Evidence from NCIN, London Cancer and London Cancer Alliance – 2nd September 2014

Eric Ollerenshaw: Can I just say, welcome back to all our readers. Given the time, I'm going to start. We're waiting for Satvinder, but I think there's problems in security.

It's not prejudiced against doctors I hope. This is going to be the last meeting of the enquiry, so I'm grateful for Chris, Andrew and Satvinder, when he comes, for attending this.

Can I just say, for the benefit of everybody, this is an All Party Group and we're looking particularly at the research end. We're hoping to produce a report, which will go to ministers in October. Everything will be recorded, but nothing will be held against you, I can assure you of that.

What I always say to people who come, if there's something that occurs to you when you leave this meeting that you think you should have said or didn't ask, then please feel free to send it to us. We just want as much as possible. When we produce the report we will make sure you're sent a draft in advance so you can say, "No, I didn't say that" or whatever. Right. It's not a kind of court thing. We're just trying to find out where we are in terms of research of this dreadful cancer.

I suppose I should introduce myself. I'm Eric Ollerenshaw. I'm Chairman of the All Party Group.

Nic Dakin: Nic Dakin, member of the All Party Group. Apologies. I have to go at half past two.

Eric Ollerenshaw: Got transport problems in Lincolnshire where he's an MP.

Jim Shannon: Jim Shannon, Member of Parliament for Strangford. I'm sorry as well. I also have to apologise. I'm speaking at an aerospace thing at half past two and I have to go to it, so it's not that I don't want to question you at length, unfortunately I won't be able to. Again, it's nice to be here.

Eric Ollerenshaw: Well, we're grateful for you being here, Jim. You've been a really good support, particularly in Westminster Hall. Also, perhaps I should say there will be a full Westminster Hall debate on pancreatic cancer lasting three hours at the instigation of one of Nic's constituents through an e-petition. We're hoping as many members of parliament will be attending that. 4:30 on Monday, isn't it, if I'm right?

We'll be airing - some of the things you say, we may use, shall we say, your comments in terms of that. If I can just let you two introduce yourselves, just a couple of minutes each, as to where you stand in terms of this. Then we'll go to questions if we can. Is that alright? We'll start with you, Chris, I think.

Chris Carrigan: I'm Chris Carrigan. I'm Director of the National Cancer Intelligence Network. NCIN is the usual acronym. The NCIN sits within Public Health England, which was formed about 18 months ago as part of the transitions. The NCIN sits essentially on top of the cancer data we've got at a national level, coordinates things, produces analyses, and has a range of other activities, which we can cover off in some more detail as you go through.

Andrew Millar: Andrew Millar, the HPB, the Hepato-Pancreatic and Biliary Pathway Director for London Cancer, which covers an area across most of North London and into Essex. My interest obviously is in managing the pathway specifically for patients coming through our systems. My role is to make sure that research is embedded into the process of managing patients and also to represent those researchers from the different areas.

Obviously there are areas within early diagnosis, therapeutics and surgery being the main big areas of research, and obviously basic science. Hopefully I'll be able to present from each of those areas as well as taking some consultations from each of those areas and hopefully be able to feed that back to you.

Eric Ollerenshaw: That's really kind. Okay, can I open to members? Perhaps we'll start with Chris first on the stat side. That might be useful. Jonathan, go on. Jonathan Reynolds, Member of Parliament for Stalybridge, Hyde.

Jonathan Reynolds: Mostly in Dukinfield.

Eric Ollerenshaw: Mostly in Dukinfield, which is my hometown, so I don't hold that against him, but I might do. They've just introduced themselves, Chris, and we're just going to ask some questions. Nic?

Nic Dakin: Just picking up the data issue and the problems with early diagnosis, there's general agreement that early diagnosis is the key to making improvement. How can data and data research improve that and where are we on the travel to that improvement.

Andrew Millar: I think a key point is that research to date in the NHS has largely been an activity carried out by individual investigators, funded by individual grants. Although it's recognised that research needs to be engrained into the NHS, we haven't, as to yet, really put it into the way we work. The only way we can work effectively in that way is to be collecting data prospectively while we're working.

Again, the collection of data has very much been done by people working, doing their clinical work. Then somebody else picks the data out of that data and puts it into some data, and some of that data is then uploaded to systems like the Cancer Intelligence Network.

We need to change that, so that when I'm working in endoscopy and I'm putting in a report, I am actually providing audit data as I work because as I report, that data is auditable, but when I see a patient in clinic, I'm not. When we do cancer MDT, some of that data is auditable, but they're not mandatory fields that we have to work with, we put them in afterwards.

So we need to change the way we collect data to be part of the prospective way of working clinically. As we work we are collecting data, and that data needs to be mandatory, it needs to be electronic, so that that data then is automatically uploaded to people who can then look at that data and provide the sort of feedback on the way we're working, which will help us to make a difference.

It also obviously makes it much easier then to do clinical trials within that aspect. If you've got a system which you fully understand, you know what's happening in that system, you can measure it, you can analyse it, if you make a small change in that system it's then very easy to understand whether that change was effective.

Again, we need to move a little bit beyond - we need to merge formal clinical research and clinical audit into something that becomes one in the same so that clinical research where you set up a complicated clinical trial, it takes years to get going, millions of pounds to fund, years before the data is known, is something that needs to move forward to become an easier activity so that we get data quicker.

Nic Dakin Is that an easy thing and practical thing to do and are there other parts of the world where that sort of approach is already [cross talk 0:20:56]?

Andrew Millar: Well, in America, the veterans' administration system, etc., are building up better data. They know much more about their patients within their medical insurance system because they have really good data about it. So yes, that is one area. I think the NHS actually is - NCIN and places are actually leading the world a little bit in that in doing something on a very big national basis. Denmark does also a pretty good job in this respect as well, but probably the best person to talk to is Chris on that.

Eric Ollerenshaw: Yes. Please, Chris. Yes.

Chris Carrigan: Yes. Just specifically on the data, if you look back, not many years actually, five, six years, the types of data we had at a national level were pretty sparse. I remember having a conversation with Mike Richards in his old job and the national figures he had on cancer were basically national statistics, incidence mortality and survival after a very long period time. There was very little at the national level.

So when we set the NCIN up six years ago it was to try and address those things. We recognised that there was a lot more we could do with the data that was already being collected, we recognised that there were lots of imperfections in the system, but we actually took a stand and said, "We need to do better with what we've got and recognise that, longer term, there's some significant improvements we need to make across information technology, data transfer across the NHS".

Where we are now is we do have a very solid, single national cancer registration service. We hadn't had that before. It's only existed for a year and a half. There's no other country in the world that's gone through the

level of change around their national cancer data processing in such a short time as we have. It's a remarkable achievement.

Now, this is not perfect, by any means. We still rely on lots of different types of data from different sources at different times in different formats, and the cancer registration infrastructure that we pay for, essentially people who pull the information from the different hospital systems to collate, check, QA and make it into an analysable record, is where we put a significant amount of people's time.

We're now in a position, even having that, that we have the widest national dataset for cancer of probably any country in the world. We've got some of the fastest data flowing through and we're now beginning to see we can use the data for new things in a much more accessible - a much more rapid fashion to produce some of the results to allow us to manage not just trends, but look at some of the activity much closer to near times, months rather than significant numbers of years after the event. So we have made a sea-change step in doing this.

An example of the benefits of doing that, smash all the data together, well, so what. What it allows you to do is, at a national level, look for some fairly interesting points. People talk about the 23, 24% of patients arriving as an emergency presentation. That wasn't known until about two years ago. We only produced that as a result of bringing these data together, working with clinicians, working with patient groups, hospital clinicians and the rest to understand what it told you and then did a national analysis of what that was.

That was complete new insight. No other countries in the world can still do that. Now we're embedding that into a more operationalised process to begin to feed that through, not a year late, but a three-month rolling window for some of the changes we've done.

So there's been significant improvements in the breadth of the data, the consistency of the data, the quality of the data and the timeliness by which we can use it. I just think it's important to realise that. Now, I'm not saying we're there yet. We are a million miles away from where the pair of us would want to be, which is much more real time, single EPR driving everything, because that would be world leading beyond recognition.

As of now, when you look at what the NCIN and the registration service does, I would argue it is world leading in lots of these different areas.

Andrew Millar: I think [I'm spoilt though]. I think it's astounding where the data has helped, how far the data has come forward. It is now down - very much up to individual clinicians and systems to decide to change things, and I think the national effort should be to do that.

We do have data now. There is a three-month delay because the data has got to go from our clinical systems into the hospital systems. Someone has got to physical upload into that system. Then that's got to be cleaned up and placed - be passed up to the NCIN and then they've got to analyse it.

Now, we have the technology to do it immediately. In the banking world, if that process didn't happen in less than half a nanosecond, someone would be fired. So there's absolutely no doubt we already possess the technology.

But there's no doubt we could do it now. As I'm seeing a patient, I could be putting the data in. If we want to know about what the patient thinks about their cancer and how it's going, we could have that data up to NCIN instantaneously. The patient could be putting that in, in real time and that is immediately transferring up.

It's not impossible. In fact it's very simple. Online patient data systems are not difficult. We think they're difficult because 'Connecting for Health' was itself a tumour in the side of IT and needs to be excised. As we realise that actually that cancer can be cured, IT is actually our - that's what's going to be the panacea to sort out how we manage what we're doing and knowing what we're doing, and we can do it now if we want to.

Eric Ollerenshaw: Jonathan?

Jonathan Reynolds: Yes, thanks, Eric. Really interesting to hear those answers, guys. A lot of the correspondence I've received is understandably focused on the relatively small percentage of research funding that pancreatic cancer gets, and you can completely understand why that's been a principal concern.

In terms of why that's the case, do you think it's because of the structural issues around data that you've just described or do you think it's perhaps also down to - I'm struggling to find the right words, but other forms of

cancer perhaps being more high profile, having a higher degree of public awareness and consciousness than pancreatic cancer does? How do you feel about that?

Andrew Millar: It's a number of issues. I think that aspect is probably separate to data. It's very much about recognition. There have been very strong and absolutely needed pushes to improve cancer care in other areas of big cancers, such as colorectal, breast and prostate. Everyone in this room has a 1-in-20 chance of getting colorectal cancer, but if we get colorectal cancer we've got a 50% chance of surviving it. Everyone in this room has a 1-in-90 chance of getting pancreatic cancer, but a 95% chance of dying if we get it.

So if you bring those two figures together, the importance of pancreatic cancer needs to be realised. I think there is no doubt that a cancer which does have such dismal survival is not going to unfortunately attract the commercial funding that something that is more likely to be treatable will.

I think another issue we need to understand is that where commercial funding is absent, government needs to step in.

Jonathan Reynolds: Has that happened for other types of cancer, for other types of ailments or is this a specific problem with the circumstances, the mortality rate around pancreatic cancer that requires something additional?

Andrew Millar: Well, I think every person managing any sort of cancer would say that their particular disease, cancer or not, is underfunded in research terms. We can always spend more money on research, but there's no doubt that more money is required in pancreatic cancer.

Jim Shannon: Yes, sure, if I could, please. Just to pay some tribute to you, Mr. Chairman, for the way that you've led this campaign as well. Ever if you needed reinforcement of the importance of the figures that you've just mentioned, Doctor Millar, about the 95% who can get pancreatic cancer and then die as a result of it, just today there, no more than half an hour ago, my colleague, David Simpson, got word of a good friend of his, who I know as well, who unfortunately has no more than about 10 days to live, and that's where we're at. So it knocks it home in relation to where we are.

He also mentioned about underfunding, but not only is there an issue with underfunding, there's also an issue with pancreatic cancer patients'

availability for clinical tests, because clinical tests will lead us forward to finding the eventual cure, hopefully, for pancreatic cancer.

I just want to know what you feel that we can do or what should be done to ensure that more pancreatic cancer patients are available for the clinical tests, which are so important to finding the cure.

Andrew Millar: Well, you've going to get me sermonising in a minute, so tell me to shut up because this is my-

Jim Shannon: Well, I get a sermon every Sunday, so you go ahead. (Laughter)

Andrew Millar: That's absolutely the key thing. In raw terms, the picture is of patients sitting at home for months on end with worsening symptoms due to their pancreatic cancer before someone recognises it. That's the truth. The majority of patients with pancreatic cancer have had symptoms for quite a long time before someone does anything about it.

Has that person been incompetent? No because the symptoms are horrendously similar to millions of other people, 15% of all GP consultations around abdominal symptoms. A GP will be surprised to see one pancreatic cancer maybe in two or three years, so we can't expect them to pick it up. It's not fair. So what we need to do is to be having much, much better availability of specialist help to general practitioners, and that includes access to diagnostic tests.

There are number of things we can do. One thing that we're doing in London Cancer is setting up, hopefully will be funded, multidisciplinary diagnostic centres, so rather than having to wait for the two-week wait or wait for the symptoms to become worthy of a two-week wait - and that's one of the key things, that many of these patients should be investigated before they get there - we can get them in quickly, diagnose it or show that it isn't cancer and get it back to the GP.

The other aspect is, as you mentioned, direct access to tests. How do we do that without ruining the country in terms of the money spent on direct access to tests? If you allowed every GP to do a CT scan on every patient with abdominal pain over the age of 50, we'd be swamping every radiology department in the country.

So we need a way in which we can sanction those tests. Again, I think that's where specialists need to be able to link into GPs and sanction tests so that those investigations will be carried out, by the GP, essentially, and then go back to primary care with the sanction of the consultant, but not having to actually come and wait for the languid process of going through the outpatient process.

How do we pay for all this? I think there's a problem in the NHS of massive, huge, wasteful inefficiency in the way we conduct - the way we carry out medicine, the fact that a doctor has to send a letter in and we have to assess it. Then we have to see them in clinic and then we have to review the results. Then we see them in clinic again and then we discharge them back to the GP. It takes weeks or months for that to happen.

We can do it differently. Something needs to be changed in the way we conduct medicine that will save a huge amount of money, just in terms of changing the data system. If we didn't have to have this data manipulated by people in offices and it automatically came to the central service it would save a huge amount of money in terms of wasted resources.

I think we need to be doing many more tests, much earlier. So we will be doing more investigations on people, it will cost more money, and then we work out how to be efficient to save the money so we can spend it on the right thing.

Chris Carrigan: Just to follow that up. In terms of the data itself, if this clinical data was to be collated as it happens, not only does it speed up the - would it speed up the job of doing the analytics, looking for trends, looking for various other things, which is where we sit, it would also open up a huge amount of opportunities for research, because don't forget, this data about an individual person sits somewhere and you've got a chronology of their care record. You've also potentially got chronology of what happened before their diagnostic point in primary care.

Now, that link, when we talk about links to primary care with a clinical perspective, also applies at the data perspective, and we don't yet have a solid link between hospital-based care and primary-care care. Those two system services are just not linked up at a data level to allow us to do this inside.

I mentioned the national level routes to diagnosis. We know how many people of a particular demographic group, of a particular age and sex and ethnicity turn up early or late for all these different cancers. We know all that. You can break it down to the nth degree.

What we can't do is to link that together and look at a research and say, "Why does that happen? Is there something about the characteristic of the patient or the way the GP needs to be assisted with electronic aids or information aids or other things that you could learn from having this data linked together between secondary care and primary care?"

In data terms, that will be a significant step forward at a national level to be able to link those things together. By definition, once you've linked those things together you're also beginning to deliver what we need from a clinical perspective, which is a patient-level view across the system, irrespective of where anybody has been for their diagnostic treatment or care or discussion, frankly.

Jim Shannon: Can I just ask, Mr. Chairman, something more if I can, please? Obviously, what's been done in London and the research that you're involved with, Doctor Millar, and yourself, Mr. Carrigan, as well, is important for the whole of the United Kingdom. What stage are the results of the clinical tests shared with the regional ministers who have a devolved responsibility for health?

I'm just asking that as well, and I spoke of this before, pancreatic cancer doesn't stop at the REC. If only, but it doesn't. I'm just conscious of what advantage you have and how those are translated to the benefit of the Scottish Assembly and of us in Northern Ireland.

Andrew Millar: Sure. The vast majority of studies are published in peer review journals, available for public consumption, but that public consumption is generally just the profession and the way it practices. Most of those clinical studies are very professional clinical studies about a new treatment, a new surgical procedure, etc.

We just haven't done enough research on things like, well, should you allow a GP access to MRI? Should you or shouldn't you? Does it save money; does it spend money? Does it work; doesn't it work? Is it a waste of

money? Is it a good way of diagnosing cancer? How would you make sure that that MRI is done appropriately? Who looks at the results? How do you connect it up? What works well in that-?

We don't study that. We don't look at that. The MDC, the multidisciplinary centre which we're proposing in setting up, we don't want to just set up a new thing in the NHS and then vaguely monitor it. We would prefer it to be a proper, robust clinical trial. We're going to involve the health behavioural research department at UCLH, so we've got proper professorial academic research so we can actually say, at the end of the day, "Actually, do you know what, this is a system which everyone should use because it works" or, "No, it doesn't work. We need to do something different".

That's the research that then needs to be looked at by health ministers and ministers and to guide policy, but I think it needs to come down as well. I think political forces need to be as a business would be. If you're running a major international business you would be promoting and getting activated research into your area, so if you're making a new car you'd say, "Well, research department, go and find out if a new small car with an electric engine is what people want and what they're going to buy and will it work and be cost effective? Go, research department, and discover it".

Well, the government should saying - I shouldn't be saying it. It should come from government circles, "Okay, what about giving GPs access to CT scanners? I tell you what, well, let's just do it". No, don't just do it, actually study it as a scientific exercise to find out whether it's something to do or not do.

Eric Ollerenshaw: Chris, yes, have you got any comment on Northern Ireland?

Chris Carrigan: On the data side, so we look at it from a data collection. What we're collecting is information on an individual person at a national level, so each record has got the person's NHS number on. So the registry system is in a very privileged position to be able to do that. It's done under law. There's a legal framework that'll actually do that.

The legal frameworks in the different countries are subtly different, so England and Wales are covered by one legal framework, Northern Ireland by another, Scotland by another, from a national perspective, as a national

organisation, to let us do some national-level analysis on what works, what doesn't work effectively.

It's quite hard when you need to get down to quite granular data because to move data across boundaries, across borders is quite tough. There's certain things we can do and loads of things we can do with more aggregate data which lets you do those things.

We provide a UK-based analytical pot, which we use routinely, but when you get down to some of the more detailed, more granular analyses you need to do - for instance, I mentioned the route-to-diagnosis work, where you have to physically get some algorithm to walk the way back through a patient record to find their first point of entry to the system. You can only do that in England because the other countries don't have that level of data.

So there are some things we can do in England which we can't do in Scotland for data reasons. It's sortable, but it needs to be sorted. There are some logistic issues around the legislative position of data sharing across different parts of the UK as well.

Eric Ollerenshaw: That's very helpful. While we're on it, what about this EU directive, Chris? Does that affect you and the data?

Chris Carrigan: It would do. It's difficult to find out whereabouts the EU directive is, but in essence, if you took it at face value then it could stop us doing what we do. It would stop that level of analytical work. It could potentially stop a lot of research work as well.

Eric Ollerenshaw: Thank you, gentlemen.

Chris Carrigan: It's interesting. When you look at what it is that's trying to be done, we're trying to protect the data that an individual gives as part of their care, because we're taking the data from the people who give their care and we're producing analysis using that data. Now, it's very difficult to get direct patient permission to let us do that, which is why there's a legal framework to do that.

But when you do ask patients what would they expect to happen with their data, by enlarge, they say, "We would expect you to make appropriate uses of the information and data we give you because when some other poor

soul gets diagnosed with this cancer six months down the line, we don't want them to go through the same experiences we've gone through". It's as simple as that.

What we've found when we've done various levels of surveys around the NCIN and other things, there's a huge amount of public support to make this happen, which is in contrast to what the EU directive is potentially saying, which is, "Let's be very, very protective of the data about an individual person and not do anything without their explicit consent", which is going to be difficult if that goes through, in the last draft I saw anyway.

Eric Ollerenshaw: So will people have to sign into the data collection - I'll come to you at the end - or is the government doing anything about this or have you got your own remedy?

Chris Carrigan: You probably need to ask the government and government officials, but I do know there are various bodies in the civil service and government who are looking quite hard at this EU directive and I know they've got several people looking at the potential implications and fighting our corner, essentially. I don't know who the best person is for you to speak to on that. We could probably point you to some people after the meeting.

Eric Ollerenshaw: Well, there's questions we could ask then, isn't there, Jon?

Jon, sorry, go on.

Jonathan Reynolds: There's something I'm always aware of, guys, whenever we're talking about changes to the NHS, and there's always change happening to the NHS at any one time and there's always a certain degree of upheaval. So I was just interested to know - and I have genuinely no political agenda to this.

In terms of the very big changes we've seen to the NHS in recent years, Health and Social Care Bill to much more focus on specialisation in hospitals, the kind of innovations that you two want around pancreatic cancer, are we likely, in your opinion, to see more of that with the structure we have set up or are there some barriers there you think we have to really look at as politicians to make this happen, basically, the kind of data changes, the kind of early intervention that you're recommending to us today?

Andrew Millar: I think the biggest sea change we need is for the clinical commissioning groups to not just commission what they see coming to them as best practice, but actually to go out and say, "Well, we'd like something different to happen". They need to be like the people running a business. They are essentially running a business, and they have a responsibility to spend their money.

I think we shouldn't go down the line of thinking we should reorganise the finances of the NHS because I think everyone will go mad, so I think we should work with what we've got. I think it's a workable system as long as we understand it well.

The key is that the clinical commissioning groups must not just sit back and accept practice as it comes to them and then select the best one. They should go out and say, "Actually, we've looked up in Northern England and there's a better way of doing it than you guys here are offering". The CCGs need to get together and ensure that they are sharing their best practice. Then the key thing is this data.

Maybe it's a bit of a radical view, but we get free treatment in the NHS. We have the best health service in the world, according to a recent study, and I think that's true. Yes, there are lots of ways we can improve it, and one of the ways we can improve it is by understanding it, and by understanding it, we need to understand what we're doing.

If you do belong to something like the veterans' administration in America, you do have all your data managed centrally, and you do in most insurance systems in America because otherwise you can't be looked after.

So I think we should - as NHS patients, we're all probably, here, NHS patients. We should accept that in exchange for getting this wonderful health service and its treatment, we accept that our data, managed appropriately under the law, is freely available to be researched and shared nationally.

That's the quid pro quo. If you don't want that, that's fine, you can opt out, you can have certain bits of your data withheld. That's fine. But if you really want to opt out, that's fine, go privately.

Eric Ollerenshaw: If Europe permits on what Andrew's suggesting.

Chris Carrigan: Yes, and I back up exactly what he said. When you talk to the patients who've been through their care and come out of the other side - we have patients on all our analytical groups. The annual conference, we've 600 people. 100 of those are patients. When you ask them, they expect this to happen. They expect us to use their data. They want us to use it to improve care for everybody else that's going to be diagnosed in the future, which could be me or you or anybody else, frankly.

So I think we're in a very strong position with the NHS. People like the NHS. I think the confidentiality debate hasn't helped. I'm not sure it's been hugely mature across the country. I think we've been battered in the past year or so with various things about Big Brother databases and the rest, which, at best, is a shame.

But when you ask patients who've been through the care of the clinical teams they come out of the other side and say, "Yes, we would want" and expect that we would use the data we have for analysis and for research. The evidence is there in the Cancer Patient Experience Survey. That's what they said. For the patients who were asked in the Experience Survey, "Were you asked to participate in research, and if not, would you have liked to have been asked?" huge majorities that didn't get asked said, "We would have loved to have been asked".

So we're not guessing at these things. We know the evidence is there that cancer patients who go through the system are very keen to make sure that we manage their data well, protect it well, put appropriate cover around it, but actually 'exploit' it, is probably the right word, in the research agenda to generate the new insights, to generate the new - all this, to give us the evidence on what needs to be commissioned better and how we can make the improvements.

Eric Ollerenshaw: Where precisely are we then with this directive then? You're saying that people are looking at it, you understand, right?

Chris Carrigan: Yes.

Eric Ollerenshaw: The directive is there, so are you just waiting for somebody to challenge what you're doing or are you just assuming it's fine? Where are you? Because you're suddenly saying you've started this and you're collecting all this data.

Chris Carrigan: Well, we've been collecting it for - the cancer registration has been going on for 40 years in this country. This is not a new science. I think if you want to know exactly where the EU directive is you have to speak to EU experts on this, I have to say. But you asked me-

Eric Ollerenshaw: But at the moment, you've got no impediment with what you're working with?

Chris Carrigan: We are able to do what we can do under a legal framework, yes. We have to do some sort of legitimacy. You can't just do things in isolation, which is why we involve patients in what we do, which is why we get 100 patients coming to the annual conference and explain what we do. We run governance sessions with them. We work with the charities to explain what it is we do with the data we hold about you.

At the conference last year, I stood up with a patient who had allowed me access to his full records and we aligned his experience of the diagnostic route for care and his outcomes with what the data told me. It was Tom versus - 'Data Tom' we called it. It's been on the web. When you talk to patients like that, they expect us to use their data.

So within the NHS, we're in a privileged position. People like the NHS. They trust the NHS. They want the NHS to do better things with it. I do think we need to make sure that we don't lose the ability to do what we can do in terms of analysis and research in the NHS.

Andrew Millar: Two points just to back that up. First of all, we have been moved forward in terms of sharing in this country. The HSCIC toolkit now makes it much easier for third parties. So long as they sign up and go through the toolkit and do all the things that they're supposed to do from a point of view of information governance, they can then share data and use that data externally, so obviously with patient permission. That is obviously one - that is a step forward.

Another thing we have to remember, very importantly, is that this data is not just for future research benefit, is actually for the benefits of current patients. One thing which we're interested in at the UCLH is cystic tumours in the pancreas and how they might turn into cancers.

Now, those are diagnosed quite frequently at - I work mainly in the north of Middlesex, by the way, so I'm not a clinician at UCLH, but I work with them closely. What we know is that these cystic tumours or cystic areas in the pancreas are picked up quite frequently on routine scans, people going for urology scans or a bit of weight loss or headaches, etc. They get a scan which involves the pancreas. We need to pick those up and follow them up.

Now, if there was a national system which automatically detected those and put an alert down to the primary care clinician to say, "Hang on, you've just had a patient. This is someone who needs to be followed up. Do not forget about it". That would actually protect current patients who exist now. So the data is protective as well as for research purposes.

Eric Ollerenshaw: Well, then how close are we to that? Because what I'm finding difficult to understand is you're talking about the data collection you're doing. I'm assuming, as a lay person, I've some idea what the data is, what you're talking about, age and all the rest of it. But some of the evidence we've had is there's regional variations in outcomes and in treatment.

That then comes into yours, Andrew, because I'm not sure what - the London Cancer Alliance, is that specific to London or has that been replicated elsewhere or, with a northern prejudice, is it London getting more than we are getting? What is it? Is it different to what's going on elsewhere?

Andrew Millar: London Cancer and the London Cancer Alliance are taking the concept of cancer networks to the next step. So cancer networks measure what's happened with the network. The London Cancer and London Cancer Alliance - and Satvinder can comment on this from South London - are actually saying, "Yes, but we want to actually drive improvement. We don't want to just measure and monitor and see what's happening. We actually want to drive improvement in our systems". Then yes, hopefully that will become national.

Just to mention quickly before Satvinder comes in, and he can comment on this as well, about national variation. Absolutely, a huge problem is that we do things slightly differently in different areas and that we measure things slightly differently in different areas, and absolutely we need to be doing that the same across the country.

Eric Ollerenshaw: Just before you come in, Satvinder - great to have you here - so you're saying London is doing this, nowhere else is doing this or what, or don't you know?

Andrew Millar: Well, none of us are doing it as well as we should be.

Eric Ollerenshaw: Well, what you're managing to do in London, is that anywhere else, to your knowledge?

Andrew Millar: Not as well as we're doing it, we think, but I don't know.

Eric Ollerenshaw: Do you want to comment on that, Satvinder, or what?

Andrew Millar: Manchester has got a very good cancer - brilliant HPB cancer network.

Eric Ollerenshaw: Greater Manchester I think.

Andrew Millar: Greater Manchester, yes. Yes, Greater Manchester.

Eric Ollerenshaw: Greater Manchester would of course.

Andrew Millar: Yes, of course.

Eric Ollerenshaw: Not with some prejudices from North Lancashire. (Laughter) Go on.

Satvinder Mudan: I agree with Andrew. I think that the drive in London is largely because there are lots of groups within the system, and whereas if you're in Manchester there's one centre for doing pancreas and that's it. So one person on his own can only have - or a centre can only have so many ideas.

I think the advantage of London, and I think this is one of the problems of too much centralisation, is that your generation of ideas become sterile. The thing in London is that because there are a number of centres - I think 'competition' is not quite the right word, but there is a drive that each centre must come up with ideas and so that follows onto the other-

Eric Ollerenshaw: Yes, so it's intellectual competition.

Satvinder Mudan: Yes, exactly, so I think the generation of new thoughts and ideas is bigger, and that's a good thing.

Eric Ollerenshaw: I still resent it, but carry on.

Satvinder Mudan: (Laughter) I think that the LCA probably has - so it's not to say, "Oh well, did that not happen before the LCA or London Cancer existed?" Of course it happened. I think what the London Cancer and the LCA has allowed that to do is to bring those ideas together, whereas previously, each hospital was generating and throwing up its own ideas and actually not talking to anybody else.

So the marshalling of the idea is a very important thing that I think we have achieved in London, and that's quite a difficult thing actually to do, to get academics together and share their thoughts and stuff. That's not an easy task.

Andrew Millar: I think we need to replicate the success that cardiovascular doctors had in carrying out really huge, massive trials into ischemic heart disease that have inevitably had fantastic results in improving patient care. We do need to generate lots of ideas, but then we need to be able to test those ideas, and to test them in a small idea will be obviously much slower than testing them in a big area.

That's what I mean about making research - extending research beyond individual investigators or even investigators who are cooperating across different areas, but actually embed it into the way we function. If we want to look at a new biomarker for pancreatic cancer, come up with the idea, put out the protocol.

If it's a good idea, this biomarker should be investigated, and you decide to just look at it at UCLH and King's and the Marsden, it may take you two or three years to find out if that biomarker is effective. If you decide that every patient in the country with suspected pancreatic cancer is not only having all their clinical data collected, but also having this biomarker checked for a period of six months, you'll know by the end of that six months whether it's

an effective biomarker or not, pretty much, because you'll have already diagnosed the patients who you were testing on and you'll very rapidly be able to answer your research questions.

So we must embed research into the way the whole community, preferably nationally, works.

Eric Ollerenshaw: Would your collection of data then show up these regional variations, Chris, or not, or are they already?

Chris Carrigan: Well, the data you talked about where it demonstrates regional variations in the diagnostic pathways, the treatment, the outcomes, is essentially what we do. That's the data that's come through the NCIN. It's the data we pulled out of clinical surveys is collated, pulled together at a national level and done your analysis on.

So that's actually where it comes from to demonstrate what those regional variations are. If you can get the data faster you can spot those variations much more quickly. If you can improve the data quality and breadth of the data you could look at individual, more specific variations, which I think is where we're going to be pushing to in the future.

The other point that was mentioned around linking different types of data, you talked about, well, what data do we have? So for an individual person, at a national level we've got who they are, the usual bit about where you live and what your age is. We've got their diagnostic route to a diagnosis, so things like outpatient attendances, bits of GP record, but not much, certain inpatient attendances, diagnostics, surgical procedures, radiotherapy, chemotherapy now, and longer-term outcomes of hospital-based interventions. Very little on primary care.

But that's essentially what you gather in terms of the record. Ultimately, death because we all die. That's what you've got on the record at the minute, and we've done a lot of work on that. The opportunities for extending that into things like genomics are now huge.

We've done a link with UK Biobank. UK Biobank was a prospective study that gathered - was that 100,000? More than that, patients, half a million

patients? You'd need to check the numbers, in. They took tissue samples, blood samples and the rest and they stored them. Then the idea is you watch these people as they get older through life.

As some of these people get older, some of them will develop cancer. We've now linked that data back, which is a huge research resource because you've got the information materially, the genetic material you gather from that patient before they were diagnosed, and now you've got them being diagnosed.

There's a lot of steps you can take by large-scale linkages of data that let you do very clever things. If you could sort out that linkage much more close to the clinical level, then everybody's problems become much easier, frankly.

Eric Ollerenshaw: Say the existing data you're saying is showing some regional variation, right?

Chris Carrigan: Yes.

Male: Whose job is it then to do something about that or is it just people look at it and then carry on? I don't know.

Chris Carrigan: No, I think it's a shared responsibility. Our responsibility is to publish and demonstrate that inequality, to do that in a clinically credible, professional, statically robust way, all those sort of things. Who takes that up are people like the clinical teams, the commissioners. Charities are very big pushers on this, parliamentarians. So this information should be out there in an accessible format for people to begin to use.

The data that we produce the analytical variations doesn't often give you the answer why. What it does do is demonstrate what the variations are and lets you quantify it. So people talk about potential numbers of lives saved, "If the most deprived area of the country matched the outcomes of the least deprived we would save X hundred lives in a particular locality".

Those things are easy to compute, but it's difficult to solve because you're talking about huge cultural and societal issues as well. The data we produce is meant to show an insight onto that. It needs to be picked up by

commissioning processes, by clinical teams, parliamentarians, local groups, the whole thing really.

Eric Ollerenshaw: If London has got this network which they think is better than anywhere else, right-

Andrew Millar: Well, it's good, but it's not as good as it could be. (Laughter) Sorry.

Eric Ollerenshaw: I think you did say better than anywhere else, but never mind. You've got all this tonnes of stats pouring out. Is anything getting better then or are you just getting clues to how it could become better? Are we beginning to see any improvement anywhere down the line?

Chris Carrigan: Yes. When you look at the stat- the improvements are there. There are improvements year on year in terms of the survival. The route to diagnosis is getting better. We're getting less people turning up as emergency presentations. You can tell that from the number.

You can tell where improvements are being made, but you can also tell where improvements are not being made or not being made as fast as we would like. That's by looking at particular cancers. So pancreatic cancer, statistically, still doesn't show the levels of improvement you would have seen in colorectal or particularly lung cancer, with the 'Be Clear on Cancer' campaigns and cough campaigns.

So you can demonstrate where the improvements are taking place, but you can also show where they are not taking place for particular cancers. That's what you use the statistics we produce to do, which then lets you ask the question, "Why are we not seeing improvements in certain types of cancer, and, indeed, do we need to invest more in research in those types of cancer?" Which is where we started the debate from.

Andrew Millar: I don't think we are - I think we should be doing better. I think setting up these systems is great, but it's just the start in terms of developing systems which actually improve mortality or improve survival. We're getting there, but it's going to take a number of years.

The route will be - as you mentioned right at the beginning, it's about early diagnosis. It's about making sure that when we get patients that - at the moment, 15%, roughly, 15 to 20% of patients come through to Satvinder for

a potential operation. That percentage needs to go up if we're going to improve survival. The only way we're going to do that is diagnose them early enough so that they can be operated on. That's going to be the key to improving survival in pancreatic cancer.

Claire Levermore: So their patients - Andrew Millar. So variation and different outcomes is actually north/south of the river, east/west of London, so unfortunately we can't even say that London has solved this variation of outcomes and care. That's where it comes into the research of understanding why people may or may not understand their symptoms and why they may or may not present earlier.

In order for research to put into those areas, is the prevention control, awareness, etc., in order to allow, which answers this gentlemen's question around the patients, in order to get them earlier. We can then do even more research and trials because they'll be at an earlier stage in order to then look at treatments, but we're so far from that.

This variation of care is from hospital to hospital, from district and borough, from one side of the river to another. It's much worse than just north to south of the country.

Eric Ollerenshaw: Then we have the anecdotal evidence, people who've travelled miles to see a particular doctor or surgeon, whatever, consultant, and had a much better outcome because of it, and some of it by simply - I don't know where the knowledge comes from, probably people chatting away on the internet and so on, that we got those variations in the system.

Satvinder Mudan: I think you should separate out though variation due to socioeconomic circumstances, so that's really late presentation meetings because - maybe to do with education in the public. That's a social construct. I think variation that's due to institutional structures, which is a different thing altogether, I think an example of that, where you see that well, is in America because the vast majority of pancreatic cancer there is not treated in specialist centres, not treated in specialists centres. The outcome for that group of patients treated outwith of the specialist centres is worse. Now, that's just the way that they do their things.

So there is something about the institution and the institutional culture that drives good outcomes beyond the point of diagnosis. Yes, there's an early diagnosis question as well. I think I come - and I've very lucky. I come from a cancer-focused institution which is research driven, and you can expect that every patient is not only in one trial, probably in several trials of something. That's the culture of the institution.

So I think part of it is creating that kind of environment that drives the institutional improvements, and that, to some extent, explains the variation between regions because not everywhere will they be solely cancer focused in the way that we are at the Marsden. The pancreatic unit will be treating benign disease and it'll be treating all sorts of other things, whereas we're very much one team does pancreas and that's all they do. That's all they think about all day. (Laughter) That's why we're so boring down there. But it tends to improve the outcome.

So there's an institutional bit and a socioeconomic bit.

Claire Levermore: That variation in both is within London as well as…

Andrew Millar: That's the barrier. You've got these highly experienced, highly specialist teams doing only one thing, and I suspect if people came up with housemaid's knee up to pancreatic unit they wouldn't know what it - never even heard of it because - [they] are probably very good doctors.

But these groups are incredibly specialised and yet outside they've got these vast numbers of GPs who have to look after every single sort of disease. Getting them across from that area into the specialist, that is where the barrier is. We're not getting patients from [WEP] early enough, from primary care into specialist centres.

Even in America, where you can get specialist help more easily, it doesn't happen because of their ridiculous insurance system. That's what stops it there. Here, we have the institutional effect of the GP gatekeeper causing that.

Eric Ollerenshaw: We also have anecdotal evidence that there's other countries in Europe perhaps that have better outcomes than we do.

Andrew Millar: They do, but then in general, in Europe, apart from in Denmark, where they also have the GP gatekeeper, where they also have lower levels of survival from rarer cancers, more cancers, everywhere else, it's much easier to get a specialist opinion.

In Germany, until recently, if you wanted to see a dermatologist, you just went and saw a dermatologist. It was still paid for under your national insurance scheme. They have actually realised that that is putting too much of a burden on specialist services and are pulling back from that themselves.

So the issue of how do you have patients with slightly odd symptoms - and most of those patients are not going to have anything significant wrong with them and probably most of them will get better by themselves or have long-term mild functional symptoms which won't affect their life end.

Against those few patients, how do you find those few patients in that large mass of patients with mild odd symptoms who you can pick out and say, "This person has got cancer. I'm going to treat them early for it"? That's the problem.

At the moment, we have a two-week wait. It's a big issue because really by the time you get to the two-week weight point, in other words, you've lost a stone in weight, it's too late. A two-week wait is too late.

Satvinder Mudan: That bit we've talked about before, and I completely agree. We've had this discussion of the model of having clinics that allow easy access into the specialist system. I think actually it's not that important which bit of the specialist system that you get into because you can expect the specialist then to pass you onto his colleague next door if it's not his area and so on. It's the getting in through that door to the specialist system that is the biggest difficult part.

Now, I think we mustn't be critical of the GPs because I think their lives are difficult. I was having a conversation with one of the doctors at the LCA whose wife is a GP. The last thing they want to do is to miss one of these patients. That's not on their agenda, so we shouldn't be critical of [them].

I think what you're asking them to do is like sitting on a motorway and you say, "Well, okay, well, when this car that you haven't ever seen before but

you've heard about comes by on the motorway, you're to raise your hand up". So you sit on the M1 looking for a car that you've never seen in your life and you might see once in a lifetime. That's a tall order for the GP, so their task is not straightforward in this.

Eric Ollerenshaw: So what's the answer? Your data, if GPs could access that, would that give them clues as to perhaps ask another question? Is that the idea we're looking towards or what?

Chris Carrigan: I think it's a slightly different question. We certainly publish profiles of GP - 'performance' is the wrong word, but GP activity. It's very difficult to measure good versus bad, but you can actually show where the variation is. We publish GP profiles for a range of cancer measures, including screening uptake rates and the emergency presentation type rates, for a couple of years now. They're up and available. You can go download your GP's now if you want and you can look at relative performance, but it's very difficult to judge good from bad.

I think to get down to the more granular detail you need to understand - get a researcher to understand, well, for this cohort of patients, what was different about the way they turned up? Is it something to do with them? Is it the GP behaviour? I simply don't know at the minute, partly because we can't get access to that linked data.

The interpretation of that is not mine. That needs to be done by an experienced clinical professional, whether it's these two guys or the RCGP or somebody else. The first thing to do it to get the bloody data together in the first place to allow a researcher to investigate and look where the [auditors] are to ask some of those questions to be answered.

Eric Ollerenshaw: But that would be one of the answers, would it, to have that with the GP or the GP's ability to access immediately?

Andrew Millar: Certainly feeding back to GPs where they've picked up something and it's not been dealt with appropriately. GPs do have a big problem, but again, sometimes the car that they're asking to go past the M1 is actually an enormous great truck and they still fail to see it.

I have GPs - the GP stories abound of patients who've been told at the age of 70 that they're doing really well dieting, that they've lost a stone in

weight. They tell the GP recurrently they didn't mean to, and only after six months does it work out that diet was not induced by anything apart from some large lump in their tummy. You think, "Well, how can that possibly have happened?"

I think what we need to do is protect GPs and patients. If we use the M1 analogy, that we put some cameras on the M1 instead of just the GP, and, in other words, we have decision support tools. That again comes down to - well, it comes down to one essential [thing], and that is really good granular data, as Chris says, that picks up details of the clinical picture and then goes, bing, bing, bing, and warns the GP. We must put those in place.

Satvinder Mudan: And funding because you can have - and I agree, you need to have a system where the threshold for a referral intervention is much lower than the two-week wait, much lower.

But having decided those criteria, which are much lower than the two-week-wait criteria at the moment, you then have the problem of, "Okay, you found all these patients, of which 9 out of 10 will not have anything wrong with them". You want to capture the one patient that does, but you've still got to process the 10 patients to capture the one. That's a massive cost implication there.

I think one of the ideas that both Andrew and I have been wrestling with is how do we put into place an effective system to allow you to process those 10 patients to find the one guy that has got pancreatic cancer or indeed actually some other heinous condition that needs intervention quickly and you've been fortunate to pick it up at a very, very early time point before the guy comes, as you said, having lost 2st in weight and unable to eat and things like this because by that stage, sadly it is too late. Whatever you do, you've missed the boat.

Eric Ollerenshaw: Again, a lot of our evidence has been it's quite often people who haven't been the doctors for years. That in itself should be a warning signal, shouldn't it, these people who don't usually come and they're coming over something that is not?

Andrew Millar: Exactly. That's exactly the sort of fact. There's a fact there. This is a patient who didn't come for years and they came once in 1960, once in 1970, once

in 1980, and then three times in 2014. The problem was, looking - the system says 'abdominal pain'.

The patient has turned up to the GP surgery three times in three months for abdominal pain. Bing, CT scan because there's enough facts there that you know that patient. You can take the decision away from the GP.

Now, we as doctors are terrible. We think that we know everything and we can do everything.

Eric Ollerenshaw: I've noticed.

Male: Exactly, and that as long as you've got MBBS you can see any patient any time.

Male: Unlike MPs. (Laughter)

Male: I thought it only applied to surgeons.

Male: No, no, no, we are very arrogant as well, terribly [cross talk 01:09:02].

Male: I thought we knew everything, Jonathan.

Male: (Laughter) The truth is that if you send someone to me, if you give me a psychiatric patient, I'm not really going to - well, actually I've lots of irritable bowel patients. I'm getting quite good at that. We all need to do different parts of medicine, but I'm not going to be an expert in things outside of my area. It's just not fair to ask the GPs to do it.

We have then, as professionals, to understand that we need systems, digital systems that will support us. That comes down to getting good data and then having that data analysed, and you have interrogation systems which alert us to problems. Pilots have it all the time. Why don't we?

Chris Carrigan: Just specifically on that example about a person who has been to their doctor, well, hardly ever and then they suddenly turn up in a burst of activity, we have the data that exists now in the NHS that would allow you to answer that question, well, how many patients who were diagnosed within a particular period hadn't attended GPs for 10 years before and attended between 1 and 5 times in a period of time? With the data that is there to let you answer, to quantify that number, to look at where those things are, to look at whether that is a research question, whether there are

things we could focus back onto GP systems to allow them to do the little alarm-bell ringing.

You could do that now. The problem is we don't have a link between the hospital-based data and our primary care data, which for a country like ours with a single NHS [number], a single state-funded system, with the patients who love the NHS, in data terms, is criminal.

If we could do that you could generate a huge amount of insight to take away some of the guesswork of where you would want to put your investment, where you want to put your little alarm bells in systems.

Andrew Millar: I believe we ought to also be getting better data from the patients themselves. I'm working with Steve Pereira at UCLH and we're setting up a study where we will cover much, much more detailed data about what the patient says their symptoms are, because weight loss, a one-stone weight loss after you've come back from - you're 22 and you come back from your trip round the world and you're half a stone lighter. That's benign weight loss.

Even if you're 65 and you've just had an operation on your hip and they didn't feed you in hospital, because they only give you one chip every three weeks, that's not weight loss. But someone who is eating totally normally and has not changed their life, has no other symptoms apart from just not - feeling a bit tired, but suddenly loses half a stone or a stone in weight, that's serious weight loss.

So weight loss depends on what sort of weight loss it is. It depends on the pattern of the symptoms. We need to get better at recording and analysing that too.

Eric Ollerenshaw: Sorry, Jonathan, [you want to…?]

Jonathan Reynolds: One of the other questions that I was interested in, given the mortality rate in the UK, was that comparative information to other western countries, and you provided that through the access to specialist point.

But on the research side, what is the picture in other countries on the research side? Are they having similar problems to us in terms of the percentage of research funding going to pancreatic cancer or is there

actually a better picture elsewhere? Are there countries particularly leading on this and particular centres leading on this?

Andrew Millar: I don't know the answer to that question I'm afraid. I don't know what percentage of research in other countries is dedicated to pancreatic cancer.

Jonathan Reynolds No, go on.

Chris Carrigan: No, I was going to say I didn't know the answer either. (Laughter) What you could do is approach the NCRI, National Cancer Research Institute, because they would have certainly UK figures and probably some EU ones as well.

Satvinder Mudan: It's low compared to other things. If you think about what's happened, say, in the last 20, 30 years, there's only really one substantial gain, and that's come out of an industry-funded study that brought Abraxane into the pancreatic arena. That's really the only - and I think part of that is that pancreatic studies, pancreatic research studies, whether they're surgical or medical, are actually very difficult to do because the patients often aren't with you for very long, so your period where you can have the patient on a trial is not good.

Then the treatments that you've got make very small adjustments, so you've got to have a very large number, a huge number of patients to pick up a very small change in outcome. With the exception of things like Abraxane, which is probably going to be applied to 100 different tumour types, the regulations around getting drug companies to fund trials for one relatively small-volume tumour, where the outcomes aren't very good anyway, doesn't make economic sense for them.

They're not going to pour money into something like pancreas cancer because it's never going to generate lots of money, unless you've got an agent which you can use across several tumour types. I think that's a different idea. But a pancreatic specific agent is not going to generate lots of industry funding. The cost of trials now is so high that there's really no other way to do that.

Eric Ollerenshaw: We raised in our previous session that the Americans have passed this Recalcitrant Cancer Act. Do you know anything about it and do you think

something like that would work here or do we not need it given we've got the incredible NHS? Do you know what it was, first of all?

Satvinder Mudan: Yes. I think what you're referring to is that what they've done is that they've got a fast-track pathway for getting drugs through the FDA approval for cancers that have no other treatments, and pancreas would certainly fall into that group. What came through it just recently?

Anyway, they've had a number of things that have come through very recently for conditions with essentially no other treatment available to get those agents through the system more quickly. I think that's right, and I think where you don't have - if you don't have other obvious options, you've got to have a different pathway for getting those through and make the life of the researchers easier. I think that's right. You've got to decide what framework that sits in to maintain the safety profile of the trials.

I think that's what the Americans have done in that last - I think that was only in the summer actually, just early part of the summer that they did that, has the FDA. Maybe that does need to come across here, yes.

Andrew Millar: If you wanted to introduce a new drug in the United Kingdom today you'd have to do, obviously, your phase-one studies and your phase-two studies and prove rough efficacy in certain small groups, and then you'd start a phase-three study. That phase-three study would cost tens of millions, if not hundreds of millions of pounds and dollars to put into place.

Actually, we don't actually need that if we had a system which measured every single thing that happened through the cancer pathway automatically, standard, that's everything, so down to symptoms, side effects, patient-related outcomes, satisfaction survey from the patients and everyone else. Actually, we could easily have a study, potentially, which put that new drug in place in certain - and you can say, "Well, [it's a] study. We're just going to use it in certain centres, it's badged now to use in certain centres".

We don’t have to put in place ridiculously expensive ethics approvals, etc. because as long as the patients receiving information believe that they're getting a new drug, actually within a few months of just using something, the data will tell us whether it's effective or not because we'll have the data

automatically. It will make doing clinical studies much, much, much cheaper. In fact it will cost almost nothing.

That would be a radical change in the way that we conduct investigational studies at the present time, which is wrapped in massive bureaucracy and protection and data analysis and keeping data from - only certain people can do the studies and you go through an enormous, lengthy process before you can even start the study, and everything has to be stored in certain ways and paper is done in quadruplet. It's so labyrinthine and elephantine to get these studies done that companies are scared of doing it.

Satvinder Mudan Companies are scared, and I think as a clinician you do have to think, "Well, how many patients who have bad diseases like pancreas do you want to enter into studies where they may not get the active treatment?"

I think there's a problem about randomised studies, in particular things like pancreas. I think it would be impossible to do a no-treatment arm in any kind of study now. Even so, if you're a patient, you'll say, "Well, look guys, if you think this works, why do I want to be randomised into treatment A and treatment B?"

Eric Ollerenshaw: "Let's just get on with it", yes.

Satvinder Mudan: "Surely I should have B because that's the one that you guys are all putting your money on". So I think the unmet need idea from the FDA is a good one because it bypasses a lot of that and expedites the drugs to come into clinical use, be it only in certain centres or still as part of a study rather than-

Eric Ollerenshaw: Are you aware of anything being tested by companies at the moment?

Satvinder Mudan: In pancreas?

Eric Ollerenshaw: Yes, which is not, shall we say, approved yet.

Andrew Millar: Well, there are studies in setup like SCALLOP and ESCALOPE II and ESCAP IV, which are the standard, and they're looking at further advances, one of them Abraxane, looking at further analyses into those new treatment agents. So those are in setup. There's a lot of respective ones.

The molecular analysis research work, they're looking at - analyse what sort of tumour is it. What are the genetic changes in this particular sort of tumour? Then treat that particular sort of pancreatic cancer with that genetic change with a drug targeted to that particular thing.

It's like looking at HER2, etc., BRACA, and part changes in the pancreatic cancer, because not every - every pancreatic cancer is a whole hotchpotch of different genetic defects that have caused it in different people.

Eric Ollerenshaw: Well, I keep hearing this and I keep hearing we're on the edge of some great revolution in terms of treatment of cancers because of that, but then I reply, "Well, what's the incredible cost of that going to be?" Because you're going to have individualised…

Andrew Millar: Well, that is the problem, but it wouldn't be expensive or anything like as expensive if we followed the model where everything is measured, everything is monitored, all data is collected all the time prospectively anyway. That's engrained into the system, and efficiently so. Then you introduce a new thing into regular - into a part of the system.

You will find out very quickly whether that new thing is a good thing or a bad thing. It will be a revolutionary way of investigating new agents, but it certainly has-

Eric Ollerenshaw: If you have all the data.

Andrew Millar: But if you had all the data - the reason why randomised, controlled studies are done so avidly is because - and you cannot just investigate in the standard clinical ways because those studies measure everything in huge detail all the way down through the process of the clinical trial. Well, if you're already doing that anyway as part of your clinical work then it would be then cheaper to do the study because you're already collecting the information anyway.

Eric Ollerenshaw: So let me get it right, so I'm going back to basics. You collect the data. Who fills in this data? Do GPs just fill it in and you collect, and how do you do it? I just don't get the mechanism.

Chris Carrigan: Okay. Well, if you walked into your local hospital they'd say, "What's your name?" You're on their computer system. The computer systems feed information to our central cancer registration system.

Eric Ollerenshaw: So that's just hospitals?

Chris Carrigan: We get it from various things, hospitals, labs, very, very limited from GP, but you get referral information for two-week wait, you get screening information, you get mortality information.

Eric Ollerenshaw: But as the solution is - well, part of the solution of a very complex problem, I accept, but a more immediate hit, if you like, in terms of improving early diagnosis would be at the GP level, wouldn't it?

Chris Carrigan: Yes. If you could link the GP data into that that would let you track forwards and backwards, you could learn a huge amount from that, yes.

Eric Ollerenshaw: Where are we with that?

Chris Carrigan: There have been various attempts to link primary care data or to extract primary care data from a multiplicity of systems. The latest one was Care.data, the programme of Care.data, which has had a troubled time to date. The basis of what we're trying to do with things like Care.data makes perfect sense. If you've got a big pot of data over here and a big pot of data over here and you've got the NHS number on both it would seem pretty sensible, if patients are up for it, to look across both those things to get a single view of the patient's NHS career history, if you want to say that.

The doing of it is significantly political. It's not massively technical. There are things you could do very quickly. A longer-term ultimate [techni-solution] will take lots more time. The real-time work that the world would love to see does take a fair amount of time to deliver. There's been a number of attempts within the NHS to do some of that, which haven't been hugely successful.

Eric Ollerenshaw: That's technical rather than - or professional or whatever you want to call it?

Chris Carrigan: No, it's a mix of things. If you're going to do real-time, real-time data collection and linkage, it costs, Proper real time costs you significant

money. What we've done within the NCIN and the registration service is a step back from real time, a three-month window, which for analytical and statistical purposes is fine. It's still a year better than any other country in the world can do, so a significant step forward.

If we're looking at being able to manage patients and linking into - and replacing the trials mechanism, a very rapid linkage of everything that happens to the patient as they go along, as it happens, a really proper real-time record, that takes a significant amount of money and I don't think we're near that yet.

Andrew Millar: Well, yes and I agree, it would take a significant amount of money if we didn't balance it by changing the way we actually work. When you go to the supermarket - in 1972 when you went to the supermarket they would sit there, they'd look at what you bought and they'd go, plunk, plunk, plunk, plunk, plunk, next item.

Now what do they do? They barcode it through. Why do they do that? Commercial imperative. It saves money, it saves operative time, so they got barcode systems, got them into everything and now everyone does that. Why don't we do-?

We're not looking at how to make medicine efficient. We're not thinking and saying, "Excuse me, I've got a sick patient here. I want to get them there to diagnosis and treatment". What do we do now and what should we do differently? Let's throw away everything that we do, potentially.

One of the things that we want - inevitably, to do that on a large scale is going to be costly and we need to investigate it. The supermarkets will have done that. They'll have done practices with barcodes and see whether it actually works and they'll have got lots of people in and old ladies and see whether they could pick up those things, etc., as well.

So what we're doing in London Cancer, and Satvinder hopefully will be joining in, in the thing, is saying, "Well, let's start with a different process". Let's say when the patient is sitting in front of a GP practice, allow them to, either online or using a touchscreen, put in their information. Let the GP put their information on the system, bring this patient into part of the system where we can very rapidly, in a more ward-round style, go

through the patients, check who has got what symptoms, get them to the right tests and then come up with a managed plan much more quickly.

Eric Ollerenshaw: By definition, I would imagine, again going back to evidence we've had in this All Party Group nonstop, is the time that's wasted going backwards and forwards, backwards and forwards until somebody down the line thinks it might be this, unfortunately usually when it's too late to do anything.

What you are saying is, and I think I would agree with it, the number of other consultants' time that's been wasted because it's random hits to see if we can find something, you could measure that, couldn't you, on a pilot stage and say, "Actually, it saves this vast amount of other time" and get on with their job actually?

Andrew Millar: Well, absolutely. I think we should have something a bit like a casualty for patients with outpatient symptoms. They just turn up, we analyse what the problem is, we have lots of different consultants available, and they don't go home at the end of the day, or maybe in two or three days, until we've sorted it out. Then they go back to the GP.

Sorry, just to finish that, we don't even need them there. The specialist sitting in that centre can simply be phoned by the GP and the specialist will go, "Well, try this and try that, and that's the right way of doing it". We don't need to see the patient. Yes, sorry for interrupting.

Satvinder Mudan: I was only going to say I think that system would be economically better because actually probably what you would not do is have your specialist right at the front door. You would actually have a triage system of people who are essentially looking for cancer. It comes back to that motorway thing. If you know what you're looking for you're more likely to see it. That doesn't actually have to be a specialist at the first point of contact.

Andrew Millar: I think actually they should be.

Eric Ollerenshaw: Isn't the issue, most of us ordinary patients, we assume that's what the GP is doing? Do you know what I mean?

Andrew Millar: You see, I think specialists should be at the front door. I think that's what we've done. We've pushed the med- the big difference between the

private sector and the public sector in health service is that in the private sector the specialist is at the front door and in the public sector the specialist is at the back door and only gets there after they've wheedled through the system.

I think we need to put the specialist - the specialist will spot - he will spot someone with pancreatic cancer very - I bet you he could spot most patients with pancreatic cancer within 20 or 30 seconds of talking to them and knowing the facts.

Satvinder Mudan: No, I meant really in imaging and things because in the end what you're almost certainly going to do is get some imaging and some blood, and I think that can be done before you get to the specialists.

Andrew Millar: Well, yes. I think it's a mixture of what we both [are doing]. I think the specialist says what should happen. Then it happens very quickly and then the specialist says, "Right, this is what to do".

Eric Ollerenshaw: It's what you said, Andrew. You could do one of your random tests on this, couldn't you?

Andrew Millar: Yes, exactly.

Eric Ollerenshaw: You could have one lot doing what you're saying, one lot doing what you're saying, and seeing what is the actual saving because they're going through much speedier without wasting, as I said, all this time in between, both to them, which is usually fatal, and for highly paid consultants. I assume you're all highly paid, by the way.

It's just a prejudice I've got. (Laughter)

Satvinder Mudan: I think one of the things I thought was very interesting listening to the dialogue here though, an observation, is it seems to me we're very good at measuring things in hospital, but we're measuring things that we can do very little about because by the time the patient gets to that point, actually we're measuring something that we can't adjust.

What we can't measure very well is what is happening in the GP bit. I suspect what is happening in GP surgeries is that the threshold for onward referral is completely different for GPs individually.

So I think one of the things might be to think about, "Well, why is that, and secondly, how can we harmonise that to be closer and tighter, so the spread isn't quite so far?" But that would require the kind of data that you say is very hard to acquire.

Eric Ollerenshaw: Interesting. Yes. I usually allow a point in time if other people would like to chip in with a quick question. We've got a few minutes left. Or a comment on where we are. Yes?

John Lancaster: I think I'd like to come back to if we are going to get more money to spend on research because obviously there's a lot of excellent work being done by Cancer Research UK. There's a new £5 million strategy. They're saying now they are going to spend more money on the pancreas. There are many other establishments that are doing good work.

But I keep coming back to the fact, and we have already mentioned it this afternoon, shouldn't the government and NHS England take a bigger responsibility for coordinating that? I'm not arguing for more money to come from the government. It's a question of how we put it all together. I come back to the fact that the outcomes, cancer outcome strategy, the main one is all about stopping people from dying. So I suppose I come back to the point that I believe it is the responsibility of NHS England, some of it, to improve the culmination of the research and to make the case for more research. That's one of the arguments that I would have to put forward.

Eric Ollerenshaw: Any comment on NHS England responsibilities?

Male: I think I'd support that. I think there is too little money going into commercial - from commercial studies because it's not in their interest [and things like that]. What you just mentioned, an initiative like in America, is something we should look at, but it needs to be properly done.

Certainly I think the NHS needs to say to itself, "How do we do our job better and in a more cheaper way?" And not just rely on local initiatives to perhaps happen and then everyone copy them, but for the NHS England to actually say, "Okay, guys, let's actually work out how we do the whole of this thing better and cheaper and save money. How can we sort it out?"

and actually put down onto people, operatives in the NHS and say, "Actually, I don't want you to do it like that anymore. We've studied this and we want you to do it like that now".

Richard Cooper: I hope I don't get shot down in flames for asking this question. My mother died in December from pancreatic cancer and my grandfather. From going onto the internet, I came across the National Familial Pancreas tumour Registry, so I put details in. At the risk of being disloyal, it's an American organisation.

It begs the question to what extent can members of the public actually put information into an international database, which I assume would help research? It probably opens up a whole can of worms, but on the data protection, can such a [role] be created for the sharing of pancreatic cases throughout the world?

Male: Well, that's exactly what we're doing - it's akin to what we're setting up, and maybe we should stretch to what you've just mentioned. We are setting up a website which will allow patients to put in their pancreatic cancer or put in their abdominal symptoms and then put in what the diagnosis is finally so that we can then look back and say, "Well, how do the symptoms relate to the final diagnosis?"

To have a registry, absolutely. Well, this goes back to what we were saying before, is that the data in the NHS needs to be known and if someone has got - if there's two members of the family which had pancreatic cancer and they're first-degree relatives then the other members of that family need to know that and their GPs need to be warned about that so that they can then think about whether those patients should be screened.

Then there needs to be some online resource really which allows the GP or some other clinician the ability to advise their patient whether they are someone that should be under screening or not. If they should be screened, then that screening should be done properly and appropriately so that the results are fed back to the GP and appropriate action taken.

We do primary screening quite well in this country, so we do screening for tumours like bowel cancer and cervical cancer. We don't do surveillance

very well, so if you've got a pancreatic cist it's down to individual clinicians at the moment to either survey that person or not. Again, that should become a national thing.

So things like that system you just suggested is actually what we should embed into the NHS, so thank you for that.

Richard Cooper: And international data?

Chris Carrigan: Well, the national data we hold within the registration service, one of the things we did last year or the couple of years we spent setting this up was around brain tumours. That was to allow brain tumour patients whose cases had been registered on the registry to actually augment it with their experience and information.

So it was a managed process where the brain tumour patients were offered this opportunity and they could see what was on their national record, but they could supplement it with other things as well. What they could also do at that point was to say, "I'd quite like to be involved in X, Y, Z" or, "I give my permission for those things".

That's at the national and that's very retrospective, but it's very popular with them and we're looking to see whether that was expandable as well. Cancer Research UK have picked that up and are now taking that forward in other areas as well.

So there's an opportunity to do that. That would be the time at which you could say to those groups of patients, "Would you be okay for this data to be shared across the Atlantic?" It isn't okay as it stands to just routinely share patient data across the Atlantic. That wouldn't be allowed within the law. There are certain things you could do with anonymised data, but once you've anonymised data it's difficult to drill down into other things and ask more granular questions.

So it's not an easy answer. The best answer is to put it in the hands of the person who has given the data in the first place, which is the patient, and explain to them the benefits of opting into these things or not.

As an NHS, I think we should be responsible enough to say to our NHS community, us, that being part of the NHS means you should be part of a

national and international calibration to use the data we've got in a responsible way with appropriate safeguards to learn these lessons to improve care for everybody else. I think people in this country will probably be up for that, frankly.

Eric Ollerenshaw: Can I just thank you again. Satvinder has been before. Just to reiterate, whatever we're going to publish will sent to you first. If there is something else that occurs and you think should enter the pile, because we're hoping ministers will actually look at this, then please get back to us and we'll certainly include it in that formal fashion. Really grateful. Thank you very much.