Q&A Transcript – IA Information Day 2025

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*Each new question is in **bold italics underlined** to aide identification, with each new speaker under a question being highlighted in red font and indented with '>>'.*

A horizontal line has been inserted between each question. The timecode has been left against some of the content to aide identification should you wish to refer to the content in the audio file.

00:00:00 Mr Gordon Carlson

So the first question is an anonymous question which always frightens me, but this I don't think is particularly disturbing. Could Natasha give an update on the drug tariff proposed changes?

>> 00:00:18 Natasha Rolls

Ohh, not really. No, ASCN are meeting with Part 9 drug tariff, Department of Health.

They are advertising for a specialist stoma care nurse to help with the process, which we think is a positive step forward because then there will be somebody with experience and expertise who is advocating on your behalf at the table, but that's all I can tell you, I'm afraid.

00:01:20 Mr Gordon Carlson

For Dominic Slade, and I think this is a fairly easy question to answer. Can a patient ask to be referred to Salford Royal if they have a peristomal hernia knowing that you are a centre of excellence if you live outside the catchment area? Dominic.

>> 00:01:39 Mr Dominic Slade

So I said I wasn't touting for business and genuinely it it is important that there are other people around the country that also I could recommend that you know are doing parastomal hernias in numbers. But by the same token, you have the right as a patient to demand or ask to be referred somewhere else and it depends who you're seeing it it's sometimes more helpful for Gordon and I, if it comes from your colorectal team, if you feel that you're not happy with what you've been told or if you would like a second opinion, you're perfectly entitled to it.

You can go to your GP and ask to be referred. But much as we'd love to help, you know that I don't want to then somebody have somebody referred to us and then have a very miserable experience waiting six months to get into our clinic because that is sort of the wait at the minute, you know it's not easy for us to see new people, but if you would like to come you're more than welcome

>>00:02:47 Mr Gordon Carlson

I'd just like to pick up on that question because I think it exposes a misconception which I was talking to someone about this morning.

Most of you, I suspect, will not realise that the NHS Constitution entitles you to be referred anywhere in the country you wish to be.

Now, Tony Blair, I think in a masterful exercise of spin told people a few years ago that they would create the right for patients to be seen in any one of four centres they wanted to go to. So actually what they'd done was restrict your choice.

From anywhere you wanted to 4 centres that might be OK to you, but the truth is you are entitled to be seen anywhere you want.

If your GP is prepared to refer you there, and that right still exists, the interesting thing is most people don't know they possess that right. I think most GP's don't realise that their patients possess that right and therefore people are still seen locally now.

Local services and often patients want to be seen locally because it's easier and closer to home, but sometimes for specialised and more complex problems, people are prepared to travel to get the right advice.

So what I would say is you're entitled to be seen anywhere. The problem, as you've heard from Dominic just now and again, this is something I've discussed this morning. If you had a restaurant that made really good burgers. You'd make fantastic burgers. You'd be on. You know TripAdvisor. Everyone would come and eat your food.

And you'd have a queue out the door, and you'd make loads of money so you'd make the restaurant bigger, then probably open a second one, you know, 5 miles down the road because excellence generates income and then income is used to develop the brand further and ultimately franchise etcetera.

Unfortunately, as I've found over the last 30 years, the precise opposite happens within the NHS. So excellence just means you get more and more people who want to come and see you and a hospital management which is not prepared to invest if there is any money to invest in your service.

So all you get is a longer and longer waiting list, which then creates dissatisfaction. And unfortunately that's a problem with the system which is broken. So the short answer your question when as you've heard, is yes, you can be seen, get your GP to refer you, but you may need to wait.

If you want to see a specific person in a specific centre.

00:05:36 Mr Gordon Carlson

Do you think patients feel empowered to speak up and explain that they have a different GI tract? If so, what are your thoughts on how to improve this?

>> 00:05:49 Uchu Meade

I feel that all patients should be empowered because it's your body. You know your body better than any healthcare professional and a lot of the time in clinic or when I'm seeing patients on the ward when I'm seeing patients, I always listen to what they're saying.

And I, and if they feel shy, I say to them, you know your body better than I do.

And I try to get them to explain as much as they can to me so that I can understand it from their point of view. A great example. I had a lady with anaemia, iron deficiency anaemia. But she's also got a mix because she's also vitamin B12 deficient. And also she's folate deficient as well. But her blood results weren't showing that she was deficient. But from what she was telling me and her past experiences of being anaemic

She was anaemic, but her blood results weren't showing it. So I went off and did some investigation, spoke to my consultant and shared the papers that I'd found. And because this

And we spoke to our Medicines Information Department and they were happy to grant us to give her iron earlier instead of waiting for her to become hydrated and then to see the deficiency in her blood. So I think that's a really good example of actually listening to people and empowering people to have that voice. And if you don't feel empowered.

Just knowing yourself, I went through a great session. The meditation session, and it's about feeling comfortable with yourself and you have to have that and that comfort that this is your condition. It's your body, you know yourself better than anybody else and just say I have an altered anatomy And if you if you don't understand your anatomy again, as I said, get them to speak to your teams. Refer or ask them to look at your medical notes and they should have a good description of that. So I would say don't feel that you can't or don't shy away from it anybody else got.

Anything to add?

>> 00:07:52 Sophie Medlin

Yeah, I think it's also really helpful just to say, just to be really clear in what you're saying to your GP. So if your GP's saying I'm not gonna give you care for that if you repeat back to them. OK, so I've got these symptoms, this is what's happening for me.

I've had a little look at the NICE guidelines. They say this, but my understanding is you're not going to give me treatment. Can you make a note of that for me, please? Generally, that might frighten them into doing something

Equally, as she was saying, is a really good idea to speak to your team. Your stoma care nurse could write to your GP and explain your different anatomy, your dietician could anyone can write to your GP, who has more understanding of these things. There's loads of downloadable information on the IA

website. You use the resources and tools you have available. If you're tech savvy or you've got family members that are, get them to have a little search of the NICE guidelines, see what you can find online and take things to them printed off. Sometimes my patients might feel too shy or too embarrassed to talk to their GP about certain things. Write it down and pass them a little note. They don't care, they just want to know, and they want to help. But sometimes they don't know all the answers, and it can be quite important to say if you're going to refuse me care for this. Can you just write it down in my record that you've made that decision today please.

>>00:09:04 Mr Gordon Carlson

I think the other point I would make is with all due respect to our colleagues, it's important that we don't overestimate the level of knowledge that some of our colleagues in primary care have.

Of about even simple things like gut anatomy, I saw someone in my clinic actually this week who was referred by their GP on a two week weight large bowel cancer pathway because they'd had a positive stool poo test from their ileostomy, having had all of their large bowel previously removed, and the GP didn't seem to be aware that you can't get large bowel cancer if you haven't got a large bowel.

So they clearly didn't kind of join those dots at all and that was a qualified GP. So it's important they don't always know best even about simple things actually.

>> 00:09:53 Uchu Meade

And if you think about it, we're in this world and we understand, but the condition is pretty rare if you think about it, how many patients does GP have on their book with these conditions versus the amount of patients they'll have of hypertension or diabetes or asthma. So they'll have more knowledge of those conditions compared to the conditions that we see on or experience on a regular basis.

Oh and another good example. Actually we asked the GP to do a urine sodium test and instead of just doing a 1 sample of urine sodium, they asked the patient to do a 24 hour urine collection and then ran the sodium that way. So if you are asking for urine sodium, it's just a one off, not a 24 hour collection.

00:10:36 Mr Gordon Carlson

Next question is for Natasha. Mike wants to know or wants to say 600 stoma care nurses in the UK and I wasn't sure whether the number was for the UK or for England and Wales is a very small number. Do you have any optimum that these? Oh sorry, do you have any optimism that these numbers will increase year on?

>> 00:11:01 Natasha Rolls

I have a lot of optimism that is accurate for the UK. Sadly, but if I I'd give up if I didn't have optimism, I think part of the advancing stoma care services is about raising our profile. So it is about enticing experienced nurses into the specialist profession. So that's one of the really big things that we're hoping to achieve.

It's also worth noting that part of our difficulty with the project is that we're not great at data collection in stoma care, so that is an estimated number and of that number some might be dual qualified, so stoma care and IBD, stoma care and colorectal cancer.

And it may not capture all the reason. One of the reasons that we started the advancing stone Medicare services was because I don't know if you've heard, but in Scotland they changed sponsorship rules and as a result, stoma care nurse numbers have dropped rapidly.

So we are keen in England and that's why the projects starting in England and that's where all our contacts are to make sure that that doesn't happen here and for the rest of the UK. But yes, I am of course optimistic.

00:12:19 Mr Gordon Carlson

It's from Stephen who wants to know how much progress has been made by research to avoid surgery caused by Crohn's and colitis, specifically medicines to stop or control inflammation in the bowel.

>> 00:12:43 Mr Dominic Slade

It's a good question and I'm not sure I'm the most qualified person in the room to talk about it, but I can tell you in my surgical lifetime and Gordons the number of people that we're operating on for.

Inflammatory bowel disease is dramatically reduced mainly because of the introduction of the antibody based immunomodulator drugs. All those ones that I can't pronounce, like feudalism and so and not only that, but there there's been an expansion in those drugs as there's 5.

That are used regularly at the minute and so when one becomes less effective, you can have a trial of one of the other drugs and they definitely keep patients away from surgeons, which is a good thing because surgery, particularly for Crohn's disease, it doesn't cure the condition as many of you may

know who have that condition, what it does is it deals with symptoms and but the end result is that you lose some bowel in each operation that you have and you're always.

And potentially at risk of the complications of surgery. So if it can be dealt with by medicine, that's so much better. There is a lot of research ongoing and you know I have given just how quickly all those drugs have expanded in such a short period time and the fact that changes to the way that we develop medicines like artificial intelligence means that the production time of those drugs is getting shorter, that there will be other drugs on the market that will be as life changing.

>> 00:14:17 Mr Gordon Carlson

That's a good answer, Dominic. And the other point I would make is there is undoubtedly now very considerable evidence that the amount of emergency surgery we're undertaking for inflammatory bowel disease is vastly less than it used to be.

It's actually pretty rare now to have to do an emergency colectomy for colitis. We are still doing some elective surgery for inflammatory bowel disease, but we're actually doing considerably less of it than we used to. Often, though, the problems are that when we are having to offer patient surgery for inflammatory bowel disease, it's because biologics have ceased working and often there's a dilemma there about whether someone's potentially put off for quite a long period of time, a decision to undertake surgery because they've gone from drug A to drug B to drug C, to drug D and actually with hindsight, when you ask the patients, they'll often tell you, you know, I've had a couple. I wish I'd just jacked it in after the couple of drugs didn't work because actually I've just been marking time and my quality of life hasn't been very good. But the overall answer is yes, we're operating much less frequently. Uchu, do you want to address that as a purveyor of some of these poisons?

>> 00:15:37 Uchu Meade

That was a brilliant answer, but not only have the number of drugs increased, but the way we're using them has increased. A good example is when I first started working in in, in IBD, we so drug called infliximab, which a lot of you might know. We used to just give it randomly. So if feeling symptomatic come in and we gave it to you and then it developed schedules. So you'd have a loading dose and then you'd have on a regular basis.

Now what we're finding actually is to if people come in and they're acutely and, well, we can, we're now changing the regimens and the way that we give them medication and the dosing and maybe shortening the time between them. So not only the number of drugs increasing, but the way that we're using them is increasing, so or changing which is really good actually.

We're getting a lot more experience with these drugs and our Commissioners for once are working with us to help us with these pathways because they know the medications a lot cheaper than surgery or any potential surgical complications.

00:16:36 Mr Gordon Carlson

OK. Next questions. And I think this question is directed to Natasha really, although it's not clear whether there's specific or generic.

Do stoma nurses have the ability to refer back to surgeons if you come across an issue that needs refashioning or surgical input or does a patient have to go back through a normal referral route again?

>> 00:17:02 Natasha Rolls

As far as I'm aware, I would refer back to our surgeons directly. So the only caveat to that is obviously if you're new to the area and you didn't originally have your surgery with anyone of my surgeons at my trust, then I might seek for you to go back to your GP, but we could always write a letter of support to your GP to help them direct sign. Post them who to refer back to. So yes, in my opinion, and certainly in my area, stoma care nurses do have that ability.

00:17:48 Mr Gordon Carlson

If my surgeon were to tell me that it was now possible to reverse my ostomy is it a no brainer or are there factors to consider which might suggest the opposite?

>> 00:18:02 Mr Dominic Slade

So I didn't say my talk that the best repair for a parastomal hernia is to get rid of your Stoma but of course, for some people that isn't an option as their stoma is permanent and there's no bowel downstream so you couldn't reverse it if you wanted to, or that the stoma was made to improve your quality of life from, say, problems with chronic constipation and reversing that stoma again is not to be contemplated but no surgery is a no brainer, you know? I mean, of course you know we do surgery because we enjoy that part of our work. In fact, if you speak to any surgeon, you know the time spent in the operating theatre is one of the most sort of enjoyable parts of the working week because you're doing something very practical. That helps.

You know, resolve problems for patients, but it comes at a cost. All operations do, and you know again Gordon and I see the outcome of operations that haven't gone right and they sometimes don't go right in our hands too. So I would never use the term and I don't mean to for the questioner. I don't mean to put them down, but I would never use the term no brainer cause every operation, whatever you have, needs a lot of thought about whether it's right for you and you know, as I always say to people when I'm talking about any operation, you know, there's what you stand to gain from the operation and what risks you're undertaking if you have an operation.

And that is that sometimes it's difficult to sort of work all those out, but an individual if you give them all the information should be able to balance that argument and see whether it is a no brainer for them or not. But you know every operation has potential to go wrong and you have to consider that too.

00:19:53 Mr Gordon Carlson

OK. The next question I think for Natasha, how do you stop a fistula bag leaking?

>> 00:20:09 Natasha Rolls

You need to go back to your stomach care nurse that that you need to go back to your stoma care team and you need to work with them to find a solution that works for you. There will be one out there, but it isn't always the first, second or third solution. And for it, fishes are notoriously difficult. But please, please go back to your stoma care team because they are the ones that will help.

>> 00:20:30 Mr Gordon Carlson

I think the other issue without wishing to tread on your toes and Natasha is it's very important that when we're talking about how we manage fistulas compared to stomas, there's a fundamental difference. A fistula is almost always an accidental, unplanned or disease-related discharge of bowel onto the abdominal wall, whereas the stoma is a planned thing so a fistula will happen. Unfortunately, where it will, whereas a Stoner is usually there because someone has put it there and therefore, if you have a patient with a fistula, actually, I think with the very best will in the world and with the very best stoma care in the world, it can be impossible to stop it. Fist at a bag applied to a fistula from leaking, because that's a product of how much is coming out and the shape of the abdominal wall. And it may not be possible to alter that.

So sometimes that is the main reason. Actually sometimes why I have to talk about operating on a patient with a fistula who is terrified of having further surgery simply because my colleagues cannot do any more to try and deal with the fistula.

00:21:42 Mr Gordon Carlson

OK. Question from Cherry, which I think is for Sophie, given the high reliance on antibiotics, why are pre and probiotics or why have they been dropped from NHS prescriptions? So there might be a bit there for Uchu (Meade) too.

>> 00:22:03 Sophie Medlin

I think probiotics are really exciting. It's really great to see us having access to these sorts of things and it's the microbiome itself is a really exciting area of research, but it's still really young research. We're not really sure, despite the Zoes (commercial company) of the world and everybody else who's telling you, that they know everything about it.

We really don't understand the full impact of taking a probiotic supplement. For example, there isn't vast amounts of research and for you guys, especially who don't have a colon, there's no research at all on whether you should be taking probiotics or prebiotics for that matter. So I think.

For something to be available on prescription, there needs to be a lot of research, especially something quite expensive like VSL and hope. You can speak to this hopefully, but I think we need to perhaps all of us nationally, internationally need to take a little bit of a step back from from the probiotic chat and go, OK, let's learn more about this before we start investing lots of money and worrying too much about it.

But of course, that's never gonna happen because there's so much money in in these kinds of products.

>> 00:23:06 Uchu Meade

Yeah, I would agree with you. When it was taken off, we wrote to NHS procurement via our procurement team to find out a little bit more information why into London procurement as well. And it was just that there was no evidence to demonstrate its effectiveness versus its cost and that's why it was removed from prescription.

You can buy it over the counter if you feel that this is something that you'd like to pursue or to use, which is an expense in itself because it's pretty expensive. But if you there's one of our patients said that she gets on a subscription and she's a member of this site, so it it's a little bit cheaper. So there are those things out there if you.

If you wanted to try it, but it's just again, we just can't demonstrate evidence based value for money in improving patient outcomes at the moment. The other thing just to say on that is that if you were on VSL 3 on prescription my understanding is that there's a company called Vivo Mix and it's the same as VSL, but it's cheaper and it's in capsules. So if you were keen to continue with something like that, but you're noticing that VSL is really eating into your budget, then vivo mix is another option for that. It's exactly the same. It's made by the same guy who invented.

VSL, it's just a cheaper presentation of the same thing.

>> 00:24:28 Mr Gordon Carlson

And also if you shop around for example, Lactobacillus plantarum 299V for which there is actually some randomised controlled trials. It's mainly about bloating in patients with functional bowel disorders rather than colitis, for example, but there's some Canadian research.

Which demonstrate that and again you can buy that on Amazon. It's not prohibitively expensive, but I think to be fair, we cannot expect the NHS, i.e. the taxpayer, to put their hands in their pocket and pay for medication in the absence of robust evidence from randomised controlled trials. I don't think it is reasonable actually.

00:25:19 Mr Gordon Carlson

When considering surgery, this is for Dominic. I think. Is there an alternative to something like TripAdvisor as to how you would decide where to have your surgery? What questions should you ask and is robotic surgery offered everywhere?

>> 00:25:38 Mr Dominic Slade

I don't think there's a TripAdvisor but there are professional associations and the Association of Coloproctology has a significant investment in patients, and you are there are patient representatives and I think you know maybe the first thing to do if you're really stuck and there's no one that can tell you about who might be your surgeon for a particular thing, and that to get in touch with them and their patient representatives, obviously stoma care nurses and anybody else who you might have a close relationship with professionally can give you some advice as well.

But what I was trying to do in my talk is to point out you may well have had brilliant surgery from the person that treated you for your cost of colitis, but they may not necessarily be the right person to do your parastomal hernia repair so it is worth asking around and seeing and in terms of robotic surgery. Fascinatingly, if you look at where robots are around the country, and they are disproportionately placed in the most affluent areas of this country. In the City of Manchester, the robots that are available for surgery are mostly in South Manchester.

And we've got one in in our hospital mainly for urological cancer and it is a real currently quite a a part of equity of access to patients that that those people who should be offered robotic surgery may not live in an area where they're going to get it. So no, it is not easy.

To access it all, and whilst it may not be the answer to everything, I think you know it's just a tool, but it's a way of doing surgery.

That, I think is the future and that people should be given the option.

>> 00:27:44 Mr Gordon Carlson

I will say in in relation to the first question is there are actually websites as in 'Iwantgreatcare.org', I would advise great caution in looking at that. You need to know that there are people who will encourage their patients, twist their patients arm to post positive reviews of the care they've received.

You may argue whether that's scrupulous or unscrupulous, but sometimes I've looked at these websites and thought, crikey, I wouldn't go and see him if they was the last person alive and there are 200 positive reviews of this person. There's a reason for that. So I'm afraid you need to exercise caution and a degree of cynicism.

00:28:39 Mr Gordon Carlson

<u>Last couple of questions, again for Dominic, sorry, regarding an ileostomy surgery, if doing open mid line surgery, are the procedures different now from 25 years ago in terms of closure and the use of mesh?</u>

>> 00:28:53 Mr Dominic Slade

And so I'm just, I mean they are, yes. I mean let let's just put it this way, there are just certain conditions where or certain times where open surgery is the right operation to do, you know that is the safest and whilst it's a big operation, if you've got a big problem you often need a big operation.

Uhm, we possibly are in a better place in relation to sort of understanding things about mesh and reducing the potential for hernias to come back. But you know, I think the concern I have at the minute is unlike something like a medicine that is very easy to put into a randomised controlled trial and to be able to say, you know that that this medicine has value or doesn't. It's much harder to do that with surgery because there's so many aspects to it. There's not an excuse for why.

The research in hernia surgery is so poor, but the fact is it is there are precious little randomised controlled trials in hernia surgery, 4 that I can think of any quality and the rest is all good people saying I did 25 of these and they went well and that's all we've got. So the world is changing because you know, everybody keeps saying the evidence we've got so poor, we've got to make it.

Better the manufacturers that make mesh are definitely coming up with better meshes and so on, and I think you know surgical techniques are they're not changing. One of the reasons why robotic surgery is so attractive to surgeons and to patients is it enables us to do all the things that Gordon and I do in a big open operation.

On the end of a camera the instruments are jointed like your wrists, so you can do that kind of surgery on the end of the camera. And the benefit of that is it reduces the risk of you having wound infection, reduces the risk of you having certain complications and certainly in robotic parastomal hernia surgery.

Your complication rate is halved, and your risk of being readmitted as a patient is halved as well. So there are definitely benefits coming from that technology.

>> 00:31:11 Mr Gordon Carlson

I'm going to draw this to an end by thanking all our speakers for joining us on the panel. I'd be very grateful if you would show your appreciation in the usual way.

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