1
00:00:01,000 --> 00:00:04,900
I've got several different clickers to make use. I might get a bit confused.

2
00:00:05,200 --> 00:00:15,880
Right. So Eve's already introduced me. I'm Russell Patmore, I'm a haematologist in Hull and I was involved in setting up this network with Eve.

3
00:00:16,990 --> 00:00:25,900
So I'm going to talk to you this morning about who we are, what it is that we do, why we do it, and why we need all of you.

4
00:00:27,350 --> 00:00:30,680
So and we started doing this.

5
00:00:31,400 --> 00:00:35,270
I hate to say it about 20 years ago, which makes me feel quite old.

6
00:00:35,900 --> 00:00:47,060
And back in 2004, what we realised was that the data on blood cancers that you could get nationally or internationally was essentially terrible.

7
00:00:48,070 --> 00:00:54,920
And that meant that blood cancers, which are actually quite common, didn't really get any headlines in the price.

8
00:00:55,280 --> 00:01:01,390
Governments didn't really tend to think about them. And we really didn't actually know what was going on when it came to blood cancers.

9
00:01:01,400 --> 00:01:09,110
So we thought that in this area there was a real opportunity to make a difference and end up getting really good data on blood cancers.

10
00:01:09,110 --> 00:01:18,530
And our aim was to collect data on every single blood cancer that occurred in an entire population over a long period of time.

11
00:01:19,490 --> 00:01:23,150
And we did that by bringing together a number of different partners.

12
00:01:23,510 --> 00:01:28,160
To start with, we had the clinical teams that worked in all of our local hospitals.

13
00:01:28,670 --> 00:01:31,940
We then had the diagnostic laboratory Leeds, HMDS,

14
00:01:32,150 --> 00:01:37,190
which is an internationally renowned diagnostic laboratories for blood cancers

15
00:01:37,190 --> 00:01:41,450
and really set the sort of way in which blood cancers should be diagnosed.

16
00:01:42,020 --> 00:01:51,560
And then the academic team in York would do all of the data crunching and the statistics and all of the really important research on what we were doing.

17
00:01:51,830 --> 00:01:55,970
So we brought everybody together and said that we were going to collect every single blood cancer.

18
00:01:56,250 --> 00:02:00,620
Now, that's something that had never been done before, and it's never been done by anybody else since.

19
00:02:02,370 --> 00:02:07,710
So this is our population, it covers 3.8 million people and about 12 hospitals.

20
00:02:08,250 --> 00:02:14,760
And the important thing about this population is it pretty accurately reflects the UK population as a whole.

21
00:02:15,180 --> 00:02:19,680
So we can extrapolate our population out to what would happen across the whole UK.

22
00:02:21,520 --> 00:02:26,640
We collect data from a whole variety of different sources.

23
00:02:26,650 --> 00:02:35,410
So we first get all the pathological data from the lab where the cases are diagnosed and in order to get onto our dataset.

24
00:02:35,410 --> 00:02:41,360
And in order to be seen and treated for a blood cancer in our area, you have to have your diagnosis through the lab in Leeds.

25
00:02:41,410 --> 00:02:42,820
So that's where we capture everybody.

26
00:02:43,360 --> 00:02:50,230
So we get all of the diagnostic data from them and we get lots of prognostic indicators and sort of molecular biology and genetics and things.

27
00:02:50,980 --> 00:02:59,260
We get all of the medical data from the hospitals. We don't trust any of the doctors to give us that data because doctors are terrible at getting things right.

28
00:02:59,980 --> 00:03:03,380
So we send out our nursing teams to go and collect the data from your notes,

29
00:03:03,400 --> 00:03:08,290
so we know exactly what's happened to patients, how difficult their disease was, what treatment they've had.

30
00:03:09,270 --> 00:03:15,870
We have lots of electronic linkages into chemotherapy systems and drug prescribing systems.

31
00:03:16,410 --> 00:03:21,690
And then because we're treated as a cancer registry, essentially, we can get a lot of national data.

32
00:03:21,690 --> 00:03:24,750
So we can find out data on every single death that's occurred.

33
00:03:25,050 --> 00:03:29,130
We know about every person who's been registered with a cancer, although we're actually registering them ourselves.

34
00:03:29,580 --> 00:03:35,400
We get data on everything that happens in every hospital so we know what's happened to patients in hospital.

35
00:03:36,060 --> 00:03:41,820
And we also have socioeconomic data. So we've got everything that we could possibly get from national data,

36
00:03:42,450 --> 00:03:47,250
and then we get a load of important data by talking to you, our patients as well.

37
00:03:50,460 --> 00:03:57,630
And it's worked. Okay. So as of now, we have almost 50,000 patients on our database.

38
00:03:57,840 --> 00:04:02,980
That's 50,000 new people diagnosed with a blood cancer since 2004.

39
00:04:03,510 --> 00:04:08,760
And that number obviously goes up all the time. And what you'll see

40
00:04:09,900 --> 00:04:15,780
So we get diagnoses from birth.

41
00:04:17,590 --> 00:04:23,200
to people up to 100 years old. The vast majority of people are older as they are with most cancers.

42
00:04:23,590 --> 00:04:30,340
But in blood cancers, there are a lot of people who get blood cancers below the age of 60, and that's very different to other types of cancers.

43
00:04:32,930 --> 00:04:38,810
Now when we started in 2004, if you'd gone to try and get data nationally on blood cancers,

44
00:04:39,110 --> 00:04:46,040
you would essentially have been able to get data on leukaemia, lymphoma and Hodgkin's disease.

45
00:04:46,610 --> 00:04:50,000
And it would've given you data in three of three or four tranches,

46
00:04:50,270 --> 00:04:56,770
and that would have included a whole load of different diagnoses and every one of those things in the leukaemia dataset,

47
00:04:57,080 --> 00:05:02,510
there'd have been data on acute leukaemias that could kill you in a few days and chronic leukaemias that

48
00:05:02,510 --> 00:05:06,319
you might have the whole life that never needed treating and it would all be lumped together.

49
00:05:06,320 --> 00:05:13,350
So it was meaningless. When you look at our data, you can see it's broken down into numerous different types of diseases.

50
00:05:13,350 --> 00:05:16,200
And in fact, this is a simplified version even of what we have.

51
00:05:16,740 --> 00:05:24,360
You got all of the myeloid malignancies over here, the leukaemias, the myeloproliferative disorders and all of these

lymphoid diseases around the other side.

52
00:05:24,360 --> 00:05:31,020
So many, many different types. And there are actually almost 100 different sorts of blood cancer if we were to break this down completely.

53
00:05:31,970 --> 00:05:36,260
The size of these boxes sort of tells you that they're at different frequencies.

54
00:05:36,260 --> 00:05:40,780
We see different amounts each year. And we can look at that this way.

55
00:05:40,800 --> 00:05:45,370
So we have about two and a half thousand new cases of blood cancer a year in our area.

56
00:05:45,430 --> 00:05:53,740
So this is not an uncommon type of cancer. And some of them are very common, so, large cell lymphoma, we'll have three hundred odd cases a year.

57
00:05:54,090 --> 00:05:59,050
But some are very rare. So Burkitt lymphoma, hairy cell leukaemia, around ten cases a year.

58
00:05:59,290 --> 00:06:03,760
And then there are some others where there are even less. So we may only get one or two cases a year.

59
00:06:03,910 --> 00:06:07,210
Sometimes there are some things we might not get cases every year.

60
00:06:07,870 --> 00:06:12,009
So it's really important that we capture every single patient and that we go on

61
00:06:12,010 --> 00:06:16,270
capturing every single patient so that we can get data on those very rarer diseases.

62
00:06:18,990 --> 00:06:23,670
What can we do with that data? So the answer is practically anything.

63
00:06:24,950 --> 00:06:28,910
This is breaking down the data by age.

64
00:06:29,060 --> 00:06:36,470

So this column here is patients less than 15 years of age and right up to this end people who are more than 70 years old.

65
00:06:37,250 --> 00:06:41,420
And what you can see, each colour is a different type of lymphoid blood cancer.

66
00:06:42,280 --> 00:06:47,320
So when you're young, in children, predominantly people get acute lymphoblastic leukaemia.

67
00:06:48,460 --> 00:06:51,870
In adolescents and young adults.

68
00:06:52,650 --> 00:07:01,490
The orange blocks which are Hodgkin's lymphoma. And when you're old, you get yellow, myeloma, or this one which is chronic lymphocytic leukaemia.

69
00:07:01,490 --> 00:07:08,720
And then something like large cell lymphoma, which is the commenest thing we see actually occurs in all ages,

70
00:07:08,930 --> 00:07:16,820
which is unique to any sort of cancer. So this sort of depth of data where the only people who can produce this.

71
00:07:19,610 --> 00:07:25,640
One really important thing is that the data we produce is very different to what you get from clinical trials.

72
00:07:26,100 --> 00:07:31,830
Okay, so. In clinical trials, which are really important.

73
00:07:31,840 --> 00:07:35,740
They're the things that make lives like clients a lot like.

74
00:07:36,710 --> 00:07:41,270
Sorry at the back, can you hear me now? Do you want me to start again?

75
00:07:42,860 --> 00:07:48,950
Okay. So I do sound a lot louder now. And what you see on this graph

76
00:07:48,980 --> 00:07:53,790
is the structure of our population, which is the red and blue bars.

77
00:07:53,870 --> 00:08:01,309
So the blues are the males and the reds are the females, and the orange are patients who've been entered into clinical

trials.

78
00:08:01,310 --> 00:08:09,170
So I hope some of you here would have been in clinical trials. You can see the orange bars are a very small proportion of all the people in our dataset.

79
00:08:09,950 --> 00:08:15,860
What you can also see is that the orange bars are skewed. They only occur in the younger patients.

80
00:08:15,980 --> 00:08:24,980
So if you look at the female population, in our general population, the median age is 71 years, whereas in the trial population it's only 58 years.

81
00:08:25,820 --> 00:08:31,460
So that means that the trials don't actually reflect what will happen in the population as a whole.

82
00:08:32,030 --> 00:08:37,399
And there are lots of other reasons why trials don't reflect the population is because quite often people who

83
00:08:37,400 --> 00:08:42,890
are very sick don't get included in trials or actually people who are very well don't get included in trials,

84
00:08:43,100 --> 00:08:49,399
people who've got other health problems often don't get included. Now trials are really, really important.

85
00:08:49,400 --> 00:08:54,980
They're the things that teach us what new drugs might work and might make treatments better.

86
00:08:55,640 --> 00:09:01,760
But what you can't take from a trial is what will happen when you apply that new treatment to a whole population.

87
00:09:02,120 --> 00:09:05,120
And our data can do that. So that makes it really vital.

88
00:09:08,470 --> 00:09:11,830
We can also look at what happens depending on your sex.

89
00:09:12,160 --> 00:09:15,880
I'm sorry to the men in the audience. Man flu is real.

90
00:09:16,070 --> 00:09:18,000

Particularly when it comes to haematological cancers.

91
00:09:18,520 --> 00:09:24,180
So this dotted line, if you're to the right of that dotted line, and we've got all of the blood cancers down the side here,

92
00:09:24,190 --> 00:09:33,249
it is more common in men, as you can see, essentially all blood cancers are more common in men. Some up here,

93
00:09:33,250 --> 00:09:36,640
Burkitt's and things, are four times more common in men than they are in women.

94
00:09:37,090 --> 00:09:40,390
There are actually no blood cancers that are more common in women than men.

95
00:09:44,580 --> 00:09:50,850
We get so much data that we can create really detailed pathways on what happens to patients.

96
00:09:51,510 --> 00:09:56,280
So this patient has myeolma. They were diagnosed up here in 2013.

97
00:09:56,850 --> 00:10:05,870
And this pathway, because we collect data over time, follows them all the way through to 2021 when unfortunately they died from their myeloma.

98
00:10:07,270 --> 00:10:11,370
In the middle here, we can record exactly what treatments they've had along the way.

99
00:10:11,380 --> 00:10:17,380
So they started off in a clinical trial, had a transplant, had lots of different treatments through their cancer journey.

100
00:10:17,740 --> 00:10:18,970
Until unfortunately, as I say,

101
00:10:19,000 --> 00:10:25,110
There were no more treatments that would work anymore, so they ended up having seven different types of treatment across their cancer journey.

102
00:10:26,250 --> 00:10:32,460
Over that time they had lots of tests which are recorded up here. They had lots of supportive treatment, which is recorded here.

103

00:10:33,090 --> 00:10:39,390
And then because we get all the hospital data, we can even see exactly how many times they came to the hospital.

104
00:10:39,750 --> 00:10:45,960
So we've got every time they were in hospital and how long, every time they went to outpatients, every time they came to A&E.

105
00:10:46,620 --> 00:10:49,320
So really detailed data on every single patient.

106
00:10:51,150 --> 00:10:58,710
And we can bring that together and combine them all into maps and pathways about what might happen to our whole group of people.

107
00:10:59,430 --> 00:11:04,800
So you have over here people diagnosed with marginal zone lymphoma, which is one of the lymphomas.

108
00:11:05,280 --> 00:11:08,760
And this is the different treatments that those different patients had up front.

109
00:11:09,000 --> 00:11:12,450
So you can see that not everybody has the same treatment. They're all different.

110
00:11:13,050 --> 00:11:18,660
And then we map what happens to them through the course of their cancer journey, and they don't follow straight lines.

111
00:11:18,900 --> 00:11:22,710
These lines cross over, they wriggle. Everything's really complicated.

112
00:11:22,920 --> 00:11:30,840
So when us as doctors are taught about how you do things, you follow a guideline, which says you do ABCD or you follow

113
00:11:30,960 --> 00:11:34,080
the research which talks about one particular treatment at a particular time.

114
00:11:34,590 --> 00:11:42,460
But real life is not like that. We can take that data and we can convert it into a model.

115
00:11:43,570 --> 00:11:47,290
So this is actually something we did with follicular lymphoma to model

116
00:11:47,290 --> 00:11:54,300
What happened to patients who had follicular lymphoma and we sort of generate a mathematical map of a cancer journey.

117
00:11:54,700 --> 00:12:01,659
And so we plug people in at the beginning because we know from our maps the different steps they go through.

118
00:12:01,660 --> 00:12:07,540
We know which proportion of people go down each particular arm as they go through each stage of their cancer journey.

119
00:12:07,720 --> 00:12:10,900
Okay. And if you calculate all that out,

120
00:12:10,900 --> 00:12:18,010
you can do things like work out how much time people would on average spend in a hospital over the course of their

121
00:12:18,010 --> 00:12:25,220
treatment for their lymphoma, or how much time out of all of the time that they survived with their lymphoma,

122
00:12:25,840 --> 00:12:28,960
how much time were they actually on treatment of some sort or another?

123
00:12:29,620 --> 00:12:36,880
Or you can put it all together and you can work out how much it costs to treat somebody with a blood cancer.

124
00:12:37,120 --> 00:12:40,630
And then you can use that data to plan what you should do.

125
00:12:41,750 --> 00:12:44,330
What you can also do is if a new treatment comes out,

126
00:12:44,390 --> 00:12:50,360
you can plug the effects of that new treatment into your model and predict what impact it might have on

127
00:12:50,360 --> 00:12:56,480
the whole pathway for people with a particular blood cancer and what that might mean then for the population as a whole.

128
00:12:58,880 --> 00:13:04,760
So this is that data for follicular lymphoma and we can extrapolate it to the UK population and say that

129
00:13:05,330 --> 00:13:10,580
there'll be about 2000 people diagnosed with a follicular lymphoma in the UK every year.

130
00:13:11,150 --> 00:13:17,330
The average cost of treating those patients through that cancer journey will be about Â£18,000.

131
00:13:17,510 --> 00:13:23,120
So the annual cost to the UK of treating follicular lymphoma will be about Â£62 million.

132
00:13:23,810 --> 00:13:27,920
You can do that for every blood cancer, but if you get slightly different treatments,

133
00:13:27,940 --> 00:13:31,140
so if you have a transplant, for instance, your treatment might be much more expensive.

134
00:13:31,520 --> 00:13:36,800
Sort of Â£60,000. So we can use that data to see what would happen if you change the treatments you're going to give.

135
00:13:39,100 --> 00:13:46,030
We can also do lots of other things. So because we're continuing to collect data and because we collect data over a long period of time,

136
00:13:46,030 --> 00:13:51,700
not just a single point in time, like a trial would usually be, we can map changes over time.

137
00:13:52,120 --> 00:13:57,800
So this is treatment for myeloma, the different columns are different time periods when people started their treatment.

138
00:13:57,820 --> 00:14:08,200
So beginning back in 2005 ending up in 2017. And back in 2005, most people got this orange treatment, which was a tablet called Melphalan.

139
00:14:08,980 --> 00:14:17,590
And now in 2017-2019, most of them get these two bars which are velcade based combinations of treatments, a very different treatment.

140
00:14:17,590 --> 00:14:24,270
And you can see the proportions change over time. You can also see at the beginning, there are about five treatment options, here

141

00:14:24,280 --> 00:14:31,090
there are nine treatment options, and probably in the next block that we do, the next cohort, it will be even more. So very complicated.

142
00:14:32,520 --> 00:14:36,840
The question is, does it make any difference? The good thing is, it usually does.

143
00:14:37,830 --> 00:14:42,600
So here we've got those same time periods as lines, and we're looking at survival, so the people,

144
00:14:42,750 --> 00:14:46,080
proportion of people who survive over a five year period.

145
00:14:46,500 --> 00:14:53,190
So at the bottom you've got the earliest timelines. And then at five years, around about 25% of people are still alive.

146
00:14:53,880 --> 00:14:59,010
The purple Line is the most recent cohort, and now about 40% of people are alive.

147
00:14:59,160 --> 00:15:06,960
So really big improvements in the outcomes in myeloma over the period of time. And we have this data for every single blood cancer,

148
00:15:07,140 --> 00:15:14,940
and we can show that for the vast majority, outcomes have improved considerably over the time we've been running and will probably continue to improve.

149
00:15:15,270 --> 00:15:19,090
But there are still some conditions where things really haven't changed very much at all.

150
00:15:19,130 --> 00:15:24,960
So we know that's what we need to focus on. We can break this data down

151
00:15:25,500 --> 00:15:33,000
even more so here we split it by age, so same data, outcomes in myeloma over a five year period.

152
00:15:33,330 --> 00:15:40,050
So in the patients under 70, it's got better, but in the patients over the age of 80, it's got massively better.

153
00:15:40,980 --> 00:15:44,010
Okay. So there's been a real benefit to the older patients.

154
00:15:44,010 --> 00:15:50,460
And people often worry that older people don't have proper access to cancer treatments and they don't get treated properly.

155
00:15:50,820 --> 00:15:53,880
And we can show that particularly in blood cancers, that's not the case.

156
00:15:54,330 --> 00:15:58,319
Treatments have got better and doctors have got more confident at being able

157
00:15:58,320 --> 00:16:02,220
to deliver those treatments safely and in the supportive care that we can give.

158
00:16:02,700 --> 00:16:07,220
So older patients are benefiting just as much, if not more, than younger patients.

159
00:16:10,050 --> 00:16:16,940
It's not all about treatment. So this graph is looking at something called promyelocytic leukaemia, which is quite rare.

160
00:16:18,020 --> 00:16:22,520
Now, it's a funny shape graph, it falls of a cliff at the beginning and then it goes pretty flat.

161
00:16:23,300 --> 00:16:29,680
So what that tells you is the treatment that we can give to these patients is really, really good, it works really well.

162
00:16:29,690 --> 00:16:36,980
And if you can give people a treatment and get them through it, they'll almost certainly survive, but still, about 30% of patients with APL will die.

163
00:16:37,920 --> 00:16:41,460
And that's because they're so sick by the time that they come to us.

164
00:16:41,940 --> 00:16:45,720
So you're never going to change that pathway by making the treatment better.

165
00:16:45,900 --> 00:16:50,490
You can only change it by doing something to diagnose people earlier, to spot people.

166
00:16:50,850 --> 00:16:54,230
So we also collect data before people are diagnosed.

167
00:16:54,240 --> 00:16:55,460
We get GP data.

168
00:16:55,470 --> 00:17:02,700
So we look at symptoms and presentations to the general practitioners to try and find ways of getting people referred into the system earlier.

169
00:17:05,440 --> 00:17:08,860
And then there are other things that impact that aren't to do with treatment.

170
00:17:09,310 --> 00:17:13,240
So this is looking at the socioeconomic status of people who are treated.

171
00:17:14,170 --> 00:17:19,960
And you've got the purple lines, which are the most deprived people and the blue is the most affluent.

172
00:17:20,080 --> 00:17:24,550
And this side is for an aggressive type of blood cancer, large cell lymphoma.

173
00:17:25,330 --> 00:17:31,090
And there is a bit of difference. So the blue line does a bit better than the purple line, but it's not very much.

174
00:17:32,090 --> 00:17:40,550
But if you look at a more chronic type of cancer that has treatment over a longer period of time, like myeloma, the difference is much greater.

175
00:17:40,850 --> 00:17:46,010
So the most deprived cohorts of patients are doing much worse than the best.

176
00:17:46,580 --> 00:17:51,200
They're not getting different treatment because we know they're getting the same treatment, but they're doing worse.

177
00:17:51,860 --> 00:17:55,250
Some of that will be because they have more other illnesses.

178
00:17:55,910 --> 00:18:00,170
But it's not just that. So I thought we'd just do a little experiment.

179
00:18:00,890 --> 00:18:06,370
So can everybody in the room whose household has a car put their hand up.

180
00:18:09,480 --> 00:18:13,170
Okay. Right. Thank you. I think that's just about everybody.

181
00:18:13,170 --> 00:18:14,740
I couldn't see anybody who didn't have a car.

182
00:18:16,200 --> 00:18:23,060
There are some parts of our population where nearly half of the people that live in those areas do not have a car.

183
00:18:24,330 --> 00:18:30,620
That makes their access to health care more difficult. Means it's much more difficult to come to a meeting like this.

184
00:18:31,070 --> 00:18:36,050
It also means if you run out of tablets, it's harder to go and get a resupply of your tablets.

185
00:18:36,350 --> 00:18:43,400
It's harder to get to all of your outpatient appointments so people don't do as well because it's harder for them to access healthcare.

186
00:18:43,820 --> 00:18:47,210
So if we aim to improve their outcomes, it's not about the treatment.

187
00:18:47,330 --> 00:18:50,630
It's about how we support people through that treatment.

188
00:18:53,230 --> 00:18:57,220
We can also look at specific questions. So I'm a lymphoma doctor.

189
00:18:57,310 --> 00:19:05,620
And the most important thing that's happened in my career in terms of improving outcomes in the environment is an antibody treatment called rituximab,

190
00:19:05,620 --> 00:19:07,900
which I'm sure quite a lot of people in this room will have had.

191
00:19:08,500 --> 00:19:16,330
And that made a really big difference to how many people survived aggressive lymphomas and for how long people lived with chronic lymphomas.

192
00:19:18,010 --> 00:19:22,870
And a few years ago, the original antibody went out of patent.

193
00:19:23,260 --> 00:19:28,270
And what happens when drugs go out of patent, you'll know, is that you get generic drugs.

194
00:19:28,270 --> 00:19:32,080
Now, if you're making a blood pressure drug, making a generic copy is really simple.

195
00:19:32,530 --> 00:19:36,100
But if you're making an antibody, it's really hard to copy that

196
00:19:36,210 --> 00:19:42,460
antibody exactly. And when you're making the antibody, it's a biological process, you can't be sure it'll end up the same. Anyway,

197
00:19:42,670 --> 00:19:49,390
things called biosimilars were made, they're an awful lot cheaper than the original MabThera rituximab.

198
00:19:49,690 --> 00:19:52,329
And so the government, quite understandably,

199
00:19:52,330 --> 00:19:59,050
decided that we were going to swap onto these biosimilars because it would save about Â£300 million a year, I think, a lot of money.

200
00:19:59,650 --> 00:20:06,459
But there really wasn't any data to say that these antibodies were as good, there were some small trials in slow growing lymphomas,

201
00:20:06,460 --> 00:20:09,270
but none in the aggressive lymphomas where it was really important.

202
00:20:09,960 --> 00:20:16,020
Now because we collect data over a long period of time, because we've got everybody, we're in a unique position to look at this.

203
00:20:16,500 --> 00:20:19,860
And what you can see here, I need to find my pointer again, I've lost it.

204
00:20:20,400 --> 00:20:23,890
In the meantime. Okay, so.

205

00:20:25,340 --> 00:20:30,620
2017 is when this mandate came out. What you can see in the blue bars prior to that,

206
00:20:31,100 --> 00:20:35,810
every single patient treated for a large cell lymphoma got the original MabThera.

207
00:20:36,110 --> 00:20:39,650
And then after that, nobody got the original MabThera and everybody got the

208
00:20:40,010 --> 00:20:44,470
new drug, okay. And the worry was it wouldn't be as good.

209
00:20:44,890 --> 00:20:50,080
But what we can show is it's exactly the same. Okay, so these are the survival curves for

210
00:20:50,260 --> 00:20:53,470
the cohorts of people in the blue line before the new agents.

211
00:20:53,860 --> 00:20:57,099
And these are the ones afterwards. So it's at least as good and no worse.

212
00:20:57,100 --> 00:20:58,560
So that's extremely reassuring.

213
00:21:01,280 --> 00:21:09,020
This graph is a little bit complicated, but it tells you in some respects why it's really important that we go on collecting the data.

214
00:21:10,100 --> 00:21:15,510
So this is looking at COVID, something that's been part of our lives for the last few years.

215
00:21:16,220 --> 00:21:19,340
And time zero here is when the pandemic started.

216
00:21:20,390 --> 00:21:27,980
What we're looking at is mortality. Okay, So the percentage of people who have died and this is people who've died and have COVID on their death certificate.

217
00:21:29,420 --> 00:21:37,750
The blue line is patients in our dataset who have blood cancers, and the red line is from our control group.

218

00:21:37,760 --> 00:21:44,210
So for every patient that we have in our database with blood cancer, we have six patients,

219
00:21:44,720 --> 00:21:51,580
ten patients, we have ten patients who are matched to the patients on all dataset.

220
00:21:51,740 --> 00:21:55,160
So same age, sex and everything else, but they don't have a blood cancer.

221
00:21:55,610 --> 00:21:57,800
Okay, So they're our control group, so we can look at them.

222
00:21:58,340 --> 00:22:07,999
So we can see that when COVID first started, lots of people in the normal population died from COVID, and then when the Omicron variant came along, a lot more people died.

223
00:22:08,000 --> 00:22:13,790
And then as everything died down and we came out of lockdown, the number of people dying has been much, much less.

224
00:22:14,810 --> 00:22:16,160
If you look at blood cancers,

225
00:22:16,160 --> 00:22:25,160
we knew people with blood cancers were more vulnerable to dying from COVID, and more died at the beginning, and then it got better, and more died during Omicron.

226
00:22:26,390 --> 00:22:31,850
But what's really interesting is the difference, if you look at those graphs in terms of the steepness,

227
00:22:31,850 --> 00:22:35,720
they're pretty similar to the normal population.

228
00:22:36,230 --> 00:22:39,710
But here the graph is much deeper than the normal population.

229
00:22:39,860 --> 00:22:44,690
So this is after we've come out of lockdown, after everybody stopped worrying about COVID.

230
00:22:46,010 --> 00:22:49,790
Patients with blood cancer are unfortunately still much more vulnerable to dying from it.

231
00:22:50,690 --> 00:22:52,249
It's got better here,

232
00:22:52,250 --> 00:22:59,150
which I think is probably largely because of the fact that the amount of COVID in the population has been so low, but now it's taken off again.

233
00:22:59,870 --> 00:23:06,610
So unfortunately, from what we can tell at the moment, anybody who's got a blood cancer still needs to be careful around COVID.

234
00:23:07,220 --> 00:23:10,970
So that's an important lesson today for many of you, unfortunately.

235
00:23:11,360 --> 00:23:14,990
But this shows why we still need to be able to collect the data all the time.

236
00:23:17,530 --> 00:23:24,430
One other thing we do is we act like big brother. So we watch all of our hospitals to make sure they're doing their job right.

237
00:23:25,200 --> 00:23:28,770
Okay, So we monitor their outcomes for all of the different blood cancers.

238
00:23:29,370 --> 00:23:35,790
These are quite complicated graphs, they're called funnel plots but essentially what you want to be is in this dark grey area.

239
00:23:36,000 --> 00:23:43,470
and you want to be green. So these are all of our hospitals and this is five year survival in acute myeloid leukaemia.

240
00:23:43,990 --> 00:23:50,220
You can see there's one hospital here which happens to be the one that treats the most patients, where if you look at it with just crude data,

241
00:23:50,670 --> 00:23:55,079
they're right outside of the funnel plot and therefore they seem to be doing

242
00:23:55,080 --> 00:23:59,910
worse than they should be. But if you correct that data for the age of their population, because

243

00:24:00,330 --> 00:24:03,960
older patients unfortunately tend to do worse. Actually, there isn't a problem.

244
00:24:04,750 --> 00:24:08,240
Okay. This one's looking at large cell lymphoma.

245
00:24:08,480 --> 00:24:15,920
There's actually two people outlying here, one that's doing a bit better than we'd expect, and one doing a bit worse. Correct for age,

246
00:24:16,190 --> 00:24:19,250
the better one goes away. But the worse one is still there.

247
00:24:19,910 --> 00:24:23,420
So that means we need to look further and see if we can find what the problem is.

248
00:24:23,420 --> 00:24:31,040
And quite often we do, so when we had a problem with large cell lymphoma before we found it was in the hospital that was treating most of the lymphomas,

249
00:24:31,040 --> 00:24:34,730
that it involved the brain. We know they did much worse. So that isn't a problem.

250
00:24:35,300 --> 00:24:38,060
So we can look at all of our data and we'll channel down.

251
00:24:38,060 --> 00:24:45,410
But if we can't find a reason for that statistically, then we'll go back to that hospital and we'll ask them to look at their data,

252
00:24:45,410 --> 00:24:48,140
look at their deaths, and see if there's anything that could be changed.

253
00:24:48,990 --> 00:24:55,160
And we've been doing this for years and we really very rarely found anything because all hospitals tend to treat people in the same way.

254
00:24:55,460 --> 00:24:59,780
But once we did find the hospital where the outcomes of the monitoring were not as good as they should be,

255
00:25:00,120 --> 00:25:03,770
we were able to show that it was because they weren't sending as many people for transplant

256
00:25:04,010 --> 00:25:07,580
and therefore we were able to change that and bring that back to where it should be.

257
00:25:08,000 --> 00:25:12,740
It's really important we do that monitoring. So what's this all about?

258
00:25:13,890 --> 00:25:21,720
Primarily it's about supporting patients and clinicians to deliver better care for blood cancers.

259
00:25:23,190 --> 00:25:29,520
It's about supporting you as patients by showing what might happen to you during your cancer journey.

260
00:25:30,270 --> 00:25:34,679
What different ways you might go through that cancer journey so that you can look at what's

261
00:25:34,680 --> 00:25:40,920
important to you and then make better choices for you about how you access care

262
00:25:41,160 --> 00:25:44,880
and what sort of care you have. Because outcomes are not the same for everybody.

263
00:25:45,450 --> 00:25:51,090
There's a pathway that will say that you are going to live for absolutely the longest you're likely to if you take this pathway.

264
00:25:51,540 --> 00:25:56,400
But if you do that, you might spend much more time in hospital or much more time on treatment.

265
00:25:56,700 --> 00:26:03,030
And that benefit that you see might not seem worth it to you. So we need to be able to empower you to be involved in those decisions.

266
00:26:04,390 --> 00:26:08,950
We need to be able to tell doctors simple things like how many patients they have because we usually don't know.

267
00:26:10,000 --> 00:26:14,950
We need to be able to tell them how their patients are really doing, because trust me,

268
00:26:15,220 --> 00:26:20,890
they don't know that either, they get this wrong and they get it wrong largely in two ways.

269
00:26:21,140 --> 00:26:27,670
So. A few doctors in the room but if I was to ask them how well their patients with leukaemia did,

270
00:26:28,030 --> 00:26:31,210
they'd almost certainly tell me that they were doing better than they actually were.

271
00:26:31,630 --> 00:26:35,470
And that's because the worst patients with leukaemia don't get into the trials,

272
00:26:36,070 --> 00:26:39,969
there are lots of patients who never get on to treatments and they don't survive because of that.

273
00:26:39,970 --> 00:26:43,030
So they tend to underestimate how badly people do.

274
00:26:43,210 --> 00:26:46,030
On the other side of the coin, people with chronic blood cancers,

275
00:26:46,030 --> 00:26:50,950
they usually think patients do worse, and that's because the good patients don't get into the trials.

276
00:26:50,950 --> 00:26:56,830
so they don't get those figures. But also the good patients don't turn up to the clinic, they don't need to because they're not having anything.

277
00:26:56,860 --> 00:27:00,310
So you focus on the patients that are doing worse and you think people are doing worse.

278
00:27:00,610 --> 00:27:07,479
So we can tell people exactly how they are doing. We can also tell you how they're doing as a hospital and as a trust to make sure they're delivering

279
00:27:07,480 --> 00:27:11,320
care correctly and we can identify areas where their treatment might be improved.

280
00:27:12,910 --> 00:27:17,050
It's about supporting researchers because we have a unique data set.

281
00:27:18,050 --> 00:27:21,830
It's a real opportunity to advance our knowledge of blood cancers.

282
00:27:22,040 --> 00:27:25,160
It provides a benchmark against which other data can be judged.

283
00:27:25,540 --> 00:27:30,020
It's a real opportunity to collaborate with other researchers in other areas of haematology.

284
00:27:30,890 --> 00:27:40,000
And we also work with the government, public health and with pharmaceutical companies to try and develop and push forward treatments in blood cancers.

285
00:27:40,010 --> 00:27:43,969
So we do a lot of work with NICE to take the data that comes from trials and to

286
00:27:43,970 --> 00:27:49,010
extrapolate it into the UK population so they can see what the costs will be

287
00:27:49,280 --> 00:27:52,400
if you actually treat a whole nation, what the benefits will be,

288
00:27:52,790 --> 00:27:58,190
because in the real world there are limited resources and we have to make sure we spend them in the best possible way.

289
00:28:00,130 --> 00:28:05,310
Why do we need you? Well, essentially, the data is the most important thing.

290
00:28:06,760 --> 00:28:13,840
The data is the thing that you gift to us about all of your care, and it's that accurate up to date data,

291
00:28:14,210 --> 00:28:18,460
that gives the power to what we do and allows us to do all the things that we can.

292
00:28:19,270 --> 00:28:22,509
It's also about telling us the things that we can't see from the data.

293
00:28:22,510 --> 00:28:27,010
And that's why being involved in the patient involvement groups and the surveys and

294
00:28:27,010 --> 00:28:34,360
some of you who've been involved in one of our research projects are so important. So essentially this only works because of all of you.

295
00:28:34,960 --> 00:28:39,010
So thank you for contributing your data and thank you for your time today.