/22</p> <p>telling [3] 28/13 93/8 108/21</p> <p>template [1] 132/18</p> <p>temporary [2] 143/3 146/8</p> <p>ten [13] 30/21 30/24 37/16 38/9 51/11 90/18 90/20 185/13 185/14 215/23 222/7 239/19 239/19</p> <p>ten hours [1] 222/7</p> <p>ten o'clock [2] 239/19 239/19</p> <p>ten years [4] 30/21 37/16 38/9 215/23</p> <p>tenacious [2] 213/8 213/10</p> <p>tenacity [1] 198/25</p> <p>tend [1] 227/23</p> <p>tended [1] 136/21</p> <p>tender [1] 16/12</p> <p>tens [1] 220/3</p> <p>Terence [1] 110/8</p> <p>term [8] 7/7 13/7 28/12 36/10 65/23 143/2 146/14 221/18</p> <p>terms [89] 1/16 7/7 7/13 7/17 11/12 22/1 24/8 28/1 30/7 31/11 31/25 33/17 34/5 35/4 37/2 37/9 37/16 37/21 39/7 40/3 42/22 44/2 52/13 62/2 62/5 64/14 65/3 65/19 65/21 66/5 67/20 67/22 69/24 80/23 86/7 87/10 87/11 94/24 96/20 104/5 104/11 109/4 114/3 122/20 128/20</p>	<p>129/16 131/4 135/24 139/24 152/9 154/14 154/15 164/8 164/9 164/14 175/22 176/8 176/20 178/3 178/6 178/19 179/2 179/5 179/12 179/18 191/2 191/5 191/8 203/19 208/7 209/19 212/6 214/25 222/18 222/23 223/10 224/6 225/15 226/2 226/3 228/7 228/9 228/14 233/2 234/14 237/10 237/21 237/22 238/9</p> <p>Terrence [4] 109/5 110/18 110/19 111/16</p> <p>terrible [2] 58/2 123/9</p> <p>terrier [1] 43/17</p> <p>terrier-like [1] 43/17</p> <p>test [5] 25/16 157/5 162/13 179/14 210/24</p> <p>tested [3] 157/7 205/11 205/22</p> <p>testing [3] 46/13 210/24 211/7</p> <p>text [1] 102/14</p> <p>texted [2] 102/2 102/10</p> <p>than [27] 12/20 13/8 28/5 29/20 42/7 65/14 66/3 68/17 76/22 107/19 108/3 124/18 128/22 140/12 153/1 183/18 185/13 187/10 195/8 200/2 202/3 207/8 220/2 222/19 227/4 237/23 238/11</p> <p>thank [35] 1/18 2/8 3/9 3/14 4/1 15/6 17/1 25/5 35/13 47/23 51/19 86/20 90/7 90/19 90/21 91/1 115/8 148/14 148/16 153/5 183/21 200/7 202/4 202/10 207/4 221/2 229/7 229/12 229/16 232/4 234/1 236/14 238/20 239/6 239/14</p> <p>thanked [1] 139/2</p> <p>thanks [2] 127/25 236/5</p> <p>that [1336]</p> <p>that I [12] 16/5 53/20 54/13 61/5 69/8 94/9 112/8 137/7 141/5 198/4 223/23 235/24</p> <p>that I'd overlooked [1] 152/11</p> <p>that is [10] 2/21 75/16 131/24 141/7 189/20</p>
---	--	---	--	--	--

<p>T</p> <p>that is... [5] 198/3 200/7 222/2 229/1 230/21</p> <p>that's [94] 2/7 4/5 7/3 7/20 10/22 11/9 21/6 22/7 23/24 24/15 26/12 28/2 29/19 33/13 35/9 37/6 44/19 49/13 54/17 55/7 62/17 63/7 74/21 77/7 77/19 78/4 78/8 78/13 78/14 86/4 87/3 92/23 93/23 94/7 102/16 102/16 107/25 111/4 112/5 113/19 114/18 116/11 116/15 117/12 117/25 125/10 125/10 132/1 132/23 134/1 138/8 139/10 141/17 143/17 150/6 151/9 152/4 152/8 153/25 162/24 164/18 168/4 170/22 175/4 175/14 175/15 175/19 177/8 177/11 179/16 183/25 189/11 190/4 193/23 194/6 194/15 194/23 196/19 198/4 199/15 200/22 200/22 208/1 208/19 212/20 217/23 219/17 220/8 223/3 223/7 227/17 227/20 229/6 238/22</p> <p>their [94] 3/19 6/10 13/11 22/25 27/10 40/3 41/14 41/17 42/8 43/1 45/7 45/10 50/22 55/24 57/3 58/3 59/25 79/11 79/12 80/3 84/2 84/11 87/8 88/9 89/10 95/25 100/14 104/20 106/15 107/6 108/9 108/24 110/13 111/9 113/18 114/17 118/8 118/14 120/1 124/19 125/25 131/20 140/22 141/9 141/17 143/21 144/21 146/9 154/11 155/25 156/11 157/15 160/1 160/11 164/12 165/22 166/22 171/8 171/18 173/20 174/9 181/22 184/18 187/18 188/2 188/16 189/3 189/7 190/19 196/21 197/4 197/5 197/8 197/11 197/18 198/3 202/25 204/9 208/19 210/20 214/9 216/25 219/18 220/8 220/13</p>	<p>221/12 222/12 232/20 233/14 233/18 233/18 233/19 233/24 237/6</p> <p>them [75] 32/13 38/14 39/21 45/20 55/5 55/21 55/23 57/6 57/23 58/5 58/18 61/24 63/4 66/19 74/23 74/23 75/6 77/6 77/24 79/20 83/1 89/4 89/6 96/6 105/4 109/1 112/7 113/20 113/21 119/25 122/14 123/18 123/25 127/12 127/13 128/2 136/4 141/16 156/2 156/2 160/1 160/1 160/19 162/24 163/7 165/14 168/11 170/4 173/8 177/8 184/17 187/5 189/9 189/13 190/21 192/13 197/8 198/4 198/9 198/23 201/4 201/4 210/19 211/24 213/18 215/15 217/11 217/21 218/19 220/11 222/1 225/8 232/19 233/24 239/12</p> <p>themselves [8] 22/25 23/11 23/12 75/17 84/9 105/4 125/8 232/23</p> <p>then [154] 2/17 6/11 9/15 10/19 14/9 15/11 15/14 15/17 16/1 21/14 21/19 23/15 26/18 29/5 30/23 34/21 34/25 35/7 36/4 38/2 38/16 39/1 39/3 45/10 45/19 46/12 46/14 46/21 47/7 47/20 47/21 49/16 50/7 50/10 53/19 58/19 64/12 71/24 76/1 76/8 79/20 79/24 80/4 80/16 81/8 81/19 83/13 83/17 84/12 84/16 84/16 85/12 85/21 86/14 91/11 91/19 92/4 92/7 93/21 95/1 97/20 101/1 102/20 102/24 105/11 106/16 107/24 108/1 110/17 110/19 112/19 113/17 114/15 114/21 114/25 115/21 116/9 117/4 117/16 118/14 118/21 119/18 120/8 121/12 121/18 124/22 124/25 125/8 125/14 125/16 126/7 127/2 127/4 130/12 132/21</p>	<p>134/2 134/6 141/22 142/21 145/6 145/14 148/3 148/13 150/12 151/3 151/6 154/23 156/19 157/12 157/17 164/2 165/14 166/3 166/11 166/20 167/17 169/25 171/18 173/3 173/12 174/3 174/11 174/12 174/20 181/20 185/5 186/2 186/21 187/3 187/8 187/24 187/25 188/19 189/5 189/7 191/25 197/12 200/15 202/2 202/14 208/5 210/14 211/6 211/18 214/1 215/25 218/22 219/17 223/21 225/8 225/12 226/25 228/3 235/22</p> <p>there [279]</p> <p>there'd [6] 28/9 75/4 75/6 81/22 86/2 206/24</p> <p>there's [42] 40/9 65/10 69/6 87/21 95/17 99/19 101/13 104/6 108/18 116/18 120/18 126/2 126/4 140/11 140/11 151/2 152/5 153/18 155/18 161/4 164/11 164/24 174/1 177/9 177/22 178/6 178/18 178/25 182/12 182/13 194/9 195/25 214/17 216/11 217/13 217/15 218/16 227/12 228/6 230/19 230/25 234/11</p> <p>therefore [23] 4/13 6/7 10/5 24/3 41/20 91/16 91/24 127/11 131/1 131/9 132/3 137/20 141/16 144/16 144/25 151/13 156/12 167/11 197/8 215/19 223/25 224/20 228/8</p> <p>these [50] 3/17 22/10 22/18 25/7 26/7 26/7 30/13 36/8 44/23 46/11 48/3 56/14 67/25 68/20 71/20 73/2 75/10 77/23 78/3 89/7 99/4 102/17 102/17 112/6 113/22 115/24 119/15 123/5 125/21 142/15 158/23 162/5 162/6 162/8 163/5 169/9 171/13 171/14 181/15 182/15 184/11 187/11 198/21 200/3 205/13 210/17</p>	<p>220/24 236/10 236/10 238/23</p> <p>they [392]</p> <p>they'd [39] 37/14 45/8 52/10 54/4 54/6 54/16 55/6 56/5 56/14 57/2 57/8 61/4 81/3 81/4 81/8 81/17 81/17 82/3 82/4 84/14 84/14 84/15 91/24 106/15 106/22 108/13 109/20 112/13 113/17 117/21 120/3 120/3 140/21 162/21 163/8 170/12 198/17 208/20 211/24</p> <p>they'll [4] 90/5 100/15 134/20 152/3</p> <p>they're [45] 12/25 60/17 64/18 108/21 110/22 110/22 114/17 119/24 120/20 120/22 121/24 121/25 122/12 123/24 124/16 125/19 125/19 126/6 150/10 151/5 161/22 161/22 163/5 163/6 170/3 173/21 173/25 174/1 174/5 174/8 175/5 175/7 175/7 175/8 175/8 182/16 185/17 187/6 200/20 201/6 213/5 217/1 217/2 233/25 236/12</p> <p>they've [11] 95/20 99/15 113/24 121/3 125/22 161/11 162/20 174/24 203/7 204/12 207/24</p> <p>thing [34] 33/5 55/20 68/17 73/3 75/16 79/14 81/3 81/20 82/20 91/19 94/8 97/8 97/18 99/10 100/3 101/8 109/3 110/17 117/20 118/20 124/9 144/3 160/8 169/1 170/6 191/16 195/8 199/11 209/14 210/15 211/7 216/20 228/2 235/10</p> <p>things [30] 15/16 19/8 34/6 49/18 54/1 58/12 59/12 62/23 66/3 71/21 74/17 79/19 94/23 99/6 109/25 120/24 122/15 137/3 146/23 147/6 174/2 176/16 184/11 197/13 199/11 209/5 213/23 216/2 217/19 236/10</p> <p>think [190] 1/3 1/23 3/12 8/9 8/19 11/5</p>	<p>11/13 14/21 16/1 21/4 24/2 24/16 30/18 31/13 32/8 33/19 34/1 34/14 35/3 35/12 37/1 37/14 41/4 42/17 43/10 43/20 44/12 44/20 54/6 55/7 60/19 61/3 63/6 63/11 65/12 65/14 67/6 67/24 68/2 70/13 71/15 71/22 72/6 72/25 75/3 77/20 78/5 78/7 80/15 81/25 82/11 86/10 87/20 87/23 89/17 89/25 91/9 93/5 93/9 93/10 99/6 99/19 100/17 100/24 102/19 102/21 104/7 105/9 107/8 107/21 110/20 112/18 113/5 117/11 117/17 117/20 117/25 118/3 119/24 126/10 128/6 133/5 133/8 133/12 143/17 144/8 146/15 148/3 149/5 149/10 150/11 150/14 152/4 152/15 154/7 155/19 156/24 159/20 161/12 162/20 163/6 163/17 164/24 170/21 176/5 176/22 178/1 178/3 178/6 178/25 182/10 183/9 183/11 183/14 184/19 185/13 189/19 190/11 190/16 193/7 194/14 194/16 195/2 195/25 196/6 197/2 197/6 197/7 199/7 199/19 200/4 200/7 200/10 201/24 203/11 203/21 203/23 204/1 204/6 205/18 206/2 206/15 207/7 207/20 207/25 208/13 208/13 209/13 210/5 210/5 210/15 212/12 214/2 215/14 215/16 216/3 216/5 216/10 216/17 216/18 216/19 216/21 216/22 217/10 219/22 222/20 223/22 224/22 225/1 225/19 226/10 226/21 226/24 226/24 227/6 227/10 227/13 228/18 229/5 229/8 236/13 236/19 237/14 237/23 237/25 238/6 238/7 238/14 239/3 239/14</p> <p>thinking [10] 20/6 33/25 37/1 37/10 64/1 70/5 99/3 108/2 137/2</p>	<p>211/11</p> <p>third [6] 14/7 20/1 23/4 97/18 129/21 131/17</p> <p>this [320]</p> <p>Thompsons [6] 10/3 10/10 30/16 66/19 68/9 68/11</p> <p>thorough [1] 23/21</p> <p>those [114] 3/20 3/21 3/24 5/21 5/22 6/8 8/9 8/10 12/19 18/22 18/24 22/4 24/1 31/17 38/24 39/5 40/2 40/17 41/25 43/16 44/17 44/19 44/20 44/21 45/7 46/8 52/4 52/10 52/20 52/21 53/18 53/23 54/1 57/21 58/16 60/3 72/19 73/19 75/25 88/17 95/8 98/6 100/8 104/3 105/16 105/25 106/8 111/10 111/19 112/14 117/2 118/2 119/7 119/10 125/11 126/18 130/4 131/20 138/22 142/19 143/9 143/11 145/9 145/15 145/16 145/17 146/7 149/23 150/14 157/23 158/11 158/21 159/15 159/17 159/24 160/5 161/19 163/19 167/21 168/18 174/3 177/10 179/3 189/6 189/17 190/1 193/6 194/1 195/22 196/8 197/25 200/14 200/25 201/19 202/16 203/21 211/13 211/13 214/14 216/2 216/13 219/21 220/25 223/13 224/22 225/11 226/7 230/8 232/21 233/17 236/13 236/19 237/5 237/11</p> <p>though [6] 22/16 121/13 174/24 187/24 206/23 236/22</p> <p>thought [32] 10/9 11/16 16/9 18/8 21/16 29/12 33/5 52/5 53/21 61/4 71/19 72/3 73/22 92/5 92/14 101/23 105/4 108/5 108/19 109/25 111/7 112/4 117/22 123/11 124/11 150/20 180/18 184/1 185/7 192/9 225/20 233/19</p> <p>thoughts [1] 229/13</p> <p>thousand [1] 221/15</p>
--	--	---	--	---	--

<p>T</p> <p>thousands [2] 211/14 220/3</p> <p>three [30] 13/15 16/4 30/9 44/23 45/7 50/4 84/13 86/18 101/9 104/23 110/20 118/13 119/20 119/21 125/5 145/10 176/25 181/18 191/24 194/2 195/21 202/11 202/13 206/25 213/21 215/13 228/21 228/25 236/19 236/25</p> <p>three years [5] 119/21 176/25 191/24 228/21 228/25</p> <p>three-year [1] 119/20</p> <p>threw [1] 71/22</p> <p>through [56] 3/19 6/11 12/6 18/23 26/13 26/25 27/2 41/14 46/4 46/9 46/19 47/13 49/19 50/6 52/15 57/3 68/4 77/21 93/21 94/10 94/16 94/18 97/18 97/23 97/24 99/5 101/22 120/16 124/6 125/14 133/15 136/24 136/25 146/5 152/16 157/15 158/1 166/22 171/17 176/12 177/11 178/15 179/15 180/10 181/5 181/7 181/8 185/11 188/3 198/10 200/12 205/20 208/24 218/3 237/3 238/12</p> <p>through -- initially [1] 136/24</p> <p>through A [1] 57/3</p> <p>throughout [5] 34/7 176/23 218/23 229/25 234/16</p> <p>throw [2] 77/2 215/2</p> <p>throwing [1] 218/11</p> <p>thrown [1] 215/3</p> <p>thunder [1] 148/4</p> <p>Thursday [1] 1/1</p> <p>Thursz [7] 181/23 181/24 182/1 182/8 185/21 185/25 186/6</p> <p>tied [1] 149/11</p> <p>tiers [1] 70/19</p> <p>ties [1] 32/8</p> <p>tight [1] 96/9</p> <p>tightening [1] 195/18</p> <p>tighter [2] 195/19 195/19</p> <p>time [103] 4/16 7/24 10/24 11/6 13/24 14/1 14/7 19/5 21/23 24/15</p> <p>24/16 28/14 29/15 31/8 33/17 37/2 37/15 40/19 43/5 43/12 44/22 45/14 45/19 46/23 48/25 49/19 49/21 51/9 51/25 54/9 55/17 56/7 56/11 59/4 66/8 66/8 67/9 67/19 67/24 68/23 76/15 81/1 81/13 82/1 82/11 84/23 85/19 92/13 92/19 93/3 93/23 94/11 96/5 97/16 97/25 99/7 99/12 101/12 103/11 109/15 131/9 135/12 136/6 136/12 147/3 153/22 153/22 156/20 160/6 160/9 162/4 168/16 173/16 173/16 174/22 181/2 184/8 185/14 189/21 192/17 195/24 200/3 201/20 205/8 206/21 207/1 208/13 208/14 211/3 214/4 217/1 217/15 218/2 220/6 222/7 222/7 223/4 226/2 228/8 229/24 232/22 236/7 238/21</p> <p>time-consuming [1] 46/23</p> <p>timeline [1] 51/8</p> <p>times [13] 35/3 43/20 44/3 64/24 66/21 78/6 192/1 199/24 203/24 205/13 206/20 213/9 239/8</p> <p>timing [2] 6/1 210/11</p> <p>tired [1] 214/6</p> <p>title [1] 139/9</p> <p>to [1486]</p> <p>to -- if [1] 113/7</p> <p>to MSPs [1] 62/10</p> <p>today [17] 2/3 2/21 47/16 48/14 51/5 54/22 64/17 65/3 69/7 103/15 148/24 193/22 215/3 232/8 236/18 237/23 238/22</p> <p>together [16] 17/16 22/6 56/24 59/24 63/7 66/5 68/9 69/17 72/5 79/11 108/17 124/2 138/16 168/5 189/6 237/1</p> <p>told [10] 54/6 58/18 85/22 108/6 110/17 110/23 113/19 130/22 181/2 221/4</p> <p>Tom [1] 235/25</p> <p>Tommy [2] 103/7</p>	<p>103/11</p> <p>tomorrow [3] 239/16 239/17 239/20</p> <p>too [6] 100/20 122/7 144/15 168/17 174/12 200/8</p> <p>took [22] 5/20 11/14 12/3 12/5 22/19 28/8 34/25 44/8 46/24 47/2 48/8 49/11 50/4 61/17 79/25 91/13 118/15 121/10 153/12 186/7 218/3 226/2</p> <p>top [4] 79/3 115/9 155/8 192/19</p> <p>topic [2] 164/20 190/22</p> <p>Tories [1] 45/1</p> <p>total [3] 6/8 65/9 211/9</p> <p>totally [4] 3/14 115/24 147/14 229/2</p> <p>touch [3] 58/9 71/9 120/7</p> <p>touched [1] 238/18</p> <p>touching [1] 176/5</p> <p>toward [1] 65/4</p> <p>towards [5] 30/4 54/22 67/3 103/15 143/3</p> <p>Towers [3] 156/3 156/10 156/15</p> <p>trace [1] 131/11</p> <p>traced [7] 158/9 158/10 158/11 158/19 158/20 158/21 159/22</p> <p>track [1] 131/14</p> <p>tracking [1] 156/13</p> <p>traditional [1] 129/1</p> <p>trail [2] 230/20 231/10</p> <p>train [1] 112/19</p> <p>training [2] 112/20 174/17</p> <p>transferred [2] 109/5 113/14</p> <p>transfusion [22] 17/8 17/22 23/19 25/9 48/10 76/21 125/17 126/5 157/6 157/15 157/21 159/16 161/21 162/17 162/22 175/5 176/6 195/6 210/3 210/18 212/5 214/15 126/5 157/6 157/15 157/21 159/16 161/21 162/17 162/22 175/5 176/6 195/6 210/3 210/18 212/5 214/15</p> <p>transfusions [8] 22/5 121/19 165/22 176/14 177/5 177/19 213/16 214/19</p> <p>transmission [7] 8/5 8/18 14/24 14/25 183/8 183/10 183/19</p> <p>transparency [3] 232/18 233/1 233/7</p>	<p>transparent [2] 141/11 216/18</p> <p>transparently [1] 147/18</p> <p>transplant [5] 56/13 104/6 174/4 179/20 187/9</p> <p>transplants [2] 101/23 187/6</p> <p>trauma [1] 178/21</p> <p>traumas [1] 178/19</p> <p>traumatic [1] 37/8</p> <p>travel [2] 54/4 130/6</p> <p>travelled [1] 199/24</p> <p>travelling [2] 20/17 136/10</p> <p>Treasury [10] 145/1 149/14 150/4 151/1 151/3 151/7 153/15 153/17 154/4 224/24</p> <p>treat [1] 160/1</p> <p>treated [7] 25/11 26/1 188/4 188/6 203/6 203/20 203/20</p> <p>treatment [38] 8/25 25/18 26/10 26/23 27/2 27/10 36/10 46/4 46/9 46/19 48/25 49/23 101/24 102/6 126/1 129/16 154/23 163/9 163/23 166/24 167/13 175/18 175/18 180/22 185/15 185/17 185/25 187/7 187/9 188/10 198/11 202/20 202/25 203/14 203/25 204/4 204/12 225/15</p> <p>treatments [6] 125/22 180/4 181/18 181/19 182/15 188/8</p> <p>tremendous [1] 236/12</p> <p>trials [1] 234/10</p> <p>Tribunal [1] 91/12</p> <p>tribute [2] 63/1 69/6</p> <p>tried [7] 6/12 25/23 62/25 66/12 92/6 109/19 137/14</p> <p>trolleys [1] 55/18</p> <p>trouble [1] 232/23</p> <p>troublemaker [2] 54/14 55/1</p> <p>true [2] 170/23 208/1</p> <p>truly [1] 232/16</p> <p>trust [35] 36/15 105/22 105/24 106/2 109/4 109/6 109/24 110/8 110/18 110/20 111/16 113/1 113/2 113/9 113/13 151/19 163/20 174/16 178/7 181/5 184/3 189/9</p>	<p>189/14 189/17 189/18 189/23 190/4 190/12 203/22 215/18 215/19 216/3 216/4 235/9 235/10</p> <p>trusted [4] 105/3 230/8 230/12 230/13</p> <p>trustee [7] 11/6 16/10 123/7 180/7 184/8 208/12 208/17</p> <p>trustees [6] 92/11 93/1 123/2 192/16 195/11 220/1</p> <p>trusts [3] 110/1 120/15 156/11</p> <p>truth [10] 26/11 27/25 28/1 28/1 92/10 108/8 108/8 196/2 232/15 233/22</p> <p>try [19] 6/12 13/7 30/12 78/10 79/12 84/14 92/14 108/14 109/2 120/13 124/1 126/17 127/12 127/19 133/23 156/8 160/19 164/4 173/8</p> <p>trying [21] 20/19 50/14 50/15 54/3 56/7 62/24 66/18 112/7 113/11 129/5 132/11 133/11 140/24 140/25 164/1 176/17 181/9 182/11 182/15 193/7 194/12</p> <p>Tuesday [2] 213/24 235/18</p> <p>tumours [1] 187/10</p> <p>turn [6] 51/21 78/22 80/10 156/24 165/13 169/25</p> <p>turned [3] 215/7 215/8 230/10</p> <p>turning [1] 83/14</p> <p>turnover [1] 193/9</p> <p>tweaks [2] 82/2 108/7</p> <p>twenty [6] 46/25 48/8 49/11 148/13 148/15 202/1</p> <p>twenty-five [2] 148/13 148/15</p> <p>twin [1] 179/18</p> <p>two [32] 22/5 24/4 52/11 67/7 68/3 70/19 74/17 90/18 90/20 101/9 101/25 116/21 127/24 154/21 156/20 161/2 176/25 177/10 187/5 191/7 192/2 195/20 205/21 206/25 207/6 208/17 212/22 213/23 217/18 218/5 221/15 230/13</p>	<p>189/14 189/17 189/18 189/23 190/4 190/12 203/22 215/18 215/19 216/3 216/4 235/9 235/10</p> <p>trusted [4] 105/3 230/8 230/12 230/13</p> <p>trustee [7] 11/6 16/10 123/7 180/7 184/8 208/12 208/17</p> <p>trustees [6] 92/11 93/1 123/2 192/16 195/11 220/1</p> <p>trusts [3] 110/1 120/15 156/11</p> <p>truth [10] 26/11 27/25 28/1 28/1 92/10 108/8 108/8 196/2 232/15 233/22</p> <p>try [19] 6/12 13/7 30/12 78/10 79/12 84/14 92/14 108/14 109/2 120/13 124/1 126/17 127/12 127/19 133/23 156/8 160/19 164/4 173/8</p> <p>trying [21] 20/19 50/14 50/15 54/3 56/7 62/24 66/18 112/7 113/11 129/5 132/11 133/11 140/24 140/25 164/1 176/17 181/9 182/11 182/15 193/7 194/12</p> <p>Tuesday [2] 213/24 235/18</p> <p>tumours [1] 187/10</p> <p>turn [6] 51/21 78/22 80/10 156/24 165/13 169/25</p> <p>turned [3] 215/7 215/8 230/10</p> <p>turning [1] 83/14</p> <p>turnover [1] 193/9</p> <p>tweaks [2] 82/2 108/7</p> <p>twenty [6] 46/25 48/8 49/11 148/13 148/15 202/1</p> <p>twenty-five [2] 148/13 148/15</p> <p>twin [1] 179/18</p> <p>two [32] 22/5 24/4 52/11 67/7 68/3 70/19 74/17 90/18 90/20 101/9 101/25 116/21 127/24 154/21 156/20 161/2 176/25 177/10 187/5 191/7 192/2 195/20 205/21 206/25 207/6 208/17 212/22 213/23 217/18 218/5 221/15 230/13</p>	<p>two paragraphs [1] 127/24</p> <p>two tiers [1] 70/19</p> <p>two years [1] 52/11</p> <p>twofold [1] 86/16</p> <p>tying [1] 181/10</p> <p>type [3] 40/5 105/14 151/18</p> <p>types [1] 25/22</p> <hr/> <p>U</p> <p>UK [23] 4/12 9/5 9/15 11/7 11/14 16/17 31/8 31/12 39/10 53/1 53/22 59/22 60/6 114/15 118/10 131/22 143/7 147/11 147/12 157/16 170/21 196/17 232/25</p> <p>UK Government [1] 31/8</p> <p>UK-wide [1] 31/12</p> <p>UKHCDO [2] 56/3 124/5</p> <p>ultimate [1] 93/22</p> <p>ultimately [4] 132/2 152/10 172/1 172/18</p> <p>um [5] 8/15 123/3 204/20 206/10 212/12</p> <p>umbrella [1] 20/5</p> <p>umpteen [1] 201/14</p> <p>unable [2] 15/24 27/9</p> <p>unanimous [5] 83/20 83/22 84/5 85/9 105/6</p> <p>uncle [2] 56/12 207/11</p> <p>uncover [3] 47/11 48/5 50/25</p> <p>Uncovering [1] 230/4</p> <p>undemocratic [1] 9/16</p> <p>under [36] 6/8 6/14 27/25 29/9 36/14 39/1 42/2 46/15 57/22 60/25 88/4 107/21 111/6 117/18 123/2 123/8 124/12 127/4 128/5 130/20 132/4 138/17 139/9 139/14 145/4 149/23 157/1 158/14 164/13 165/17 165/25 173/19 173/25 178/14 221/15 224/22</p> <p>underestimate [1] 46/11</p> <p>underground [1] 207/15</p> <p>underlined [1] 166/5</p> <p>underlining [1] 155/18</p> <p>understand [21] 3/3 4/11 73/18 85/12</p>
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<p>U</p> <p>understand... [17] 110/10 114/10 132/13 150/13 184/15 184/16 184/23 192/14 204/1 208/8 215/17 218/12 224/12 225/4 225/5 232/24 233/20</p> <p>understandable [2] 11/7 25/14</p> <p>understanding [15] 9/24 10/23 31/14 34/9 47/4 48/11 90/2 93/19 111/22 116/4 179/23 193/17 198/12 198/15 216/11</p> <p>understood [3] 1/17 18/11 223/15</p> <p>undertake [2] 23/6 97/4</p> <p>undertakings [1] 67/25</p> <p>underwhelming [1] 88/21</p> <p>undiagnosed [2] 157/16 157/25</p> <p>unease [1] 28/25</p> <p>unfair [1] 111/8</p> <p>unfortunately [5] 42/20 67/13 195/16 199/12 213/5</p> <p>unhappy [1] 130/1</p> <p>unit [2] 177/8 201/1</p> <p>united [6] 2/5 3/5 17/20 134/25 135/4 224/5</p> <p>United Kingdom [4] 2/5 3/5 135/4 224/5</p> <p>University [1] 166/10</p> <p>unknown [1] 156/9</p> <p>unless [7] 57/14 133/14 164/17 169/23 169/24 173/17 175/5</p> <p>unlike [2] 65/9 76/13</p> <p>unlikely [1] 48/5</p> <p>unmonitored [1] 174/5</p> <p>unpersuasive [1] 219/15</p> <p>unsatisfactory [2] 131/2 131/3</p> <p>Unsurprising [2] 130/17 130/17</p> <p>untangle [1] 128/11</p> <p>until [20] 20/18 25/18 28/8 30/2 51/11 52/12 74/18 74/18 127/1 127/3 141/23 141/25 148/13 176/21 207/10 207/12 207/19 226/7 227/6 239/22</p>	<p>until 2011 [1] 52/12</p> <p>unusable [1] 25/22</p> <p>unwell [1] 15/23</p> <p>unwillingness [1] 233/4</p> <p>up [120] 3/12 4/25 5/7 5/9 5/10 5/20 14/16 18/3 20/8 20/17 21/16 23/2 25/4 28/21 29/5 33/15 35/15 37/16 38/3 38/6 40/17 40/20 45/13 46/14 48/23 49/2 49/25 50/2 53/14 55/17 57/6 60/8 62/7 62/11 62/13 69/23 71/13 75/7 75/20 76/5 77/3 78/21 78/24 80/9 81/18 87/9 88/11 94/23 97/21 98/1 98/12 98/17 98/22 99/10 102/10 103/14 104/25 105/20 106/22 107/1 108/24 109/19 112/6 112/15 113/3 116/11 120/1 120/9 120/18 124/11 125/1 126/8 127/1 129/19 129/21 132/17 134/3 134/6 140/24 142/2 142/6 145/10 145/15 147/15 151/21 152/13 159/10 159/14 163/3 163/4 166/21 169/2 172/11 173/14 176/15 180/16 182/18 186/22 187/19 193/1 193/2 194/13 196/1 198/19 199/11 199/11 199/15 200/7 201/9 218/20 219/7 226/13 228/21 230/13 230/14 230/19 231/10 232/2 238/21 239/7</p> <p>uplift [4] 142/17 146/5 149/20 149/21</p> <p>uplifted [1] 137/21</p> <p>upon [4] 64/11 68/14 199/5 238/19</p> <p>upset [1] 72/2</p> <p>upsetting [1] 122/8</p> <p>urge [1] 23/17</p> <p>urgency [3] 16/15 74/10 184/16</p> <p>urgent [1] 195/8</p> <p>us [142] 1/24 1/25 3/5 4/9 5/2 5/9 6/4 6/10 6/11 7/21 9/17 11/1 12/6 12/12 12/23 13/11 15/16 17/3 20/24 24/16 27/20 28/13 28/20 28/20 29/22 31/17 31/22</p>	<p>31/24 32/10 33/24 37/12 38/3 38/11 39/16 39/17 40/9 43/13 45/5 51/17 61/10 62/5 63/3 65/5 66/11 68/4 68/10 68/12 68/15 68/18 69/20 72/23 73/6 75/24 76/9 77/24 85/16 86/6 86/13 86/14 88/16 91/6 92/9 92/22 95/8 96/14 98/11 98/18 100/16 102/21 104/13 104/23 105/24 108/6 108/21 116/12 118/2 119/8 122/24 123/10 127/1 127/19 133/18 134/2 135/19 136/4 138/8 139/16 141/12 141/13 145/25 147/18 152/1 153/10 153/12 158/24 159/21 173/5 176/22 178/18 180/9 182/23 189/16 191/2 191/9 193/5 194/22 194/24 195/8 197/9 198/8 198/9 198/13 198/16 198/17 198/18 200/10 202/12 205/25 207/22 210/19 210/21 212/21 213/6 214/18 215/10 215/10 217/8 217/8 220/21 221/4 226/4 230/8 230/9 235/15 235/15 236/11 237/6 237/14 237/16 238/9 239/2 239/13</p> <p>usable [1] 25/24</p> <p>use [8] 7/6 13/7 64/16 112/17 142/24 179/2 226/20 238/8</p> <p>used [12] 22/14 34/5 44/19 79/21 111/17 112/18 150/7 150/9 156/5 178/13 221/18 237/23</p> <p>useful [7] 4/21 30/20 127/12 144/10 190/2 193/2 213/24</p> <p>usefulness [1] 179/2</p> <p>uses [1] 28/12</p> <p>usual [3] 2/20 2/25 82/20</p> <p>usually [1] 194/24</p> <p>utilised [1] 178/13</p> <p>Utterly [1] 64/4</p>	<p>169/17 170/1</p> <p>Valley [1] 80/16</p> <p>valuable [3] 44/21 131/4 133/5</p> <p>value [2] 133/14 239/12</p> <p>variant [1] 61/16</p> <p>variant CJD [1] 61/16</p> <p>variations [1] 236/23</p> <p>varied [2] 237/13 237/14</p> <p>various [13] 2/4 3/18 14/18 43/19 64/13 65/20 65/24 66/22 79/5 111/17 166/7 169/22 222/8</p> <p>vary [1] 143/7</p> <p>varying [1] 127/16</p> <p>vast [1] 234/9</p> <p>Vaughan [5] 82/13 85/13 85/24 116/9 116/22</p> <p>Vaughan Gething [3] 85/13 85/24 116/22</p> <p>veer [1] 83/5</p> <p>vehicle [1] 219/23</p> <p>Velindre [1] 120/18</p> <p>verbal [1] 229/21</p> <p>very [150] 1/11 7/25 8/15 8/16 8/22 9/3 9/20 11/1 11/6 11/8 13/3 15/17 16/16 18/25 20/4 20/12 20/19 21/1 21/22 33/2 33/2 34/12 38/14 40/3 44/3 44/5 44/22 45/5 45/6 45/23 47/8 49/18 49/21 50/20 52/23 54/23 55/6 55/24 57/19 58/17 64/5 64/22 65/4 67/14 67/18 70/9 72/2 72/2 73/5 76/14 77/17 78/13 81/15 87/3 87/20 88/22 90/12 91/9 96/3 96/9 97/25 97/25 99/5 99/9 99/22 100/15 101/20 108/16 112/23 112/25 113/22 115/22 119/11 122/12 123/24 124/16 124/16 124/20 126/20 127/2 129/5 132/10 135/10 135/10 136/11 136/15 136/15 136/15 136/18 137/1 138/21 139/8 140/7 140/13 141/2 141/14 144/17 144/21 145/9 146/20 147/19 148/10 151/25 152/10 154/3 160/2 160/15 160/16 164/12 172/14</p>	<p>173/18 174/10 174/11 176/10 176/21 177/2 177/3 178/10 179/21 187/20 189/19 190/2 190/5 192/24 193/2 193/8 194/14 195/2 195/14 200/10 203/4 203/13 206/1 209/16 210/13 210/17 212/7 213/7 213/9 213/18 213/18 218/1 219/17 221/19 229/7 229/12 229/14 236/21 237/21 239/12</p> <p>vested [1] 163/19</p> <p>vexed [2] 41/11 165/2</p> <p>via [4] 20/8 36/15 44/4 78/10</p> <p>vicinity [1] 194/3</p> <p>victim [1] 6/7</p> <p>victims [18] 17/9 17/22 87/17 105/2 105/2 139/25 164/15 195/6 196/21 225/2 230/11 230/13 230/14 231/13 231/25 232/12 233/16 233/22</p> <p>victory [1] 139/16</p> <p>view [14] 11/10 36/5 48/1 50/22 51/5 130/16 132/20 147/24 148/25 153/13 154/12 195/22 202/22 225/13</p> <p>views [13] 6/10 42/10 68/22 78/17 114/17 116/24 118/6 118/8 130/5 131/21 153/16 192/22 220/22</p> <p>VIII [3] 13/24 14/4 14/6</p> <p>viral [1] 188/3</p> <p>virals [1] 187/16</p> <p>virtually [1] 193/24</p> <p>virtue [1] 137/10</p> <p>virus [5] 25/13 25/17 41/15 174/24 174/25</p> <p>viruses [1] 171/14</p> <p>visually [1] 211/20</p> <p>voice [12] 5/18 5/19 6/9 6/13 17/20 20/20 89/10 89/10 98/24 111/11 112/5 239/5</p> <p>voiced [1] 110/14</p> <p>voices [1] 237/1</p> <p>voicing [1] 171/8</p> <p>volume [1] 212/6</p> <p>volunteers [4] 92/12 111/21 192/8 192/24</p> <p>von [2] 5/6 5/16</p> <p>von Willebrand's [2] 5/6 5/16</p> <p>vote [5] 83/20 83/22</p>	<p>84/4 84/5 85/9</p> <p>voteable [1] 84/5</p> <p>voted [1] 83/18</p> <p>vulnerability [1] 235/14</p>
<p>W</p> <p>wage [3] 100/4 100/6 221/6</p> <p>wages [1] 100/5</p> <p>wailing [1] 218/12</p> <p>wait [8] 68/3 92/13 101/8 182/4 182/5 203/2 229/22 229/24</p> <p>waiting [5] 56/13 188/7 203/2 229/1 238/13</p> <p>waivers [2] 40/20 42/25</p> <p>Wales [122] 4/16 13/12 13/19 14/14 14/20 15/9 15/18 16/17 16/18 17/3 17/4 17/7 17/7 18/23 40/12 51/22 52/17 52/23 52/25 53/4 53/21 54/16 54/22 55/23 57/1 59/1 60/12 60/14 60/17 61/9 61/10 61/21 70/19 79/14 79/16 82/25 83/4 85/19 85/21 87/15 93/15 93/15 105/20 109/15 109/17 110/12 110/24 111/4 111/6 111/11 111/25 112/6 114/5 115/1 115/3 115/4 115/16 116/1 117/2 117/18 117/19 118/1 118/6 118/23 119/17 120/8 120/22 121/6 121/9 121/21 122/6 122/21 122/23 122/23 123/6 123/7 123/14 123/15 123/17 124/12 144/13 144/14 154/23 161/4 164/23 165/1 165/4 165/6 165/6 165/11 166/1 166/17 167/16 168/10 169/11 170/2 171/8 171/11 175/21 176/18 176/18 176/21 176/23 185/9 185/11 185/14 186/17 186/22 188/1 188/5 194/23 201/2 201/3 208/2 225/12 226/18 227/15 227/16 227/17 227/19 227/20 232/9</p> <p>Wales-specific [1] 115/3</p>					

<p>W</p> <p>walked [1] 180/15 walking [1] 160/4 wander [1] 160/18 want [88] 1/13 3/2 3/3 8/17 14/9 19/5 24/25 25/2 27/22 35/13 35/14 45/13 45/19 49/8 51/16 54/19 56/3 57/18 60/24 64/2 67/1 72/20 78/22 80/8 89/13 90/7 94/20 97/22 97/23 98/1 98/20 99/12 102/11 102/24 104/16 104/18 106/20 108/2 108/20 108/22 108/25 110/7 111/14 111/15 111/24 112/5 118/5 124/10 140/3 149/3 151/17 151/20 151/22 152/5 152/18 153/23 154/6 154/20 154/21 156/19 161/25 162/23 163/15 164/4 165/13 170/4 170/11 170/24 172/22 173/8 173/8 177/7 182/4 182/5 187/19 192/8 192/20 192/20 196/1 199/15 200/4 203/9 212/6 216/15 218/4 218/6 218/25 220/17 wanted [43] 6/10 6/10 9/23 24/8 27/20 28/18 28/19 38/3 50/1 56/13 60/10 60/24 66/3 90/6 96/11 98/9 98/10 98/12 98/15 101/11 108/7 108/8 108/8 108/10 108/10 109/25 111/14 118/12 118/13 119/17 122/5 152/2 155/1 158/23 162/22 173/18 175/17 192/12 206/8 214/8 229/8 235/10 239/9 wanting [2] 71/7 138/3 wants [2] 80/15 234/5 ward [1] 58/5 was [824] was behind [1] 38/17 was extended [1] 177/1 was: [1] 151/17 was: do [1] 151/17 wasn't [38] 5/8 13/17 37/4 41/3 43/22 50/11 52/20 55/22 57/14 57/16 64/21 67/15</p>	<p>69/8 75/10 83/16 86/5 88/1 96/13 107/13 107/18 109/21 111/12 112/23 116/16 118/16 122/2 122/23 133/25 136/19 163/7 165/9 168/15 170/9 174/18 174/18 206/10 215/24 228/24 waste [1] 200/3 watch [1] 64/25 watching [5] 2/3 64/17 78/16 127/15 127/16 Watkins [3] 92/24 92/25 189/15 Watt [1] 72/24 way [55] 3/11 11/19 11/19 16/14 37/12 56/23 62/23 65/16 72/15 75/23 77/1 83/17 86/5 88/22 92/10 105/21 107/1 107/9 119/16 124/20 132/14 136/24 137/14 144/23 146/3 146/12 146/17 147/17 170/15 176/23 176/23 176/23 182/25 185/24 194/6 194/7 196/2 196/3 203/15 203/16 204/5 212/9 214/9 215/4 216/6 216/8 218/6 220/25 229/4 230/17 230/19 236/25 237/15 238/16 239/14 ways [7] 20/22 87/5 99/21 195/23 214/3 236/21 239/12 we [771] we'd [55] 20/13 21/13 37/3 44/23 44/24 52/15 54/9 56/25 58/25 58/25 60/12 63/14 63/14 65/21 67/19 67/24 70/1 70/9 70/11 70/23 70/24 70/25 71/1 71/4 71/9 71/25 72/12 74/20 81/19 81/24 84/7 84/8 84/16 85/19 89/12 92/14 93/3 94/13 96/4 98/16 99/7 101/13 106/9 109/20 111/6 111/13 119/16 149/18 160/9 181/22 187/7 194/20 206/13 206/16 223/5 we'll [13] 2/9 6/25 24/8 33/15 39/25 62/13 63/23 67/4 71/17 91/25 94/22</p>	<p>148/12 221/5 we're [51] 8/19 10/12 18/16 21/16 21/25 31/2 32/11 37/18 49/7 54/20 70/5 74/24 86/17 92/11 108/16 108/19 108/20 108/25 109/1 111/1 111/20 119/15 121/2 128/16 146/4 153/25 155/4 177/21 181/10 182/11 182/14 183/20 189/22 191/6 191/10 192/7 192/23 192/23 194/5 194/6 195/1 198/14 198/14 200/6 215/17 215/18 218/19 225/23 234/25 234/25 235/1 we've [47] 13/9 16/21 18/16 23/1 24/24 35/10 40/12 48/16 62/2 81/12 82/9 90/11 94/22 99/2 105/1 116/10 129/18 147/16 152/16 153/24 155/17 159/21 163/2 164/12 175/10 175/11 176/4 176/11 184/21 187/12 193/23 194/17 194/19 195/5 195/5 199/2 199/3 201/14 205/12 215/9 217/7 217/13 225/19 226/18 227/7 228/18 235/15 weak [1] 80/4 wear [1] 58/9 weary [1] 234/25 Web [3] 64/16 64/18 65/1 website [5] 3/23 16/24 41/1 50/18 187/13 wee [1] 236/3 week [5] 67/4 69/23 70/10 222/7 222/8 weekend [2] 194/21 194/23 weeks [2] 139/22 177/4 weird [9] 33/5 67/8 67/8 67/8 68/7 68/17 68/20 68/21 68/22 welcome [6] 31/23 36/3 49/4 49/5 49/14 198/25 welcomed [3] 12/15 21/18 143/1 welfare [6] 111/5 119/2 120/11 120/19 130/25 227/2 well [176] 7/24 11/3 12/14 17/8 18/8 18/25 19/25 21/16 22/24</p>	<p>23/9 25/3 26/7 30/6 32/11 37/1 38/12 38/14 39/20 42/11 43/1 43/15 45/2 47/22 51/10 51/17 52/5 53/25 54/17 55/2 55/7 55/24 56/2 56/15 56/18 57/12 57/19 58/8 58/17 59/19 60/11 63/8 63/18 68/19 68/20 69/22 71/18 72/7 73/1 73/4 75/21 76/23 78/7 79/12 79/14 79/20 85/24 86/3 90/14 91/9 91/24 92/14 92/16 92/18 92/21 93/10 93/14 94/8 95/10 96/7 99/22 100/11 104/1 106/1 106/19 107/17 107/21 108/6 108/19 109/11 109/11 109/25 110/12 110/16 110/23 112/4 112/15 112/17 112/24 113/2 113/19 114/12 114/16 114/22 114/25 120/25 121/4 121/23 122/4 122/5 122/9 122/18 123/3 124/12 124/25 126/19 127/5 128/11 128/22 129/5 131/9 131/24 132/14 133/8 134/17 136/5 137/14 138/1 141/9 143/11 146/13 147/18 150/8 163/25 164/11 164/11 168/12 169/3 169/8 169/23 173/12 176/14 176/21 178/25 179/21 180/8 184/17 184/19 185/7 191/4 192/7 192/16 192/23 192/24 194/16 195/7 201/24 202/12 202/23 202/24 203/3 204/13 204/13 204/14 204/20 205/20 207/25 208/11 209/2 211/1 211/11 211/22 213/25 214/25 217/12 218/19 219/24 221/5 224/15 225/14 226/17 227/1 229/6 235/4 237/6 237/20 238/24 well-informed [1] 163/25 wellbeing [1] 230/7 Welsh [67] 15/10 15/14 15/15 15/17 17/10 17/11 17/14 18/6 52/22 54/17 55/4 58/12 58/15 58/19</p>	<p>58/23 59/18 60/16 61/19 73/4 79/8 81/23 81/25 82/1 82/18 83/12 83/18 84/10 85/10 85/21 86/3 86/11 86/14 89/21 91/20 95/2 107/4 109/13 109/19 110/3 110/12 113/6 115/13 115/25 116/8 118/4 118/17 118/22 119/23 120/5 124/14 125/1 167/19 168/25 169/20 169/24 170/2 170/3 171/7 171/9 181/21 185/4 185/10 186/20 186/21 188/20 192/10 233/8 Welsh Government [2] 83/18 86/14 Welsh MPs [1] 84/10 went [35] 9/17 20/6 21/9 21/10 22/6 26/16 31/14 44/6 45/10 52/10 52/22 76/1 91/19 93/1 93/1 97/6 97/7 98/23 100/20 113/11 114/18 159/8 159/17 180/20 182/18 183/3 183/25 184/4 186/2 186/21 187/5 208/17 208/24 218/18 226/9 went to [1] 31/14 wept [1] 75/23 were [383] weren't [34] 10/5 14/17 16/14 17/13 22/19 36/19 40/17 55/4 55/15 55/15 57/3 58/19 59/3 59/12 64/25 65/1 65/2 67/21 79/9 80/7 83/8 102/18 106/5 106/23 108/6 110/1 110/4 110/17 119/4 119/9 119/11 123/20 170/8 210/8 Westminster [19] 14/1 18/5 20/14 31/7 42/5 44/16 81/14 81/21 82/19 83/5 83/16 84/7 89/3 109/12 126/14 126/21 126/22 201/14 201/16 what [238] 1/13 1/24 4/18 5/2 6/12 17/3 20/11 20/23 20/24 24/16 24/25 26/6 27/11 27/19 28/3 28/7 29/23 30/3 30/25 31/4 31/6 31/6 31/19 32/10 32/10 33/24 34/5</p>	<p>36/23 38/11 38/11 38/15 38/16 38/17 39/6 39/13 40/6 41/6 42/7 43/13 44/23 47/2 48/16 49/25 51/21 52/4 54/7 56/25 59/2 59/17 62/21 64/2 64/14 66/13 68/13 69/20 69/24 70/5 70/7 70/23 71/20 72/5 72/12 73/12 75/6 75/21 76/7 76/10 76/12 76/17 76/19 76/22 77/16 77/21 77/22 78/7 79/2 80/14 80/14 80/25 80/25 82/15 86/4 86/8 86/24 88/17 88/19 88/20 89/2 89/16 90/2 90/6 91/6 92/20 93/2 94/22 95/8 95/15 97/6 97/19 98/8 98/10 99/12 100/19 102/20 103/23 104/14 105/11 105/25 106/5 107/11 108/9 108/20 108/21 109/10 110/2 110/23 111/13 111/14 111/24 112/4 112/5 112/13 113/8 113/19 113/24 114/19 116/12 116/13 117/16 118/2 118/3 118/12 118/19 119/1 120/7 121/14 122/18 122/25 123/3 128/20 130/16 132/2 132/13 133/18 135/17 136/4 139/11 139/17 140/4 142/5 143/17 145/22 148/24 149/1 150/2 152/5 152/16 153/25 155/4 155/7 156/8 157/9 158/24 159/9 160/25 161/2 163/6 163/22 164/4 167/25 168/2 168/22 169/20 172/22 172/22 175/9 175/20 175/25 178/2 180/4 180/17 182/19 184/13 184/16 185/1 185/3 185/5 186/10 186/19 191/2 192/12 192/25 195/1 195/10 196/1 198/16 199/4 199/4 200/7 202/20 204/17 206/7 209/18 210/10 210/20 210/23 212/3 212/9 212/21 214/23 215/12 215/13 215/17 215/18 217/9 217/22 217/23 218/7 219/18 219/22 222/13 222/20</p>
--	---	---	--	--	---

<p>W</p> <p>what... [16] 225/12 226/1 226/9 231/12 231/16 231/20 231/20 233/16 233/22 233/24 234/14 235/5 236/5 237/8 237/9 238/4</p> <p>what's [14] 34/8 77/8 100/11 144/5 150/13 176/19 177/24 192/6 201/14 202/21 204/18 218/7 225/13 225/15</p> <p>whatever [9] 27/9 30/18 57/25 63/9 82/2 108/25 207/20 213/22 231/7</p> <p>when [118] 3/10 3/21 5/19 6/16 6/17 11/21 12/3 12/7 12/20 13/13 13/25 14/9 14/12 17/16 19/6 23/8 24/3 28/8 30/12 30/21 36/22 39/13 43/12 43/24 44/8 45/15 48/15 49/19 52/5 52/10 61/14 61/15 62/7 64/5 65/21 67/17 70/16 72/16 75/1 76/4 79/8 85/17 86/12 88/19 91/7 91/11 92/2 92/2 92/23 93/6 100/2 100/11 102/4 104/17 107/25 109/4 112/20 113/2 114/13 117/25 118/11 119/24 123/4 125/16 127/3 128/3 128/21 130/22 134/23 136/9 137/20 138/13 140/20 142/2 150/12 150/19 152/2 152/11 152/17 159/5 167/24 168/3 168/8 168/13 173/1 178/23 179/15 180/4 180/6 180/9 180/15 180/20 182/8 183/3 184/17 189/12 191/18 193/1 195/20 196/21 197/9 197/17 203/24 205/8 205/12 205/22 208/11 209/3 212/14 215/9 216/20 221/4 225/22 230/6 231/1 231/18 234/21 239/8</p> <p>Whenever [1] 34/18</p> <p>where [74] 5/11 11/5 11/8 12/2 27/7 28/15 33/8 34/14 35/4 39/4 50/5 55/11 58/22 61/13 61/23 62/20 63/7 63/10 64/13</p>	<p>67/20 77/7 77/23 81/16 85/21 87/10 102/10 106/17 107/9 111/10 111/20 112/13 113/3 113/4 113/5 113/10 114/22 119/13 120/23 124/23 128/13 132/12 133/2 134/16 135/9 138/9 139/22 145/7 151/9 152/5 159/18 160/9 161/11 166/20 166/21 173/21 175/20 181/21 182/6 190/10 191/11 193/23 202/25 208/2 208/19 209/6 211/4 221/18 225/6 225/11 227/11 233/9 233/12 233/13 234/9</p> <p>Where's [1] 77/13</p> <p>whereabouts [1] 156/9</p> <p>whereas [6] 52/25 66/20 137/7 174/5 187/7 192/12</p> <p>wherever [1] 106/18</p> <p>whether [21] 3/10 22/9 28/11 35/24 42/4 51/4 69/11 91/6 148/25 149/3 156/1 156/7 156/12 159/25 163/8 169/9 221/10 223/12 223/12 228/10 232/1</p> <p>which [90] 2/24 9/6 11/13 13/1 14/19 15/11 16/10 20/9 25/1 25/12 28/24 30/15 30/25 33/4 37/15 41/13 42/6 45/13 46/23 46/24 47/9 47/24 48/8 49/11 51/3 64/13 67/5 67/10 80/6 97/15 100/2 107/15 110/11 117/22 119/11 123/14 123/16 125/2 125/20 126/23 130/22 131/11 131/14 132/1 134/15 135/20 138/3 141/16 143/14 146/3 146/17 146/21 147/3 158/4 166/4 167/22 168/15 169/10 170/2 176/7 178/4 178/22 178/24 179/1 181/4 181/13 183/4 187/13 187/19 190/6 190/17 194/3 205/7 205/7 212/10 214/3 214/12 216/5 217/25 220/5 220/17 222/9 222/20 225/8 229/1 229/22</p>	<p>237/16 238/17 238/22 238/25</p> <p>whichever [1] 196/2</p> <p>while [8] 22/18 34/12 129/23 144/10 177/21 229/23 229/25 234/8</p> <p>whilst [2] 143/1 155/25</p> <p>whip [2] 40/1 84/13</p> <p>whitewash [5] 70/21 71/4 73/14 73/17 86/24</p> <p>who [164] 2/7 4/20 6/10 6/10 6/14 8/3 9/23 10/3 14/1 14/20 17/12 17/12 18/3 18/4 18/19 20/15 20/16 21/19 23/9 24/13 27/1 27/8 28/4 29/10 30/18 32/21 34/22 34/24 36/9 38/14 38/24 40/2 44/6 45/4 46/8 53/2 53/11 57/9 57/18 57/24 58/1 58/4 58/23 59/24 60/10 60/15 65/9 65/11 68/6 69/7 69/10 70/19 70/20 70/20 72/22 72/22 73/19 78/11 79/25 83/25 87/17 89/18 92/8 92/22 93/8 94/10 97/10 104/3 107/5 110/21 112/2 112/25 113/23 114/10 119/4 119/17 121/19 122/7 125/6 125/13 125/13 126/2 126/19 129/12 131/20 132/24 135/1 139/1 144/2 150/13 150/19 151/3 151/5 152/10 156/15 157/6 157/7 157/15 157/16 157/21 161/4 171/7 172/4 172/24 174/7 176/1 176/6 177/4 177/5 177/7 178/23 179/10 179/18 179/19 180/13 180/14 181/17 181/21 181/23 181/24 182/22 185/14 186/5 186/12 189/2 189/15 190/3 190/19 190/19 190/19 194/14 197/21 200/12 200/13 201/1 203/25 206/22 206/25 207/1 207/10 212/14 213/4 213/16 213/20 214/8 214/14 214/18 214/19 216/13 219/21 221/11 221/12 221/24 222/10 223/13 226/13 226/20 230/8 231/16</p>	<p>232/22 233/17 235/23 236/10 236/19</p> <p>who'd [9] 22/4 31/17 65/5 104/3 159/15 159/16 159/18 222/25 223/2</p> <p>who's [3] 71/16 103/7 208/12</p> <p>whoever [2] 50/13 237/18</p> <p>whole [30] 9/4 12/18 20/7 28/1 28/1 28/8 28/13 32/23 35/5 40/4 50/21 53/14 60/25 71/3 73/5 100/3 100/7 104/3 106/12 106/12 107/13 114/14 148/5 163/2 188/1 199/10 211/7 211/17 225/20 228/11</p> <p>whom [2] 23/13 163/19</p> <p>whose [3] 156/9 158/17 236/1</p> <p>WHSCC [1] 60/15</p> <p>WHSSC [2] 166/22 171/10</p> <p>why [35] 4/9 25/14 31/9 37/15 39/19 40/16 41/23 57/6 57/10 78/13 85/3 93/11 95/23 105/3 105/3 110/12 111/8 122/24 123/4 123/20 124/9 160/3 160/5 161/5 162/11 162/12 162/13 162/13 162/14 162/24 168/18 185/24 195/22 219/14 236/18</p> <p>wide [6] 23/21 31/12 39/10 53/1 59/22 238/4</p> <p>widely [1] 65/24</p> <p>widened [1] 147/9</p> <p>wider [6] 16/17 29/18 42/10 74/6 107/14 119/5</p> <p>widow [2] 102/12 235/2</p> <p>widowers [1] 145/19</p> <p>widows [17] 92/4 99/21 99/23 99/23 99/25 100/10 107/12 112/16 112/24 117/21 119/4 119/21 119/23 145/18 146/1 146/3 235/25</p> <p>widows' [1] 100/14</p> <p>wife [8] 9/1 12/8 50/14 66/16 67/15 72/21 205/21 221/21</p> <p>wife's [2] 155/16</p>	<p>155/20</p> <p>wilderness [1] 141/25</p> <p>will [50] 2/2 2/10 3/22 13/7 16/24 28/7 28/18 42/4 50/17 51/10 67/5 74/8 78/9 78/10 91/25 93/7 95/23 115/19 115/20 117/9 117/13 125/25 128/2 128/8 130/10 131/14 131/18 132/2 147/22 148/3 149/4 154/2 164/3 175/6 179/1 187/13 192/16 193/8 194/7 209/5 218/12 225/18 226/1 229/14 231/23 232/19 233/16 233/21 236/20 237/14</p> <p>Willebrand's [2] 5/6 5/16</p> <p>WILLIAM [4] 2/14 234/4 240/5 240/10</p> <p>willing [2] 145/25 189/19</p> <p>willingness [2] 232/18 233/2</p> <p>Wilson [2] 112/10 113/4</p> <p>win [1] 168/24</p> <p>wiped [1] 205/25</p> <p>Wisdom [1] 44/17</p> <p>wish [2] 2/22 48/22</p> <p>with [295] with it [1] 114/16</p> <p>withdrawn [1] 200/22</p> <p>withdrew [1] 45/15</p> <p>within [38] 7/15 8/23 20/4 20/7 20/14 21/7 24/14 31/8 34/4 34/10 34/15 42/23 59/13 66/10 67/22 118/24 126/21 129/1 138/20 139/7 139/25 144/7 156/17 164/22 167/23 175/16 177/4 179/4 188/2 190/13 194/2 194/3 203/18 212/4 217/14 218/14 226/10 237/10</p> <p>without [14] 55/19 72/14 103/13 164/1 171/18 171/23 171/23 174/10 190/2 203/1 215/10 217/8 228/21 235/15</p> <p>WITN2287021 [1] 209/25</p> <p>WITN2287022 [1] 19/12</p> <p>WITN2287024 [1] 23/2</p> <p>WITN2287025 [1] 25/3</p> <p>WITN2287026 [1]</p>	<p>26/16</p> <p>WITN2287028 [1] 35/12</p> <p>WITN2287029 [2] 28/22 152/21</p> <p>WITN2287031 [1] 38/3</p> <p>WITN2287040 [1] 45/20</p> <p>WITN2287042 [1] 47/23</p> <p>WITN2287053 [1] 155/2</p> <p>WITN2287054 [1] 156/21</p> <p>WITN2287055 [1] 158/2</p> <p>WITN2287078 [1] 73/9</p> <p>WITN2339018 [1] 127/22</p> <p>WITN2339020 [1] 129/20</p> <p>WITN2339021 [1] 131/7</p> <p>WITN2339034 [1] 142/7</p> <p>WITN3988008 [1] 115/7</p> <p>WITN3988009 [1] 116/17</p> <p>WITN3988013 [1] 165/15</p> <p>WITN3988014 [1] 167/3</p> <p>WITN3988072 [1] 79/1</p> <p>witness [3] 30/17 95/13 152/20</p> <p>witness 051 [1] 95/13</p> <p>witnesses [6] 3/17 46/24 48/7 49/11 65/9 65/10</p> <p>woman [4] 12/9 45/4 71/15 72/22</p> <p>women [2] 72/19 235/23</p> <p>women's [1] 5/17</p> <p>won [3] 139/24 231/7 231/7</p> <p>won't [3] 14/22 148/4 216/6</p> <p>wonder [2] 51/9 201/22</p> <p>wondered [2] 236/17 236/18</p> <p>word [8] 7/6 22/15 28/6 66/2 105/2 163/2 204/22 238/8</p> <p>wording [1] 102/14</p> <p>words [18] 42/20 44/14 44/17 44/19 44/20 44/21 68/15 75/7 75/11 75/25 95/18 151/5 200/6</p>
---	--	--	--	---	---

<p>W</p> <p>words... [5] 211/21 211/24 211/25 222/22 234/7</p> <p>work [38] 12/21 17/9 19/7 43/14 50/2 62/14 62/23 74/13 80/23 86/5 86/8 107/22 107/22 109/22 112/20 123/25 124/13 133/22 138/10 147/10 151/10 153/7 164/21 166/16 166/22 168/9 170/15 173/8 176/17 193/22 195/3 195/21 205/1 209/11 213/25 214/5 222/11 226/25</p> <p>worked [15] 20/1 20/1 23/13 25/18 120/21 188/12 189/8 190/3 190/19 191/20 207/15 207/16 207/18 213/18 226/19</p> <p>workers [1] 169/8</p> <p>working [19] 1/14 2/18 20/1 42/3 45/5 69/8 70/9 73/2 122/18 124/10 156/23 157/8 158/7 158/18 159/13 160/20 182/16 211/4 222/6</p> <p>workload [1] 125/14</p> <p>works [4] 121/4 121/23 122/9 144/23</p> <p>workshop [2] 180/12 183/4</p> <p>workshops [2] 85/20 118/1</p> <p>world [7] 96/2 101/17 160/10 177/17 208/15 211/4 218/14</p> <p>Wormald [1] 94/16</p> <p>worries [1] 198/16</p> <p>worry [2] 111/16 159/24</p> <p>worse [5] 96/21 97/17 115/20 117/18 153/9</p> <p>worst [3] 89/22 160/13 223/1</p> <p>worth [3] 24/2 192/17 239/14</p> <p>worthwhile [1] 239/1</p> <p>worthy [2] 137/25 160/16</p> <p>would [233] 4/17 4/21 6/9 11/16 11/19 15/10 16/8 16/9 17/15 18/8 19/2 24/1 24/19 24/21 26/24 29/12 29/16 29/16 31/23 35/23 36/2 37/23 37/25 39/9</p>	<p>40/20 42/19 46/22 46/23 46/25 47/3 47/11 47/14 47/18 47/18 48/4 48/6 48/9 48/10 48/12 48/21 49/3 49/5 49/10 50/24 51/24 53/1 53/12 53/14 53/15 53/15 53/22 54/5 54/8 54/10 55/2 56/4 56/18 56/23 57/7 58/21 59/13 59/16 61/4 61/21 61/22 63/7 65/6 67/11 68/1 68/12 69/5 74/13 76/19 76/21 81/8 81/9 81/15 82/1 82/3 82/17 82/21 84/12 84/13 84/20 85/3 85/6 85/6 85/17 86/2 87/1 87/12 88/2 88/2 88/5 88/21 89/2 89/16 89/21 91/22 92/22 93/10 94/17 101/15 102/11 102/13 106/2 106/4 106/13 107/3 107/9 107/16 107/22 110/6 110/24 111/17 112/22 117/18 117/25 118/5 122/7 123/3 123/14 124/20 124/23 125/13 127/12 127/17 128/9 130/25 131/5 132/17 132/19 132/19 132/21 132/21 133/1 133/13 133/13 134/15 134/24 136/23 138/1 138/4 139/5 139/20 139/20 140/12 143/14 145/6 145/7 145/17 145/18 146/2 146/10 146/19 147/14 147/16 149/19 149/19 149/24 149/24 149/25 150/20 152/10 153/21 153/23 154/10 154/15 155/25 159/23 161/14 161/17 161/19 162/2 162/21 162/23 164/8 164/14 169/25 170/4 170/11 170/18 170/18 170/19 170/20 171/19 171/25 172/15 176/6 176/8 178/5 180/16 182/17 183/23 184/9 184/22 185/9 186/14 189/5 190/16 193/5 193/16 193/19 194/10 195/12 199/18 202/23 205/24 206/2 206/19 206/22 206/23 207/24 209/3 209/4 216/25 223/6 223/22 224/11 224/15 224/17</p>	<p>224/18 224/20 225/5 225/7 225/9 226/23 227/3 227/3 227/6 229/1 229/1 229/10 wouldn't [32] 53/17 54/11 81/14 81/20 88/10 88/11 93/11 93/11 93/12 94/15 106/3 107/10 111/18 112/17 119/7 124/8 124/21 133/8 153/23 154/20 162/1 168/20 170/14 171/19 171/25 173/15 173/16 200/24 211/22 225/3 229/4 237/23</p> <p>wound [2] 15/20 113/3</p> <p>woven [1] 94/22</p> <p>wow [2] 70/5 218/16</p> <p>wrangle [1] 225/21</p> <p>wrecking [2] 84/14 84/20</p> <p>Wright [8] 1/20 2/14 51/4 65/7 73/21 234/4 240/5 240/10</p> <p>Wright's [1] 95/22</p> <p>write [8] 42/19 79/11 85/17 85/25 89/3 126/2 172/2 196/21</p> <p>writing [7] 7/13 20/20 46/1 62/9 77/4 82/12 135/13</p> <p>written [3] 64/11 191/8 191/22</p> <p>wrong [13] 26/14 76/25 77/1 99/20 108/4 108/13 117/20 123/11 160/23 174/2 184/1 197/18 221/16</p> <p>wronged [1] 239/4</p> <p>wrongly [2] 67/23 198/2</p> <p>wrongs [1] 230/17</p> <p>wrote [15] 22/16 23/1 40/23 41/7 42/9 77/3 88/14 92/7 126/13 129/7 142/4 171/6 171/9 188/20 207/1</p>	<p>123/22 125/12 126/4 134/5 134/17 150/3 152/20 152/25 153/21 161/1 171/1 171/4 171/6 172/10 174/18 186/21 187/2 188/18 197/2 205/12 207/20 208/11 210/4 212/12 216/17</p> <p>year [11] 29/9 48/24 119/20 143/3 188/2 191/25 199/4 199/4 199/5 200/16 200/19</p> <p>yearly [2] 96/7 228/14</p> <p>years [48] 7/5 12/6 28/19 30/3 30/21 30/24 37/16 38/9 46/25 48/8 49/12 49/13 50/4 52/11 67/7 68/3 83/12 87/8 91/18 101/9 116/25 119/21 120/1 120/1 129/2 138/12 149/18 153/12 159/23 160/21 164/21 174/9 176/24 176/25 189/22 191/18 191/24 196/9 196/19 200/8 201/1 215/7 215/23 228/12 228/21 228/25 230/15 232/19</p> <p>yellow [1] 39/4</p> <p>yes [132] 1/7 2/1 2/6 3/9 4/5 4/8 4/11 5/4 6/19 6/24 7/3 7/10 7/13 8/6 8/20 9/8 9/10 9/13 10/17 12/25 14/11 15/9 15/22 15/25 16/3 16/20 18/2 22/21 24/2 29/21 32/20 36/18 36/21 37/24 42/12 43/8 49/21 51/10 51/15 51/18 51/19 52/2 53/9 56/18 58/14 59/8 63/19 63/22 69/16 69/19 70/15 72/11 79/7 80/22 82/8 82/10 82/14 85/11 85/15 88/15 89/20 90/25 93/20 95/3 95/5 97/1 103/1 103/3 103/6 103/16 109/7 109/9 112/12 122/19 125/12 126/11 126/15 128/11 129/10 130/15 131/8 131/13 131/24 132/9 134/8 134/12 135/8 135/23 136/3 138/11 143/19 144/18 145/20 145/23 147/1 147/5 147/23 148/11 148/22 149/4 153/14 153/17</p>	<p>154/7 155/22 163/17 165/6 171/1 172/3 172/6 172/20 178/1 185/2 186/18 188/14 188/22 188/25 189/11 190/15 192/2 198/7 199/7 201/24 207/13 207/21 214/17 215/11 219/1 219/11 221/7 222/22 229/12 236/7</p> <p>yesterday [8] 3/19 45/7 73/22 75/2 95/10 104/8 225/14 236/4</p> <p>yet [5] 3/21 162/3 201/6 208/5 217/1</p> <p>you [645]</p> <p>you'd [6] 1/20 54/11 62/9 84/21 107/21 159/25</p> <p>you'll [5] 21/6 43/25 63/24 108/1 173/2</p> <p>you're [16] 1/9 1/19 1/23 2/7 7/5 60/5 68/12 93/9 107/2 114/15 130/12 169/9 217/21 222/18 222/20 227/8</p> <p>you've [47] 2/23 4/2 7/4 7/7 17/2 17/24 28/24 33/20 39/3 45/14 54/25 58/12 62/18 66/23 86/19 86/20 86/23 95/6 99/19 103/19 107/4 115/23 119/14 125/17 126/1 131/11 134/13 142/10 175/20 175/21 176/16 182/10 187/20 189/8 190/25 208/7 208/8 219/15 219/25 237/9 237/16 237/20 238/7 238/9 238/10 238/18 239/3</p> <p>young [2] 5/14 5/15</p> <p>younger [1] 209/12</p> <p>your [105] 6/17 10/15 22/8 22/15 23/4 23/18 23/22 24/20 26/6 27/11 28/24 30/4 32/6 32/8 33/18 33/20 39/8 39/13 42/22 43/13 45/14 52/4 54/23 55/7 60/19 62/11 62/14 62/18 68/13 68/25 72/15 80/11 80/12 86/9 86/19 86/20 86/21 91/5 93/8 103/19 105/22 109/10 112/14 114/4 115/22 116/2 122/25 127/25 128/2 128/20 130/16 131/4 133/5 134/1</p>	<p>134/13 137/9 137/13 138/9 141/3 142/10 143/18 147/3 147/19 147/24 148/4 148/25 149/2 155/20 156/25 158/24 164/21 165/2 170/24 177/25 182/24 183/11 184/25 190/25 192/6 195/21 195/22 202/14 202/22 204/25 207/8 207/9 207/10 207/11 210/5 217/22 217/23 222/17 223/21 225/13 226/9 229/14 236/20 237/6 237/15 237/16 237/17 238/7 238/12 238/21 239/11</p> <p>your deliberations [1] 222/17</p> <p>yours [1] 199/19</p> <p>yourself [2] 237/20 237/22</p> <p>yourselves [1] 2/20</p> <hr/> <p>Z</p> <p>Zoom [1] 178/15</p>
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