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OFFICIAL REPORT AITHISG OIFIGEIL

Health and Sport Committee

Tuesday 31 October 2017



The Scottish Parliament Pàrlamaid na h-Alba

Session 5

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HEALTH AND SPORT COMMITTEE 24th Meeting 2017, Session 5

CONVENER

*Neil Findlay (Lothian) (Lab)

DEPUTY CONVENER

*Clare Haughey (Rutherglen) (SNP)

COMMITTEE MEMBERS

*Tom Arthur (Renfrewshire South) (SNP) *Miles Briggs (Lothian) (Con) *Alex Cole-Hamilton (Edinburgh Western) (LD) *Jenny Gilruth (Mid Fife and Glenrothes) (SNP) *Alison Johnstone (Lothian) (Green) *Ivan McKee (Glasgow Provan) (SNP) *Colin Smyth (South Scotland) (Lab) *Maree Todd (Highlands and Islands) (SNP) *Brian Whittle (South Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Jeremy Balfour (Lothian) (Con) Aileen Bryson (Royal Pharmaceutical Society Scotland) Aileen Campbell (Minister for Public Health and Sport) Dr David Chung (Royal College of Emergency Medicine Scotland) Chaloner Chute (The Digital Health and Care Institute) Maureen Falconer (Information Commissioner's Office) Professor Brian McKinstry (University of Edinburgh) Rami Okasha (Care Inspectorate) Dr Juliet Spiller (Scottish Partnership for Palliative Care) Stephen Whiston (Argyll and Bute Health and Social Care Partnership)

CLERK TO THE COMMITTEE

David Cullum

LOCATION The James Clerk Maxwell Room (CR4)

Scottish Parliament

Health and Sport Committee

Tuesday 31 October 2017

[The Convener opened the meeting at 10:01]

Technology and Innovation in Health and Social Care

The Convener (Neil Findlay): Good morning, and welcome to the 24th meeting in 2017 of the Health and Sport Committee. I ask everyone to ensure that their mobile phones are on silent. It is acceptable to use mobile devices for social media, but please do not photograph or record proceedings.

The first item on the agenda is our second evidence session on technology and innovation in health and social care. We have a cast of thousands today; we will introduce ourselves in a moment. If anyone wants to contribute, they should catch my eye or the committee clerk's eye, and we will do our utmost to get everybody in. We want the discussion to flow freely, so I ask everyone to keep their contributions pretty sharp, given that we have so many people here today.

Given the subject matter, I know that some members of the committee will wish to declare an interest. I begin by declaring an interest, as a close member of my family works in the health technology field.

Brian Whittle (South Scotland) (Con): I am a director of a collaboration and communication platform that includes health services.

Maree Todd (Highlands and Islands) (SNP): I am a pharmacist registered with the General Pharmaceutical Council.

The Convener: Thank you. I will introduce myself, and then we will go round the table and people can introduce themselves briefly. I am convener of the Health and Sport Committee and an MSP for Lothian.

Clare Haughey (Rutherglen) (SNP): I am deputy convener of the committee, and the MSP for Rutherglen.

Professor Brian McKinstry (University of Edinburgh): I am a professor of primary care e-health at the University of Edinburgh, and a working general practitioner.

Tom Arthur (Renfrewshire South) (SNP): I am the MSP for Renfrewshire South.

Dr Juliet Spiller (Scottish Partnership for Palliative Care): I am a consultant in palliative medicine at the Marie Curie hospice in Edinburgh, and I am representing the Scottish Partnership for Palliative Care.

Miles Briggs (Lothian) (Con): I am an MSP for Lothian.

Rami Okasha (Care Inspectorate): I am executive director of strategy and improvement at the Care Inspectorate.

Alex Cole-Hamilton (Edinburgh Western) (LD): I am the Liberal Democrat MSP for Edinburgh Western.

Stephen Whiston (Argyll and Bute Health and Social Care Partnership): I am head of strategic planning and performance for Argyll and Bute health and social care partnership.

Jenny Gilruth (Mid Fife and Glenrothes) (SNP): I am the MSP for Mid Fife and Glenrothes.

Dr David Chung (Royal College of Emergency Medicine Scotland): I am a consultant in emergency medicine at University Hospital Crosshouse in Kilmarnock, and vice president of the Royal College of Emergency Medicine.

Alison Johnstone (Lothian) (Green): I am an MSP for Lothian.

Aileen Bryson (Royal Pharmaceutical Society Scotland): I am practice and policy lead at the Royal Pharmaceutical Society Scotland.

Ivan McKee (Glasgow Provan) (SNP): I am the MSP for Glasgow Provan.

Chaloner Chute (The Digital Health and Care Institute): I am chief technology officer with the digital health and care institute.

Brian Whittle: I am an MSP for South Scotland.

Maree Todd: I am an MSP for Highlands and Islands.

Maureen Falconer (Information Commissioner's Office): I am regional manager of the Information Commissioner's Office in Scotland.

Colin Smyth (South Scotland) (Lab): I am an MSP for South Scotland.

The Convener: Thank you. We have between one hour and 75 minutes for the session, so we need to get under way quickly. Colin Smyth will begin.

Colin Smyth: One of the reasons why the committee decided to inquire into technology and innovation in health and social care is that, in almost every aspect of our work, from looking at healthcare in prisons to speaking to GPs about new models of care, we have found that there is huge frustration at the barriers to sharing patient

information among healthcare professionals. I want to hear people's thoughts on why, in 2017, there is still such a wide variation in recording data in the national health service, a complete lack of integration of the various systems and no single platform for patient information.

The Convener: Well, that is an easy question. Who wants to go first?

Maureen Falconer: I will attempt to answer that one. Fundamentally, the problem is historical. When we moved to the so-called internal market in health, all the unified systems were broken up and became quite disparate. My research prior to my joining the Information Commissioner's Office was in health, and the issues that you raise certainly came to the fore when I spoke to health boards across Scotland. The big issue was trying to bring the systems back together again. The attitude in respect of technology tended to be, "If that's how Glasgow's doing it, Edinburgh's not going to do it like that." People said, "No, we're not going to use that system—we'll use this system." There is a need to bring those parts back together.

In addition to the technological problems, the elephant in the room is data protection, which people often see as a stumbling block and an obstacle to information sharing. I should put it on record that both the preamble to the Data Protection Act 1998 and the new European General Data Protection Regulation that comes into force on 25 May next year not only refer to the protection of personal information but state-as a lot of people do not realise-that the legislative framework is set up to allow for the free movement of personal information. A lot of our work in Scotland, particularly in health, involves saying to people, "Can you share? Yes, you can." The Data Protection Act 1998 is a framework for safe and secure sharing of information; it is not the barrier that a lot of people think that it is.

Professor McKinstry: I echo that. The major issue is information technology governance across various places. There is a marked difference in the interpretation of the regulations by different health boards. For example, NHS Lothian banned Google Chrome, whereas the rest of the country is still using it. We need a single IT governance system for the whole of Scotland. It is crazy to have all these different small groups making up their own minds as to what is or is not acceptable.

Chaloner Chute: I was going to give the same answer to Colin Smyth's question. The distribution of decision making around investment in IT infrastructure is a big issue. Finland, Estonia, Galicia and other European countries and regions are progressing quite quickly in these spaces. They have a slightly more authoritarian approach with regard to setting a common standard, and a central voice that says, "This is the way we're going to do this." In some countries, the Prime Minister chairs the data-sharing committees and there is an authority on how things should be done.

The Convener: Is it better that way, with a bit of diktat?

Chaloner Chute: I am sure that plenty of people would argue either way, but on digital accessibility measures, based on benchmarking across Europe, those countries and regions are significantly further ahead than other areas.

Dr Spiller: I absolutely agree. We need a single IT governance structure for what we need to do in Scotland for e-health. I make a plea, though, that we should have significant resource to support that with clinical expertise, because we do not currently resource clinicians properly to provide their time to support the IT work that happens.

Most of the work that happens in Scotland that improves IT resources and focuses them on what patients need is delivered by patients, carers and clinicians who are doing it in their own time. If you want it done better and quicker, you need to resource people to do it properly and to work together with people in IT who know how to do it. We have huge amounts of expertise in Scotland, especially in e-health and IT and what can be done in that respect, but we need the clinicians and the IT experts to work together with patients and carers to make the system exactly what people need.

Stephen Whiston: I echo what everyone else has said so far, but in my view the material point relates to the integration of health and social care information. It is great to hear that there should be no bar to sharing appropriate information, with read-and-write access for all, because that issue is the biggest frustration among all the health and care professionals I speak to and among our third sector partners.

We want to radically transform health and social care. That is where we have got to address it, and we have a plethora of systems at the moment, which just piles on frustration. It piles on mythology about data protection, with people saying, "We can't do this because of Caldicott guardian rules, I've got to go through this board and that local authority's data controller," and so on and so forth. We set ourselves up to fail because we are tripping over duplication. I know that my colleagues at the health and care coalface would welcome with open arms anything that we can do to simplify that.

The Convener: Are you doing stuff to simplify it?

Stephen Whiston: We are attempting to, within the resources that we have—my colleagues made

that point. We are attempting to bring our community nurses on to the same social care system in Argyll and Bute. That is taking a long time, and there are a lot of cultural and professional issues around that: I am looking at the new GP contract that is being negotiated; I have practice nurses who can access the GP system and health visitors and district nurses who cannot; and I have GPs who will share some of that information with social work colleagues. It is just bonkers and it is our biggest frustration. We are attempting that work, but we have limited resources to put a simpler system in place and I am dealing with primary care, which is an independent business; with social care, which is a local authority system; and with the NHS system.

The Convener: What would it take to get the system to where you want it to be?

Stephen Whiston: It takes that single type of approach—a single governance with a single agency driving it would be my recommendation.

The Convener: Does anybody around the table disagree with that?

Chaloner Chute: I would just like to comment that, if you are looking at international comparators, it is not just about health and care. Things such as the benefits system and social security are critical components, so there is a big opportunity to dovetail that kind of work.

Rami Okasha: The evidence that we have collected suggests that the points that have been made are very much borne out in terms of the interoperability of information and communications technology systems across health and social care. It is worth pointing out two things. First, the lack of interoperability does not prevent effective systems from being put in place to support access to those systems for different professionals, and there is some evidence of examples where that is working, although I appreciate that that is a workaround, rather than a solution to the problem.

The second point relates to what Stephen Whiston said about the complexity of the health and social care partners that are working together. It is not just about ICT systems that are in use in health boards, or indeed in the 31 integration authorities. There are some 4,000 individual care service providers for adults across Scotland, and organisations are commissioned those by integration authorities but are not part of integration authorities. There is a really complex landscape that needs to be borne in mind when we think about what one system might look like.

Dr Chung: I echo everything that has been said. Whether it is the reality of the situation or not, operationally data protection is considered to be the biggest barrier. Who owns the data?

I will give an example. Every single GP out-ofhours system in Scotland cannot access the data for that practice's patients, which is just insane. An out-of-hours GP goes to see a patient and cannot find out anything about them, so they do the safest thing, which is probably to admit them to hospital. Out-of-hours services cannot even access care.

The question is, who owns the data? I say that we should be more radical and let the patient own their own data. The patients already think that we know everything about them. They come to an emergency department and say, "It's all in my record, doctor." We have to say, "We don't know what's in your record. We don't know anything." They think that we are joking, or that we are lazy and do not want to look, because they are used to information about every other aspect of their life being shared. Facebook and Google know everything about them and people have consented to that data sharing.

We are hamstrung by that. If we gave a patient options and said, "Do you want a smart card with your data on?" lots of people would take it. They would say, "I know where my records are and then I can give it to you and you will know where my records are." That is what I want to do, but people are different and resources are very different, even on more basic operational levels. Good software has been brought in, but various bits of the healthcare system have said, "We'd like to have that but we've been told there's no cash for it this year, so we've not got a portal for these results. You'll have to apply to get the paper notes." That is what is happening at an even more basic level than development.

The third thing that I want to say is that, if you are going to bring in a system, please engage the front-line clinicians and ask them what they want the system to do. A lot of the existing software has come from other countries, where its main purpose appears to be to collect data to bill, rather than to do a clinical job, to do the best thing for the patient and to share information to their benefit.

Jenny Gilruth: Aileen Bryson, in your submission you say:

"Pharmacist access to the patient health record would improve patient care by enabling pharmacists to play an even greater role in the provision of safe and effective unscheduled care".

I should also say that I have visited a couple of community pharmacies, one of them with Aileen Bryson, to see how that can work and how data sharing can sometimes block what the pharmacist is trying to do.

This question might be for Aileen Bryson specifically, but is anyone aware of areas in which that data sharing is working well and that other areas can learn from? If you all agree that there should be an agreed national standard, there must be areas that other parts of the country could look at for best practice.

10:15

Aileen Bryson: You are quite right. I echo everything that has already been said. It is very interesting to hear everyone talk about how disparate and piecemeal it is-everyone is singing from the same hymn sheet on that point. Even where data sharing, although piecemeal, has been piloted and might be working, it is sometimes very clumsy and is not smart working. For example, even where the pharmacist has access to the portal, they may have to have the patient's permission each time that they use it. Given that most of our prescribing and dispensing is done ahead of time to help with work planning and patient access, it means that if there is a query on a prescription-up to one in 20 prescriptions may have a query, although the General Medical Council would say that only one in 500 has a clinically significant error-the pharmacist has to try to get hold of the patient to get their permission to use the portal. If it is a carer or a family member who collects the prescription, how can the pharmacist access the portal? Those are very clumsy ways of doing things.

Pharmacists can access the emergency care summary, but they have to do it through NHS 24; there is no direct access even though that has been promised since 2014. We have to phone NHS 24 to gain access and often there are extra phone calls, which cost extra time. We have lobbied for a long time on that point. We can work much smarter with what we have got, but we need extra resource and at the moment there is no national leadership or driver to pull all that together.

I am heartened to hear all the comments that have been made round the table because they echo our sentiments exactly.

Say a lady is supposed to get a phone call from her GP practice about her warfarin, which is a high risk medicine, on a Friday night. For lots of reasons that phone call does not come. The little old lady is totally distressed and rings NHS 24 wanting to know how many tablets she needs to take at 6 o'clock at night, but we cannot do anything about that until Monday. However, if we had direct access, we could sort that out and ensure that she got the right dose. If she does not get the right dose, she might well end up in hospital again next week.

It is sometimes difficult to quantify, but everyone has the same aims and long-term objectives. There are short and long-term gains and we are missing out on them all. **Maree Todd:** When I was working as a pharmacist, I was struck by the differences in the profession: community pharmacists have no access to data and hospital pharmacists have access to all the data. In the hospital, I could access medical notes and lab results. That situation makes it impossible for community pharmacists to fulfil their pharmaceutical care obligations. For example, I worked in psychiatry and I know that dispensing the drug lithium obliges the pharmacist to check whether certain tests have been done. How on earth can a community pharmacist do that without access to lab results?

Aileen Bryson: We have a situation where the same health professional can access different information depending on where they work: if they work in the community, they cannot access some things that they are able to access if they work in a GP practice. Many pharmacists work in a hybrid model and that seems to be working well because they know the patients really well.

As the Royal College of Emergency Medicine has said, out-of-hours care is exactly where it falls down. As Jenny Gilruth says, that is important for continuity of care. There are patient safety issues—we have lots of examples of where patients can be put at risk because high-risk medicines need to be monitored and not everyone has access to the information. That includes social care, where there have been examples of pharmacists going round the houses to get information from social care, which, had it been at their fingertips, would have been very helpful when going into a domiciliary visit.

Those are small, piecemeal issues that, taken together, mean that we are not getting the impetus and traction that we need.

The Convener: Alex Cole-Hamilton wants to move on to another topic, but I will let other panel members comment on that point first.

Dr Spiller: You mentioned the out-of-hours issue. When we look at the care of patients with complex, long-term conditions and patients with terminal illness in particular, out-of-hours care is where it often all falls down. One of our great achievements in Scotland is the key information summary, which is a one-Scotland approach to out-of-hours emergency information. It is heartening that that is in place, but we need to use it better.

There are lots of pockets of expertise where clinicians, teams, patients and carers have done workarounds, but nobody has time to pick their head up and look at what other people are doing, and nobody has time to take their local practice and make it more widely known. Again, somebody needs to have the overview to look at local practice and say, "Well, that is working really well there; I wonder whether it would work in different health boards." We end up with lots of different areas of local practice and disparate effects. One of the things that we know is that patients who have a terminal illness absolutely need a key information summary—a KIS—and one of the visions for the Scottish Government is that, by 2021, every patient who would benefit from a KIS in Scotland will have one.

We know from the figures that Marie Curie has collected that approximately half of the patients who died in Scotland last year who had palliative care needs had a KIS in place. We are getting there, but we are far short of the mark. We also do not know what the quality of that KIS information is.

When the patient hits the front door for secondary care, how many of those clinicians know that a KIS exists, how to access it, and how to make use of the information? The quality improvement work that we did in West Lothian showed that, of the patients who had a KIS, only 4 per cent of the information was accessed when they hit the front door of the acute hospital.

Quality improvement work can improve that, but all these projects are happening right across Scotland and nobody is pulling it all together. That is a system that we have in place that could work dramatically well to change patient care overnight if we resourced it and did it properly.

That is not to mention what we need for the future. The KIS is fine, but we have pushed it as far as we can. For the complex level of advanced decision-making that we need to meet patients' future needs in Scotland, we need something much more sophisticated and accessible.

Professor McKinstry: One of the main reasons that that is not done is because the systems are so hard to use. General practice systems are not fit for purpose-that is the single biggest complaint in general practice across the country. We are dealing with Windows XP and Internet Explorer 6. It takes ages to do anything. Completing a KIS is difficult because you have to go through several different screens and it is very hard. Sending messages to pharmacists is difficult. I have to sit and watch the hourglass when I do my repeat prescribing. I have to do five repeat prescriptions and there is this hourglass sitting in front of me. All over the country, there are GPs and nurses looking at this hourglass, waiting for it to clear so that they can do the next prescription. It is disgraceful. We are working with a 4MB download speed and a 0.4MB upload speed. How many of you would accept that in your own houses? Nobody would. We are working with that day in, day out.

The Convener: On the back of that, I suppose that the key question is, what is being done about it? Are we seeing any progress? We have been in here only 20 minutes and we have got the picture. We certainly get the picture, and I am glad that you told it like you did because that is what we need to hear. What is being done?

Dr Chung: In Ayrshire, where I work, we only got the portal system in the past 12 months. Glasgow had it for ages before us. Now that we have got it, in an emergency department situation, it is invaluable to have access to the most up-to-date clinicians' opinions, the emergency care summary and the KIS. It is much faster and that is better. That is a system that has shown some promise in giving clinicians some of what they want and it is reasonably easy to use.

Has everywhere that needs it got it? Not everywhere has. Which systems do we have that people are happy with, and can we roll them out as soon as possible to get people believing in them? Everybody thinks that they cannot be bothered with another failed information technology solution and asks why they should invest effort in it because they are all rubbish and people just get told to use them and they do not want to.

There is a cultural bias to overcome. If we use best practice and make it happen in as many places as possible, people start to say, "D'you know, that's all right. I can see why I might invest some time and do a bit of training in this."

The Convener: But that seems like an extremely ad hoc approach. Where are the national programmes or the roll out of successful integrated systems? Is there a plan? When we speak to some of the civil servants, they shrug their shoulders and say that things take time.

Dr Chung: I think that you might have hit the nail on the head. There is no national programme so, locally, everybody has different priorities. One chief executive might say that money is the bottom line, while another might say that it is a certain patient safety issue, and they will trim their sails accordingly.

The Convener: Okay. A large number of people want to come in on a number of issues, but we will have questions on this issue first.

Ivan McKee: Following up on the convener's question, I am interested to know what people think needs to be done to move things forward. There seems to be consensus that there needs to be a bit more centralisation—which is a horrible word for a politician to use—but how do we get from where we are to where we need to be? Does it require legislation, reorganisation, the Government to do something about pulling stuff back to the centre or the direction of resources?

What needs to happen to get to where I think everybody agrees we need to be?

Chaloner Chute: My point was linked to that. I want to present some of the global market analysis work that we do as part of the day job. If you hear me talking about other countries, that is because I am here to reflect on what is happening in those countries.

People say that Estonia and Finland are different in some ways and similar in others, but they do some common things. The first is that, to them, information sharing is not an IT issue but a fundamental service design issue; it is not something that can be fixed by IT managers getting together. As a result, the people involved in creating the solutions are a very mixed bag. They have the very highest level of political mandate and leadership, with someone saying, "This is the way that it is going to happen."

Secondly, Estonia and Finland have something similar to the once-for-Scotland thought process, but they do not let that become the kind of national IT project in which everything is created centrally, distant from the use case and constructed in isolation, that we have seen a few times in the United Kingdom. Instead, they ask what tools and standards can be put in place and then consider how to enforce some of those things in such a way that everyone is in the same playground, playing with the same toys. When people make their first choices at the point of care-after all, that is what they will have to do, and clinical and patient requirements will need to be satisfied-that can happen in a way that at least attaches to a consistent and mandated spine, and there is no choice but to aggregate to it.

Those are the two main things that the countries that are leapfrogging ahead seem to be doing.

The Convener: Just to clarify for a technophobe like me, are we talking about a central system that different elements are plugged into and coordinated through?

Chaloner Chute: Yes. There is not, by any stretch of the imagination, any one package or software solution that will do that, and it is complete folly for any thought process to think that it can be created; there are tens of thousands of use cases with tens of thousands of interfaces. The situation for someone living with multiple sclerosis is completely different from that for someone living with diabetes and so on, and we have to respect that.

However, there are things that you can do. For example, we have talked about personally held data or the citizen having their own data. There is no vehicle by which a citizen can hold their own data, so a role for Government could be to ask how a citizen can hold a version of their record. We could put in place something that allowed them to do that; it would be open and allow the citizen to consent to the sharing of that data whenever they wanted to, but it would not require them to use a specific interface based on a central Government programme. You can put in a lot of enablers without necessarily mandating a very specific experience.

The Convener: I am pretending that I know what you are talking about, and I suspect that a few others around the table are doing the same. However, I think that I have actually got the thread of what you are saying.

Chaloner Chute: A once-for-Scotland approach does not necessarily mean that there will be one software system that everyone is forced to use.

Dr Spiller: Some quite exciting things have been happening over the past few years around palliative and end-of-life care and anticipatory care and I would like the planning, Scottish Government to value strong clinical leadership in taking forward the recommendations of a number of Government commissions. It should find out what is happening, take those commissions' recommendations and roll all that out and embed it in clinical practice. That is the bit that we do not resource. We resource the commissions and sometimes the IT know-how-although that is usually very squeezed-but sometimes once those commissions finish their work, nothing happens. We just end up with a report.

10:30

For example, I have been asking the Scottish Government for two years now to work out why all the independent Scottish hospices cannot link with NHS IT systems and what is needed to sort that. The hospices have rolled out electronic patient record systems that are all slightly different; some are the same, some are different, but none of them can link directly from the patient record to the NHS IT system. It is bonkers. The Government has just recently agreed to set up a commission to look at that, but what terrifies me is that it will find out what the problems are and then nothing will happen.

We need strong and resourced clinical leadership to make sure that the commission's work results in action. You cannot tell independent hospices what to do, but you can set standards, make clear what is recommended and make that in their best interest. Everybody wants to provide good patient care as efficiently and effectively as possible, so the NHS should provide independent hospices, care homes and social carers with the resources and IT support to access NHS IT systems. The initial bit is finding out why that does not happen, but the next bit is more important. The Convener: So are reports saying, "This is what you have to do to take this agenda forward" just sitting on desks somewhere?

Dr Spiller: The reports make recommendations.

The Convener: Yes. So the reports say, "We recommend you do X, Y and Z", but they sit in a civil servant's cupboard or perhaps on a civil servant's computer system, and no actions are taken forward. Is that description too general, or is that what happens?

Stephen Whiston: It is probably a little too general. The issue comes back to priorities, of which there is a vast number in health and social care. The point is to mandate what we must do to make information sharing happen.

That is precisely what our community and our users assume is happening. They say, "I expect you to know this or that about me. Why, when I pitch up here, do you ask me the same question for the 15th time?" Why do we not share the information? The answer is that we are not mandated to do so. Information governance is not an issue—it can be addressed.

The Convener: Who is stopping that happening?

Stephen Whiston: It has stopped because we have not been mandated or directed to do it.

The Convener: But who should do the mandating?

Stephen Whiston: A number of agencies should do it, but no policy is trickling down to say, "You must share this information in the best interests of your client and user." The myth is that we cannot do it because of data protection.

The Convener: Have you demanded such a mandate? Have you said, "This is what we need from Government, the health boards or whoever"?

Stephen Whiston: Let me give you an example. In Argyll and Bute, we are working hard to integrate our GP out-of-hours services with community hospital acute services and daytime care services. A practice will look at its out-of-hours records and will say to another, "I need a Vision record. Because you're not in my practice— I'm covering this service for you—you need to share that record with me, as I am admitting your patient to your local community hospital." The other one will come back and say, "Actually, I might be able to give you read access, but I am not sure whether I can. I will have to go to my Caldicott guardian." The clinicians just fall away.

The Convener: Why do they do that?

Stephen Whiston: The clinicians are independent practices with their own independent requirements for Caldicott guardianship.

The Convener: Are the clinicians not allowed to share information under the rules set down by statute, information commissioner's guidance or whatever?

Maureen Falconer: The NHS has formally set up GP practices as data controllers, which makes them the legal entity with regard to the personal information that they use and process in any shape, manner or form.

The problem is that nothing in the Data Protection Act 1998-and nothing other than a court order-can compel data controllers to give out any information. It is up to them to be satisfied that they can do whatever they are asked to do. When we in the Information Commissioner's Office go out and about, talking to people about the integration of health and social care or, indeed, named person issues-I hope that I can say that without being struck down-we will tell GP practices and so on that they can share, by and large. The issue is all about proportionate and appropriate sharing to the appropriate person and looking to the data protection framework to be allowed to do that. Too often, that approach is seen as too hard; people do not understand it. Consent is seen as the be-all and end-all; people will say, "If I don't have consent, I can't do anything with this information and I can't share it." That could not be further from the truth.

The Convener: Having listened to what Maureen Falconer and Stephen Whiston have said, I think that, if you two were to speak to each other after the meeting, you could sort the situation. [*Laughter.*]

Maureen Falconer: We could sort it for us. The problem is that I would need to speak to every single GP practice.

The Convener: I encourage you to do so; it would be one tick that we could put against today's session. I am being serious—if people do not speak to each other, we will not resolve these problems.

Professor McKinstry: One of the main reasons for the situation—indeed, the main reason—is that people are risk averse. They do not understand the 1998 act; because they do not have the time to find out about it, they default to what they think is safest. That is why people are worried about sharing data.

Maureen Falconer might say that it is okay to share data if that is appropriate, but people wonder what is appropriate. They are worried about being slapped with a £10,000 fine for revealing information that they should not have revealed. I know that the likelihood of that happening is very small, but we are talking about people who, given the choice of one way or another, will choose the safer thing to do. In some ways, it would be so much better if GPs were not the data controllers and if there were one data controller for the whole NHS.

Chaloner Chute: The data controller should be the citizen.

The Convener: Do you want to make another point, Alison? You have been waiting very patiently for a long time now.

Alison Johnstone: My point is about access to data, so it is definitely connected to the present discussion.

My questions are for Maureen Falconer. As you have suggested in your evidence-and from what I have been hearing-this is all about appropriate and proportional access to data. I hear what Dr Chung has said about patients being in control of their own data and who has access to it. I suppose that if they were in control they would have to be very well versed in the implications and safety aspects of that. Imagine what would happen if commercial interests got their hands on some of that data; the impacts could be quite devastating. What are your views on making sure that access is proportionate? You mention in your evidence that, in some circumstances, councillors and nonmedical professionals have access to patient data, because of partnerships with the third sector, for example. How do we make sure that that data is never accessed by those who should not have access to it?

Maureen Falconer: I suppose that that speaks to Brian McKinstry's point that very often GP practices are just scared. I do not believe that anyone is deliberately obstructive; I think that people are genuinely scared and, as Brian has said, risk averse. Therefore, the safest thing for them to do is not to share data and to hold on to it all.

The question of GPs being data controllers is being looked at by the Scottish Government, and we are working with the Government on it. Determination of the question of who a data controller is, is fundamentally down to seeing who determines the purpose and the manner of processing. There is much to suggest that the health board, via the regulations sitting around GP practices, has a lot of say in the purpose and the manner of processing; in fact, it has absolutely everything to say about the manner of processing. A GP under the NHS can process data only using an IT system that has been sanctioned by the Scottish Government; that is why all the systems are currently either EMIS or Vision. If a practice wants to use paper records, it can use only the form that the health board has determined that it can use.

There is therefore a lot to suggest that it is quite right to say that GP practices are taking on data controllership responsibilities and liabilities for a lot of things that they do not actually have any meaningful control over. The question whether the health board should take some control, liability and responsibility for the GP patient record is being looked at, too.

The Convener: What does "being looked at" mean in terms of a timeline?

Maureen Falconer: Brian McKinstry will correct me if I am wrong, but I think that the GP contract comes out in November. The working group will therefore have to report soon to feed in to the timetable for agreeing it.

The Convener: So it will be this month.

Maureen Falconer: Yes.

Clare Haughey: I thank everyone for coming along today. My query, which has been partly answered by Maureen Falconer, is on something that Professor McKinstry said about GP IT systems. Professor McKinstry, you were quite vocal about the difficulties that you have. Who owns those GP IT systems?

Professor McKinstry: Individual health boards own them; they have bought them. GPs do not own them.

Clare Haughey: We have been talking about connectivity to the web and how quickly things download. I am as much of a Luddite as Mr Findlay when it comes to IT. Who is responsible for the part of the system that deals with accessing the internet?

Professor McKinstry: Again, it is individual health boards. A lot of GPs gave up long ago and now use their phone when they want to look up something or find out about an illness, because the internet connection can be so slow. It is quicker for a GP to use their own phone on 3G or 4G to get information. When we tried to introduce video consulting in Lothian, we had to put separate IT systems into each practice, because video could not run on the systems that we had.

Clare Haughey: And what about the broadband that GPs are accessing?

Professor McKinstry: It runs at very slow speeds. We can use it, but it is very clunky indeed. People would never put up with it in any other sphere.

Clare Haughey: Is there an option for GPs to upgrade in the way that you might do in your home?

Professor McKinstry: No, not in the NHS. At the moment, if I wanted faster speed in my surgery, I could not get it. The only way that I could do it would be to purchase a separate

broadband service that would not be linked to the NHS.

Clare Haughey: In my constituency work, I have come up against an issue of a GP practice that does not have an email system. Have you come across cases of GPs not accessing what to most of us would be everyday technology?

Professor McKinstry: When we surveyed practices across the UK on their use of email, we found that only a very small minority of GPs used it, and only a tiny proportion of them used it regularly. There are two reasons for that. First, some health boards do not permit GPs or doctors of any kind to use email for clinical reasons, because they do not regard it as secure. Secondly, doctors are very worried about the possible workload implications of setting up email services. We found in our survey that they are worried that they will be swamped with requests.

Clare Haughey: Requests for what?

Professor McKinstry: Requests for information, to which they would have to reply. The problem is that we are talking about a system that is already bursting at the seams. We all know that. General practitioners are not looking for any more work at the moment.

Clare Haughey: I was not suggesting that we give them more work. However, the situation means that, instead of our being able to email GPs, we have to write to them. That does not reduce the workload; it actually increases it and, indeed, the time that it takes to seek information.

Professor McKinstry: This might sound terrible, but it is a lot harder to send a letter than it is to send an email.

The Convener: You have raised a number of very interesting points, and I thank you for being so straight with us on the matter.

Alex Cole-Hamilton: Good morning, panel, and thank you for coming to see us today. As a bookend to that discussion, I would like to request that Dr Spiller liaise with the clerks on what commission recommendations are sitting in civil service drawers, so that the committee can crossexamine that and interrogate the Scottish Government on what has been recommended to it over the past few years, and what we might implement to improve practice.

It strikes me that in the case of community pharmacies, on which I have done a lot of work with Aileen Bryson, there is a solution to the much broader crisis of staffing in our GP sector. Our GPs are on their knees at the moment, in terms of workload and capacity, and community pharmacists could provide much of the solution by doing prescribing, which would be enhanced if they had ready access to patient records. I will move the discussion to another aspect of innovation and technology in health and social care. Around this time last year, I had the case of a constituent who had spent several hundred days in hospital beyond the point at which they had been declared fit to go home, because there was not an adequate social care package available for them. It was costing NHS Lothian £400 a night to retain that patient, who was in a positive state of health, in a hospital where they did not need to be, because there was no means by which to give that patient a bed check for incontinence in their home at night.

I spoke to the chair of the integration joint board: as soon as I alerted them to the matter, they said that technologies are available that could have performed that late-night check without the need to employ a member of staff to come in.

I love that we have technology such as that, but I am concerned. If we cannot get the basic IT right, as we have just discussed, in respect of information sharing and cross-fertilisation of IT systems, how close are we to being able to roll out such technology, which was eventually offered to my constituent and they were allowed to go home?

10:45

The Convener: Who would like to start us off on that?

Chaloner Chute: I will raise a slightly different example from which members can read across, and with which Brian McKinstry is very familiar. The example is remote blood pressure monitoring. Three in seven practice nurse appointments involve a blood pressure check.

Professor McKinstry: In Scotland, some 1.2 million appointments every year are for nothing but blood pressure checks.

Chaloner Chute: We have long had medically regulated devices that anyone can use with a very small amount of training, and which can automatically upload readings from anywhere into NHS systems. Brian McKinstry has done a bunch of work on that, and a lot of us have been pushing hard on this very simple thing for about 10 years. How many people in Scotland are using those devices remotely?

Professor McKinstry: The technology is just starting to take off, actually. In Lothian, we now have 1,300 people using the technology, and we hope that that number will increase sharply. Use of the technology seems to have taken off, at long last.

Chaloner Chute: The question is, fundamentally, whether we trust patients to collect

information about themselves and contribute it to the system.

Professor McKinstry: Absolutely.

Chaloner Chute: The answer is that we do not, at system level, trust them.

Professor McKinstry: Patients are much better at checking blood pressure than doctors and nurses are. That is the truth.

Chaloner Chute: That evidence is not reflected in our cultural approach, however. Similar technology exists to do all sorts of things. It is just that at system level, for some reason, we do not place trust in citizens to be able to do those things. As soon as data comes from somewhere that is outwith our control, we treat it as being immediately suspect and having low integrity. A lot of the data protection changes and the trust measures are enablers for such things.

Professor McKinstry: This is a lot to do with the systems behind collection of data. There are different ways of doing it. The system that we use in NHS Lothian collects the data and sends it via Docman, which is the usual way that GPs get their lab results, hospital letters and so on. It has been extremely popular; some 40 per cent of GP practices in Lothian have taken it up and others are looking for it. If we get the formula correct, people take up such things.

Chaloner Chute: To be facetious, I guess that the point is about the stage at which we can say that, by 2022, we will not have routine blood pressure checks being done in GP surgeries. At some point, someone has to say that what is happening is not good enough and put in place provision such that everyone must, by a certain date, adopt the technology.

Professor McKinstry: We need a HEAT health improvement, efficiency, access and treatment—target or similar.

Aileen Bryson: I completely agree with all that has been said, but it is not just about not trusting citizens with taking their own blood pressure nobody trusts even other health professionals with data. The duplication that is routinely found in the system is horrendous. That is why we talk about working smarter. Yes—we need lots of extra resource for the big IT projects that are the enablers of the culture, but there are lots of things that we could do with what we already have and are not making use of.

The Convener: I am sorry, Rami—I meant to bring you in earlier. Has the point passed?

Rami Okasha: The point has passed.

The Convener: Okay. I am sorry about that.

Stephen Whiston: We should consider the example of telecare, rather than telehealth, applications. The TEC—technology enabled care—initiative has driven that forward; 1,800 people in Argyll and Bute NHS are now using telecare systems to keep people independent and at home. I suppose that the material issue is that that funding stream will come to an end this year. How, therefore, is the approach to be embedded nationally in order that it can move forward?

Also, telecare uses—this is where I am a bit of a luddite—analogue rather than digital technology, and there is a big transformational cost to shifting on to the digital platforms, which is key. That would enable us to link health and care information and responses, and it very much supports community resilience. The responder in the example that Alex Cole-Hamilton gave could well be a neighbour who could help because they have been trained and supported in the partnership environment, or the responder could be a voluntary agency. It need not necessarily be a health professional or even a care professional; it could be somebody who is working within their community, doing neighbourhood responses.

Telecare is a very big material win that will help us to manage demand on the health service. Colleagues have flagged up the demand on our creaking services, which is such that we need to transform radically how we deliver services.

I get Brian McKinstry's point about email traffic into primary care but, to be honest, we have to change how we deliver and operate our services. The NHS cannot even offer people online appointments, but—I do not even need to say this—people can get them for everything else. Why cannot we do that? Our colleagues at the front line are on their knees, but they are worried about that change. That is a mandate to change; we have to change radically.

I have seen some small evidence of that happening. I have, for example, seen practices using the telephone system to provide the first line of response—to triage the work then redirect calls—but that is only the telephone: there could be videoconferencing consultations.

Culturally, we do not grab such opportunities. Why not? The material issue is that we do not train the people who are coming through the system in what technology can bring. We expect people to understand, almost by osmosis, how technology can be used and applied. That is why we will fail if we do not pick up the pace in the next three or four years and give our clinical colleagues space in that regard.

Rami Okasha: That is an important point. The evidence that we have collected from our joint inspections of health and social care partnerships over the years suggests that the investment in telehealth and telecare has had positive impacts, particularly for people who are managing risk in frail older people and supporting such people to live independently at home. The approach has brought peace of mind to frail older people and their carers and loved ones, which is important.

However, the pace of change has not been consistent throughout Scotland. There are partnerships where the pace has accelerated very rapidly, which might in part relate to the point that Mr Cole-Hamilton made a moment ago.

It is worth saying that the pace of change in the digital world is reflected in the new health and social care standards, which were published in June. The standards set the expectation that people will benefit from technology that might be able to support them to live independently. I appreciate that the publication of a set of standards does not ensure that everyone will experience care that is consistent with those standards. However, it is an important policy driver for partnerships as they think about how to put in place measures to support people to live independently at home, when they can and want to do so.

Alex Cole-Hamilton: I am struck by the answers to my question. I spent a fascinating afternoon with Dr Chung and his colleagues at the Royal College of Emergency Medicine. They opened my eyes to the fact that problems with accident and emergency targets are the result not of inadequacy in our emergency departments but of interruptions in flow throughout the health service. The problem is caused by the lack of adequate social care provision in our communities, which means that people stay in hospital for longer, so it is impossible for A and E doctors to admit patients to the wider hospital, because no beds are available.

I think that we all agree that social care is the weak link in the chain, so I was astonished to hear Stephen Whiston talk about funding coming to an end in relation to roll-out of telecare. I was also astonished to hear Chaloner Chute talk about cultural resistance to trusting patients and technology. How do we get past those things? Does Parliament need to take on the matter? Do we need to mandate health boards more? Does it need legislation?

Chaloner Chute: There are very tangible things that we can do, if we learn from what other countries do in this space—I am sorry to keep rabbiting on about that. The first solution is a technical one, so I will not get into the depths of the issue. Other countries have adopted the principle of creating data once; they say, "You can have your own data base, your own system and your own software package"—so there can be huge diversity—"as long as you share it in a central bridge." There is one bridge, and everyone has to connect to that bridge. That is a technical solution that is entirely feasible now—

Alex Cole-Hamilton: That is the spine that you were describing earlier.

Chaloner Chute: Yes. In Estonia it is called X-Road, and DigitalHealth.London has done it across all the trusts in London; there is one bridge, to which everyone connects. That includes patients—the patient can connect to the bridge, see who is looking at their data and withdraw consent if they feel that someone is misusing their data or using it in a way that is not in line with their wishes. That is the patient empowerment, citizen rights and data protection win.

The bridge is a very technical piece of the picture. It requires leadership, so that someone says, "Here is the IT plan, and it says that there will be this bridge." Everyone has to connect to the bridge, but they can have their own stuff. We will not try to control every single thing that they do, as long as they connect to the bridge, because that is where the standards are set. The technical requirement is to get all the different things speaking to one another in one bridge.

In Estonia, the bridge is for not just health and care: it is also for banking, the post office and benefits. As soon as they did it in health and care, everyone wanted it, because all of a sudden people did not have to fill in forms every single time they wanted to do something. All of a sudden, organisations did not have to agree one with the other about data sharing, and have two years of information-governance wrangling just to share data between the two, because everyone connected to one thing. That is the solution that some countries are rolling out.

Alex Cole-Hamilton: You mentioned DigitalHealth.London. How much does a spine such as that cost?

Chaloner Chute: In Estonia, the cost was £3 million.

Alex Cole-Hamilton: Is that all?

Chaloner Chute: It is not about the tech.

Alex Cole-Hamilton: I can hear colleagues laughing, but I am looking at other IT systems that this Government has employed to failure, and they cost significantly more than that.

Chaloner Chute: Interoperability is not just a technical issue; it is a political, organisational, semantic and technical issue, and that last—the technical bit—is actually the easiest bit. It is about agreeing the common definitions that everyone will work to, so that, for example, when we say "blood pressure", everyone understands what we mean

by that and, when we say "paramedic", everyone understands that. If all those things are agreed, the technical bit is the easy bit. Political drive in those other countries has done that, and technical solutions follow quickly once the other bits have been agreed.

The Convener: If that is the case, why do so many IT projects fail?

Chaloner Chute: I could rant for a long time about that, but I am not sure that you will want to hear it.

The Convener: Maybe I should not ask for an answer to that. If it is all so easy, why does it end up in such a complete bloody mess?

Professor McKinstry: We are talking about systems starting from scratch, as opposed to having lots of legacy systems.

Chaloner Chute: Well, the Estonian system started from scratch, but the Finnish system had the legacy systems that we have and it has been done there. The same is being done in the Galician system, and in Holland.

Maree Todd: I would like Professor McKinstry to clarify something. I do not know whether I was the only person at the table who was shocked to hear that GPs might not use email at all. I presume that you mean that GPs do not use email to communicate directly with patients.

Professor McKinstry: They do not use email routinely to communicate with patients, but they can all use email, believe it or not. The major issue is the concern about being overwhelmed with email. The only cost to seeing a doctor is the difficulty in making an appointment. If you lower the cost, you will increase their workload. That is simple economics. It is as simple as that.

Tom Arthur: There has been much discussion about the relatively better performance in e-health of many of our European partners. I was intrigued to learn that the European Commission has been consulting on how we can promote and further integrate e-health around Europe and, in particular, that there is potential for cross-border interesting, communication. That is verv particularly in relation to the European health insurance card. However, we are in a very uncertain situation with Brexit, so I am keen to hear comments on the opportunities for further integration that could be missed as а consequence of Brexit and, more generally, on the potential risks that Brexit poses to the further development of e-health in Scotland. Who would like to go first?

Professor McKinstry: One example on the research side is the call for the "scale-up blood pressure" project by 2022, which is absolutely up

our street. We could really do it, because Scotland already leads Europe in that.

The big concern that a lot of people have now is that, despite the fact that we are allowed to apply for such things, European partners are wary about taking on UK partners because they think that that might reduce their chances of being funded.

Tom Arthur: Have you experienced that already?

Professor McKinstry: We do not know, but we would like to think that that is why we are not getting funded, rather than because our applications are not very good.

Maureen Falconer: I want to clarify that Brexit will not make any difference in terms of data protection, in case anyone thinks that it will go out of the window once we leave the EU. The General Data Protection Regulation will be transposed into UK legislation. For as long as we continue to trade with Europe, if trade involves sharing of personal information, we will have to have a data-sharing regime that is on a par with the one in Europe. Data protection will continue, if anybody thought that it was going away.

11:00

Chaloner Chute: There is also a potential problem in terms of trade. With the new datasharing norms that are starting to pop up around Europe, our companies will not be able to take advantage of those markets if we do not do similar things. Estonia gets a lot of press because it has created a cottage industry: it gives away its X-Road system for free. It is open source; you can literally go on to a website, download everything that you need and build your own system without paying anything. It has done that because hundreds of small and medium-sized enterprises in Estonia then offer services, saying that they know exactly how to optimise clinical systems on the back of those sorts of bridges, for example. That is Estonia's tactic.

In the post-Brexit situation, if we let ourselves diverge technically from the rest of the market, the stuff that we are selling will not be that interesting to it. That is a risk.

Tom Arthur: I would like clarification. If the European Union of 27 moves to having greater interoperability between various systems, will it be the case that, for EU nationals of one country travelling in another who require medical treatment, that treatment could be provided with greater efficacy than would treatment for people from countries outwith that integrated system?

Aileen Bryson: The only example that I have is a story of an American lady who did not have her medication and asked a pharmacist whether they could help. The names of medicines and the doses are all completely different here, but she asked whether the pharmacist had access to the internet. Not all our pharmacies have internet access, but this one did. Using the woman's password, the pharmacist accessed her medical information, including her hospital records and consultants' notes. The pharmacist could get absolutely everything that was necessary to know what medication she was on and to provide continuity of care. It sounds simplistic when you say it like that, but that is not the case in the European Union.

We did not address the European consultation because we have so many issues with trying to get interoperability between our systems at home, as has been commented on. It was too big a question for us as an organisation. However, obviously, it can be done.

The Convener: I would have thought that something as simple as access to the internet would be a condition of the licence that is given to operate a pharmacy. How does a pharmacist keep up with the latest information on pharmacy issues without access to the internet?

Aileen Bryson: They would do that outside working hours. During a normal working day in a community pharmacy, when the pharmacist is run off their feet, they will not have the necessary downtime to keep up to date.

The Convener: Is there an expectation that pharmacists will do that in their spare time?

Aileen Bryson: Of course.

The Convener: I find that outrageous.

Clare Haughey: All health professionals do that.

Aileen Bryson: Like all the other professions, we have continuing professional development that has to be done.

The Convener: Personally, I find that unacceptable.

Aileen Bryson: Not having access to the internet will obviously hamper certain IT enablers. Some premises have access and some do not, because of a corporate decision not to let staff have access to the internet. Similarly to the email situation for doctors, that is a stumbling block for certain things, depending on what IT solutions are being considered.

The Convener: If somebody presents with a condition, the pharmacist cannot look that up and find out the latest information.

Aileen Bryson: They cannot do that using the internet in some places. However, they should have that information anyway, so it will not be a

day-to-day issue in practice. However, some systems work through the internet to allow access to health board information or various other sites, but that cannot be accessed on a day-to-day basis.

Ivan McKee: People might not be able to answer this question, so you might want to take it away and come back with data or point us in the direction of some. We have talked about a number of examples where the lack of joined-up IT systems causes difficulties with service levels for patients, but there are clearly cost impacts as well. We have heard that 1.2 million blood pressure readings could be done at home and uploaded, which would greatly reduce the amount of resource that is required in practice. Does anybody have any examples of-or are you aware of any research on-potential cost or efficiency savings that could be had from joining up IT in a better way? That might mean savings today or it might mean that we do not need as much resource in future as we otherwise would.

Professor McKinstry: A good example of the use of technology can be found in diabetes. Scotland has a marvellous system called SCI-Diabetes; all information is uploaded centrally twice a day from general practitioners and podiatrists all over the country, and keeping that single record has had a dramatic effect in some areas. For example, diabetic foot amputations have dropped dramatically over the past few years, and it is considered that that is due, at least in part, to having this very joined-up system.

Ivan McKee: I suppose that we are looking for some numbers. For example, how much money is that saving us?

Professor McKinstry: I could not tell you.

Chaloner Chute: I can give you a number from another European country—again, Estonia. According to its economic analysis, having that bridge and avoiding duplication of data sharing and input is saving, in a country of 1.2 million people, 800 years of effort every year.

Professor McKinstry: We spend 100 years just booting up the computers in general practice. [*Laughter*.]

Chaloner Chute: I am not sure what that translates to in pound signs, but huge administrative savings can be made in the huge staffing budgets that are associated with simply repeating the same processes over and over again.

Stephen Whiston: That is the material point: productivity gains can be made and the burden of work reduced for our staff. David Chung talked about how long he and his team have to wait in order to find information or even to make a decision, simply because all the information is not in front of the clinician. I know from our staff that they are repeating assessments and other things, and it is just a waste of their time.

It is also a source of much frustration to the patient or client at the other end of the process. They say, "But you've asked me this question already", only to be told, "It wasn't me, and I have to check, because it is not on my system." We would free up so much time resource for our staff. I am not surprised by the 800-years figure that Chaloner Chute mentioned; I think that it would be that kind of factor. Moreover, we should remember that demand is increasing, so the question is how we work more efficiently to cope with that. At the moment, we are burdening our staff with systems that do not ease the situation.

Ivan McKee: I get all of that, and we all agree on it. I suppose that I am just trying to dig down and find whether anyone has any actual numbers for any of this. After all, that is what we need at the end of the day.

Aileen Bryson: I do not have any numbers as such, but I know of a small study in England in which 140 community pharmacists got access to records, and about 92 per cent of them said that they had used them to stop signposting patients elsewhere. In 56 per cent of cases that would have been signposted, it would have been to a GP appointment, so all those GP appointments were immediately saved. That is what I was getting at with regard to productivity. Only 1 per cent of cases would have been signposted to A and E, while 22 per cent would have been signposted to out-of-hours services. The issue, therefore, is the impact on out-of-hours services and GPs and the duplication down the line that we have all been talking about.

Chaloner Chute: Nesta carried out a literature review of different studies on giving citizens the ability to contribute more actively to management of care, and it found an average 7 per cent saving for out-patient, primary care and intermediate care solutions, simply through giving citizens a more active role.

The Convener: Brian Whittle's question will have to be the final one, because we really are pressed for time.

Brian Whittle: Good morning. What you seem to be describing is a situation in which disparate IT systems are under quite a bit of stress, and it seems to happen when we try to upgrade outdated systems by bolting on software and degrading the effectiveness of systems that are not designed for current health requirements. Just to finish up, do you think that we should continue along that line, or should we just start again and establish a build protocol based on sustainability and scaleability?

The Convener: If no one wishes to respond to that question and given that we are nearly finished, I suggest that we go round our guests at the table and give them 30 seconds or a minute to have their final say. Perhaps you can respond to Brian Whittle's question and then highlight some of your wider asks with regard to what you think should be the main things that we should examine in our report on this topic.

Maureen Falconer: The issue for me is the apparent obstruction that data protection seems to cause. Brian Whittle has just talked about disparate IT systems and bolting things on, but the Government policy that comes down tends to be a bit disparate, too.

When we are called in to assist from a data protection perspective, it is often the case that the right hand does not know what the left hand is doing on the policy. I am thinking of health in particular. One of my biggest concerns has been about the fact that, on one side, we have an information-sharing project and, on the other, we have an integration initiative. The public do not get it, because they are not being engaged as a whole. All that the public see are the various disparate bits of work that are being done and then, all of a sudden, they feel that their information is out there.

We took a call from a member of the public about the Scottish primary care information resource—SPIRE—project, which involves the extraction of data from GP records. We sat on the steering group for that project, for which an excellent privacy impact assessment was done. That fell down, because the member of the public in question missed all the public information campaigns, went along to his GP practice, looked at a poster, contacted the telephone number on it and did not get the answers that he should have got by ringing that number. Fortunately, because I had been involved in the project, I was able to tell him to go to the website, to look at how the project works and to look at the privacy impact assessment. In that way, I managed to talk him down off the ceiling, as it were.

Sadly, although everyone in this room can see the benefit of an integrated approach, the public often cannot—all that they see is Big Brother. Therefore, in my view, any such initiative must be accompanied by public engagement.

The Convener: People need to be a bit briefer than that.

Maureen Falconer: Sorry.

Chaloner Chute: I agree with that. My summary of the principle that should be followed is that data

should be created once and reused many times. That bridge concept seems to be critical in the countries that are making progress. I think that the GDPR represents an opportunity rather than a barrier. If we want to centre care on the citizen, we should not balk at the idea that the citizen should have some sort of consent-based authority in the system. That is an enabler, because it means that someone can take their record to the pharmacy and it can be shared in that way, instead of there being disparate back-office systems that connect with one another but exclude the patient.

Aileen Bryson: Absolutely. I think that some of the DHI's solutions are great. The bridge sounds really good.

However, I think that we need to look at consent in more detail, because we do not have an overall system for that. I understand the concerns that are mentioned in the Information Commissioner's Office's submission. Patients expect their information to be confidential and the governance around that is extremely important, but patients expect healthcare professionals to have the information that they need to treat them. We have implicit consent and, in some places, we have explicit consent, but there are gaps all over the NHS that prevent the system from running smoothly. Patients need to own a lot more of that. To go back to what was said earlier, it is extremely important that, when we design the new systems, not just the IT specialists but the patients, the public and the practitioners are all involved in the process.

Dr Chung: My view is pretty much the same. We should enable a framework that is partly legislative and partly technical so that data can be shared through consent. The patient should be able to sign up to receive social care or healthcare and, as part of that bargain, it should be explained to them that their information will be shared. Their agreement for that should be sought in advance, because asking people for their consent for things when they are unwell is absolutely not the time to do it. It is proven that, legally, they cannot give consent then; it needs to be given beforehand.

Stephen Whiston: I echo what Aileen Bryson and David Chung said—for me, those are the key elements. In addition, we have to step up to the mark when it comes to the training and cultural requirements so that we can support our professional clinical colleagues at the front line. At the moment, they struggle to understand what the transformation agenda can bring. If we are to embed that agenda and drive it forward, we need to bring that aspect to the fore.

Rami Okasha: We have talked a lot about information sharing and the systems that are used by professionals to share information. Those systems are important, but they are only one part

of the technology in digital health and care. It is important not to forget the many emerging and sometimes quite simple technologies that can support people directly to live in their own homes or to live in residential care homes. The evidence that we have obtained on that suggests that there are some small and simple interventions that allow people to live well, to live independently and to live with a sense of wellbeing and fulfilment. Technology can play a big role in that. Therefore, although information sharing is important, it is not the only part of what we need to do.

11:15

Dr Spiller: I agree. Digital healthcare literacy will be crucial as we move forward, not just for patients and carers, but for staff and social carers.

I make a plea for a once-for-Scotland approach to the communication of information on emergency and anticipatory care planning, because we have a significant opportunity in that area. I am engaged in a UK-wide project that is looking at that. The Scottish Government is engaging with that workin fact, it has resourced some of the work on setting standards and developing a clinical archetype that would work with a spine in the way that has been discussed. That would be a UKwide approach to accessing the kind of information that makes a difference to the patient at 3 in the morning when they do not want to be admitted to hospital, or when they want to be admitted to hospital and know exactly what kind of care they want but are unable, in that crisis, to say what they want. That is a huge opportunity, and it is one that we need to resource and engage with.

Professor McKinstry: We should rationalise IT governance, boost bandwidth, improve GP systems and promote telehealth.

The Convener: Thank you very much. It has been a very interesting session, and I thank everyone for coming.

I invite Maureen Falconer and Stephen Whiston to go for a cup of coffee and try to resolve the issue that emerged and to report back to us on how they get on in doing so. I say that in all seriousness.

I suspend the meeting briefly before we move to the next item.

11:16

Meeting suspended.

11:23

On resuming—

Subordinate Legislation

Functions of Health Boards (Scotland) Amendment Order 2017 (SSI 2017/304)

The Convener: Item 2 is consideration of a negative Scottish statutory instrument. The committee will take evidence from the Minister for Public Health and Sport on the Functions of Health Boards (Scotland) Amendment Order 2017. Jeremy Balfour MSP has lodged a motion to annul the order that we will formally consider later.

I welcome to the committee Aileen Campbell, the Minister for Public Health and Sport, and from the Scottish Government, Mary Stewart, team leader in the health protection division, and Lindsay Anderson, solicitor. I invite the minister to make a short opening statement.

The Minister for Public Health and Sport (Aileen Campbell): Thank you for the opportunity to discuss with the committee Mr Balfour's motion to annul the Functions of Health Boards (Scotland) Amendment Order 2017. As you have pointed out, I am joined by Mary Stewart, who is team leader in the health protection division, and Lindsay Anderson, who is a solicitor from the legal directorate.

The order is required to empower national health service boards to provide free abortion services in Scotland to women who normally live in Northern Ireland. In developing the order, we have consulted a wide range of stakeholders, including third sector organisations and NHS experts. In Northern Ireland, abortion is permitted in only very limited circumstances, and therefore hundreds of women travel to Scotland and England each year to access services. That creates an inequality, but it is significantly addressed if those women do not have to pay for treatment. It is important that, alongside similar provision that is being made by the UK Government, Scotland enables the women who travel here from Northern Ireland to receive clinically safe NHS treatment without being charged.

I recognise that abortion can be an emotive subject and that there is a range of views on it in Scotland, including in this committee room. However, similarly to the UK Government, we believe that abortion should be available as part of a standard healthcare service for all women. Women in Northern Ireland who need abortion services face considerable challenges in accessing them, so it is right that Scotland plays its part in providing clinically safe and legal care for women who have made the decision to access those services.

In light of those remarks, I hope that Mr Balfour will consider withdrawing his motion.

The Convener: Thank you, minister. I welcome Jeremy Balfour to the committee and I invite him to ask any questions that he might have.

Jeremy Balfour (Lothian) (Con): Thank you for having me here, convener. I agree with the minister's closing remark that abortion is an emotive subject on which people have different views. The questions that I have are not about the issue of abortion itself but about some of the issues behind it.

My first question for the minister is about the cost of what is proposed. We are all very aware, particularly given the committee's earlier discussion, that our NHS in Scotland has cost pressures and that there are already pressures on hospitals, doctors and so on. What will the cost to Scotland be of what is proposed. How much will it cost and how many people might come from Northern Ireland to Scotland to use the service, particularly if we offer it as a free service, compared to the number who go to England, as some people do at the moment?

Secondly, does the proposed provision set a precedent for treatment? For example, if we in Scotland find a cancer drug that might help three or four-year-old children but that drug is not funded in Northern Ireland, are we going to say that, because people in Northern Ireland do not have it, we can fund it? I wonder whether we are creating a precedent here with regard to other jurisdictions.

My final question is about parliamentary jurisdiction. Whatever our view on the subject of abortion, the Northern Ireland Assembly has taken a view on it. I wonder whether we are interfering in another jurisdiction and why the order relates just to Northern Ireland. There are other countries in Europe with a view on abortion that is similar to that of Northern Ireland. Why are we limiting provision simply to Northern Ireland? Why are we not seeking to expand it to central European countries as well?

Those are the questions that I have for the minister.

The Convener: Thank you. I invite the minister to respond.

Aileen Campbell: I am not sure whether Mr Balfour has had a chance to look at the business and regulatory impact assessment, but it sets out that the cost of the policy will depend on the number of women who choose to travel to Scotland and that we have estimated that that cost will be between £17,000 and £98,000. However, it is also important to recognise that the Scottish Government will receive consequentials because of the new spend that is required to fund the equivalent policy that the UK Government announced for England. Those consequentials will be used to fund the service in Scotland.

We are confident that Scottish abortion services will have the capacity to be able to treat women from Northern Ireland without that having a detrimental impact on the service to women in Scotland. However, that will require continual monitoring, which is what we will endeavour to do.

With regard to interfering with the devolved Northern Ireland Assembly, abortion remains a devolved matter for Northern Ireland. However, if a woman from Northern Ireland chooses to travel to Scotland for an abortion, we want to provide her with the same service and care that women in Scotland receive without being charged—that is the difference. Women from Northern Ireland should therefore be given the same care and support as women in Scotland.

The Republic of Ireland is a separate country in its own right. What we are proposing is about tackling inequalities in the UK context. The UK Government announced that it will seek to ensure that women from Northern Ireland going to England for an abortion receive the same care and support that women in England receive, and we want to do the same in Scotland for women who come here from Northern Ireland for an abortion. There is therefore a distinct difference between women from Northern Ireland and those from the Republic of Ireland who come to England and Wales or Scotland for an abortion. What we are doing is in line with what the UK Government is doing.

11:30

The Convener: Does Jeremy Balfour want to come back on any of that?

Jeremy Balfour: No.

The Convener: Do any members wish to ask any questions?

Miles Briggs: For clarity, minister, do you have an estimate of how much the Barnett consequentials are likely to be on this matter?

Aileen Campbell: I do not think that we have that information at present, but we continue to work with the UK Government on that. We have set out the anticipated costs in the Scottish context, and any funding that we get from the UK will be used to fund the service in Scotland. We will continue to work with colleagues in the UK Government on that, because we want to provide care and support to women travelling to Scotland from Northern Ireland to have this very difficult procedure.

The Convener: Does anyone else want to comment?

Members: No.

The Convener: Do you wish to make any final comments, minister?

Aileen Campbell: No.

The Convener: We move to formal consideration of motion S5M-08451, in the name of Jeremy Balfour MSP, which asks the Health and Sport Committee to recommend that the Functions Health Boards (Scotland) of Amendment Order 2017 (SSI 2017/304) be annulled. If Jeremy Balfour wishes to proceed with the motion, he will speak to it and move it. There will then be an opportunity for members to debate the motion and for the minister to respond. Following that debate, Mr Balfour will be asked whether he wishes to press or withdraw his motion. Under standing orders, the debate cannot last longer than 90 minutes. I do not think that it will last that long.

I ask Jeremy Balfour to speak to and move the motion.

Jeremy Balfour: In the light of the minister's answers to my questions, I withdraw the motion.

The Convener: Thank you.

As agreed, therefore, we now go into private session.

11:31

Meeting continued in private until 12:26.

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Published in Edinburgh by the Scottish Parliamentary Corporate Body, the Scottish Parliament, Edinburgh, EH99 1SP

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