1
00:00:01,540 --> 00:00:06,220
Thanks very much for that, Eve. And just a massive welcome to everybody.

2
00:00:07,780 --> 00:00:14,829
Getting together with patients and some of the clinical staff, families, friends is one of the most

3
00:00:14,830 --> 00:00:22,540
important aspects of our work because it gives us the opportunity to feed some of our results back to you,

4
00:00:22,540 --> 00:00:25,390
but also, please tell us about your experiences.

5
00:00:25,960 --> 00:00:35,920
So we really appreciate being able to have these events and unfortunately we haven't been able to do it for a number of years because of COVID.

6
00:00:36,160 --> 00:00:43,000
And so it's absolutely great for us to come back and to get together with people and to see so many people here today.

7
00:00:43,180 --> 00:00:46,270
So thank you very much for coming.

8
00:00:47,140 --> 00:00:49,540
And thanks to Eve for the introduction.

9
00:00:51,100 --> 00:01:01,330
My background is in nursing, although I've worked in blood cancer research on patient experiences for more decades than I'd like to recall actually.

10
00:01:02,470 --> 00:01:09,460
So it's great to be here today to be able to tell you some of the findings from our work.

11
00:01:09,760 --> 00:01:17,770
So I'm going to talk mostly about patient experiences, but also I've got a few slides about patient involvement in the work that we do as well.

12
00:01:19,790 --> 00:01:25,640
So I want to pick up, first of all, by looking at the slide that Russell first showed.

13
00:01:26,600 --> 00:01:36,650

And he talked mostly about the right hand side of this diagram, about the data we collect from medical records and from cancer registry data.

14
00:01:37,310 --> 00:01:43,040
What I want to talk about now is about the information that people like you and all the other

15
00:01:43,430 --> 00:01:49,580
patients that are part of our research contribute to the study about their experiences.

16
00:01:52,150 --> 00:01:57,210
And I just dropped this next slide in just to highlight the differences between

17
00:01:57,460 --> 00:02:00,970
the strands of work that we do within our unit.

18
00:02:01,330 --> 00:02:07,780
So there's the type of work that Russell's talked about this morning, which involves collecting all the data from medical records.

19
00:02:08,110 --> 00:02:15,250
And it's about counting and measuring largely, so it's basically about how many people get blood cancers,

20
00:02:15,610 --> 00:02:20,499
who gets what type of blood cancer, what type of treatments are used for

21
00:02:20,500 --> 00:02:24,790
people across the whole population and how do people respond to treatment?

22
00:02:24,850 --> 00:02:27,580
And why do they not all respond in the same way?

23
00:02:28,560 --> 00:02:34,890
So the other strand of work that we do within our group takes a very different approach to that,

24
00:02:35,210 --> 00:02:42,780
and what we actually do is meet with patients and ask them, How was it for you?

25
00:02:42,780 --> 00:02:48,980
"What was your experience?" So that we can learn more about it from their personal points of view and

26
00:02:49,350 --> 00:02:53,310

from their experiences of being diagnosed and being treated for these diseases.

27
00:02:54,420 --> 00:03:01,620
So we ask them things like, you know, what was it like being diagnosed and how did that come to happen for you?

28
00:03:02,380 --> 00:03:07,350
And we ask them what it's like to live with blood cancer on a day to day basis.

29
00:03:07,620 --> 00:03:13,130
Because we as researchers don't know that. We can look at medical records and we can look at cancer registry data,

30
00:03:13,500 --> 00:03:17,130
but we don't know what it's like to live with these diseases on a day to day basis,

31
00:03:17,460 --> 00:03:22,980
within individual settings, within individual contexts and within individual lives.

32
00:03:23,800 --> 00:03:28,410
And so we go into that in a great deal of detail.

33
00:03:28,770 --> 00:03:32,310
We can find out about what issues people struggle with.

34
00:03:32,640 --> 00:03:36,690
So, for example, even if they've never had any treatment,

35
00:03:36,690 --> 00:03:44,459
if they've been on Watch and Wait or if they've had chemotherapy and they're now in the survivorship phase following chemotherapy,

36
00:03:44,460 --> 00:03:46,920
you know what issues are so troubling people.

37
00:03:47,640 --> 00:03:54,360
We can also ask them about what went well and what could have been improved so that we can we can feed this back into the system.

38
00:03:54,780 --> 00:03:58,320
So the two strands of our research are really complementary.

39
00:04:01,400 --> 00:04:07,370

So this is just a little bit more about the type of data that we collect for this strand of our work.

40
00:04:08,000 --> 00:04:13,850
So as I said, it involves talking to people, to patients about their experiences,

41
00:04:13,850 --> 00:04:17,450
so a lot of this is 1-to-1 interviews with people.

42
00:04:18,110 --> 00:04:20,669
And we also have group discussions.

43
00:04:20,670 --> 00:04:28,820
so we might, for example, bring everyone together who's got follicular lymphoma or a different kind of lymphoma, or everyone in a specific age group.

44
00:04:29,060 --> 00:04:35,780
And then we talk about the area of research interest that that study is particularly looking at.

45
00:04:36,750 --> 00:04:42,680
And we also have surveys often asking people, for example, about their symptoms,

46
00:04:43,190 --> 00:04:48,440
about their help-seeking behaviour and about their quality of life, among other things.

47
00:04:49,680 --> 00:04:55,290
And most of our research that we do in this respect focuses on patient experiences,

48
00:04:55,560 --> 00:05:01,650
but we've also done the work in the past with relatives and carers of people with blood cancers.

49
00:05:02,040 --> 00:05:09,120
And we've also interviewed clinical staff to ask about their experiences of delivering care to patients,

50
00:05:09,480 --> 00:05:12,990
and that's usually with a view to trying to improve care.

51
00:05:14,260 --> 00:05:19,600
And we might look at a single event, so we might focus on someone's diagnosis and ask them about that.

52
00:05:20,110 --> 00:05:22,649
Or we might look across multiple time points.

53
00:05:22,650 --> 00:05:28,780
So I'm sure many of you in the audience will have filled in the questionnaires that we send to you about quality of life,

54
00:05:28,780 --> 00:05:36,999
and we send them out at various intervals over time and all that information is fed back

55
00:05:37,000 --> 00:05:41,530
into the system and complements the data that's collected from medical records.

56
00:05:42,600 --> 00:05:45,629
So we used to interview people face to face all the time.

57
00:05:45,630 --> 00:05:51,330
That was the main way of sort of interacting with people, but things have changed now and everyone knows how to use Zoom.

58
00:05:52,500 --> 00:05:59,150
Some people prefer to use that way of communicating and meeting with people, especially if they're immunocompromised.

59
00:05:59,460 --> 00:06:07,140
So we do do some Zoom interviews with people, and we talk to people over the phone as well.

60
00:06:09,820 --> 00:06:22,000
So what I want to do now is talk about two specific areas of the patient pathway that we look at and these are to do with symptoms and also watch

61
00:06:22,000 --> 00:06:32,470
and wait for chronic cancers because, we kind of chose these areas as things that people might have a particular interest in and might really relate to.

62
00:06:33,070 --> 00:06:44,410
So we actually, this is a schematic of a patient pathway going from the pre diagnostic, symptom time through symptoms,

63
00:06:44,860 --> 00:06:53,020
referral, diagnosis and to treatment. And we actually do research all along that patient pathway, as Russell said.

64
00:06:54,350 --> 00:06:59,660
But what I'll be focusing on in this talk is the time from symptoms going right through to treatment and beyond.

65
00:07:02,200 --> 00:07:08,769
Okay, so this slide shows the areas where we've done our work on patient experiences.

66
00:07:08,770 --> 00:07:17,559
And you can clearly see from that we've gone all the way across looking at looking at symptoms, route to diagnosis, treatment

67
00:07:17,560 --> 00:07:25,210
adherence right through to end of life care for one of our studies and the areas shaded in the darker blue,

68
00:07:25,510 --> 00:07:28,780
where we want to focus on going forward from here.

69
00:07:29,080 --> 00:07:37,870
So we hope to do some work on CAR-T therapy in the future. And we also want to do some work on the experience of younger people with blood cancers,

70
00:07:38,530 --> 00:07:43,540
which we aim to do to involve Bob Phillips with, who's the next speaker.

71
00:07:45,330 --> 00:07:48,480
And so, as I said, I want to focus on two areas now.

72
00:07:48,600 --> 00:07:52,810
One of them being the symptom profiles and the other one between Watch and Wait.

73
00:07:57,160 --> 00:08:07,270
Okay, so I've dropped this slide in to really explain why we were doing work on symptoms in the first place and probably a decade or more ago,

74
00:08:07,270 --> 00:08:15,040
it was recognised that patients with blood cancers took longer to be diagnosed than those with lots of other different types of cancer.

75
00:08:16,120 --> 00:08:24,940
And this led to a lot of research being instigated in this area across the different cancer groups because it was a particular problem

76
00:08:25,390 --> 00:08:28,660
for blood cancer we did some quite sort of detailed work on it, really.

77

00:08:29,110 --> 00:08:32,680
And this just shows that for patients with myeloma,

78
00:08:32,980 --> 00:08:39,040
they were most likely to have more than three GP visits before they were actually referred to hospital,

79
00:08:40,900 --> 00:08:47,740
so they were the worst of all the cancers. And you can see lymphoma and leukaemia in there as well.

80
00:08:47,740 --> 00:08:54,690
And you can see that there's clearly room for improvement. So that's why we did some more work on this.

81
00:08:54,690 --> 00:08:59,459
And we asked patients to tell us in their questionnaires about the symptoms leading up to diagnosis,

82
00:08:59,460 --> 00:09:02,370
and we also did a huge series of interviews,

83
00:09:02,370 --> 00:09:08,760
55 interviews with patients across different disease groups to find out more about this point in time.

84
00:09:10,350 --> 00:09:15,780
So the interview material was really, really interesting.

85
00:09:16,230 --> 00:09:21,060
And there definitely was a problem that was shared by virtually everyone.

86
00:09:22,050 --> 00:09:27,330
And one of the key things that people said was that they described this kind of general feeling of ill health.

87
00:09:27,640 --> 00:09:36,360
They couldn't really explain it, they couldn't put their finger on it. They just felt under the weather, rotten and were catching one thing after another.

88
00:09:37,170 --> 00:09:42,450
And they found it really hard to explain to people exactly what the problem was and

89
00:09:42,450 --> 00:09:46,170
how they felt even when they went to seek help from the medical profession.

90
00:09:46,950 --> 00:09:53,970

Another issue that came up across all the different diagnostic groups was about tiredness and a lack of energy.

91
00:09:54,330 --> 00:09:57,940
And this didn't seem to be a kind of tiredness where you just needed an early night,

92
00:09:58,350 --> 00:10:03,660
It seemed to have a massive impact on people's lives and just gradually got worse.

93
00:10:03,930 --> 00:10:10,200
So the characteristics were that it was debilitating, immense, extreme and prolonged,

94
00:10:10,470 --> 00:10:17,070
and it had a massive impact on them and they said they felt flattened, and no reserves and depleted, so really strong language,

95
00:10:17,310 --> 00:10:24,210
and this had a huge impact on their life and their ability to undertake the usual activities that they would be involved in.

96
00:10:26,370 --> 00:10:31,470
And this slide, I mean, this is just a snapshot of the different symptoms that people told us that they had.

97
00:10:32,130 --> 00:10:34,800
So in some respects, when you see a list like that,

98
00:10:34,800 --> 00:10:42,630
it makes you understand a bit more about the diagnostic delay because the range of symptoms that people come with are just, is just huge.

99
00:10:43,350 --> 00:10:48,480
And some of them are kind of more specific to different diagnostic groups,

100
00:10:48,990 --> 00:10:58,460
so the musculoskeletal issues are obviously more common with the myelomas, and the lumps and swellings are more common with the lymphomas.

101
00:10:59,790 --> 00:11:05,720
And for some people they don't have any symptoms at all and they're just diagnosed after following a routine blood test.

102
00:11:05,730 --> 00:11:11,670
So that's kind of quite shocking for them to suddenly find out that they've been diagnosed with a blood cancer.

103

00:11:14,890 --> 00:11:22,750
And so this is what people said that they thought about the symptoms and they put it down to lots of other illnesses that they thought they had.

104
00:11:23,050 --> 00:11:28,000
Some of them thought it was making that symptom worse and others they felt it was a new thing.

105
00:11:28,000 --> 00:11:30,940
Some just thought that they were down and flattened

106
00:11:30,940 --> 00:11:39,130
and tired because they were depressed, for example, and virtually everybody that was spoken to talked about,

107
00:11:39,580 --> 00:11:44,050
they felt that they were tired and they had aches and pains, but that's just part of the normal ageing process.

108
00:11:45,400 --> 00:11:48,060
Or they had excessive night sweats,

109
00:11:48,070 --> 00:11:54,730
but that was because of the menopause or it was because they were so busy and hectic and overdoing things and rushing around and

110
00:11:54,740 --> 00:12:00,220
that's why they were tired. So.

111
00:12:01,650 --> 00:12:08,370
I'm sure that these will resonate with a lot of people here, these kinds of symptoms from people that are in the audience and these experiences.

112
00:12:08,790 --> 00:12:17,579
And as I said, it's just a snapshot but what we do with this data then is that we write it all into scientific papers and they're published in journals,

113
00:12:17,580 --> 00:12:25,830
and then that contributes to the literature about why diagnostic delay occurs for patients with these types of diseases.

114
00:12:26,100 --> 00:12:35,659
And there has been some changes in practice recently so that now vague symptom clinics and rapid diagnostic centres as well,

115
00:12:35,660 --> 00:12:41,580

so things do change sort of gradually and it's our job to kind of feed into the

116
00:12:41,580 --> 00:12:46,230
literature to sort of enable the evidence to be built for those changes to take place.

117
00:12:48,400 --> 00:12:56,530
So, now to move on to the Watch and Wait point of the pathway and again, this is an issue that a lot of people told us about,

118
00:12:57,040 --> 00:13:01,210
was the difficulties with Watch and Wait,

119
00:13:02,020 --> 00:13:09,909
which is when people are diagnosed with a chronic blood cancer and then they're observed until the point in time when they need treatment,

120
00:13:09,910 --> 00:13:19,250
if they ever need treatment at all, which some don't. Okay, So these are just a few facts from our data.

121
00:13:19,250 --> 00:13:22,790
We can see that about 60% of people have chronic blood cancers.

122
00:13:23,600 --> 00:13:25,160
So they're actually the most common type.

123
00:13:25,670 --> 00:13:33,230
And although most of them can't be cured, a lot of them can be managed on Watch and Wait, which I've just mentioned, and that can continue for months,

124
00:13:33,470 --> 00:13:36,980
decades. And as I said, some people may never need treatment.

125
00:13:37,400 --> 00:13:40,820
Other people go on and off treatments as part of a cycle.

126
00:13:41,180 --> 00:13:50,420
So we interviewed a group of patients and relatives again to ask about their experiences with this type of treatment or management.

127
00:13:50,990 --> 00:13:54,350
So what we found was that for some people it was a massive relief to be told

```
128
00:13:54,350 --> 00:13:57,590
that they had a chronic blood cancer and not something like acute leukaemia.

129
00:13:58,940 --> 00:14:05,329
And they remembered hearing certain phrases when they went to hospital like that

130
00:14:05,330 --> 00:14:13,540
it was slow growing, very treatable, not life threatening, go and live your life.

131
00:14:13,550 --> 00:14:18,500
And they saw that as really positive and a big ray of hope. And for some people that was enough for them.

132
00:14:19,010 --> 00:14:24,290
As long as they knew they were okay, they didn't want to think about the cancer anymore until they needed to.

133
00:14:24,300 --> 00:14:30,750
So, for example, if it progressed. But for others they were really worried.

134
00:14:31,170 --> 00:14:36,210
And the first thing they were worried about was that they weren't being treated as soon as they were diagnosed with cancer.

135
00:14:36,630 --> 00:14:43,170
And it was their expectation from what they heard on the news and what you hear in society generally,

136
00:14:43,380 --> 00:14:46,830
that the sooner that you're treated for the cancer, the better it is.

137
00:14:47,040 --> 00:14:53,970
So they couldn't understand and they found it really hard to wait for their cancer to get worse before they could receive any treatment.

138
00:14:55,700 --> 00:15:03,120
And the terminology impacted on this as well, so people who heard the word leukaemia, so for example,

139
00:15:03,190 --> 00:15:11,080
if they had chronic lymphocytic leukaemia, immediately thought that that would be treated because of people's perceptions of leukaemia.

140
00:15:13,000 --> 00:15:17,230
Another thing that worries people was the uncertainty of their future pathway.
```

141
00:15:17,500 --> 00:15:22,659
So this was largely caused by caused by worrying about if they would need treatment in the future,

142
00:15:22,660 --> 00:15:31,420
and if so, when would this be? And the quotes on there just show some of the examples of what people were told.

143
00:15:31,720 --> 00:15:36,070
And you can see, you know, nothing might happen. Sometimes something might happen.

144
00:15:36,070 --> 00:15:40,510
You can't predict when something is going to happen and it's just like a raffle.

145
00:15:40,960 --> 00:15:50,530
So people did very much appreciate that that information wasn't there and available for the clinical staff to give them these kind of predictions,

146
00:15:50,920 --> 00:15:54,370
but they found it really hard to live with that kind of uncertainty.

147
00:15:55,030 --> 00:15:58,720
So it caused them a lot of anxiety and distress.

148
00:15:59,110 --> 00:16:03,370
And in some work that we did on this population from surveys as well,

149
00:16:03,700 --> 00:16:15,190
we found higher rates of anxiety and depression among patients with chronic blood cancers compared to those in the general population.

150
00:16:16,620 --> 00:16:22,980
So for some people they became really preoccupied and overwhelmed with their diagnosis and focussed on it all the time.

151
00:16:23,790 --> 00:16:25,559
So it could be quite intense.

152
00:16:25,560 --> 00:16:32,190
It could be prolonged because it could go on for years and years and it really affected their ability to plan for the future.

153
00:16:33,150 --> 00:16:41,300

So. Again, this is a piece of work that we just finished quite recently.

154
00:16:41,630 --> 00:16:49,490
And in the newsletters in your bags, you've got some information in there about Watch and Wait and also about some of the things that other

155
00:16:49,490 --> 00:16:55,910
people said about information needs and what they would like to know that could reassure them somewhat.

156
00:16:55,910 --> 00:17:02,940
And as Eve said, and Russell, that's the kind of thing that's going to underpin what we do,

157
00:17:03,170 --> 00:17:06,470
the work that we do on information for patients in the future.

158
00:17:10,190 --> 00:17:14,989
And all this work's been published as well. And so in your newsletters there's a list of publications in the back.

159
00:17:14,990 --> 00:17:23,600
So if you wanted to read more about that, you could find out there. And the last few slides are really about, um, patient involvement in our work.

160
00:17:23,870 --> 00:17:28,999
And there are two types of involvement. The first is about the work that I've just been talking about,

161
00:17:29,000 --> 00:17:34,010
where you're actually interviewed and you tell us about things that we use, so you're a research participant.

162
00:17:34,340 --> 00:17:37,790
And the other is where we work alongside you.

163
00:17:37,790 --> 00:17:41,870
So you're considered a co-worker and you work in partnership with the research team,

164
00:17:42,380 --> 00:17:54,940
and you help us to identify and prioritise research areas and determine the study format, and help us to feedback to other patients as well.

165
00:17:54,950 --> 00:18:04,340
So for example, we do a lot of work with patients like Carol who are our patients speakers at events like this.

166

00:18:06,010 --> 00:18:13,710
Um, there are two aspects that I've just raised today because, well,

167
00:18:13,780 --> 00:18:19,000
one's our favourite and the other one's really big and important to us as well.

168
00:18:19,360 --> 00:18:25,360
So we involve patients in our work by working alongside the York Haematology Support Group.

169
00:18:25,720 --> 00:18:31,270
And we've been working with Carol and the rest of the group for well over ten years now.

170
00:18:31,810 --> 00:18:36,850
And it's brilliant because we get to hear about patient experiences on a

171
00:18:36,850 --> 00:18:40,810
monthly basis when we go to their meetings or between that sometimes as well,

172
00:18:41,080 --> 00:18:46,629
we get to tell them about our work and feedback our findings, and we can also use them as a sounding board.

173
00:18:46,630 --> 00:18:50,260
So if we've got an idea for a study or they've got an idea for a study,

174
00:18:50,290 --> 00:18:56,259
we can all talk about it together and they can tell us what we think and I know that the group's been to Biology

175
00:18:56,260 --> 00:18:59,889
and have commented on a lot of their work as well.

176
00:18:59,890 --> 00:19:03,130
So it's great to have their input and feedback.

177
00:19:03,620 --> 00:19:05,140
We also have a patient partnership.

178
00:19:05,620 --> 00:19:16,150
So when we contact people, we ask them to consent so that we have permission to contact them again if we want for other research studies.

179
00:19:16,720 --> 00:19:25,150

And so we've got thousands of people in those groups and they are all of different diagnostic groups, different age groups.

180
00:19:25,360 --> 00:19:31,960
So it means that if we want to interview people about Watch and Wait like we did, we can target specific individuals to be able to do that.

181
00:19:33,460 --> 00:19:40,300
And yeah, this is a shameless plug that this group is overseen by steering committee that we

182
00:19:40,300 --> 00:19:46,390
are re-establishing following COVID and we're looking to recruit to that committee.

183
00:19:46,390 --> 00:19:48,940
So if anyone's interested in doing any further work with us,

184
00:19:49,360 --> 00:19:55,210
the information leaflets have got our contact details on the back so you can get in touch and we can discuss with you.

185
00:19:58,620 --> 00:20:01,699
And what are the benefits of being involved in our work? Well,

186
00:20:01,700 --> 00:20:09,679
you can make an absolutely massive difference to care in the future going forward because you can give

187
00:20:09,680 --> 00:20:16,700
us insight into what it's like to live with a blood cancer day to day across weeks, months, years, decades.

188
00:20:17,000 --> 00:20:23,330
And we just don't, we don't have that information. So that's really, really important to us.

189
00:20:23,960 --> 00:20:28,520
And you can tell us what's relevant and important to you.

190
00:20:28,670 --> 00:20:31,190
And that means that we can integrate that into our studies.

191
00:20:31,400 --> 00:20:37,070
and our studies will therefore have more impact going forward because they're about real issues that patients are concerned about.

192

00:20:38,160 --> 00:20:43,440
And by working with us to set up studies, it means that the recruitment's better, the conduct of

193
00:20:43,440 --> 00:20:49,200
the study is better because patients who are the people who are taking part in these studies have told us what they want

194
00:20:49,200 --> 00:20:56,740
to see and how they would like to take part. So all of the information that's been shown to you today,

195
00:20:57,280 --> 00:21:03,669
has come from the questionnaire surveys that you've been sent and that have come

196
00:21:03,670 --> 00:21:08,500
back to us and from interviews that have taken place with patients like yourselves.

197
00:21:09,580 --> 00:21:13,960
And as I said before, that feeds into the whole of the data that we have on the study.

198
00:21:14,800 --> 00:21:26,290
So it complements all the different patient treatment pathways and it forms an absolutely huge resource from which we hope to improve care in the future.

199
00:21:27,060 --> 00:21:35,770
So finally, I just wanted to say thank you again very much for coming, we really, really appreciate it and thank you to our funders as well.

200
00:21:35,890 --> 00:21:43,600
Cancer Research UK, Blood Cancer UK, and also our NHS colleagues that we work with closely on the study as well.

201
00:21:43,900 --> 00:21:44,890
So thank you very much.