HOUSE OF COMMONS

Health and Social Care Committee

Oral evidence: Cancer services, HC 551

Tuesday 9 November 2021

Ordered by the House of Commons to be published on 9 November 2021.

Watch the meeting

Members present: Jeremy Hunt (Chair); Lucy Allan; Paul Bristow; Dean Russell.

Questions 277 - 339[1]

Witnesses

I: Katy Hall, cancer patient.

II: Professor David Baldwin, Chair, Lung Cancer Clinical Expert Group; Anna Jewell, Chair, Less Survivable Cancers Taskforce; and Jane Lyons, Chief Executive, Cancer52.

III: Professor David Shackley, Director, Greater Manchester Cancer; Ian Vousden, Programme Director, Kent and Medway Cancer Alliance; and Sarah Stevens, Deputy Director, National Disease Registration Service, NHS Digital.

[1] Note from Committee: There was a numbering error made on this transcript. Q277 follows on from Q196 as the next question asked for this inquiry. There are no missing questions in-between.

Examination of witness

Witness: Katy Hall.

Chair: Good morning. Welcome to the fourth session of the Health and Social Care Select Committee inquiry into cancer services.

Our aim in this inquiry has been to examine why cancer outcomes in England continue to lag behind those in comparable countries such as Denmark and Australia. One of the key puzzles is the large variation in outcomes within England, both between different types of cancer and across different regions of the country. Today we are going to do a deep dive into what the cause of those variations is, what we can learn from them and how we can put them right.

We will hear later from some experts: Jane Lyons, the chief executive of Cancer52; Anna Jewell, the chair of the Less Survivable Cancers Taskforce; and Professor David Baldwin from the Roy Castle Lung Cancer Clinical Expert Group. Thank you very much for joining us. Later, we will look at the regional variations. We will talk to another set of experts about that.

Before that, we are very pleased to be joined by Katy Hall. Welcome, Katy. Thank you very much for joining us today. We really appreciate your coming. It is a very brave thing to speak publicly about something as personal as a medical condition. Katy has an extremely rare kidney cancer, which was initially misdiagnosed as a benign tumour. She is going to be asked some questions by my colleague Paul Bristow.

Q277 **Paul Bristow:** Katy, thank you again for being so brave and coming to us to talk about your experiences. Can you tell us a little about your experience and when you were diagnosed with cancer?

Katy Hall: Yes. I was diagnosed when I was 29, which was five years ago. That is when I first went to the hospital. I went to my GP because I had a pain in my lower left-hand side and was sent to the hospital for suspected appendicitis. They did an ultrasound scan and found what was described as a lump on my kidney. No further scans were completed. I was told that it was benign and nothing to worry about.

I underwent 12-monthly ultrasound scans. In each scan, it grew in size, roughly half a centimetre each year. In 2019, I fell pregnant with my first baby, my little boy. It just ballooned up in pregnancy. I ended up having to have a caesarean over it. They started to get a bit worried at that point.

When my little boy was born in 2019, I had another scan. They said that it had reduced slightly in size, so they were just going to leave me and to continue monitoring me. I rang up and said, "No, I want it gone. It ruined my pregnancy. It's been ongoing for a number of years. Can we just remove it?" At that point, in January 2020, I was sent for a CT scan. I had a letter saying that I had moved during the scan and they had to do

another one, but, due to Covid, it was going to be delayed. That was about a week before we went into the lockdown in March. I did not get another CT scan until June. At that CT scan in June 2020, I was called into the hospital. The first words from the doctor were, "It's not what we thought it was." It was at that point that I was diagnosed with cancer.

Q278 **Paul Bristow:** Wow. I just want to reiterate that point. It was down to you specifically asking for it to be removed that action took place. They still thought that it was benign at the time and they were going to leave it.

Katy Hall: Yes, they were. When I had the follow-up scan after my little boy was born, it had reduced from, I think, about 5 cm down to just under 4 cm. The plan was just to continue monitoring me on a 12-monthly basis. I rang the consultant's secretary and said no. It completely ruined my pregnancy. It was my first pregnancy and I wanted to give birth naturally. I had big plans, as you do when starting motherhood. This overtook the whole pregnancy. I needed a caesarean over it. I had to have a urology team on standby in theatre in case it erupted during the caesarean. There was so much added pressure, at an already very difficult time when you are due to give birth and your baby is coming into the world.

When I got the letter saying that they were going to continue monitoring me every 12 months, I thought, "No, I don't want that. I want it gone. I want it removed." That phone call was the reason that they sent me for the CT scan, which, ultimately, diagnosed that it was not what they thought it was and that it was cancer.

Q279 **Paul Bristow:** When were you told the details about the cancer and the fact that it was so rare?

Katy Hall: That was following my operation. When I was diagnosed, everything happened very quickly. It was a week after my little boy's first birthday, in July 2020. Within three weeks, I was in hospital, during the height of Covid. I had two thirds of my kidney removed, along with the tumour, under open surgery. I then waited around four to five weeks for the pathology to come back. Everything was over the phone. Nothing was face to face. I got a phone call for the appointment, when my consultant said, "We can confirm that it is cancer. However, it is an extremely rare type of cancer called MiT family translocation renal cell carcinoma."

Paul Bristow: Well done.

Katy Hall: I'm used to saying that. There was just no information out there. I was not able to be given a grade, so they could not give me any guidance on the chances of recurrence. I spent hours researching online. I managed to find a lady from California who was roughly my age and had been diagnosed with the same type of cancer, but so far along my journey she is the only person I have been able to find with this type of cancer in adults.

Following that, I am on scans every six months. During my pregnancy, the cancer grew rapidly. It really increased in size. I keep asking the question, "Can I have more children?" We want to expand our family, but no one is able to give me any answers on that. The information just is not out there. The only information that we have is, "Yes, it did grow in pregnancy. It grew rapidly, but we can't say for certain whether or not being pregnant would bring it back or anything like that." There is just nothing out there for me.

Q280 **Paul Bristow:** You have made it very clear that it is a real challenge. Because it is so rare, you do not have other people who have gone through the same experience. You cannot find much information about this particular type of cancer. What other challenges have you faced that you think are unique to your having such a rare cancer?

Katy Hall: I am not sure whether it is unique to having a rare type of cancer, but it is about mental health support. Getting a cancer diagnosis at any point in your life is going to be an absolutely horrendous experience for anyone, but especially when you have such a rare type of diagnosis. When we are floored and are given information that is going to change the rest of our lives, our natural reaction is to want to know everything about that particular thing—any triggers, what we can do to improve our lifestyle, how we can prevent it ourselves and how we can do the best that we can to look after ourselves to make sure that we are here to watch our children grow. Not having that information available has been a massive strain on my mental health.

Ultimately, it is about the mental health support with a cancer diagnosis. There is very little support. I have scans every six months, due to my rare type of cancer. I am only 34. In between those scans, there is nothing. I have been fortunate in that I have reached out to the Kidney Cancer Support Network and the kidney cancer charities, which can provide support. Other than that, you are not given anything. You are expected to turn up at the hospital for your scan, go away, wait four to five weeks with the worst feeling that you can ever imagine, get your results and then disappear again until your next scan is due. There is very little support.

Q281 **Paul Bristow:** You said something very powerful about your wanting to have more children and not knowing whether you can or should have more children because of your experience during pregnancy. Do you want to explain to us a bit more what that is like?

Katy Hall: When I was going to the annual ultrasound scans, the cancer was growing roughly half a centimetre each year, so it was progressing, but in pregnancy it grew 2 cm within the space of six or seven months. In comparison with how it had been growing previously, that was a massive increase.

I was referred to the Christie, which is a leading kidney cancer centre in Manchester. I saw a specialist there and I asked the direct question: "I

want more children. We want to expand our family. What is the likelihood of this being a trigger for the cancer coming back?" The specialist there was unable to say anything. I understand that. As I said, there are no statistics. There is nothing to compare it with.

Having that decision in my cards has a massive impact on my mental health. As much as I want more children—we always had more children in our family plan—it is a case of saying, "Do I take that risk?" My little boy is now only two. Ultimately, my life goal is to see him start school. Eighteen months ago, it would have been, "I want to progress at work. I want to do this. I want to move to a nice house in the country. I want a promotion," but now my only goal in life is to see him start school. It has changed every outlook imaginable in my life.

Q282 **Paul Bristow:** I can imagine. What would you want to tell the Government right now? What would be your message to the Government and the NHS to improve care for people with rare cancers?

Katy Hall: Cancer does not fit into just one bracket. Because I was not male and over a certain age—say, 55—the right scans and tests were not done in the beginning, when my tumour was first found. Because I was a young female, they did not do the correct scans. We need to be mindful that cancer does not have a one-size-fits-all approach. If someone goes to their GP or the hospital and something is found, do the correct tests. Get an early diagnosis, because it could be the difference in someone living to see their little boy or their young children start school. Do the tests and give that support.

Q283 **Paul Bristow:** Thank you very much. That was a really moving story. Your little boy is lucky to have you. We really appreciate your testimony.

Katy Hall: Thank you.

Chair: Thank you, Katy. Let me add from everyone else on the Committee that that was very moving and powerful. We are all rooting for you. I hope that you will get long beyond seeing your son go to school. What a wonderful thing to say. Thank you for joining us this morning.

Katy Hall: Thank you.

Examination of witnesses

Witnesses: Professor Baldwin, Anna Jewell and Jane Lyons.

Chair: Following that testimony, I welcome our first panel of witnesses: Jane Lyons, the chief executive of Cancer52; Anna Jewell, the chair of the Less Survivable Cancers Taskforce; and Professor David Baldwin from the Roy Castle Lung Cancer Clinical Expert Group. Welcome to you all.

My colleague Paul Bristow has a brief declaration of a connection.

Paul Bristow: Yes. As always, I refer Members' attention to my entry in the Register of Members' Financial Interests. At the same time, I declare that in the past Jane and I have worked with each other, at the consultancy that I used to own some time ago.

Q284 **Chair:** Thank you.

Let me start with you, Jane. Thank you for joining us. How typical is Katy's story, in your experience?

Jane Lyons: Thank you very much for having me here today. I also want to say a huge thank you to Katy, because that is a distressing and powerful story to have to tell. She told it very well.

Before I go on to say how typical Katy's experience is and to compare it with the things that we hear across the much wider rare and less common cancer community, I would like to mention that there are many rare and less common cancers. Something like 47% of all cancer diagnoses are for rare and less common cancers, but they account for 55% of all cancer deaths. Although we use the word "rare", across the board the rare and less common cancers, which are all cancers outside the four more common ones, affect a massive number of people and pose a massive number of challenges. They are a massive number of cancers, of which Katy's is one.

To the question of whether Katy's story is typical, there are a couple of differences, in her youth and the fact that we have a pandemic overlay, but the broad and most affirmative answer is yes. I thank Katy for her extraordinary and moving testament. What I understand from it is that diagnosis took a long time. Katy used the phrase, "It's not what we thought it was," when they finally arrived at some kind of cancer diagnosis, which was four or five years down the line. That is not atypical. It is comparatively common. Symptoms can often be vaguer, less well known and confused with other, more common conditions. IBS is a favourite, if you have anything going on in your tummy over the age of 50 and are female. Often people go numerous times to see, usually, their primary care person, before some kind of action is taken.

That relates to another thing that is a very common entity within the rare and less common cancer sector, which is the broader lack of knowledge and awareness. It is not an intentional thing. It is just something that is out there. Most people do not know much about what could be cancer. There is a lot of work going on in that, but where you have some much vaguer and lesser-known symptoms, it takes someone to push. Katy is a shining example. She pushed and pushed and pushed to get to the right people and to get better work on it. That is worrying, because not everybody will push.

Finally, the other thing that is horribly typical is Katy's comment on the mental health challenges and the support between actual medical interventions. That is very true for all cancers, but more so, we believe,

for rare and less common cancers, because the expertise is not there, the centres are more widely spread and people do not know what you are talking about. Katy found somebody in California and, fortunately, then got some support from UK charities on the broader issue of kidney cancer. The feeling of isolation and being on your own is already strong, we understand, and added on top of that is the fact that there are probably only 10 or 20 of you across the country. In many ways, it is very typical.

The things that were not typical, of course, were that Katy is young and female with a particular cancer that is much more common in men over a certain age. The pandemic, layered on top of all that, made most of the things that are already an issue worse.

Q285 **Chair:** We should add that your organisation's name, Cancer52, comes because when you were set up 52% of cancer deaths were from so-called rare cancers. That has now gone up to 55%.

Jane Lyons: Thank you very much for explaining that. Yes, 52% of all deaths from cancer were from rare and less common cancers when the organisation was originally set up. It is now 55%, so it is not going in the right direction; and that is against a diagnosis rate of about 47%. Those are 2017 numbers, so they are out of date, but they are not going in the right direction.

Q286 **Chair:** Anna Jewell, you are chair of the Less Survivable Cancers Task Force. Having listened to what Jane is saying and to what we heard from Katy, can you say whether this is a problem all over the world with rare and less survivable cancers? Are there other countries that have particular models that are more effective at tackling less survivable and rarer cancers than we have here?

Anna Jewell: Thank you very much for the opportunity to come and talk to you today. We are very pleased that the Committee has recognised the need to look at how we can make improvements for the less survivable cancers.

I will start by explaining that we represent the six less survivable common cancers, which are brain, liver, lung, oesophageal, pancreatic and stomach cancer. There are issues with the diagnosis, treatment and outcomes for all of those cancers around the world. We need more research and investment to find better ways to diagnose and treat those diseases, but there are definitely things that we can learn from how they are treated in other parts of the world. There are issues that we need to tackle in the UK to improve diagnosis of these diseases in particular. We need to find better ways to diagnose and treat them and to get faster diagnosis.

To reflect on Katy's story, we definitely hear that a lot of our patients spend time going back to the GP a number of times. Often these cancers are diagnosed with vague symptoms, which means that they are often

picked up quite late. It can be a real challenge to get the cancers diagnosed early enough to be treated.

There are issues with getting people into treatment fast enough. There is variation in the treatment that people receive around England. It is crucial that we look at the variation that we have in England in different rates of treatment and different outcomes, and that we try to learn from best practice and disseminate it to improve outcomes.

Q287 **Chair:** Which countries, in your mind, are the benchmark in both speed of diagnosis and speed of getting to treatment?

Anna Jewell: We have definitely seen that some things have been learnt where we have brought in rapid diagnostic clinics. We have looked to places like Scandinavia to learn about those clinics, which can help to speed up the routes to diagnosis for people with vague symptoms of cancer. We have seen some good outcomes for pancreatic cancer, which I represent, from some of the work that is being done in Australia to get people into fast treatment.

It is very much about looking across Europe. From the latest data put together by the London School of Hygiene and Tropical Medicine, through the CONCORD-3 study, we know that we rank right at the bottom of the table in Europe for the cancers that we represent. We are 23rd, 24th or 29th in our survival rates, compared with other European countries.

Q288 **Chair:** For which cancers is that?

Anna Jewell: For pancreatic, liver and lung cancer—all of the less survivable cancers—we rank down in the low 20s when our survival rates are compared with those of other European countries.

Q289 **Chair:** Can you send us that data?

Anna Jewell: We can. Absolutely.

Q290 **Chair:** That would be really helpful.

Let me bring in Professor Baldwin. I will then hand over to my colleagues. I want to talk to you a little about lung cancer. Are the issues we heard Katy talk about, and the issues Jane and Anna have talked about on late diagnosis and, sometimes, delays in accessing treatment, also true for lung cancer, which has one of the lowest survival rates?

Professor Baldwin: Yes, they are. Thank you very much for the opportunity to talk about lung cancer. It is not an opportunity that we get very often in the lung cancer world because there is a degree of prejudice against this disease, which kills 18% of the people who die from cancer, more than breast and bowel cancer put together by a substantial number.

I pay tribute to the late James Brokenshire, who was one of the politicians who helped us enormously in some of our efforts and is largely responsible for the progress we are making. He helped us to advertise our national optimal lung cancer pathway, which was the first of the rapid

diagnosis pathways and led to the development of other pathways, including for pancreatic cancer. The targeted lung health check programme was also brought to the attention of Parliament through James, so we are very grateful to him.

For lung cancer, there is a real issue with late diagnosis. It is the main issue, in fact. We know that if we diagnose lung cancer early we have very high cure rates. Sadly, about 65% of people who are diagnosed with lung cancer have late-stage disease, when cure is very rare indeed. Furthermore, by the time they get to clinical services, many of the patients are unfit, so they cannot receive the relatively good systemic treatment that is now available for lung cancer at late stage. It is really important not only that we get people diagnosed early so that they can be cured, but that we get them diagnosed early even when they have late-stage disease, so that they can receive the better treatments that we have right now. I echo everything that has been said. The only difference with lung cancer is that it is the most common cancer killer and, therefore, a really big health burden.

Q291 **Chair:** What is the thing that we are not doing that we should be doing? We have the announcement of the 100 new diagnostic centres. Will that be a help? Are there other things that we should be learning from other countries?

Professor Baldwin: Everything is going in the right direction at the moment, but maybe not at the scale we need to plan for. Ideally, we need individuals who are worried that they may have cancer to seek help early and to recognise the problem. When they seek help, they should have ready access. When that ready access is activated, there should be recognition that the person needs an appropriate diagnostic test, which, in the case of lung cancer, is a CT scan. Once that CT scan has been done, we know with much more certainty whether or not they have cancer. Then we need a rapid diagnostic pathway they can progress through so that they can get to treatment at a time when they are still fit enough to receive and benefit from it.

On the back of all of that, we also need a screening programme. As you know, that is under way at the moment. I can tell you that, on the international stage, it is actually the envy of the world as a national implementation programme. We are still waiting for the UK National Screening Committee to sanction that programme and to tell us exactly how far it can go in terms of cost-effectiveness. Nevertheless, it is a world leader we can be proud off.

The combination of screening and early awareness, access, presentation and diagnosis is what we need. Things are going in the right direction, but there are other things that we can do, particularly to address variation, which we will go on to subsequently, I imagine. I can talk about that.

Chair: Thank you. Let me bring in my colleagues.

Q292 **Lucy Allan:** Thank you, Professor Baldwin, for paying tribute to James Brokenshire. I am sure that that is much appreciated by all colleagues.

You mentioned awareness and the need to understand when to seek help. Can you say a bit more about what people should be looking for when it comes to awareness, as well as about the hurdles that people face when they present and communicate their concerns, which then lead to getting on to the treatment pathway? What more could be done around those two issues?

Professor Baldwin: It is very important. The Covid pandemic has shown us just what happens when we turn off access to early diagnosis and scanning. Quite necessarily, we had to keep people at home. It kept lung cancer patients at home more often, so we saw a 69% reduction in referrals. The message was to stay at home if you had a cough, so we saw a 30% reduction in lung cancer incidents, and no recovery. Those poor people were never diagnosed with lung cancer. They probably had lung cancer, were never diagnosed and died with another diagnosis.

The first thing is that you need to have the awareness campaigns linked to the access programme. They should not be isolated. If you do an awareness campaign, by whatever means—national media or targeted contact with patients—it has to be linked to the referral process: "If you are worried, phone this number." At the moment, it is, "See your GP," but GPs are really overwhelmed, so maybe we need a different system. I know that you have discussed cancer hotlines, which are a really good idea and would allow people to be triaged according to set processes.

They should then go straight to a CT scan. It is really important that we scan people. As an aside, it is the CT scan that detects most of the cancers, across the board. In the rapid diagnostic centres, it is the CT scan that detects the cancers, not the endoscopy or the ultrasound scans. The majority are detected by CT scans. Scan them. That is the first thing. Once they have been scanned, they should go straight through the pathway as fast as possible.

Q293 **Lucy Allan:** I am fortunate enough to be getting a new community diagnostic hub in my constituency. Will that assist in detecting rates of lung cancer?

Professor Baldwin: Undoubtedly, because it will lead to more people having CT scans. Obviously, it has to be managed correctly. That is another discussion.

Q294 **Lucy Allan:** They will get treatment more quickly, presumably.

Professor Baldwin: Scans are really sensitive, even for early-stage lung cancer. Once you have had your scan, you are away. You start the pathway. We have the national optimal pathway, so you should progress very quickly.

Lucy Allan: Thank you.

Q295 **Paul Bristow:** You talked a little about variation, Professor Baldwin, and said that we might get on to that later. Do you want to start that discussion now?

Professor Baldwin: We have done some work on this at Nottingham, using large datasets on lung cancer. That enables us to control or account for all the factors that might influence variation, which are what you would expect.

What we found is that if you are first referred to a surgical centre for your lung cancer, as opposed to a centre that does not have surgery on site, initially at least, you are 51% more likely to get surgery for your lung cancer. That is accounting for all the things that might influence whether or not you get surgery. We looked at it about four years later and it was about 39%. Both of those studies are published.

I will not bore you with the detail of the research, but there are lots of other elements of variation we can tell you about. There is variation. There is variation in radiotherapy rates and chemotherapy rates. In lots of things you look at, you find that there is variation—unacceptable variation. Then there are the results of the national lung cancer audit, which show massive differences, by cancer alliance, CCG or whatever you look at, in the proportion of people who get surgery. There are really big differences.

Q296 **Paul Bristow:** How can that be explained?

Professor Baldwin: Good point. We think that the main difference is the fact that there are differences in the teams that look after the patients. There is a difference in expertise levels, a difference in the levels of equipment they have and a difference of approaches. There is also a problem with distance. We know that distance, not just in the UK but in other countries, is related to treatment rates, so there is distance to travel—reluctance of people to travel. We think that those two things are very much operative in the UK.

The hub and spoke model is great for producing really good local expertise and fantastic centres and raising the standards in cancer care, but the inevitable consequence is that, because you have a hub, you have spokes that are less well off. What we need to do, in my opinion and in the opinion of the CEG, is to try to equate the care that patients get wherever they are referred. That means giving them the same level of time, expertise and equipment as you get in the centre, except for certain things that have to be done in the centre like advanced surgery, and so on.

Q297 **Paul Bristow:** The whole idea behind the very existence of the hub and spoke model and the fact that you have cancer alliances across the country is that you would still have access to the hub even if you were at a spoke; they all feed into the one centre. But that is not working.

Professor Baldwin: That is exactly what we should be doing. One of the things I try to say is that, as a person who is lucky enough to work in a big centre, I should really have responsibility for all the patients we serve. For any patient who potentially uses our surgical centre, we should have some form of responsibility to make sure that they have the best chance of getting surgery. It is not sufficient just to have surgeons having multidisciplinary team meetings with the local clinicians. That was going on anyway and we still see variation.

There is a really radical solution. It was published by NHS England through the CEG, which was originally an NHS England body, as advice to commissioners on the commissioning of lung cancer services. It says that, if you are a commissioner, you commission the amount of expertise, time and equipment that you require to manage the patient with lung cancer wherever you are. If you cannot commission it locally—if it just is not available locally—you commission it from the local centre, to be delivered locally. It is not like an outreach service; it is actually part of your service. It is trying to get the expertise that we have in the centres to help the very busy spokes as well. It is quite a controversial suggestion, and it is a radical change, but in my view, unless we do something really radical, we are always going to have a problem with variation.

Q298 **Paul Bristow:** Jane, is this variation common across all less common or rarer cancers?

Jane Lyons: What we understand to be the case is that there are some specialist centres, sometimes as few as two or three, across England for example, if you have a particularly rare form of cancer.

It was interesting to hear Professor Baldwin's comment. When we have done surveys of patients about how far they would travel for their treatment, there has been quite a strong sense, especially when they have a less common or rare cancer, that they will go wherever the expertise is because there is such a strong relation between people who deal with that cancer and your outcome. There are not so many of them and you have to seek them out. That is the fact of the matter, I think.

Yes, we see a lot of variations across regional centres. I cannot give you the detail or the data, but this is where charities come in a lot, knowing where the best experts are, where the best treatments are likely to be and the kind of support along the way to get there.

Q299 **Paul Bristow:** You found there was no reluctance from patients. They would go from one end of the country to the other, in effect.

Jane Lyons: I wouldn't say no reluctance. I am just saying that the sense has always been, when we have asked people, "Would you rather go somewhere that is local that does not have somebody who knows about your cancer?"—to be fair, this was pre-Covid—most people wanted

to travel to where the knowledge was. They preferred to and were prepared to, definitely.

Q300 **Paul Bristow:** Anna, similarly, is this variation common among some of the less survivable cancers, in your experience? Is it the same situation?

Anna Jewell: Unfortunately, I would echo a lot of what David said for the rest of the less survivable cancers. It is something that we are very concerned about. One big issue is that we have not had enough clinical audits carried out within our cancer types to really understand the variation that has been happening. We have had an announcement that there will be one carried out in pancreatic cancer, which is great. There is one in lung cancer and oesophageal, but not the rest of the less survivable cancers.

The data that we have from health professionals and researchers who have, for example, looked at pancreatic cancer shows us concerning levels of variation. For example, if we look at the levels of people who are inoperable who get chemotherapy, the variation between cancer alliances or chemotherapy rates varies between 25% and 35%. If we look at those who have surgery and adjuvant chemotherapy for pancreatic cancer, the rate of chemotherapy provision varies between 40% and 65%. Those are big levels of variation that we are very concerned about.

We have the same issue when we have specialist centres for pancreatic cancer. Only about 20% of patients will be seen in a specialist centre, with 80% of people being seen in the spoke model that we were talking about. The data again suggests that the treatment people receive in those centres is not always up to the same level in the units outside the specialist centres.

Most recently, we have been looking with Pancreatic Cancer UK at the use of enzyme replacement therapy, which is really important for helping people to stay well enough to have treatment and not become malnourished. Only 50% of patients receive enzyme replacement therapy, when it should be close to 100%. There is much more variation in those who are inoperable and are seen outside the specialist centres.

As a taskforce, we are calling for optimal care pathways, optimal diagnosis and optimal treatment pathways for all of the less survivable cancers so that we can try to ensure that people get fast access to the best available treatment options available. We believe that could make a transformational difference to the outcomes for the less survivable cancers.

Q301 **Paul Bristow:** Are cancer alliances ranked in their performance—audited is the wrong word—on cancer outcomes and other metrics? If they are not, should they be?

Anna Jewell: I do not think they are ranked in their metrics for their performance. Where there are clinical audits, obviously they can be used, but not necessarily as a ranking. I guess what is important is to identify

where there is best practice that we can learn from, so that we can look at where it is helping to improve outcomes and where there is poorer practice that we need to be able to tackle.

It is interesting. I sat on the HPB—hepato pancreatic biliary—clinical advisory group at NHS England for a number of years, where we have been putting in place a service specification for pancreatic cancer and liver cancer. We can then use that to audit and track care. Those service specifications have been stuck in the system for quite a long time, getting renewed, and that means that we have not had a chance to see the data that we would like to see in order to look at performance across different cancer alliances and look at where we need to improve care.

Q302 **Paul Bristow:** How long have they been looking at those service specifications?

Anna Jewell: I think I am coming up for six years on that group, which is too long.

Paul Bristow: Thank you.

Q303 **Chair:** I have some questions before I come to my colleague, Dean Russell. I am very interested in what you are saying. NHS England's view is that cancer is one of the areas of NHS provision with high levels of consistency across the NHS. They think they do pretty well in cancer care on consistency, so are the alliances working in the way they should? I will ask you all to comment on this, if I may. Please be as frank as you can because it is very helpful for us to understand this as a Committee.

Are the alliances working as they should? Secondly, is there transparency? Do we actually know which alliances are working better or not? Thirdly, how much is it part of the job description for a cancer consultant to be aware of what best practice is in their field throughout the whole system, and are they checked or measured on how much they keep abreast with the very latest things that are going on?

Professor Baldwin: Taking the cancer alliances to start, I was the clinical director for the East Midlands Cancer Alliance when it was first set up, and I think the idea is absolutely fantastic. The cancer alliance structure is very good. It is significantly better than the old networks. The process or the way that national bids and money come through the alliance and are bid for was very successful. It was the one reason that the transformation money with the national optimal lung cancer pathway was a national priority. What we did was to produce lots of template bids for all the trusts in the whole country, and they all sent them in. It then became a national priority for all the alliances. That is really good. They are very good at that.

I think that the alliance structure is working very well. The problem is the disparity in the delivery mechanism. We have a workforce who are very challenged, especially in the spokes. Trying to achieve the very high standards that we are setting is really difficult in that setting. That is why

I think we need a slight restructure, to try to help the areas that struggle to deliver what they need to deliver.

Q304 **Chair:** What about transparency and the consultants?

Professor Baldwin: The other thing about the alliances is that there are dashboards available. You can compare the alliances' performances and you can compare individual trust performances. They are there to do that.

There are local audits. Data is very important. The cancer audits are really important. The reason they are important is that they often contain the extra data items that might not be available elsewhere that enable you to control for the confounding factors, so you can get more meaningful data.

Sorry, what was the other question?

Chair: Consultants.

Professor Baldwin: One of the things that we stipulate in our aforementioned service guidance—the commissioning guidance—is the amount of time required in direct clinical care from a respiratory consultant dedicated to lung cancer. That is a measure of the amount of time you spend on lung cancer. For oncologists, radiologists and all the other professions, we have said that at least a third of their clinical time is to be spent doing lung cancer. In answer to your question, no, people are not checked regularly on the way they are abreast of the latest guidance. That would be very difficult, but our service guidance at least says that you are meant to be doing it often, and therefore you are likely to be more of an expert.

Q305 **Chair:** Thank you very much. Jane and Anna, do you agree with Professor Baldwin's characterisation, that the principle of the alliances is great, but the delivery networks underneath them are patchy? I think that was basically what he was saying.

Jane Lyons: Broadly, absolutely. Professor Baldwin also touched on the workforce issue. It is much more difficult to recruit people to some areas than others. I absolutely agree that the principle of the alliances is right. Some things are really starting to work quite well. There are some good, targeted initiatives going on. Then again, we come back to the overarching thing that has remained unspoken thus far about having the workforce to deliver on it.

On transparency, perhaps I could comment on this point as well, Chair. Speaking from a charity perspective, Cancer52 has 103 charity members, all of whom have an enormous amount of expertise and specialist knowledge in their particular cancer sector. From our point of view, we would like to be able to know who to talk to within those alliances, where they are best placed, who we should be thinking to and where our members should be networking to. One of the asks that we would like to

be considered would be that there would be somebody in an alliance with "rare and less common cancer" in their job title. Then it is part of their responsibility to focus on that, and we at least know where to start the networking. It is an offer of expertise as well, but transparency-wise that kind of aspect is currently a bit difficult.

Anna Jewell: I echo most of the points made by Jane and David. The less survivable cancers represent a quarter of all cancer diagnoses and a staggering half of all cancer deaths. We have a five-year survival rate of just 16% for the less survivable cancers overall.

The cancer alliances are a good idea and a good structure, but one of the issues is about prioritisation of these diseases, and prioritisation within cancer alliances of the need to make improvements for the less survivable cancers. Often, when there is national cancer policy or when there is funding, sometimes the less survivable and the rarer and less common cancers are not always at the front of the queue for new initiatives. We often introduce them for the more common cancers first to see how they work, before they are then moved on to the less survivable cancers. This is where we have seen issues such as not having enough clinical audits to have transparency of data, and things like ensuring that we have the optimal pathways that I talked about before.

One of the issues is making sure that we have the priorities of those right in cancer delivery. Transparency of data is a big issue for all of the less survivable cancers. We have issues getting hold of the data that we need. There can be big gaps in the data—big gaps in staging data have been a big issue for us—so that we can really look at the progress we are making.

On your final point about the consultants we talk to, we work a lot at Pancreatic Cancer UK in particular with health professionals working right across the UK and in England at specialist centres. A lot of those consultants are very keen to try to make improvements in the care that is delivered, not just at their specialist centre but at the spokes and units that feed into them. Again, I think it is about workforce and capacity to enable them to do that, and making sure that they have the time and the capacity so that people get the best care wherever they are treated.

Chair: Thank you.

Q306 **Dean Russell:** This session is deeply personal to me. Over the past two years I have had family, friends, colleagues and constituents who have had various forms of cancer. Some of them are no longer with me. Some of them miraculously are. I have seen from the outside the whole pathway and the impact that cancer has on individuals.

From a patient point of view, could you explain this? Most people do not go to their GP thinking they have cancer. It is probably one of the rare times when they have not looked it up beforehand. Most people go in with a thought of their diagnosis. From a basic level, when a patient goes

to the GP what is the process there to get to the point of a cancer diagnosis, especially a rare cancer diagnosis?

Anna Jewell: For the cancers that I represent, quite often people go to their GP with what can often be seen as vague symptoms. It might be back pain, bowel problems or headaches. Those are often put down to a lot of other conditions, particularly if people are younger or they do not fit the profile. What we hear about far too often are people going back to their GP over a number of months, or even years, saying that they are starting to feel worse, but they are not being referred. That is often because, although we have some excellent guidelines and referral for cancer patients through normal routes if you have a red flag symptom, if you have one of those vaguer symptoms it can often be put down to something else. They might see a number of different specialists before they are diagnosed with the right cancer.

That is why we think it is so important to have the rapid diagnostic clinics that have been brought in, to try to speed up diagnosis and have a place for someone with vague symptoms to be referred to, so that they can try to speed up the pathway and stop the traumatising issue where people often keep going back to their GP. Particularly when they are diagnosed when they are no longer operable, and they are terminal or metastatic in their disease, to feel that they were going back and back to see someone and that diagnosis was missed is devastating for them and their family. It is something we hear about all too often at the charities I represent.

What is crucial is the investment that we need to find better ways to diagnose and test for these diseases earlier. It is important that we bring in issues such as lung cancer screening, where we are starting to see the use of cytosponge for Barrett's oesophagus disease, which is an early precursor of oesophageal cancer. There is surveillance that can be carried out for liver cancer for a lot of patients who have cirrhosis. For cancers such as stomach, brain and pancreatic, we need more investment in developing biomarkers that can help pick up those cancers at a much earlier stage, when they are not advanced and when we can treat them.

Q307 **Dean Russell:** In terms of the barriers that you have seen for patients—those who go back and back—is there a pattern? Is it because the GPs either are not picking up on it or do not know the pathways to get them referred? What is the barrier? I would imagine that, if a GP thinks a patient could have cancer, they are not going to not want to refer them. What do you think the barrier is?

Anna Jewell: One of the barriers is that we have to be honest and know that, within a GP's career lifetime, they will only see a few each of most of the cancers I represent. We need better tools to help GPs. The use of decision-making tools can help people; they put in the symptoms and see the risk of cancer. As I say, we need different pathways into vague symptom clinics that they know they can refer people to. They might pick up cancer or another condition. We need better pathways where GPs can refer people who are coming back to them.

We probably need a system where we make sure that people do not come back and back a number of times. If people come back a couple of times, they need to be referred to something like a rapid diagnostic clinic. I think that would make a huge difference. We need the development of tests to help GPs to better triage, to indicate which patients, through a blood test, need to be referred for further tests, investigations and scans for cancer. That would really help.

Q308 **Dean Russell:** Jane, if I may, I will ask you the same question. Obviously, you work with a huge number of smaller charities. Is that the story you hear as well?

Jane Lyons: Anna has described very well the visit to the GP experience. I would just add that what I think would be helpful—there has been some work on this—is to try to build awareness of rare and less common cancers among the general population. Through the NHS Help Us, Help You campaign, there has been a focus recently on abdominal and urological, which has helped, because they are vaguer than everything else. If we had a more empowered and powerful patient population—touch wood, they are not patients now, and frankly I agree with you, who wants to be one? I don't—and if they were better informed and could explain themselves a bit better, that would be helpful. It is about broader knowledge and awareness. It also might help people who work in primary care. Anna has quite rightly identified that some people will only see certain cancers two or three times in their career. I suggest that we support those awareness campaigns.

In many ways, cancer is still a disease of age. We are talking about a population that does not want to bother their GP. As Professor Baldwin has already referenced, the stay-away from the system messaging was pretty strong during Covid. We need to try to support people to come forward, and we need better knowledge and awareness-tracking of what people do know. They do not want to make the phone call because they do not want the news even if they get it. They at least need to come forward a bit earlier and we need to get across the message that the sooner you get there, honestly, even if it is not what you are hoping for, probably the outcome will be better. I know that is hugely sweeping and generic, but that is the message that needs to come through.

Q309 **Dean Russell:** In terms of those symptoms, is there anywhere online where you can check? I did a lot of work on websites for the NHS years ago. I remember that there were thousands of websites, all for the same thing and all telling you different information. Other than the NHS website, is there a source to go to?

Jane Lyons: You have to understand that putting in something that specifies a cancer and a type of cancer, which is even worse, you are mentally well ahead of where you are before you get to the GP, so to speak. There are some trials going on. Most of our member charities have a patient support helpline, so once you are through the system and know

what you are facing, there is a good deal of support. That plays very much to the point Katy made about support as you go through.

It is not just symptoms helplines, although there are a good many. There are some trials going on among alliances for cancer symptoms hotlines, which I believe is what they are called. We are sharing information from the charity sector, having had a lot of experience in that, with the alliances. We are sharing learning sessions and hoping to make those better. Yes, there are, but I think I would caution too much about googling things that you are not sure about.

Q310 **Dean Russell:** Yes; I am always wary of that.

Jane Lyons: It is a balance. Some people are happy googling and others are happier not.

Q311 **Dean Russell:** It is a rabbit hole of misinformation sometimes.

Jane Lyons: Indeed.

Q312 **Dean Russell:** I want to ask a slightly different question. I have a constituent—I have heard this many times—where there is a trial drug or something in another part of the world that they cannot access in the UK, and they have to do fundraisers to raise tens of thousands of pounds sometimes to be able to access it. Is that something you see regularly, and is there a way of solving that problem, so that if there is a potential solution somewhere else, it is not forcing people in the UK to have to fundraise to access it? Do you have any thoughts on that from your experience?

Jane Lyons: It is a very upsetting experience if that is the case, and it has sometimes been the case. From a patient perspective, I would try to urge a bit of caution on that. What it touches on, though, is the requirement to try to speed up access to the newer drugs in England and the UK. That takes us to a whole other range of how NICE works or does not, and the MHRA. If you are in that situation, it is extraordinarily sad. Industry can step up and help more if that is the case; maybe it is not their drug or maybe it is. I think there are all sorts of potential solutions. It is very sad if you feel you have to take an, often, younger member of the family out of the system.

Q313 **Dean Russell:** Professor Baldwin, I am interested in your take. Obviously, everyone seems to know about lung cancer but no one seems to want to go to the GP with a cough, especially if they have had it over a period of time. From your perspective, are you also seeing a lack of pathways from GPs through to the experts, to the end diagnosis and so on? Is that rooted in people not coming to the GP and explaining the symptoms? I would be interested in your take on all of this.

Professor Baldwin: Yes, absolutely. Before Covid it was a problem, in the sense that people were afraid to recognise symptoms. They were afraid to take that step and go forward. They are often from deprived

groups as well, so they do not necessarily access their GP services very easily. They are quite often not insistent. It is not an easy thing, as we all know, to get to see a GP. There are barriers anyway.

Once the GP is involved, things should progress. There are still delays in clinic. I see it all the time. I have been in lung cancer for quite a long time, but with Covid it was like working 20 to 25 years ago. That is what it was like, with late-stage disease and horrible presentations. There were all sorts of things that we had actually forgotten about because we have made so much progress on the early diagnosis pathway. We can go so much further, though. We need easy access, as I am trying to emphasise. It has to be linked with the awareness programme, so that people know that if they finally recognise that they have a symptom they have to sort out—it may not be cancer—they can get in easily. That is the crucial thing. That is the first step, and very important.

Q314 **Dean Russell:** In the UK where do we sit globally? For anyone who is worried, is diagnosis in the UK good compared with other countries? Where are we in comparison?

Professor Baldwin: The international cancer benchmarking partnership is the study to go to. That shows consistently that early diagnosis is one of the leading things that we do not do terribly well in the UK. That is one of the main reasons why we are behind other equivalent countries.

We also diagnose more of our cases. The international cancer benchmarking partnership is based on registry data, with very good registry, but if you never make the diagnosis you do not register them as cancers. We have shown that, if you increase the number of chest X-rays as a general practitioner, you detect more lung cancer and, importantly, more people who have a very short survival. There is a lot of cancer that we do not necessarily recognise. I think in other countries that may not be recognised. That might be part of the explanation. The main explanation is that we are just not very good at diagnosing early. I think that is the key.

Dean Russell: Thank you.

Q315 **Lucy Allan:** Professor Baldwin, your testimony throughout this session has been truly shocking about the impact of Covid on the failure to diagnose lung cancer. I have been quite taken aback by some of what you said. Can you tell us what is being done now to try to address that, and to bring us back up on a par with other cancers?

Professor Baldwin: Absolutely. It has been devastating for me as well to see all the work that we have done over the last few years being undone. One of the things I have written about is to say that we cannot let this pass without something positive coming out of it.

There are lots of positive things. The use of digital media is so much better. We have almost been vindicated in what we are doing. All that we have done so far has worked. When you take it off, it stops working, so

we need to do it even more. We need to get the CT screening programme up and running and at scale. We need to take the early diagnosis initiatives seriously and maximise the use of the optimal pathways. If we do all of that, and scan more people through the diagnostic centres, we will fix it again. That is what we need to do, and that is what we are determined to do.

Lucy Allan: Thank you.

Q316 **Paul Bristow:** NICE is undertaking a methods review into access to technologies and drugs. Do you think that what NICE has proposed so far is ambitious enough?

Jane Lyons: No, but it is extraordinarily complex, and they have left the door open. We have responded from the point of view of patient voice and patient involvement as our particular ask. I think that we could move faster. I think we could have more resource put into NICE to ensure that the patient voice is heard better. That is my answer from our point of view.

Anna Jewell: I echo that. It is really important that we ensure that the patient voice can be heard. We have struggled sometimes in the past with smaller patient populations, where the treatments that come through NICE for our diseases, like pancreatic cancer, were only adding a couple of months of extra life, unfortunately. That is not always considered cost-effective enough, but for something like pancreatic cancer even two more months of extra life can be incredibly important to people. It is also incredibly important that we try to get more people into trials.

Unfortunately, for the cancers I represent we simply do not see enough new treatments coming through NICE at the moment. What we really need is investment in research to get new effective treatments and new treatment targets for our diseases. I wish we saw more treatments coming through NICE.

Paul Bristow: I will leave it at that.

Chair: Thank you. We have had a very good discussion about rarer and less survivable cancers. We are very grateful to you for sparing the time this morning. It has been very informative. Thank you very much indeed, Anna Jewell, Jane Lyons and Professor David Baldwin. We will feed your excellent testimony into our report, which we will publish early next year. Thank you very much indeed.

Examination of witnesses

Witnesses: Professor Shackley, Ian Vousden and Sarah Stevens.

Q317 **Chair:** As our final panel this morning are finding their seats, I welcome Sarah Stevens, deputy director of the National Disease Registration service at NHS Digital; Ian Vousden, programme director of the Kent and

Medway Cancer Alliance; and Professor David Shackley, director of Greater Manchester Cancer. Thank you very much for joining us this morning.

Sarah Stevens, perhaps I could start with you about the issue of variation. We were hearing in the earlier session about variation when it comes to rarer and less survivable cancers, and how even though best practice might be well known at the top of a cancer alliance, delivery at the lower levels is not always consistent.

I wondered if there were also regional variations. If you look at cancer survival rates as a whole, are there some parts of the country where you are more likely to survive cancer than others?

Sarah Stevens: In England, we have 327,000 new diagnoses a year. That is on average about 900 a day. We have obviously seen an improvement in survival over time, in both one-year and five-year survival, for all cancers and for both sexes, except for bladder cancer.

We see variation by cancer alliance on the one-year survival rates. The minimum would be a variation from breast cancer at about 1.5 percentage points, to 13.1 percentage points for brain cancer. That is the range that we see over the one-year survival rates.

Q318 **Chair:** Can we quantify what the regions are. Which regions have the best survival rates for brain cancer and which regions are less good?

Sarah Stevens: That is a very good question. I do not have the data to hand for the specifics on the alliances, unless my colleagues can tell me, but I can get it to you.

Q319 **Chair:** Could you send that to us for the report? Basically, there is not a huge variation in breast cancer, but for brain cancer there is the biggest variation.

Sarah Stevens: Yes. That is the tumour type with the biggest variation. Brain cancer is one that is typically more likely to present in emergency presentation than through the two-week waits. That is where we see the greatest variation in survival.

Q320 **Chair:** What is the reason for that?

Sarah Stevens: I would have to go to my clinical colleagues to answer that. As I say, we know that brain tumours are more likely to be an emergency presentation than a two-week wait. It affects younger age groups rather than older ages.

Q321 **Chair:** Ian Vousden, in Kent, your area, are you conscious of differences between your performance and the performance, say, in Manchester, which we will come to in a minute? Are you conscious of variation within the area you are responsible for? If so, why? And thank you for joining us.

Ian Vousden: No problem. Thank you for inviting me.

One of the fundamental issues and reasons around this variation is very strongly linked to deprivation. Within alliances there is a very strong link between areas of deprivation and subsequent early diagnosis and outcome of cancers. I think that is fairly prevalent across the board.

From a performance perspective, particularly in relation to the constitutional standards, the performance in Kent and Medway has been particularly good and has improved significantly over the last 18 months, particularly around our 62-day cancer performance. We have done a lot of work on supporting improvements in our prostate cancer pathway. Over an 18-month period, in Kent and Medway we went from being one of the most challenged cancer alliances, from a 62-day performance perspective, to being one of the best.

Q322 **Chair:** Are you back to pre-pandemic levels for your 62-day?

Ian Vousden: In our performance? No, we are just below that.

Q323 **Chair:** One of the things that we were discussing in the earlier panel—I will ask you and then I will ask Professor Shackley the same question—is trying to understand how good the system is at spreading best practice. If you are looking at this from the outside, you would say that for something like brain cancer there is established best practice that the top consultants at UCLH or the Christie will all know about. They say, "Well, can't you just spread the message everywhere?" Why does that not happen?

Ian Vousden: I can only speak for my local area in relation to that. From a cancer alliance perspective, we have what we call tumour groups established for all of the major tumour types, cancer types, in Kent and Medway. Those groups of clinicians get together twice or three times a year to discuss best practice in relation to how pathways are going to be managed within a local area.

That innovation and clinical best practice tends to spread across the clinical community. There are some potential challenges around delivery, as we heard earlier, in how systems are set up and in moving some of that work forward. Across the clinical community, generally speaking, there is fair consensus on how some of those pathways should be delivered. Then it is around the subsequent implementation, agreement and commissioning of the pathways.

Q324 **Chair:** Before I bring in Professor Shackley, let me ask you a much more general question. Why do you think that they have higher cancer survival rates in Denmark and Australia?

Ian Vousden: From my perspective, one of the things that is often referenced in some of the international cancer benchmarking is that some of that data is quite old now in relation to some of the outcomes. What I would say from a local perspective, in relation to the work we are doing in Kent and Medway, is that there is lots of innovation and lots of work to support improvements in cancer pathways.

I just caveat the point that I think some of that data is relatively old. There have been improvements made since some of the data has been looked at in the international perspective.

Q325 **Chair:** I appreciate that you represent the NHS, but I used to be responsible for the NHS and I am a little bit sceptical about that answer, I have to be honest. It is impossible to challenge it. What I found people on the inside of the NHS used to say was, "Of course we are getting better," and we usually shout about the improvement in cancer survival rates, but other countries are also getting better. What people generally acknowledge—say, Professor Sir Mike Richards—is that cancer survival rates are higher in Denmark and Australia, which are the places that we benchmark ourselves against. They are often higher in America too, which is not a health system that we generally admire.

Let me bring in Professor Shackley. I would be interested in your perspective, and on the deprivation point we heard about earlier. I am sure you will have something to say about that.

Professor Shackley: Thank you very much for having Greater Manchester here. I think I would echo Ian's comments about deprivation. We have to be clear that there is a massive impact from deprivation on cancer outcomes. In early-stage diagnosis, one of the key markers that is in the long-term plan at stages one and two—the more treatable cancers—and in the quintiles of deprivation, is that the most deprived have 48% at early stage, whereas the least deprived have 59%. That is across the country. There is a huge impact from deprivation. We are more deprived in Greater Manchester than others. You will be familiar with STPs—the areas across England that will become integrated care systems. There are 42 of those; Greater Manchester is the 39th most deprived. As well as deprivation, it is lifestyle. A marker of our lifestyle in Greater Manchester is the smoking rate. We were hearing about that before with lung cancer. We are 2% above the English average and 39th out of 42, so we are not doing particularly well.

We have that at the Greater Manchester level, and each of our localities or CCGs also has deprivation pockets and affluent areas. When we have looked at it, we can see that there is some association with deaths. In the more deprived localities, like Oldham, Rochdale and so on, the one-year overall pooled survival that we heard about before is lower in our area in Greater Manchester.

I want to talk about the second point you asked, which was the difference between alliances. For some reason, Greater Manchester was quite poor on pooled one-year survival. We were 4% behind the England average about 15 years ago and now we have drawn level, on the last figures, so you can make a difference with targeted action.

On your final point about spreading best practice, I think that is where the alliance really comes into its own. Without the alliance, you do not have a mechanism, a convener or an expert in a system to actually talk

about cancer. You just have individual providers and commissioners. An alliance brings people together around the cancer question.

We have had an alliance in Manchester for nine years. One of the big things that we have been doing is pushing innovations that we want everyone to do; FIT testing would be a good example, recently, to triage. Also we promote by bidding for money innovation ideas such as Prehab4Cancer, where we have put 2,000 patients through a specific prehab programme to optimise their care, particularly in lung cancer and colorectal cancer, so that we can get patients fitter for their interventions. That is a targeted approach, and then we would roll it out across. An alliance is essential to that spreading of best practice.

Q326 **Chair:** I think you heard the whole of the previous panel. Having heard that, are you confident that the cancer alliances are as good at spreading best practice for the rarer and less survivable cancers as for the more common ones?

Professor Shackley: We can always do better. As in Kent and Medway, since 2013 Greater Manchester has had pathway boards. We have appointed independently clinical leaders to look after certain disease areas within cancer. Of course, we have lung cancer leads, bowel cancer leads, breast cancer leads and so on. We also have the haematological and the rarer cancers represented, including pancreatic and other areas. Having a designated clinical lead who leads a board of people who come together in your area—the commissioners, the providers, PCSE and patients—who then talk about standards and performance in your area is the way forward. That is the method we have been employing, and I think it is a more targeted approach.

Chair: Thank you.

Q327 **Paul Bristow:** The Chair asked Ian Vousden about Australia and Denmark. Professor Shackley, what do you think? Why are we not reaching the same levels as Australia and Denmark?

Professor Shackley: There is a difference between faster diagnosis and earlier diagnosis. We talked about rapid diagnostic centres. Those are initiatives that drive the diagnosis once the patient has some symptoms, or very quickly at that point. Arguably—there is a little bit of evidence for this—you need to be diagnosing early. You want patients, when they get symptoms, very quickly to go to their GP or access care.

It might well be that the public in Britain are less likely to go and bother their GP: "I'll leave it a little bit. I'll see whether my symptoms get better on their own." There is some evidence that there might be different behaviour by our public with regard to going when they have symptoms.

We also have a primary care system that is quite complete as a gatekeeper. That is a uniquish situation. It requires patients to present earlier. It requires the GP to refer onwards very promptly. Those two factors are things that are particularly different, I would say, in England.

Q328 **Paul Bristow:** Do you think that the establishment of the diagnostic centres will help address that issue?

Professor Shackley: I think they will particularly help address the issue of vague symptoms. Lots of cancers have very specific symptoms; coughing up blood, haemoptysis, is quite specific for lung cancer. But a lot of patients present with cancer who have weight loss, do not feel well and generically are not doing well. The GP thinks, with a sixth sense, that they have cancer or something serious going on. Up until the RDCs—the rapid diagnostic centres—we did not have a pathway to send those patients. The GP would say, "I had better put them on a lung cancer pathway or the bowel cancer pathway." What we have now with RDCs is a vague symptoms pathway. For patients in Greater Manchester who have gone through this—about 2,000 over the last 15 months—from referral to "Have you got cancer, yes or no?" it is about 16 days with a very streamlined service. I come back to the points made before. Fundamental to that is a CT scan for all our patients.

Q329 **Paul Bristow:** Ian and Professor Shackley, we talked a little about the spreading of best practice and how cancer alliances were able to do that within a certain geographical location. Do cancer alliances talk to one another on a regular basis about best practice across the country?

Ian Vousden: Yes, we do. Through NHS England and the national cancer programme that has been established, there are a number of different methods by which we have conversations with other cancer alliances nationally. We convene share and learn events between and across alliances. If a particular alliance is doing an innovation or a particular piece of work, we have a method by which we can share that with colleagues. The national cancer programme team is good at identifying particular innovation within certain alliance areas, helping to facilitate and support the spread of innovation across to the other alliances.

Q330 **Paul Bristow:** Is there an innovation you have adopted from another cancer alliance elsewhere that has worked in your area?

Ian Vousden: In the innovation space, one of the things that we have obviously learnt nationally is around the targeted lung health check programme, which is now being spread out across the alliances. In Kent and Medway, we will be adopting that from next year, which is really exciting for our population in relation to making, potentially, a real difference in addressing earlier cancer diagnosis for lung cancer patients.

In Kent and Medway, we have been chosen to be part of the Galleri GRAIL trial, which I know the Committee is aware of from previous conversations. That could be a significant game changer in identifying patients without symptoms who would then, potentially, be predisposed to going on to have cancers, particularly some of the rarer and more difficult cancers to diagnose initially.

Q331 **Paul Bristow:** Professor Shackley, do you believe that cancer alliances are effectively sharing best practice across the country?

Professor Shackley: Yes, we are. I have just written down a few things. We obviously have the national grouping. There are 21 of us. We get together very frequently, both from a performance perspective and a clinical perspective, and then all together. We have a north-west group. There are three of us in the north-west that get together every week. Peter Johnson, whom you have heard from in this panel before, is the national clinical director. He gets people like me, the clinical chairs, together every month. We talk about things and share approaches. We have the Future NHS forum as well and various workshops.

I want to talk very briefly about the national cancer vanguard between 2015 and 2018, which was a partnership between Greater Manchester and London. It was very effective in driving a number of the innovations that are now spreading through. There are things like the best practice pathways that David was involved with, in that vanguard. There are lots of other things, such as GatewayC, which is a GP education tool.

Alliances are quite a big driver of innovation, and I have seen lots of evidence where we have been sharing that—colon capsule endoscopy, for example. There are lots of areas where we have copied others.

Paul Bristow: That is reassuring to know.

Q332 **Lucy Allan:** At the beginning of this session, the Chair asked about variations and reasons for variations. I thought it was fascinating that it was not until Professor Shackley got involved that we started talking about health inequalities. I think it is incredibly important that it is recognised right across the country that outcomes and health inequalities go hand in hand in terms of variation.

I want to ask a question of all three of you. Is lack of capacity for diagnostic processes also aligned with an area's disadvantage? If you are in a more disadvantaged area, are you less likely to be able to access diagnostic capacity?

Sarah Stevens: Rates of cancer diagnosis are higher in areas of high deprivation. We know that. It is about 16% higher from the 20% most deprived to the 20% most affluent. It is not the same for every tumour type. We do not see it in breast, prostate and skin cancer, but we see variation in diagnosis, referrals and referral routes by deprivation.

Q333 **Lucy Allan:** Ian, is there better access to capacity for diagnostics in your area than perhaps in a more disadvantaged area?

Ian Vousden: In access to diagnostics, even across the geography of Kent and Medway, there are challenges, given what I described around areas of deprivation. One thing that the community diagnostic centres and the rapid diagnostic models that we have described—particularly the community diagnostic centres—will mean is that there will be an impact on addressing and being out in the community, particularly areas of higher deprivation. Certainly in Kent and Medway, we are looking at establishing community diagnostic centres in areas of challenge

deprivation, so that access to diagnostics is easier for those local communities.

Q334 **Lucy Allan:** Is it recognised within the NHS that health inequalities are going to be hand in glove with poorer outcomes and poorer early diagnostic tests?

Ian Vousden: Yes. I think we have referenced the deprivation issue. I think I mentioned it earlier. There is absolutely a link between that and some of the challenges that we have around earlier diagnosis and subsequently some of the cancer outcomes. Some of the things we have described will certainly help address that.

Q335 **Lucy Allan:** Professor Shackley, do you feel there is sufficient recognition of health inequalities and the causes of poor outcomes?

Professor Shackley: With regard to diagnostics, yes. I think we could always do with more diagnostic capacity, of course. Diagnostics are the central challenge in getting patients through the system at the moment. It is not treatment; it is diagnostics.

We have set up a live data feed, within an envelope called GM Tableau, which looks in real time at all the providers and where they are with what we call milestone waits, the time before they get the first diagnostic and the time from diagnostic to being seen and told they have cancer. It is a bit of a mixed picture in deprivation areas. Of course, people are looked at in different areas. You might have a patient with a rarer cancer diagnosed in that area, but they come over to a centre somewhere else, so you get a kind of mixed picture. One of the things that we are doing in Greater Manchester increasingly—we have done it with some rare diagnostics, but we are rolling it out more—is the concept of a single queue, which I think would be a good idea to try in other areas as well.

There is something called a PET-CT, which is quite a sophisticated test. We have three places in Greater Manchester doing that, but everyone in Greater Manchester will need to get access to that. Rather than "What is your wait in your local one?", we have a single queue. Everyone in Greater Manchester enters that queue. We have now started that for endoscopic ultrasound scans and EBUS, which are two tests for lung cancer. It is very popular with patients. There is still a choice element. Patients can still go locally if they wish, but they have the offer of going more quickly somewhere else. We spoke before about travel. We have not seen travel being a particular barrier with regard to that.

Lucy Allan: Thank you.

Chair: Last but not least, Dean Russell.

Q336 **Dean Russell:** Thank you, Chair. Sarah, obviously working within NHS Digital one of the key aspects of your role is around data. Could you explain the importance of data in diagnosis and in the future plans for the NHS to prevent cancers?

Sarah Stevens: Thank you for the opportunity to do that. We have just moved to NHSD. The National Disease Registration Service was in Public Health England, and we moved as part of the recent public health reform. I have only been in the organisation since 1 October. Our work in national disease registration will continue.

My response to the question about how we improve information sharing and best practice starts, unsurprisingly, with the data and having high-quality, timely and accurate information to help support and inform the alliances. We do a lot of work in partnership with NHS England on providing information to the alliances to support them to do that.

Registration is a complex programme of work. It takes us time to get to the gold standard data and to make sure that it is comprehensive. We cover all diagnoses made in England and all tumour types for the whole population and for the whole of England. That is not matched in every part of the world. We work very closely with alliances, clinicians, researchers and the voluntary sector to make sure that what we are doing is as clinically relevant as possible, working with them to look at how our data can help inform clinical practice and support high-quality clinical practice.

Q337 **Dean Russell:** Over the past few months, there has been a lot of debate about data in the NHS and a certain amount of fearmongering about how it is used. Could you give some reassurances about how that data is protected, pseudo-anonymised and so on, just so that people realise this is at the heart of how we save lives in the future?

Sarah Stevens: Absolutely. It is an incredible privilege that we have this information. We collect identifiable information. We have to in order to be able to link patients with episodes of care. Obviously, many of those patients will be coming back. We follow up across the whole life course. They could be coming back a number of times throughout that time, so we collect identifiable information, but we have very strict procedures in place around confidentiality, privacy and security.

We only have the staff who absolutely need to see that identifiable information working on it. We minimise data sharing in identifiable form as much as possible. Our analytical teams work on de-identified data. Data requests that come to us go through a service called the office of data release, to make sure that they have the right information governance processes in place. All the staff are highly trained. They have done information governance training. We have now moved towards the legal basis of section 254 of the Health and Social Care Act, which gives us the ability to collect the information.

Q338 **Dean Russell:** Thank you; that is really helpful.

Ian, talking about the innovation side of things, where have you seen the greatest innovation over the past few years in early diagnosis? What would you like to see, moving forward?

Ian Vousden: I think, from my perspective, and to define the challenges and differences between faster diagnosis and earlier diagnosis, within the earlier diagnosis arena the advent of, and roll-out of, targeted lung health checks, which I mentioned before, could be a significant improvement and innovation that supports access to, and achieves, earlier diagnosis for lung cancer patients. I think that is certainly one of the innovations where we are starting to see the impact in areas that have been running it for a while.

I mentioned Galleri GRAIL. I will mention it again. Specifically being able to target patients who are more likely or predisposed to have cancer in that way, when they are not presenting with symptoms, would be a game changer. We heard earlier that the challenge for our primary care colleagues is to try to identify cancers, which often is a bit like finding a needle in a haystack for some of the rarer tumours. If we can identify patients without symptoms, who are then more likely to go on and have a cancer diagnosis, it could be significant within the earlier diagnosis arena.

Q339 **Dean Russell:** Professor Shackley, I will ask you a slightly different question. You mentioned the variations across the country, and talked about deprivation and all of those things. I am interested to get your take on this. If there is an area that is struggling, do they have to flag that they are struggling and reach out to other groups to say, "Can you share your best practice?", or do those that are doing well reach out to those that are not doing well and say, "We'll come and help"? What is the mechanism for areas that are not doing so well to increase their success rates?

Professor Shackley: I do not think there is a clear answer to that, you will be surprised to know. People who are performing poorly sometimes do not realise it. Sometimes they do, and once they recognise it they reach out. Sometimes other people develop innovations and people go, "Oh, I like the look of that. We'll bring that in."

We do not have league tables, which is a question you asked earlier about alliances, but we have open data around different performance or uptake in new innovations. We can look at our relative position with regard to different things. It is a mixed bag. It requires people constantly to be looking at their own performance and whether they are taking ownership themselves. To come back to your question about data and information, that is absolutely critical, especially the benchmarking information.

Dean Russell: Thank you very much.

Chair: Thank you. That is perfect timing because the bell has gone. We are very grateful to you. It is very interesting and important evidence. It is very good to hear what is happening in the alliances on the ground. The question we are still wrestling with as a Committee is whether the new announcement of the 100 new diagnostic centres is going to be enough to bridge that gap. Before that announcement, everyone was

saying it was all about early diagnosis. That is a very major step in that direction. What we heard in the first part of the morning about the challenges with rarer cancers and less survivable cancers is an indication that there is a need for other things to happen as well, welcome though those diagnostic centres are.

Thank you very much for your time, Sara Stevens, Ian Vousden and Professor Shackley. We really appreciate it. We will feed your important testimony into our report.