OFFICIAL REPORT
AITHISG OIFIGEIL

Health, Social Care and Sport Committee

Tuesday 4 June 2024

Session 6

The Scottish Parliament
Pàrlamaid na h-Alba

Tuesday 4 June 2024

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HEALTH, SOCIAL CARE AND SPORT COMMITTEE
18th Meeting 2024, Session 6

CONVENER

*Clare Haughey (Rutherglen) (SNP)

DEPUTY CONVENER

*Paul Sweeney (Glasgow) (Lab)

COMMITTEE MEMBERS

*Sandesh Gulhane (Glasgow) (Con)
*Emma Harper (South Scotland) (SNP)
*Gillian Mackay (Central Scotland) (Green)
*Ruth Maguire (Cunninghame South) (SNP)
*Carol Mochan (South Scotland) (Lab)
David Torrance (Kirkcaldy) (SNP)
*Tess White (North East Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Kaylie Allen (Inspiring Scotland)
Katie Cuthbertson (NHS Scotland Centre for Sustainable Delivery)
Professor Farhat Din (Royal College of Surgeons of Edinburgh)
James Dornan (Glasgow Cathcart) (SNP) (Committee Substitute)
Peter Hastie (Macmillan Cancer Support)
Dr Jane Kellock (Social Work Scotland)
Pauline Lunn (In Control Scotland)
Donald Macleod (Self Directed Support Scotland)
Max Warner (Institute for Fiscal Studies)

CLERK TO THE COMMITTEE

Alex Bruce

LOCATION

The Sir Alexander Fleming Room (CR3)

Scottish Parliament

Health, Social Care and Sport Committee

Tuesday 4 June 2024

[The Convener opened the meeting at 09:15]

Decision on Taking Business in Private

The Convener (Clare Haughey): Good morning, and welcome to the 18th meeting in 2024 of the Health, Social Care and Sport Committee. We have received apologies from David Torrance. James Dornan and Carol Mochan join us remotely.

The first item on our agenda is to decide whether to take items 4, 5 and 6 in private. Are members agreed?

Members *indicated agreement.*

National Health Service Waiting Times

09:16

The Convener: The second item is an evidence session on NHS waiting times. I welcome to the committee Katie Cuthbertson, who is the national director of NHS Scotland's national centre for sustainable delivery; Professor Farhat Din, who is a council member of the Royal College of Surgeons of Edinburgh; and Peter Hastie, who is the policy and public affairs manger, Scotland, from Macmillan Cancer Support. Max Warner, who joins us remotely, is a research economist at the Institute for Fiscal Studies. We will move straight to questions.

Gillian Mackay (Central Scotland) (Green): Good morning, panel. Audit Scotland has highlighted that waiting time standards

> "do not provide a comprehensive picture of postpandemic service performance or recovery."

What additional measures or indicators could offer a more comprehensive assessment of healthcare performance and recovery post pandemic?

Katie Cuthbertson (NHS Scotland Centre for Sustainable Delivery): The centre for sustainable delivery's work is about redesigning services and looking at alternative ways of delivering services. That means understanding changes in the data and then understanding what might be helpful in respect of changes to the indicators. We need to understand the impact of that work before we can say what it might look like, but there are opportunities. We are focused on redesign and considering the alternatives.

Peter Hastie (Macmillan Cancer Support): The existing cancer waiting time target has not been hit for 12 years, and that is difficult for cancer patients; you can imagine the stress of waiting for diagnosis and then going through cancer treatment. Therefore, although I understand that it is always good to get more and broader data, the 62-day target being missed is quite a clear example of where the health service has been going wrong.

The last time that we hit the target was in 2012, and the situation has been getting worse every year since. In fact, at one point last year, only 69 per cent of cancer patients were seen within the waiting time target. Staging data shows that far too many Scots are diagnosed with cancer at stages 2, 3 and 4 and not at stage 1, and then people face a further delay for diagnostics and the beginning of treatment. Although the 62-day target is not perfect, it being missed is a strong indicator that something is going badly wrong in cancer services.

We have staging data and cancer incidence data, but it is important that we hold the Government to account on the cancer waiting time standard. In the programme for government, which was published last September, the then First Minister called for demonstrable improvement in cancer waiting times. I would welcome the committee seeking to understand what that means. We would like to know more about that. That target was meant to be hit by April 2024, but it has not been met. What does "demonstrable improvement" mean for cancer waiting times?

Professor Farhat Din (Royal College of Surgeons of Edinburgh): I will follow that up. As a cancer surgeon, when patients in my clinic ask me when their operation will be or when they will have their staging scan to judge whether they have secondaries, that is a very difficult conversation to have, because I might have to tell them that, for example, based on the data from last week, the diagnostics waiting times for CT scans have increased by 20 per cent and the waiting time for MRI scans has gone up by 7 per cent. Each of those people is part of a family, and there is anxiety for them. There is also anxiety for clinicians, because we are trying to deliver care, but we cannot deliver the high standard of care that we have been trained to deliver.

Gillian Mackay: How do we balance the need for accountability and the need to capture high-quality data, and how can we have flexibility to adapt and improve indicators and targets? I take on board that many of the targets are not being hit at the moment. How can we use the data so that things are more realistic for people?

Professor Din: The issue with targets and indicators is that it is key to have the right target and to understand exactly what it is measuring. As Peter Hastie said, we can get an indication of the direction of travel from the targets. None of the targets are perfect, but they tell us when a system is failing, and we need to look closer at the system to try to determine—along the entire patient journey—where those failures are. Although imperfect, they tell us to look closer.

The issue with meeting some targets is that doing so will detract from other patients, such as non-cancer patients and patients who are on waiting lists for operations that seriously affect their quality of life—knee replacements and pelvic floor surgery for incontinence, for example. We must be able to look at the entire picture and get an indication from a target, rather than making the target front and centre ahead of everything that is peripheral to it.

Gillian Mackay: Is there any data that we should be capturing to inform the targets and indicators that we are not capturing now? If there is, what data should the Government capture?

Katie Cuthbertson: Part of our day-to-day job in the centre for sustainable delivery involves working across all health boards in Scotland. We need to understand local data collection as well, because certain data points are reported through national data sets, and then as systems change, processes change locally and pathways change, we need to update the data recording so that we understand and are able to demonstrate what is happening in different services.

As we modernise ways of delivering services, we need to modernise the data sets in order to understand the pathways and the impact that they have on patients. That work with health boards is on-going. It aims to support the discussion on standardisation across Scotland in order to reduce variation in the data collection.

Sandesh Gulhane (Glasgow) (Con): I declare an interest as a practising NHS general practitioner.

More than 840 Scots are on waiting lists currently, one in three cancer patients is not being seen within 62 days and out-patient waits of more than one year have gone up by 11,000. If we look at our workforce, there are more than 4,000 nursing vacancies in NHS Scotland, and whole-time equivalent GP numbers have decreased by 42. Katie Cuthbertson, why are we not seeing significant improvements?

Katie Cuthbertson: The work of CFSD is focused on improvement opportunity and on working with health boards to understand the particular challenges across the pathway. The CFSD is commissioned to work on the earlier cancer diagnosis element of cancer work.

As an NHS unit, we work across Scotland with all services, identifying where particular challenges are. Diagnostics—whether diagnostic imaging or scope-based diagnostics—which have been mentioned already, is one particular area. It is about using the framework for effective cancer management and considering all the identified opportunities. Critically, it is also about learning from what is working well in one service in one health board and sharing best practice to avoid reinventing the wheel or duplicating effort each time a board looks to redesign and implement changes.

Sandesh Gulhane: That is what you are trying to do, but I asked why we are not seeing improvements. That work has been going on and it sounds great, but what is the product? What is the big benefit that we have had?

Katie Cuthbertson: We are seeing improvements in services that are implementing those redesigned ways of working. Our job is to translate them across Scotland; to share that best practice as a national team, which helps boards to implement that practice quicker; and to make visible data on where changes are impacting positively on patient journeys, in order to share that learning quickly across our networks. We work weekly and monthly with clinical leads across all services, looking to transfer that learning.

It is absolutely about transferring opportunities into benefit for patients, and we in CFSD will continue to focus on that work across all the different portfolios.

The Convener: Max Warner wants to come in on that question.

Max Warner (Institute for Fiscal Studies): There is also a broader context here, which is that the NHS as a whole is struggling to recover treatment volumes. It is not just about cancer services; it points to quite a large productivity challenge in which there is additional funding and staffing relative to pre-pandemic levels but no corresponding increase in output. Indeed, most treatment volumes for other parts of the NHS are below those levels. That broader productivity challenge plays a role in the challenges with cancer and elective waiting times.

Ruth Maguire (Cunninghame South) (SNP): Good morning, panel. Thanks for being with us. I would like to ask about unmet need post-Covid-19. To what extent is there unmet need and hidden patients?

Professor Din: Nobody was prepared for the pandemic. When I think about cancer services in particular, although the bulk of cancer surgery, when it did in fact take place, was successfully carried out despite fairly adverse conditions to the health of patients and, indeed, the health of staff—which I think we should be proud of—we know that patients did not come forward and present to their GPs. I have seen several patients who, when phoning up their surgery, got the Covid message, did not wait to make an appointment and presented six to eight months later. We are probably only starting to see the tip of the iceberg with regard to patients who did not come forward. That was coupled with a pause in screening and in pretty much all diagnostics, so we have been left with a huge backlog and we do not really know what the magnitude of the unmet need is.

Ruth Maguire: Thank you for that answer, Professor Din. Do you have any notion of which groups of people were more likely to not come forward? We can probably intuitively guess which ones those will be. Are we talking about older people? Is there a greater impact on access to that first line of care for folk from areas of greater deprivation?

Professor Din: It is both those groups specifically. The older population, for instance, does not want to make a fuss about troubling anybody—whether that is doctors or primary care. Equally, in areas of lower socioeconomic wealth, the magnitude of impact is much greater. In fact, we will see—and we are seeing—a worse divide in health inequalities, which is secondary to Covid.

The reality is that, as the work that Cancer Research UK has carried out shows, patients know what the red-flag symptoms are—they can recognise 12 out of 15 of them—but they do not seek advice for them, which is interesting. In fact, a lot of work needs to be done on public awareness and allowing patients to access services.

I am afraid that it comes down to investment. We need more investment in services across the piece.

09:30

Ruth Maguire: I am sure that we will dig into that in a little while. Peter Hastie, do you have any reflections on those questions?

Peter Hastie: I will add to the point that you and Professor Din made about the point of need. Cancer patients vary in their needs. We think of cancer patients as a group, but, as you suggested, there is a group of cancer patients with far greater needs. Macmillan has been working in partnership with the Scottish Government to transform care after treatment across Scotland. By the end of this year, our partnership should reach every cancer patient in Scotland to address their wider holistic needs.

We want to add to that sense that some patients have far greater needs when they are diagnosed. Of course, all cancer patients need to be treated as quickly as possible, but for some patients we would like to see much earlier person-centred care intervention to try to stop repeat journeys to hospital or to accident and emergency departments. If we can put in place much more social care support for people with comorbidities, that can prevent difficult episodes from happening. Not all cancer patients need the same level of support, and we think that if we can, in partnership with the Scottish Government, bring in that early person-centred care intervention, it could save the NHS a huge amount of repeat visits and return journeys.

That is hard work, however, and it involves shifting the nature of the workforce. It is not additional work, but it is about shifting existing ways of working, and we appreciate that that is hard.

Ruth Maguire: Katie Cuthbertson, do you have any comments on the question of unmet need and potential hidden patients?

Katie Cuthbertson: I do not have any data on that specifically. The work that we do is very much about creating the demand to meet the capacity. We know that there is a demand-capacity imbalance, and all work is targeted at reducing that imbalance.

We are called the centre for sustainable delivery, so we are concerned with sustainable solutions. We know that there will be shorter-term initiatives to tackle the needs of some of the patients who are currently waiting the longest, but we are also working in tandem to implement more sustainable solutions, so that we do not see those waits creep back up thereafter.

Ruth Maguire: That is helpful.

The Convener: I think that Mr Warner wants to come in.

Ruth Maguire: Yes, I was just going to ask if he wanted to come in on that.

Max Warner: I want to provide some numbers, as we have looked at the issue a lot. If we look at the elective waiting list, which covers most pre-planned, non-urgent care, and compare what happened before the pandemic with what has happened to referrals over the past four years, about 1.5 million pathways have not occurred—that is, 1.5 million people have not even been referred. That is not 1.5 million people not being treated—it is people not even joining the list. That is a huge number.

What is most striking is that there has been no sign of those referral numbers bouncing up. Even now, for the elective waiting list, referrals are still about 10 per cent below pre-pandemic levels. I do not think that anyone here thinks that underlying need is still 10 per cent below what it was, especially given the missed referrals.

Cancer is a slightly different, and more positive, story, as we see referrals rising more or less in line with pre-pandemic trends. For the elective waiting list, however, more than a million people were just not referred at all in the first place during the pandemic.

Ruth Maguire: In your answer to Sandesh Gulhane, you touched on productivity. Will you give us a notion of what factors might have contributed to the fall in hospital productivity, as reported by the Institute for Fiscal Studies?

Max Warner: Absolutely. The first thing to say is that this is not a Scotland-specific problem. We see an almost identical fall in productivity in English hospitals so, as a first pass, that is not just a policy failure but a fundamental challenge that health systems are facing.

There is a range of potential explanations. Currently, one of the leading explanations is what we, as economists, would call the input mix. By that, I mean that, since the start of the pandemic, we have seen a big increase in the number of front-line staff. The NHS in Scotland now has more doctors and nurses, for example, than it had before the pandemic. However, we do not see a corresponding increase in the other things that matter too, such as capital spending and hospital beds, among other areas.

That is part of the challenge. Another part is that it is likely—to come back to the issue of higher or unmet need—that patients are just coming back sicker and needing more care. Even if you are treating fewer patients, therefore, you may well still be delivering more care. Ultimately, there is a range of potential explanations, and there is still very little evidence of what is driving the situation, but the issue is a major challenge.

Ruth Maguire: Do you have any reflections on what can be done to address that? You have spoken about reductions in capital spend. How would you respond to that?

Max Warner: Our view is that capital spending is important. You could make an argument that it has perhaps been underprioritised, given the pressures that health services across the United Kingdom have faced. That is one area that we would be focusing on. There is still not really conclusive evidence on that issue. It is a major issue, but we still do not have perfect answers.

Ruth Maguire: That is helpful.

I wonder whether other panel members have an opinion on the impact of the budget pressures that everyone is facing and about the pausing of capital spending—of spending on capacity, I guess.

Peter Hastie: I had a quick look at last quarter's cancer waiting times. When Shona Robison was health secretary, Macmillan campaigned successfully to get each health board to state why it had missed the cancer waiting times target, and that was helpful. In December 2023, the Ayrshire, Dumfries and Galloway, Forth Valley and Lanarkshire health boards all said that they had had scanner breakdowns or problems with their scanner equipment. That is a straightforward example.

I wonder whether the committee could ask the Scottish Parliament information centre to do some research on all the previous quarters' data. I can tell you what happened in the most recent quarter, but if SPICe could collate across the past four, eight or 12 quarters, you would get a fuller picture. For instance, in the most recent quarter, scanners have been mentioned four times by four different health boards, and my guess is that that would probably be repeated. Other health boards say different things, but if somebody could do the research to pull all that together, it might give you some of the answers better than I am able to do today.

Ruth Maguire: Professor, you spoke about the impact on other conditions. I guess that MRIs and CT scans are not just used for cancer treatment, and that element will have a knock-on effect across the board.

Professor Din: Yes, absolutely. That is not news to anybody in this room. The increase in the rate of referrals is and has been exponential, and that is still without all those missing referrals that have come through. You cannot expect delivery of an adequate standard of healthcare with fewer resources, fewer functioning resources, less infrastructure and a workforce that does not have all the key components—nursing staff, doctors and all the allied health professionals—that build the system and allow it to work.

The Convener: Before we move on, I will make a declaration and refer to my entry in the register of members' interests. I hold a bank nurse contract with NHS Greater Glasgow and Clyde.

I am a little bit confused. We seem to be getting pieces of evidence that run counter to each other. Mr Warner spoke about decreased productivity with increased staffing levels, but Professor Din is saying that there is a lack of resource. I am keen to find out whether the issue is one of productivity. If so, what is the centre for sustainable delivery doing in that regard? I cannot see anything in your submission on that. Is it about increased demand? What do we think is driving that?

Professor Din: I am coming at this simply as an end user—as a surgeon who works on patients with cancer and patients without cancer. We can see that we do not have enough staff to see patients in secondary care with the demand from referrals from primary care. That is a straightforward fact. We know that patients are waiting longer for their investigations and to access surgery. Importantly, that is not just for cancer surgery; it is for surgery that affects a lot of angles of quality of life. That is my view as an end user of our system.

The Convener: Is it about productivity or the efficiency with which services are run? I open up that question more widely.

Katie Cuthbertson: Our work in CFSD is very much about seeking to maximise the use of our resources, so it looks across the various component parts of the pathway. Workforce challenges can vary across different services, but we explore opportunities for using alternative service models.

We work closely with NHS Education Scotland and NHS Scotland Academy to examine accelerated models to upskill staff. For example, that could involve alternative workforce models for nurse endoscopy or working with boards from day to day to identify opportunities and support their implementation. Therefore working across a number of areas, including productivity, and maximising our resources are very much part of what we do in CFSD.

The Convener: Is there a specific workstream that explores productivity as opposed to service redesign, or is that a thread that runs through your work?

Katie Cuthbertson: We would see it all as part and parcel of everything that we do, not just in the cancer workstreams in CFSD but across all our workstreams. Exploring what more we can do is a thread that runs through every bit of our workstreams.

The Convener: Does it cover not only staffing but other resources?

Katie Cuthbertson: That depends on whether you mean resources such as CT and MRI scanners, or staffing resource, in which we explore how we can support staff through using alternative health technologies to help services to be more efficient. For example, as an alternative to upper gastrointestinal endoscopy for certain patient groups, we recently introduced sponge technology, which this year became a business-as-usual approach. Because that is a nurse-led service, more patients can be seen in one session than would be the case with traditional upper GI endoscopy. Therefore we are also exploring where we can introduce technology to help services to be more productive.

The Convener: When do you anticipate that you will start to see that being reflected in waiting times coming down, either for diagnostics or for patients waiting to be seen?

Katie Cuthbertson: As we roll out those models and embed those ways of working, we start to see improvements. We cannot yet say that we are seeing maximum benefit from some of those initiatives. When services have introduced and embedded them as business-as-usual approaches, we are seeing improvements in shortening patient pathways. As you will know, however, it is not just about one component part but about bringing together many such parts to give us the overall gains.

Tess White (North East Scotland) (Con): I want to come back to what Peter Hastie said about it being good to have the data from previous quarters. That is such a basic point. Why is the centre for sustainable delivery not providing that data? Why would you need to come to us and ask SPICe to do that research? To me, everything is about the data. Perhaps Katie Cuthbertson could answer Peter's question about why the data is not there.

Katie Cuthbertson: We are a commissioned body of the Scottish Government, so I do not represent the Government. The Scottish Government has certain data and we focus on improvement data and understanding what is changing as part of service redesign. However, I will be happy to have a further discussion or to provide further information after the meeting.

Tess White: So you do not have the performance data to look at sustainable development. I am just wondering how you can do sustainable development if you do not have basic data.

Katie Cuthbertson: Sorry; yes we do have that. I thought that you were referring to the particular issues in boards around—

Tess White: I was asking about Peter Hastie's question about looking back at the quarters when the kit broke down.

Katie Cuthbertson: I could not comment on that specifically today, but we do have access to the published performance data and we examine it regularly to help us to understand where the challenges are.

Tess White: Therefore we do not need SPICe to produce that data, because you say that you can produce it.

Katie Cuthbertson: We can look at doing that. I thought that you were making a point about particular capital.

Tess White: Thank you.

Emma Harper (South Scotland) (SNP): Good morning to you all. I am interested in the good work that is being done on establishing rapid cancer diagnostic services. They were launched in Dumfries and Galloway, Ayrshire and Arran, Lanarkshire and the Borders in 2021, since when the uptake for bowel cancer screening seems to have become the highest ever in Scotland.

On 30 April 2022, there was a 67 per cent uptake in people returning their bowel screening kits, which is the highest in the programme's history. Do we have enough data about breast screening, bowel screening and other screening uptake and how that leads to the requirement for intervention? I am looking at Katie Cuthbertson, because I got most of that information from the centre for sustainable delivery.

09:45

Katie Cuthbertson: Although the screening programme sits separately from the CFSD, we are working in partnership across all the different partners to understand clearly how the elements that we are focused on—earlier cancer diagnosis and pathways within boards—need to be adapted to accommodate that. I do not know if that is particularly the case with rapid cancer diagnostic services, but, as you say, a number of health boards have introduced those in the past 18 months, and there have been positive outcomes from it.

Research recently published by the University of Strathclyde shows that more than 96 per cent of patients were satisfied, and the rating of services was eight out of 10 or more. Similarly, in primary care, positive feedback on those services was received from clinicians.

For patients who do not have specific symptoms and may not fit neatly into one particular pathway, we are opening up the opportunity to refer them to that one-stop rapid service to make sure that patients are not waiting for that diagnosis longer than is absolutely necessary during a very anxious time.

Emma Harper: I must remind everybody that I am still a registered nurse, and I worked in the operating theatre and recovery room in NHS Dumfries and Galloway. I am looking at information that says that patients are sicker than they were pre-pandemic and that they have multiple comorbidities. How does making a patient ready for surgery affect waiting times and preparation? Is that a factor that we need to think about? I see Peter Hastie, Katie Cuthbertson and Professor Din nodding.

Professor Din: I come back to your previous comment about screening, particularly bowel screening. We know that cervical screening uptake has decreased. It is important to focus on that area to try to understand the drivers behind that decrease.

Thanks to the faecal immunochemical test, which is an easier test to do than its predecessor, the uptake of bowel screening has certainly improved, but I will comment on bowel screening and on the threshold set for bowel screening. For bowel screening, we screen patients at 80 micrograms of haemoglobin per gram of faeces, but in fact the test is positive at 10 micrograms. We know that screening capacity, or rather the threshold, is titrated against the endoscopy capacity to test positive results. If we want to detect cancer early, there is an obvious way to do that with the system that we have, by thinking about models that lower the threshold. I have led work on that in our region. We know that we will miss that around 35 to 40 per cent of patients will have had a positive test but they are not at the threshold for colonoscopy.

The knock-on effect of that is that patients are falsely reassured. Patients then come to clinic within that two-year period and say, "I did my bowel screening six months ago, so how come you are telling me that I now have a bowel cancer?" There is a lot of work to be done on thinking about how we address capacity issues with bowel screening. Uptake is good, but we could detect more cancers.

On your question about prehabilitation, an important piece of work is being done and rolled out. We know that if we can make patients fitter for surgery, their overall outcomes are better. When we have a cancer timeline with a patient who is potentially symptomatic from the cancer itself, it is a balance between what the gain is versus further symptoms due to the cancer, but it is certainly important to optimise patients for surgery and improve their fitness, and resource in that area is certainly welcomed.

Emma Harper: You said that cervical cancer screening uptake has reduced, but I am aware that there is self-sampling research going on now, and there is also research about urine testing for the human papillomavirus. Would that help? It is less invasive than traditional screening, so can we chivvy along that research so that we can also use either self-sampling or urine testing to screen people?

Professor Din: Yes. There are a few folk in the room who will have had a smear and will know that nobody looks forward to it. Any research that can lead to a different test is important.

That brings us on to the question of how we drive innovation. In my view, it is through increased investment in research endeavours in partnership with research organisations and universities to consider innovative solutions within a constrained model of finance.

Sandesh Gulhane: I refer to something that Professor Din was talking about: the qFIT, or quantitative faecal immunochemical test. One issue that I have in primary care is that I do not have access in all the different health boards to request tumour marker tests. Aside from tumour markers, one condition that probably has a worse outcome than cancer is heart failure, and I cannot request a proBNP everywhere. Surely it would be a good first step in detecting those things earlier if GPs were able to request such tests.

Professor Din: Absolutely. That is a good point. When it comes to the sensitivity of tests, in some of the discussions that we have had in secondary care about whether some of the tests that are available have low sensitivity, we have found that a positive test has the danger of generating a lot of referrals in itself. I cannot particularly comment on proBNP and its sensitivity, but the key thing that comes across is that everything needs to be done in partnership, not in silos.

As for primary care and secondary care, we rolled out our qFIT within secondary care for triage—which resulted in a decrease of about 60 per cent in new colonoscopy requests—in conjunction with our primary care colleagues and colleagues in gastroenterology, radiology and management. That shows us that, if we align everybody's priorities and what they want to achieve, we can get a new model of activity.

I would say that the conversation about proBNP is for you to have with secondary heart-care specialists to determine the best model that will help you with your patients in primary care.

Sandesh Gulhane: It is the standardisation that is the problem. I can request a proBNP in some places, while I cannot do so in other places. As a surgeon, how many sessions are you personally operating, on average?

Professor Din: Most surgeons will probably say not enough. Some work is being done to potentially think about other administrative roles that clinicians have—not just surgeons—and whether some of those administrative tasks can be removed so that they can undertake more clinical duties, whether it is surgery or seeing new patients and out-patients, or indeed performing endoscopy, in my line of work. It is about utilising the skill set to people's best ability.

Sandesh Gulhane: You are right. Lots of friends of mine who are orthopaedic surgeons say that they are over the moon if they have an all-day operating list. They do not get to operate as an orthopaedic surgeon or general surgeon. I used to be an orthopaedic trainee, and those guys train so that they can operate. If they are just getting a day a week of operating time, that is simply not good enough. It is not the fault of the surgeons. They are desperate to operate, but many of them are not getting to do so. If you are not getting into theatre to operate on patients, how on earth can we clear the backlog?

Professor Din: You have posed the question that I would pose to the committee. You are absolutely right about having a workforce with the right skill set but not utilising it to capacity.

The issue with access to theatres is not necessarily that there are not enough surgeons; it is more about the entire infrastructure and the entire team being able to deliver surgery safely. That will be the case across all the various strata and types of surgeons. We are in our happy place when we are operating. If you look at the model in this country versus those in others where surgeons operate three times per week, you will see that they are very different.

Emma Harper: You have answered a lot of questions about cancer treatment waiting times, and we have said a little about pre-operative screening. I would like to pick up on what Sandesh Gulhane said about the perioperative environment. I have worked there, so I know that you need lab and X-ray support, recovery rooms and pre-operative support. That is why elective surgeries are not done at 10 o'clock at night. The capacity of the perioperative environment depends on the wider team. I know orthopaedic surgeons who would be really happy to just do arthroscopies and hips and knees all day, but the wider team is required for those.

Where should there be improvements? What could be done to improve cancer treatment approaches? We have addressed the diagnostic part, but then there is intervention. We might need more CT scanners, but we also need people to read the scans and diagnose patients from them. The situation is complex, but can you suggest anything that could be done differently? I will come first to Katie Cuthbertson and then to Professor Din.

Katie Cuthbertson: I go back to the point about making the best use of our resources. On the perioperative pathway, we must consider how we can support surgeons when they are in theatre and have a full-day list, such as by ensuring that sessions are scheduled appropriately and getting as many patients operated on in one session as we can safely manage. Initiatives such as rolling out our theatre scheduling tool across Scotland to increase efficiency in theatre time allocation, and exploring opportunities for digital pre-op assessments will streamline that pathway for patients.

That links to the point about optimising patients prior to their going to theatre and then supporting optimised post-operative periods. CFSD's perioperative delivery group is conducting a number of workstreams, including one on workforce opportunities. For example, as you will know, theatre staffing can present challenges, in that various staff need to be present at any one time. We are exploring opportunities to upskill certain staff groups to support theatre teams to ensure that we can be as productive as possible in those theatre slots.

Professor Din: It is challenging to come into work wanting to operate but then to have to tell a patient that we cannot do their operation that day because of capacity issues. I would therefore very much welcome an examination of the entire pathway. For patients who have previously fasted, then come in for their operation and got into their gown, it is the worst thing possible to be told, "Actually, we are cancelling your operation." There is a metric by which we can measure efficiency and productivity through the number of cancellations across the boards.

10:00

Tess White: I declare that I am a fellow of the Chartered Institute of Personnel and Development. I am gobsmacked by what I have heard. The issue is crying out for a work study to be done, to look at efficiency. It makes you wonder why we are not all over this. A work study should have been done, and one needs to be done with urgency. As Professor Din said, the entire pathway needs to be examined, so I am delighted that, as a committee, we are addressing the matter and treating it as important.

I have two questions on the theme of the barriers to meeting cancer waiting times. In its "NHS in Scotland 2023" report, Audit Scotland said:

> "Meeting waiting times standards for cancer remains a priority, but performance against the 62-day standard is poor".

Peter Hastie, you said:

> "something is going badly wrong".

What do you think are the main barriers to putting the wheels back on the bus, or—given that this has been an issue for a while—to putting them on the bus? We have talked about the fact that the surgeons just want to get in there and do their surgery. What are the other main barriers to meeting the waiting time standards?

Peter Hastie: As I suggested earlier, the statistics are there—we get them every quarter. They are very varied, but I think that they can be split into two. The first barrier relates to equipment. Obviously, there are technological advances all the time, but we need to have the basic equipment, which needs to be funded. Secondly, it is clear that the workforce planning has not been done. I have been working in cancer for 15 years. I do not think that there is anybody out there, in any statistical analysis, or any politician who does not know that the baby boom generation that we had after the second world war is getting to an age at which most people have a chance of getting cancer.

I appreciate that cancer is changing. As we saw this week, lots of under-50s are starting to get cancer, but, by and large, we understand cancer to be mostly a disease of ageing. We have known about the ageing population for an incredibly long time and we have simply not put in the workforce planning to deal with that. I am talking about the workforce across the board. There is no simple solution. Each health board has a different workforce issue every quarter. Different health boards have different issues, so I cannot point to one type of workforce that is needed. The answers are simple, but there are issues across all types of workforce.

Tess White: I want to ask you about the equipment issue. Is the equipment not there or is it simply the case that it is not maintained, so it breaks?

Peter Hastie: The stats say that it is a mixture of both—equipment breaking down and a lack of capacity, which means that people are not able to use the equipment.

Tess White: Is the equipment old or is it breaking because it has not been maintained? Perhaps you do not have that data.

Peter Hastie: I do not know. It seems to me that it is a mixture of both.

Tess White: If the kit is not working, we need to ask why that is. That needs to be looked at.

With regard to workforce planning, each individual health board seems to do its own workforce planning, but we do not have a holistic Scotland-wide workforce plan. The danger of that is that we rob Peter to pay Paul. People might flock to where there are specialists in, say, cancer treatment, which creates an issue. Would you say that having a holistic workforce plan is a massive priority?

Peter Hastie: Absolutely. I think that the three cancer networks try to pull together across the boards, but the fact that all 14 health boards have different capacity and different challenges at different times clearly causes a major problem. We must face up to the fact that Scotland has a huge rural and island population, which makes things very difficult. People do not support the centralisation of services. Members all know that from their constituencies.

Tess White: So we need to have a workforce plan.

I would like to go to Professor Din, who was nodding. We talked about the fact that surgeons are in their happy place when they are doing surgery. What other barriers are there?

Professor Din: Without wanting to say the same things again, I think that it is a case of having the allied health professionals and infrastructure in place and having kit that is fit for purpose.

If we think about the capital investment that is required to keep hospitals running, we know that they have maintenance bills that are off the scale. All the little segments of time that are consumed with, for example, information technology, such as getting an old computer to start up, add up and that increases the lag within the system.

System-wide, I do not have a quick solution for that but, to my mind, it is really important that we have a workforce that we can recruit and retain in Scotland. Surgery is one thing: we know that, for at least 32 per cent of all solid cancers, surgery is the mainstay of treatment. Providing that we detect cancer early, that is the best way to afford a cure for those patients and, indeed, improve the economy by having a workforce that is in work.

It is not just about increasing the workforce in isolation. We also need the equipment for the workforce. For example, we need to have enough CT scanners to meet the demand that is created by referrals from primary care as well as from emergency presentations. We know that around 20 per cent of all cancers will be picked up through the emergency pathway. Any flicker of change in that percentage is a good barometer of how well we are doing.

However, emergency presentations of cancers have not decreased and there has been no real change. We know that screening will detect around only 7 per cent of all cancer, so there is a huge gap of symptomatic patients that fall in between. As secondary care clinicians, we need to work in partnership with primary care providers to address that gap and work out how to enrich the response to serious symptoms that can then be filtered into constrained diagnostics.

Tess White: So, overall, we need a Scotland-wide plan and we need to make sure that the kit is there and that it is properly maintained. I know that this may sound like a basic question, but in your view, what impact do longer waiting times have on outcomes for cancer patients?

Professor Din: I will start by talking about the impact on mental health, because I think that that is absolutely critical. Anyone who has cancer wants it to be treated or operated on the next day—that is in our nature as humans. The uncharted impact on mental health for patients, their families, the clinicians and other healthcare givers who work with those patients is huge. As patients wait longer, they will potentially be more deconditioned and frailer, which will increase the risk of any treatment, whether that is surgery or chemotherapy, and potentially there will be more complications.

The impact of increased waiting times is not to be underestimated on many different levels, including mental health and physical health. That results in an opportunity cost in other non-cancer areas that we would not be addressing.

Tess White: In your view, what further action is needed to target improved outcomes? If you were the Scottish Government and you could work on a plan for this year and next year, where would you focus the targets, effort and resources?

Professor Din: I am not the Scottish Government. From my perspective, we cannot treat our way out of cancer. As you mentioned, we know, because we have an ageing population, that in approximately 15 years, there will be an increase in cancer cases of around 30 per cent. CRUK has clear data with various projections and there is also data on that in Scotland's cancer plan.

Therefore, we have to think innovatively and, in order to do that, the investment has to go into research and evidence-driven initiatives to improve cancer outcomes. For every £1 invested in research, we get a £2.80 return, and, as we get an increase in the prevalence of cancer, you will get a return on that investment into cancer research for the health of the population.

For me, the focus would be on research investment, which is not just basic science but outcomes research. We cannot work out where things are going wrong if we do not have real-time outcomes research so that we can actually detect the performance of a pathway in real time.

The Convener: What role, if any, does the centre for sustainable delivery have in workforce planning?

Katie Cuthbertson: We do not have a role in workforce planning specifically. Through our structures—such as special delivery groups—we work with a number of specialties, looking at high-impact opportunities to make changes that will positively impact on patient waiting times. That involves working with clinical and operational management leads from all health boards who come together to discuss specialities, such as respiratory medicine and cardiology.

Workforce opportunities might be identified as part of that work. For example, if one health board is implementing an alternative workforce solution with regard to a theatre team and how roles are being upskilled in theatre settings, we would work with our partner organisations, such as NHS Education for Scotland.

The Convener: I do not mean to be rude but there is an awful lot of management speak in there.

Katie Cuthbertson: I am sorry.

The Convener: In essence, you do not have a role in workforce planning—

Katie Cuthbertson: No, not in management and planning, but we contribute to the overall work that that leads to. Our work is more about identifying the opportunities, what impact those might have and then being able to show data to represent that, but we would not do the overall planning piece.

The Convener: So you input data.

Katie Cuthbertson: We would be able to share data and share what boards are doing locally around redesign, how that is impacting positively and how that might contribute to a broader strategy in the future.

James Dornan (Glasgow Cathcart) (SNP): I have some questions about early cancer detection. Coincidentally, I had to take a call from a consultant just now, so some of my questions might have been covered while I was on the call. What factors contribute to longer waits for diagnostic tests and can you outline how those factors can be overcome?

Katie Cuthbertson: I am happy to start. Earlier, we talked a wee bit about diagnostics. As we know from the data on some of the waits, the delivery of diagnostics contribute to a reduced performance on the 62-day standard. The work on diagnostics is looking at how to maximise and make best use of some of the infrastructure but also at staffing models in support of the delivery of diagnostics. For example, in scope-based diagnostics, we look at how we can use alternative workforce models, such as nurse endoscopists, endoscopy assistant practitioners and so on, and offering more outpatient-based diagnostics as an alternative to scopes for certain patient cohorts, which will help to free up capacity for patients who need to undergo particular tests. Offering alternatives for other patients cohorts will speed up that journey.

James Dornan: What progress has been made to ensure that rapid cancer diagnosis is available across the country, and what more needs to be done?

Katie Cuthbertson: We have the Strathclyde report, which was published earlier this year. Earlier, we touched on some of the positive outcomes that were demonstrated in that report. The CFSD will continue to work with boards and to share that learning and the positive impact that that work is already having in some boards across other boards in order to support implementation across further services and open that up to more patients across Scotland.

James Dornan: You will also have discussed this earlier, but what impact has Covid had on the stage of cancer presentations. I heard a wee bit of an earlier response but my mind was elsewhere.

10:15

Peter Hastie: I think that we are still waiting to find out, Mr Dornan. There was the six-month delay in the screening programmes, so this year's cancer staging data might give us a better picture.

Unfortunately, Public Health Scotland, unusually, has not set out when the cancer staging data will come this year. We are still waiting for cancer mortality stats from last year, and there is no indicator of cancer incidence or mortality or staging data for this year. We really need Public Health Scotland to publish those figures, which would give a better indicator.

No doubt your question alludes to the fact that people will have been getting diagnosed later, which adds to the huge pressure on the cancer workforce. The later somebody is diagnosed, the more strenuous the efforts, the more intensive the surgery and the longer the chemotherapy and radiotherapy sessions, which all then add to cancer waiting times. In your area, Greater Glasgow and Clyde NHS board said last month that there was significant pressure on diagnostic procedures. There is a backlog that is building up, and my fear is that that will push people into later-stage diagnosis, with all its subsequent effects.

James Dornan: So before we can move forward, we need to find out what has been happening in the past, so we need to get those stats from Public Health Scotland.

Peter Hastie: Absolutely, yes.

James Dornan: Okay; thanks very much for that.

Paul Sweeney (Glasgow) (Lab): Thank you to the witnesses for their contributions so far. We are looking at the factors that contribute to longer waits for diagnostic tests, which certainly chimes with what we heard from oncologists, who said that it is agonising for them to watch patients go from diagnosis to a terminal situation.

What factors are contributing to that, what progress has been made to ensure that rapid cancer diagnosis is available across Scotland, and what more needs to be done?

Peter Hastie: I will start with the broader picture and go back to what Emma Harper said. We have seen really excellent bowel screening uptake—it is getting to 66 or 67 per cent, which is the best ever. However, that still means that a third of people are not sending back their kit, and I wonder whether we need more innovative ideas—I will leave that up to you—about how more pressure could be put on and how we get a better understanding and provide more support for people.

At the same time, Fife, for example, has exactly the same take-up as the rest of Scotland, but only 50 per cent of Fife men in the lowest 20 per cent of incomes are returning the kit. There is therefore also a massive socioeconomic divide in screening and until we really challenge that and get people in all income levels up to 67, 70 or 80 per cent uptake, we will always have horrendous economic factors. We need to look at the social justice element of cancer far more closely, because far more people from lower income groups get cancer, get diagnosed later and have worse outcomes.

Paul Sweeney: That certainly chimes with an experience that I had visiting a Marie Curie hospice in Glasgow, where I met a lady with throat cancer. She lived in Bridgeton, in the east end of Glasgow, and she expressed her devastation that, on presenting to her GP, she was fobbed off repeatedly. By the time she got a diagnosis, it was terminal, and she was only in her early 40s. That was quite harrowing. She died the day after my visit.

What practical steps can we take to address that? Is it an attitudinal or cultural issue? Is it a practical thing? Is there a means of better escalation for patients who feel that they are not being listened to? Is it purely about patient agency? What other aspects could we consider?

Professor Din: It is challenging because of the pressures. I am a secondary care clinician, but I know that the pressures on primary care are phenomenal with regard to the number of patients they see. For each patient who is seen and has a misdiagnosis, there is a huge number of patients who have been seen and have been treated effectively and efficiently. The question is, in the vast thousands of patients who are seen, how do we strive towards picking out patients who have the symptoms that need to be escalated?

I come back to the idea that we need more research into primary care and symptomology. If we had access to the data around patients in multiple areas of the whole natural experiment that is the NHS, and if a research culture were embedded into the NHS, we could ask questions at scale, such as what the likelihood is of somebody having a cancer if they come in with X or Y symptom. However, you need access to all that data.

I would push for something that we can do, which is to try to embed access to patient data and surplus patient tissues and blood, with the appropriate data governance to reassure patients. What Covid taught us is that patients want treatment and want you to use your knowledge to develop better treatments for them. That whole area is challenging for researchers to access in order to generate ideas and answers that can then lead to better early detection strategies.

Paul Sweeney: Is the issue then not just about the structure of GPs as individual contractors, if you like, and their obligations to undertake data gathering and so on, but also about the work that is currently being done to understand where late-stage referrals are happening and whether they correlate to areas of high deprivation, and to then investigate the cause of that late presentation—whether it was frustration with access or simply that the person had not presented until a late stage? Is there any data around that at the moment that will give us an insight?

Katie Cuthbertson: I could provide further information on that point, following today's meeting. As you will see in our briefing, the work that CFSD does is about targeting, as well as supporting, those areas of deprivation. Going back to your point, one of the pieces of work is about getting patients on that pathway as quickly as possible.

The refresh of the Scottish referral guidelines for urgent suspicion of cancer is on-going and the update will be published early next year. It is about using that up-to-date evidence to ensure that those guidelines are appropriate for use in primary care. There is also the launch of GatewayC, which is a support platform to help primary care clinicians identify those symptoms, support making the decision about the most appropriate pathway for that patient and get the patient on the right pathway the first time.

Professor Din: Absolutely. For instance, if we looked back at scale to the 20 per cent of patients that present as emergencies through A and E departments or emergency referrals across the health boards, to try to identify how many instances of contact those patients had had with primary care or with emergency services, or whether they had just not contacted anybody in primary care—as we often know that certain demographics do not—having that data would really go some way towards understanding what some of those barriers are.

Paul Sweeney: That is helpful.

I met some GPs in Glasgow, who indicated that even referrals to urgent suspicion of cancer have become a meaningless escalation, because of the scale of the demand. Would you agree with that? If even a referral that is marked as urgent is not necessarily being addressed with the urgency that one would expect, how do we address that issue?

Peter Hastie: It is deeply concerning. One of the positives and great advantages that we have seen so far with the rapid cancer diagnostic centres is that they have been able to rule out cancer for a lot of people—perhaps only about 12 per cent of patients turn out to have cancers—which is an enormous relief. It might mean that they have something else, which will then head off to a different part of the health service.

It is so important that people are either given peace of mind or are diagnosed quickly and sent to another part of the system. I understand why doctors get frustrated. They send someone for a test, it is not cancer, they come back, the doctor sends them somewhere else and it is not cancer. One of the ideas behind the rapid cancer diagnostic centres is that they will be a one-stop shop and that people will find out. The idea that urgent cancer referrals are not being regarded as urgent is deeply concerning.

As Professor Din said, most people are quite shocked when Macmillan tells them that 20 to 25 per cent of cancers are diagnosed at A and E. That is just horrific and the cost to the NHS is incredible. There is no system within which that is a proper cancer pathway and the financial cost of that is off the scale. I am really concerned that you are hearing that sort of feedback.

Paul Sweeney: Would the cancers that are being diagnosed at A and E ones typically be diagnosed through screening?

Peter Hastie: There is a lot of stage 4 lung cancer diagnosis, but it happens across cancers. Sadly, too often, A and E diagnoses come very late.

Paul Sweeney: Some of the organisations that run screening programmes for the NHS have said that invitations to present for screening can vary widely across different social and demographic areas. For example, there is a difference between getting a letter and getting a text message. Have you seen differences in how people react to different types of screening invitation?

Peter Hastie: The detect cancer early programme board would be able to provide that information. There has been some fantastic innovation. That brown letter coming through the door might look like yet another problem. Even members of Macmillan staff have told me they have difficulty getting to breast screening because they work long hours and have stuff to do. Screening is not easy and it is not much fun, so we need innovative ways to get people to do it.

One of the great tragedies of the screening delay during Covid—which is nobody's fault—was that invitations for bowel screening stopped arriving on people's birthdays. People used to get them at 50, 52, 54, 56 and 58, so they kind of knew it was happening. My invitations now come at 54 and half, 56 and a half, 58 and a half. I know that the invitation is coming, but it has got away from that pattern. We need people to talk about it and to encourage their friends and family, on their 50th birthday, to use their screening kit. We must make that a much more normal conversation because it is about our loved ones.

It is a hassle to go for screening. Going for breast or cervical screening is no one's idea of fun, and nor is doing the bowel screening kit, but we must encourage people. I have no doubt that new screening will come on board. We hear about innovative ideas all the time. There are lots of campaigns for lung screening. Screening could also be more targeted at people whose family members have a history of cancer. We could work in more specifically targeted ways to improve take-up.

Paul Sweeney: I have a question about the impact of Covid on late-stage diagnosis and the severity of presentation. Have you noticed an effect? I have certainly heard plenty of anecdotal evidence of that. What impact has it had and what can we do to control and counteract it?

Peter Hastie: There is no doubt that that is coming through anecdotally, but we are still waiting for the statistics. The Scottish Government, in partnership with Macmillan Cancer Support, has just launched the third Scottish cancer patient experience survey. That survey is in the field now and the results, which will be out in September, will be a huge aid to the committee's understanding of what happened to cancer patients during Covid, because the cohort is from that period. That might give some of the evidence that you are asking about. We are still waiting for Public Health Scotland to give a publication date for this year's cancer staging data. That will tell one of the biggest stories and go beyond the anecdotal.

Sandesh Gulhane: My question is for Katie Cuthbertson and is about IT. Your website shows that you are involved in that. How long have we been trying to get IT systems to talk to each other?

Katie Cuthbertson: That is not necessarily the work that we are leading on. Our work is on the opportunities to introduce alternative health technologies that may, absolutely, need to talk to other systems within health boards. The work that we focus on is identification of the high-impact opportunities.

Where are the technologies that are available now to purchase in the market? We are not focused on the research and development stage in our work, but what emerging technologies could we introduce into our services to improve waiting times? For example, we have a number that support various cancer pathways. The digital dermatology programme was recently approved for national roll-out. Obviously, that will also support skin cancer pathways. As I mentioned earlier, some alternative diagnostics were introduced, and with the sponge technology now embedded as business as usual, that is supporting scope pathways and reducing waits. Other technologies that are under evaluation at the moment will, I hope, support lung and breast cancer pathways.

10:30

Sandesh Gulhane: We will certainly come on to that.

The national workforce strategy refers to

> "collaborative working across RCGP, CfSD, Scottish Government, Health Board Interface Groups and other relevant stakeholders to identify new opportunities for redesign of ways of working that can be applied nationally to challenges across the interface. Potential examples for scoping may include referral guidelines, IT, Community Treatment and Care services and unscheduled care."

What have you done with that IT? Speaking as a national health service worker, it is appalling.

Katie Cuthbertson: The specific pieces of IT work that we are involved in are around the particular technologies that will help with productivity challenges. For example, digital dermatology will support making the process for GPs to attach images to dermatology referrals much more streamlined and easier.

Sandesh Gulhane: That is great, but if it takes me 15 minutes to get into my computer in the morning and I cannot access basic stuff from the hospital, and I am not able to access other data sets when I am working in the hospital, what is the point of all of that additional stuff when the basics are not being done?

Katie Cuthbertson: I cannot comment on that work specifically. I am not involved in that work as part of the CFSD.

Sandesh Gulhane: Okay. It seems rather disappointing that the strategy talks about

> "opportunities for redesign of ways of working"

when surely IT, including basic IT, is the most important way of redesigning for interface.

Katie Cuthbertson: We work with partners that are involved in that work, but we are involved in specifics around particular patient pathways and where we can support efficiency and productivity in those.

Sandesh Gulhane: Okay. I turn to lung screening. A number of years ago, I spoke to the then health secretary about the potential for purchasing mobile lung screening CT machines that could go to the north of our country and rural and island areas to provide lung screening at not a great cost. Where are we with that?

Katie Cuthbertson: Apologies, but that work is not being led by the CFSD. The screening work involves NHS National Services Scotland and the Scottish Government. We would stay connected to any on-going discussions. Obviously, depending on the outcome of the lung cancer screening discussions, we would stay aligned with that, but we do not have responsibility for that at the moment.

Sandesh Gulhane: You mentioned lung screening in your response to me.

Katie Cuthbertson: The technology that we are looking at as part of the work within the CFSD would support the lung pathway in the early identification of patients who have had a chest X-ray and may have suspicious symptoms and fast tracking them on to a CT scan for a potential diagnosis of lung cancer. That is the particular piece of work that we are involved in.

Sandesh Gulhane: Okay. On the NHS's engagement with technology—I am talking about all technology—what work are you doing to standardise the way in which companies can come in and say, "Let us get approval with either yourselves or with a health board" and not have to do that on a repeated and significantly different basis with all health boards?

Katie Cuthbertson: That work is being done through partners in NHS National Services Scotland and so on. We are connected when high-impact opportunities are identified that might support some of our most challenged areas with the introduction of the accelerated national innovation adoption pathway across Scotland, which looks at horizon scanning and understanding what opportunities might exist, and working through a pathway to a stage-gate process to essentially assess technologies and understand whether we should be looking at them in Scotland, and then going into more detail about the potential impact, cost effectiveness and so on.

Sandesh Gulhane: Therefore, you have done that piece of work and you have found that there is a cost-effective piece of technology that is going to work—such as artificial intelligence when it comes to reading our X-rays and computed tomography, as an example. How can somebody get that piece of technology across Scotland in a way that is easy to access that does not involve going to every health board and convincing them individually?

Katie Cuthbertson: The national team that works as part of CFSD, as part of the ANIA collaborative, is responsible for rolling out digital dermatology, for example. That team will work across all health boards, depending on the procurement process, to procure the particular software and then work on a one-Scotland basis so that there are not different pathways in different health boards. That is the nature of the ANIA work—the word "accelerated" is in the title—to get technologies into the hands of clinicians and benefiting patients much more quickly.

Sandesh Gulhane: Professor Din, what would be the most helpful technological input in your everyday work?

Professor Din: There are two things, and you have absolutely hit the nail on the head with regard to one of those, in that it is not just about new technology; it is about having fit-for-purpose technology in all the basic things that we try to do, whether that is the IT system through which we try to order investigations or whether we are just trying to use the computer. I completely share your frustrations that primary care data cannot be accessed by secondary care clinicians—and vice versa, to an extent. We cannot see the helpful notes that you have written when somebody has come to see you two or three times beforehand. There must be integration of those systems so that we can access data. Scotland has a rich history in innovation, particularly in data-driven innovation, which, over the past five to 10 years in particular, has come forward with DataLoch and other initiatives.

You need to be able to access data and I need to be able to access data so that we can answer fairly straightforward questions at scale. I will take one specific example of the fact that the focus on cancer sometimes perhaps detracts from other patients. In my line of work, we can think about hereditary conditions such as Lynch syndrome and familial adenomatous polyposis, which carry a very high risk of bowel cancer. We know that people with those syndromes have a much higher risk of cancer than the general population. We have a load of cancer targets for the general population but, because those particular patients do not have a cancer at this point, despite being at extremely high risk of cancer, they fall into a sort of surveillance that is often not fit for purpose. In fact, we are doing a disservice to those patients.

We have made some improvements in our health board to address that situation but, at a very simple level, we need to be able to set up a Scotland-wide registry so that we have the functionality for all the health boards to input their high-risk patients for colorectal cancer or other conditions, because we have identified them as high risk but we then slightly abandon them with no fit-for-purpose system to monitor them. We do not have the IT functionality for all those health boards to link in.

Therefore, if there was one piece of work that I would be very keen to take forward, it would certainly be that—how we can interdigitate primary and secondary care and then do that across Scotland for high-risk patients. That is an example from my field.

Sandesh Gulhane: It would be good if I could just see another GP's notes when a patient is transferred.

I will address my final question to Peter Hastie. Professor Din talked about straightforward questions, and the most straightforward questions that I am asked by my patients when they are on a waiting list are, "How long am I going to have to wait?" and "Where am I on that list?" Do you agree that patients should have access to that information? If so, how can we make that happen?

Peter Hastie: That is an interesting question, because cancer patients themselves are often not aware of the 62-day target. Why should they be? Policy makers know about it, but the patients often do not, although they know that they are waiting for diagnostics and for treatment to begin. We know when the decision has been made for treatment to begin—we are hitting the 31-day target and we should celebrate that.

The question comes back to person-centred care and the need to treat the patient as an individual as they follow their pathway. There was a period when the cancer waiting time targets started to be missed really badly, but Lanarkshire was still hitting them. That was because the health board had focused on person-centred care and on individuals. It had somebody tracking the individual, treating them as an individual, seeing that the end of their waiting time was coming up and booking that space. I appreciate that we are dealing with thousands of people and that what I am asking for is really hard, but if we can focus on person-centred care and give the individual cancer patient the support that they need, we will have far better outcomes. However, you are absolutely right: the cancer patient deserves to be in charge of their journey, and they are not at the moment. Instead, they are sitting waiting for far too long.

Emma Harper: I want to ask about technological innovation and the use of artificial intelligence, which could help to reduce bed days, for instance. Last week Dr Tom Mackay, Catherine Kelly and Dr Mary Melville from NHS Borders gave a presentation to the lung health cross-party group, which I co-convene, about keeping chronic obstructive pulmonary disease and asthma patients out of hospital. They showed us that, among that small amount of patients, the implementation of artificial intelligence technology saved 236 bed days and removed the need for patients in remote and rural areas to have to make 50-mile or 100-mile round trips to get to hospital. I should say that patients in the NHS Dumfries and Galloway area have to travel similar distances.

What are your thoughts about the implementation of technology such as AI for out-of-hospital assessments, and can you tell us what other exciting technology is out there? We know that there are research studies about using such technology to examine X-rays to diagnose lung cancer, for instance. I would be interested to hear about something positive as we look at helping our NHS to address waiting times and so on.

Peter Hastie: Last week, the Scottish Government announced a national theatre scheduling tool. That might not sound like the greatest thing in the world, but it is an example of the sort of innovations that are constantly being made.

You are absolutely correct in what you say. We are all used to using Zoom and Teams, but a lot of older people are not. However, there is a new generation of people coming through who would not think twice about having their follow-up appointment on Zoom, and that approach would remove the need for patients from Dumfries and Galloway to travel to Edinburgh or Glasgow, patients from Orkney and Shetland to travel to Aberdeen and patients from the Western Isles to travel to Glasgow.

There are many innovation possibilities, but it is hard to implement them because people are not used to doing things in the new way and are not used to change, and they might feel that they are missing out on something. However, sometimes I worry about a lack of face-to-face contact, and I do not think that using Zoom and Teams is the perfect solution for everybody.

There is no one particular breakthrough that I can point to immediately, but I honestly do not believe that there has ever been a time of more exciting innovation. As you say, AI can be used to scan data and can spot more cancers than the human eye would. There are amazing possibilities there but, behind it all, you need that workforce to be able to do the scanning and look at the results, and you need workforce planning behind it. If you can marry those two aspects—technological innovation and the workforce—there could be great outcomes. People are living with cancer longer than ever, but we are not detecting cancer quickly enough and, until we get that right, all the other things have to wait.

Emma Harper: I have a quick question for Max Warner, as I am conscious that he has not said a lot.

The Convener: We need to finish this session, so please be brief.

Emma Harper: We are running out of time—okay.

Max Warner, you have done modelling around investment in prevention to keep folk healthier. What modelling has been done to show that up-front investment will prevent cancer, reduce obesity and diagnose type 2 diabetes earlier, and have you done modelling that shows that preventing things now will save £X in terms of secondary care?

10:45

Max Warner: We have not looked at that ourselves, but a lot of modelling has been done on the benefits of prevention and catching things earlier. We discussed that earlier in relation to cancer. However, there is always a need to be cautious in relation to prevention. The motivation for prevention should be that, if you catch things earlier and enable people to avoid developing conditions, that will allow people to live better lives.

The financial motivations for prevention are not always positive, and we should not be driven by them. There is a risk in advocating for prevention only in terms of saving money, because, frankly, people living longer is expensive. However, people living longer is desirable, so we should be motivated to prevent conditions for that reason, not always for reasons of pure financial gain for the Government, because that gain will not always be there, and that is okay: a lot of Government spending is designed to improve quality of life, rather than just prevent future Government spending.

Emma Harper: Thank you. The convener is giving me the eye, so I think that I should make that my final question.

The Convener: I thank our panel members for joining us. We will suspend briefly to change witnesses.

10:46

Meeting suspended.

10:54

On resuming—

Social Care (Self-directed Support) (Scotland) Act 2013 (Post-legislative Scrutiny)

The Convener: Item 3 is an evidence session with organisations that are currently funded to deliver activities that are detailed in the Scottish Government's "Self-Directed Support Improvement Plan 2023-27", as part of phase 2 of our post-legislative scrutiny of the Social Care (Self-Directed Support) (Scotland) Act 2013.

I welcome to the committee Kaylie Allen, director of funds at Inspiring Scotland; Dr Jane Kellock, project lead and consultant, self-directed support team at Social Work Scotland; Pauline Lunn, director of In Control Scotland; and Donald Macleod, chief executive of Self Directed Support Scotland. We move straight to questions from Tess White.

Tess White: Thank you, convener. Hello, panel members. I have two questions. I will put the first question to Dr Jane Kellock and then Donald Macleod. Given the changes since the 2013 act was introduced, particularly the integration of health and social care and the proposed national care service, do you think that the act requires amendment?

Dr Jane Kellock (Social Work Scotland): I do not know that I would say that the legislation requires amendment. What we have heard from our members and from people who we have consulted over the past while is that the self-directed support legislation is good legislation. People want it to be in place. It is the implementation that is the issue.

Donald Macleod (Self Directed Support Scotland): I would say the same. We conducted some research in 2020 of people's experience of self-directed support. The overwhelming sense was that, where it works, it works well, and that there is nothing wrong with the legislation. It is about the implementation, the local variation and the lack of data and accountability. What people are proposing is more investment in the infrastructure.

Tess White: Before I go on to my second question, I note that some areas or regions would say that they do implement self-directed support, while some scarcely implement it. Do you have any views on that, Dr Kellock?

Dr Kellock: Yes. There is huge variation across Scotland in the implementation of self-directed support. It is a complex area to implement well, and it is a complex area to implement across all the populations that should have access to self-directed support.

I think that I have mentioned before that we feel that the implementation of self-directed support somewhat stalled at the point when the Public Bodies (Joint Working) (Scotland) Act 2014 came into play, because there simply was not enough developmental or implementation resource at the local level to be able to do everything well. We tended to see self-directed support being implemented reasonably well for adults with physical disabilities and sometimes reasonably well for children with disabilities and people with learning disabilities.

However, there are lots of populations that, in general, do not get good access to self-directed support. That includes people with mental health problems, people with social care needs that are perhaps outwith the regular populations that you would think of—homeless people, say, or people who have substance use issues—and the older population. There tends to be a more transactional service delivery to the older population and those with dementia. There are a lot of populations that do not have access.

Donald Macleod: There are a number of important factors in the lack of success in some local areas. There are no effective legal mechanisms for individuals who are seeking social care support to be able to challenge decisions. That is generally done through the local authority complaints process, which is opaque and quite general. There is a lack of data to inform improvement. There is so much local interpretation of legislation. Social workers vary in how well informed they are, and SDS is not routinely on the curriculum for social work students.

On national consistency, as Dr Kellock pointed out, there is a lack of availability of all four SDS options across the board in some areas, particularly rural areas. That is creating pressure points in the system, which is overloading another part of the system. Perhaps we will come on to that later. It is creating pressure currently, particularly when it comes to option 1.

Tess White: My second question is whether panel members think that amendments to the National Care Service (Scotland) Bill or the Public Bodies (Joint Working) (Scotland) Act 2014 are required to ensure the successful implementation of self-directed support. Has the SDS collaboration discussed that? Who would like to go first on that question?

11:00

Pauline Lunn (In Control Scotland): I am happy to go first. I am not sure whether this requires an amendment specifically, but there has been a lack of self-directed support altogether in the development of the legislation, or at least there has in the conversations that we have been part of. Many members of the national collaboration have taken part in the development of the NCS: some of us are on the expert legislative group and some have been on the advisory group or in other co-production spaces. It feels as if we regularly have to remind the policy writers that—with few exceptions—self-directed support is the cornerstone delivery vehicle for all social care. Although it would not be a change to the legislation, there should be a reinforcement that that is the national policy for social care.

Tess White: One concern that I have heard, and one reason why the committee is doing this study, is that we need to understand why self-directed support has not been implemented. We want to look at the areas where it has and has not been implemented.

Kaylie Allen, do you have any comment on what Pauline Lunn just said?

Kaylie Allen (Inspiring Scotland): Independent support has a role. There has been some discussion about where advocacy would fit into the NCS. I represent Inspiring Scotland and the support in the right direction organisations that provide independent support. We want to champion the importance of independent support and the range of activity to help people access their rights through self-directed support.

You can have policy and legislation, but people need support to access that properly and they need that throughout their social care journey, from pre-assessment, through having the social care assessment and on to managing their social care budget. That support is on-going.

We would have expected to see more prominence of the importance of independent support and of how advocacy is part of that. The support works best when it is preventative and when people get access right from the beginning of their social care journey, which can mean discussing what their social care needs are before they have an assessment.

Tess White: Dr Kellock, the first theme for our questions is the collaboration between areas. What are your thoughts about collaboration gaps?

Dr Kellock: I think there is a huge collaboration gap. When the legislation was first enacted, local authorities had recourse to statutory guidance and a little bit of practice guidance, but the transformative nature of the legislation was, and still is, misunderstood. We see that in the plans for the national care service, where the expression “SDS” represents a huge number of different aspects and elements.

We have recently refreshed the self-directed support standards. There are 12 foundational standards and more than 50 core components, which are the elements that we believe are essential to good self-directed support. That in itself says that a really complex infrastructure is needed for self-directed support to work well. When there is a lack of understanding within national policy of the level of detail of self-directed support, you get lip service being paid to it, without enough detail.

We would like to see the self-directed support standards and the core components being written in detail into all relevant policies across Scotland, so that we can see how different policy areas would pick up on different aspects of self-directed support to make that a reality within the national care service.

Tess White: Kaylie Allen also spoke about budget.

Emma Harper: I am interested in the improvement plan, which has been updated for 2023 to 2027. I would like to hear your thoughts about how that update is different to previous plans. Does it allow people to have more choice about and control of the plans for their care?

Dr Kellock: The improvement plan was co-designed to a certain extent, and it reflects a lot of the core areas for improvement that are common across the collaboration of stakeholders that are involved in self-directed support. It is an iterative journey. I do not think that one improvement plan over four years can make all the changes that are necessary. I also note that it is not particularly well funded. We are working within an envelope of the funding that is available and not the funding that we think is necessary in order to really make it happen. I think that all the organisations that are represented on the panel are working with less available grant funding than we had in previous years. We are feeling the pinch and we are having to prioritise what we pay attention to.

We are now more knowledgeable about what implementation takes, and the implementation gap. In the stakeholder collaboration, we have done a lot of work on taking a learning approach to developments and implementation. We are probably on the front foot there. We are turning our attention to the right things because we understand what the implementation gap is. However, it is a huge area, and the more we explore and understand what the problem is, the vaster the gap that we see becomes. There is a lot to be done at both national and local level to make SDS work.

Emma Harper: The data in Public Health Scotland's dashboard is really helpful. We can look at the data for all of Scotland or break it down by age group, choice of option or local authority. It shows that people up to the age of 18 have predominantly chosen option 1, which is direct payment, and that most people over 18 have chosen the option that involves help from the local authority or a combination. I found all that data interesting when I was analysing it.

I learned previously that people do not really equate self-directed support with what the local authority gives them. They say, "The local authority is doing this for me," rather than, "This was my choice." Should we in some way enhance people's knowledge about what the self-directed support options 1, 2, 3 and 4 are so that people know that they are making a personal choice even if they have chosen the local authority option?

Pauline Lunn: On your first point, there is a danger in assuming that the data that we see on the options that people are using reflects the options that people have chosen. They are not always the same thing. We know that the availability of services is incredibly limited, the pressures that local authorities and support providers are under is intense and eligibility criteria are higher than ever before, which results in people sometimes not having the support that they would choose.

The fact that we have that data does not necessarily mean that there have been active choices. I think that we all agree that that is one of the big data gaps. It is not just about recording who is using what; it is also about the extent to which there have been active choices and what people might have chosen otherwise.

That applies in particular to option 3, whereby the local authority arranges support on the person's behalf. In Control Scotland published some research on that last year, which I hope you have seen. If not, I will provide it after this session. We looked at examples of good practice or emerging good practice in relation to option 3, because you are absolutely right that the principles and values of self-directed support apply to all four options and not just the ones whereby people are in control of the budget. We learned that there is still some misunderstanding, even in local authorities, of the fact that option 3 is still self-directed support and people who have chosen that option should still have flexibility and freedom to have a little bit of choice and control in what their support looks like.

Our learning has been that the services that are involved in that are often the highest-volume services, such as care at home and older people's services. However, there are some brilliant examples where local authorities have promoted flexibility, choice and control in those really high-volume services. They are in the research that I mentioned, if you want to have a wee look at some of them.

Emma Harper: In each of your organisations, there are budgetary constraints. You have mentioned that already. Would any of you be happy to tell us about a good example of work that your organisation is doing to achieve the revised plan outcomes?

Dr Kellock: I think that we are all doing the right work, because we now understand better what it will take to deliver on self-directed support.

On the project side, Social Work Scotland has seven workstreams on different themes and areas. I will highlight a couple of those.

I mentioned that we have revised the self-directed support standards. We did that in a very co-productive way, with a whole range of stakeholders across supported people. We looked through different lenses to see who got access to self-directed support and who did not. We also looked through a geographical lens at the challenges in different geographies in Scotland.

All of that helped us to revise the standards and make them more accessible and understandable, and to bring them up to date for post-pandemic Scotland. We have those standards now, and we are about to go out with them on roadshows over the summer to develop an approach with local authorities, looking at how they might bring those standards to life in their own areas—because, ultimately, that is what we want. We are working at an intermediary level, if you like, between national policy and local practice. We want to drive good practice and consistency locally.

We are also testing out an approach to self-evaluation and improvement, which will be of use to social work and social care leadership in local authority areas. So far, that has been tested by three local authorities, and we will roll it out to a further three to five in the coming year as a second iteration. That is very much based on taking a learning approach—looking qualitatively at people's experience.

To go back to what Pauline Lunn said, you cannot tell how people have found the experience of the self-direction of their social care just by looking at the options. You have to delve in and understand what their experience has been like.

Those are two examples of big areas of work that we are engaged in.

Donald Macleod: We support the improvement plan with some of the tools for the job, such as the information systems. We recently launched the national SDS online handbook, which should be a one-stop shop for anybody who is trying to access information on SDS. It is based on the success of the personal assistant online handbooks and the personal assistant employer handbooks.

When it comes to the option 1 arrangements, I chair the personal assistant programme board. We have been working to improve awareness of the personal assistant role and parity between that component of the workforce and the rest of the social care workforce. We look at improving data, the awareness of the role, the recruitment infrastructure and the training infrastructure. We have developed a training framework with modules that focus on PA wellbeing and on direct payments. We are working with Social Work Scotland on a national direct payment agreement. One of the inconsistencies across the local authorities is that there are 32 different ways of applying a national direct payment agreement.

We also have a group that works on peer support networks. We are trying to make that part of the infrastructure as robust as possible.

Pauline Lunn: I am happy to comment on our work. What we at In Control Scotland do that is a little bit different is that we run national and local programmes, all of which are founded on co-production. All of our work involves disabled people, unpaid carers, support providers and local authority staff working collaboratively to solve problems.

On a national level, we do that through a programme called working together for change, through which we bring together folk on a development journey. The interesting thing about that—this is probably true for all of our work—is that you do not see real change at the end of any particular programme; it comes over time. For example, a senior leader from a local authority came on our working together for change programme three years ago, and it inspired him to change the way that he was writing the strategy for self-directed support in his local authority. That then changed the way that he was working to develop worker autonomy practices, and different approaches to eligibility criteria were developed. All those things came as a result of a bit of work that happened three years ago.

Change can sometimes be hard to measure at the time, but it can happen over time. When you are working in a systems change environment, that is the nature of the beast.

11:15

Kaylie Allen: I can talk about the support in the right direction programme, which contributes to outcome 1 of the improvement plan. The programme provides practical support for supported people and carers to exercise choice and control. It is a Scottish Government-funded programme for which we are the strategic delivery partners. We have 33 projects, with a presence in every local authority. Those projects involve local community anchor organisations, carers centres, disabled people's organisations, centres for inclusive living and some SDS forums. The programme employs approximately 70 staff across the country who provide practical support for people as they go through their journey.

Our role is to collect information about what people are doing in relation to advocacy, brokerage and providing support around option 1 and what being a PA employer means. We collect information on all the work that goes on to help people through the assessment process and to think about creative options for their budgets and about what personal outcomes mean. Those 70 funded staff provide a lot of practical support, and we gather information on that, so we will be able to collect data on the point at which people come for independent support and who is not getting independent support—with the best will in the world, there will be a lot of people whom the 70 staff are not going to be able to reach.

The programme involves providing people with information about what the process actually means. We gather information on whether people are feeling more confident to manage their budgets, whether they feel that they have had a choice and have some control over their social care plan and on what support they need to put that in place.

To go back to Emma Harper's point about the options, those organisations get a lot of information about what is happening locally, what the available options are, and what people understand about their options. Do they even know what option 1 is? They might be on it, but do they know that it is option 1? We gather a lot of information about people's experience on the ground and feed it into the collaboration and to the Scottish Government.

The organisations often work with people when things are not going well. People will get a referral to an organisation, which can support them to feel better about their care, or get the things put in place that need to be put in place for them to feel that they are more in control of their care. However, as I said, ultimately, it works much better when the organisations support people before there is a problem and use things such as peer support to enable people to speak to others who have been through the process. That allows people to understand what it is like. It can inspire them about the different creative options that there might be and allow them to think about other community supports that they might be able to access.

Our real drive is to raise awareness of the importance of independent support, which is needed for people to be able to access social care, and to gather as much learning as possible to feed that back into the plan.

Emma Harper: Thank you.

The Convener: I will come to Sandesh Gulhane in a minute, but I first want to pick up on one point. You might well not be able to answer this question because you are not local authority representatives. However, I have heard a couple of times from panel members about gaps in staff knowledge or understanding of SDS. Do you know of any work that local authorities are doing to address that, or would that be better put to the Convention of Scottish Local Authorities?

Dr Kellock: I think that you would be well advised to put those questions to COSLA and to senior leaders, who I know are coming to give evidence at a future meeting. However, we work with a community of practice of local authority SDS leads and others who are involved in the local implementation of self-directed support and, in our experience, staff understanding—social work and social work practitioner understanding—of self-directed support is not particularly good.

The availability of training for social workers and social work practitioners is not particularly good. I suppose that that speaks more to the enabling context that sits around self-directed support than it does to self-directed support itself. For example, there is no protected time for social workers to learn, so they tend to get training in areas such as child protection and adult protection on the job. At the moment, the training that is afforded to them for self-directed support is very poor. We are doing a piece of research to look at the availability of training, and I will be able to speak about that at some point during the summer when we get evidence from that.

Our understanding is that the training is fairly poor and that the understanding of self-directed support across the social work profession is not good. The model of practice that adult social care works under is care management, and we know that that is not the right practice model if we want to support people to have choice and control. It is necessary to have more of a relationship-based practice model, and sometimes we do not have that at the moment. Especially when people's needs are critical, things such as eligibility criteria force practice down to a level where there is no meaningful choice to be had. If your needs are critical, you just need support to be put in place.

All sorts of things are hampering and hindering the system at the moment. There is no magic bullet. Our understanding of implementation science tells us that there are multiple factors that need to be in place. The main idea that we work with is the notion that it is the relationship between the supported person and the practitioner—the social worker or the paraprofessional who works with them—that draws out the solutions in respect of what matters for that individual. That relationship-based practice is absolutely at the heart of self-directed support. It is not possible to have choice and control unless you understand what matters to the person.

The Convener: Thank you. We might go into that in a bit more detail later on.

Sandesh Gulhane: I declare an interest as a practising NHS GP. This question is for Dr Kellock. We have strategies such as the dementia strategy, we have the Promise and we have the proposal for a national care service. There are times when those policies will rub up against one another. How will we be able to navigate our way through that?

Dr Kellock: I go back to the point that I made earlier about the need for a nuanced understanding of self-directed support throughout all the related policy areas. Rather than self-directed support simply being mentioned in a policy area, it would be useful for the self-directed support standards, which represent the agreed position across all the stakeholders on what good looks like when it comes to self-directed support, to be looked at carefully by the likes of The Promise Scotland and the national social work agency, and for them to have an understanding of what it will take to implement those standards.

Those elements would help at the policy development level, and they would certainly help with the implementation of any of those policies. We really need to have self-directed support more closely weaving through all those policy areas.

We have a national collaboration—a voluntary collaboration—that involves all the stakeholders across the SDS community, which would be more than willing to be involved in any of those areas. We are there for the asking. That is a punt, I suppose, to get us more involved in the development of other policy areas.

The Convener: I want to move on to the issue of evaluation of the implementation plan. Jane Kellock, you mentioned that you feel that you are "doing the right work". How are you monitoring the effectiveness of that work?

Dr Kellock: There is a range of ways of doing that. We always evaluate the work that we are doing. We all do that across the piece, and that gets fed into the general understanding of how effective our work is. It is difficult to measure such things quantitatively, because we are dealing with issues of fundamental change, implementation and development, both nationally and locally. However, it is possible to look at all this through a learning lens to see what we can understand and learn and how we are putting in place different strategies to meet different needs at a local level. At the moment, we are working with our Scottish Government colleagues on the monitoring and evaluation of the improvement plan and are involved in the co-production of that.

The Convener: That question was not specifically directed at Jane Kellock, but I thank her for answering first. I will bring in Kaylie Allen and then come to Pauline Lunn.

Kaylie Allen: I guess that we are in a slightly different situation. Because we have organisations that deliver for people, we are able to gather feedback from those people about the difference that their independent support is making to them. We collect both quantitative and qualitative data, and that tells us about the number of people who are getting support; the number of people who have been helped with advocacy or to prepare for assessments; and the number of people who are getting support for their option 1 arrangements and how they are managing as a PA employer or just as an employer. We will also gather information on how people are feeling about that, whether they are feeling less stressed or anxious about their support, or whether they have been able to live more independently as a result of the independent support that they got to enable them to make the most of their social care.

We are working with our 33 funded organisations, and we will be gathering and feeding in data on a quarterly and six-monthly basis. However, it is all about the experience of people and carers, how they use independent support and how that has helped them with their social care.

Pauline Lunn: With the strength of the national collaboration and the relationships that we have together, we have a really good opportunity to learn through this learning-based approach. It is not just about numbers. We might see that we had delivered 100 sessions, but so what? What difference did they make? A hundred people could, in answer to a survey, say that they had really enjoyed the sessions. Again, so what? How do we know that they made a difference?

The real learning comes when folk such as the funded organisations and all the people who actually work on the ground in the national collaboration come together and look at the patterns that they have spotted in all the things that we are learning. We can anticipate the things that we might have to address and see what areas are evolving well enough that we can probably leave them alone. The important thing is to have that iterative, shared and collaborative learning.

Data is meaningful only if we learn from it. We can gather as much data as we like, but the question is: what are we doing with it? For those of us working in self-directed support and thinking about outcomes, the question is always: so what? What does it mean? How do we learn from it? I think that we are now, perhaps, in a position to do that in a way that we might not have been able to do with other plans.

The Convener: That is a really important point. We MSPs talk about data a lot, but the question is: what do we do with it? You might have the numbers or the facts and figures, but the issue is how you use them to improve lives.

Donald Macleod, did you want to come in?

Donald Macleod: I do not have a huge amount to add, except to say that taking a human learning systems approach and looking at people's experience of self-directed support will be a way forward instead of considering systems-based data. The collaboration has been involved in co-producing the improvement plan and the monitoring and evaluation format; given that both involve Government and COSLA, they will be a compromise in some ways, but there will be more of a focus on people's experience.

The Convener: Thank you.

This question might be more difficult to answer. An additional £200 million has been added to this year's budget for adult social care and the national care service. How should that money be allocated to achieve the most effective outcomes? You can see now why I said that it might be more difficult for you to answer.

Pauline Lunn: We have conversations with front-line social workers every day. During our option 3 research, people spoke about feeling like they were on a hamster wheel—that is, constantly in motion but not getting anywhere.

The current models, systems and practices are bureaucratic and unwieldy. These things were put in place to support workers, but they have become burdensome. We have massive scrutiny panels and reports have to be written for those. Those things take time, energy and effort and they are not the reasons why people become social workers. People do not become social workers because they want to fill out forms and present to panels. They become social workers or social care workers because they care about people and want to make their lives better.

11:30

However, every portion of the sector has been facing the worst challenges with regard to recruitment and retention that most of us have ever seen. My personal priority—I think that my organisation would agree—is investment in the social care and social work workforces. Many of the system's problems will automatically become easier to deal with if there are more people to do the work. However, at the same time, complementary to that, we need to think about reducing bureaucracy—we need to think about the things that people could be not doing as well as what they could be doing.

Dr Kellock: I definitely agree with that. I would draw the distinction between the volume of people that we need—we need more workers, they need to be better paid and we need to attract people into the sector—and the systems issue. At the moment, the practice model is not right. The systems that sit behind social workers and social work practitioners and local authorities are cumbersome and difficult to navigate, so improvements are definitely needed in order that we have a practice model that is well placed to support the fundamental principle of self-directed support, which is choice and control.

Donald Macleod: I will refer back to the independent review of adult care in Scotland, in which Derek Feeley advocated a national care service that was delivered with the full involvement of the independent living movement—the disabled people's independent living movement in Scotland. That part of the infrastructure is chronically underfunded and underresourced as people struggle to deal with their own lives and to get choice and control for themselves.

During the pandemic, disabled people felt that their lives were becoming deprioritised. The proposed disability equality strategy has not been delivered, and we have not had an immediate priorities plan for disabled people. More investment is needed in the infrastructure and the organisations that support disabled people.

Kaylie Allen has spoken about the independent support organisations. With regard to those organisations but especially the people's collectives that are governed and delivered by disabled people themselves, such as the centres for inclusive living, we found that it was extremely difficult to deliver the Covid payment to front-line workers—personal assistants—because those organisations do not have the capacity. Therefore, more investment is needed in that, and more investment and credibility need to be given to independent living.

Gillian Mackay: I want to build on the questions that the convener asked about training and awareness in local authorities. A lot of best practice guidance has been written over the past 10 years. What are the panel's thoughts on the quality of the guidance, and on how it is or is not being used in local authorities? There is a lot of nodding going on. I will pick Donald Macleod first, if that is okay.

Donald Macleod: That is fine. We were all involved in the review of the SDS practice guidance. It is great stuff and it is good that it was reviewed. It is very thorough. It is the nuts and bolts of daily delivery, but it does not improve delivery in and of itself—it is just a nuts and bolts manual on how to do things.

With regard to investment in the training infrastructure and the gaps that you have heard about in the knowledge and awareness of local authority front-line workers, a lot of the independence support organisations provide some of that training and awareness for local authority staff. We are currently delivering a national brokerage framework with a Scottish Qualifications Authority accredited award, which a lot of local authority staff are taking part in. More investment is needed in that. As I said, the statutory guidance itself is a good piece of work, but it is just a nuts-and-bolts manual.

Dr Kellock: We have done a lot of work over the past few years to review and refresh all the bits of guidance in the self-directed support library, which is an online resource. We have reviewed that, brought it up to date, aligned all the material with the standards and recently developed new practitioner guidance that sits alongside the more general SDS handbook. We launched that, and we are monitoring how accessible it is for social work practitioners on the front line.

The community brokerage training for self-directed support is second to none. It is a fantastic training resource, and we would love to see that being used more. I heard recently from social work colleagues that they cannot afford at local authority level to pay for that training, nor can they afford to free up their staff to undertake the training. We have to understand that it is not just about the quality of the resource that is available; it is about what we would call the installation of it. How does it land? Can people use it in a meaningful way on a day-to-day basis? That is where we are finding most of the difficulty.

Over the summer, we will be exploring in depth with three local authorities how easy or otherwise it will be for them to use the self-directed support standards and to bring those standards to life. We will get an immense amount of information and data from that process, and we will really understand what is going on at a local level that would militate against the standards being fully brought into play.

There is more to be understood. It is a very complex system. Yes, there are resources and training, but there are many other enabling or disabling factors in respect of people being able to use it.

Kaylie Allen: I will talk about the independent support organisations. The guidance is there, and those organisations know it well—they know it inside out. They often support social workers by pointing to bits of the guidance and saying, “This is where it is.” They have reported pockets of good practice in which independent support is alongside social work and the former can show them what the guidance means practically, give examples, show how the guidance could make things easier, show what a good conversation looks like and talk about other ways that they have been able to make the guidance come to life. There is a very close relationship and alignment between social work and independent support.

Gillian Mackay: The point about how the guidance is used and how it can be embedded is important. National consistency always comes up in relation to self-directed support. Which of the activities in the improvement plan will or will not help to address national consistency, and should or could any aspects of SDS be standardised nationally?

Pauline Lunn: On the second part of your question, we have uncovered something around definitions. At the very beginning of somebody’s journey, when they stick up their hand and say, “I need some help,” the information on self-directed support that they are presented with sits separately on a local authority’s website to the rest of social care, so we have already othered it as something different and more complicated.

People who have heard me speak before will know that I am fond of saying that we need to stop talking about self-directed support, because it is just business as usual; it is just the way that we do social care. By giving it a name and putting it on a different bit of the website, we make things seem more complicated than they actually are. In our learning, particularly the bits of research that we have done recently on options 2 and 3, there are differences in the language that is used to describe the options, which can be problematic—the differences can be subtle but powerful.

I will give examples from our research on how option 3 was described by three local authorities. You can “choose” to let the local authority arrange support, “ask” for support to be arranged on your behalf or “wish” for support to be arranged by the local authority. Those three words are quite different, so there is the opportunity for inconsistency from the very beginning. I can wish to win the lottery, which does not mean that I will, but me actively choosing that is a different strength of word.

From the very beginning there are issues around the shared understanding and definitions of what self-directed support is and could be. There was some improvement when the statutory guidance was updated, because the definition of option 2 is a bit less woolly than it was before, but as soon as you are at the front door there can be inconsistencies that arise from the language and the way that we describe things.

Dr Kellock: I am not sure whether it could be standardised in the way that something more procedural might be standardised. Self-directed support is not procedural. We are all involved in work at intermediary level to bring consistent best practice approaches to the fore so that we can encourage and support local authorities to adopt those.

We are involved in the self-evaluation and improvement framework and are trying to get a common approach that can sit across the range of improvement models that local authorities might already be engaged in through their health and social care partnerships. Pauline Lunn was involved in testing a framework in one local authority. We are trying to build frameworks that support people to come together to learn and understand what needs to be done in their local authority, and to do that by using the SDS standards, because that is the most standardised tool in our toolkit at the moment.

We are also bringing together local authorities to engage in their self-improvement journey through a community of practice. We think that that will bring benefits because people will be able to learn from one another. We also host a group of self-directed support leads who are looking at policies and procedures and we are trying to bring them together to do that more systematically, so that they are not developing things separately in their own local authority bubbles.

That is all co-production work. We are trying to work together with people and to benefit from the experience of supported people and carers along the way.

Sandesh Gulhane: Dr Kellock, I have a number of very direct questions, so it is fair enough if you do not know the answers. How many social workers do we have in Scotland?

Dr Kellock: That is not something that I can answer. It would be wrong of me to suggest an answer to that. There are thousands of social workers. The Scottish Social Services Council would have the most up-to-date statistics for how many social workers are registered, but I have not seen the most recent statistics.

Sandesh Gulhane: There are about 6,000 in local authorities and about 10,000 registered. What is the average working life of a social worker in Scotland?

Dr Kellock: Social Work Scotland did some research just the other year. We found that some social workers were leaving the profession within six years, although it is our understanding that that number is less than it used to be. All sorts of reasons were cited, including terms and conditions and work-life balance. The practice model is also a contributory factor.

Sandesh Gulhane: On the subject of training and social workers coming into the workforce, do we know how many are being trained each year? Is there any significant increase on what that number was in the past?

Dr Kellock: I am afraid that I do not have those statistics to hand, but we do know that number. Work is under way to improve social work education and the support for newly qualified social workers. That really valuable work is happening at national level and through universities. Improvements are definitely being made.

There has already been mention that people do not get a particularly high awareness of self-directed support when they are training at university to become social workers. People often come out of courses without much understanding of self-directed support, so they have to learn on the job. There are issues there, for sure.

11:45

Sandesh Gulhane: It is safe to say that social workers are not sitting idle; they are very busy doing what they do. Some 40 per cent of social workers reported that their workload was unmanageable; 70 per cent of social workers reported that they could not complete their work in their contracted hours; and 20 per cent of the social work workforce left in 2020, with 40 per cent planning to leave in the next three years. On top of that, rural areas find it hard to recruit and train social workers.

However, everything that I see coming through from the Scottish Government requires social workers. For example, the implementation of the Children (Care and Justice) (Scotland) Bill requires 500 social workers. So, even with more money coming in to be spent, if we do not have the necessary number of social workers and the ones that we have leave after only six or seven years, how can we possibly implement policies successfully?

Dr Kellock: I would not disagree with any of that; it is a major issue for the social care profession. The social care workforce does not have enough resource and is extremely pressurised at the front line.

There are quite a few paraprofessionals—unqualified people—working in social work teams, too, and we need to address that balance to ensure that we get it right. We also need to ensure that we are training those members of staff in order to enable the delivery of policies such as self-directed support. You are right to say that there are a lot of issues within the social work profession.

Sandesh Gulhane: That is relevant to what was said earlier about people coming out of university and not being trained highly enough, especially around self-directed support, and the fact that there is no protected time for social workers to do some learning, even though people in every profession need to continue to do professional development.

Training more people is one thing, but we also have to retain them. What can we do to retain social workers and stop them leaving the profession?

Dr Kellock: One of the big things that came out of the recent research that Social Work Scotland commissioned concerned the case load balance for social workers—that was a huge issue. As the profession has increasingly relied on paraprofessionals to do some of the less complex work, the case loads of qualified social workers have become more complex and larger. Social workers are faced with really complex work that often has to be done at the point of crisis, which causes quite a lot of stress for the worker. Those sorts of issues are relevant to your question.

Workers are leaving the profession earlier, and we have also seen quite a lot of social workers retiring relatively recently without a sufficient workforce coming in to fill the gap. We are definitely seeing newly qualified social workers having to take on more complex cases than they might have done when I was a chief social work officer some years ago, just because of the nature of the work and also the size of the teams.

There are big issues there and, if social workers are leaving after six years, there is no way that you would want to put people through a four-year degree course only to have a career that is six years long. There is not a good work balance for social workers.

Sandesh Gulhane: On your point about social workers dealing with people in crisis, in my conversations with social workers, they tell me that the fun has gone from their jobs and that, whereas, previously, they were seen as somebody who helps and ensures that people do not get to the point of crisis, all they are doing now is crisis management and they are often seen as the bad person—the person you do not want to come knocking on your door. That is quite a step change for them. How can we make the job what it should be, which is about prevention?

Dr Kellock: I would go so far as to say that it is unethical to expect a workforce to deal with crisis at that level for such a long period. When you are dealing only with people in crisis, you lose some of the skill and ability to think creatively with people, which is really what is needed for self-directed support. You need the time to explore with a supported person what matters to them and how they can have their needs met.

The practice model is not necessarily a quick win, but it is something that we can definitely work on. As part of it, we would not expect a transactional care management approach; instead, it is about moving towards more relationship-based practice. Again, though, it is difficult for workers who do not have the time or who have huge case loads to get through a checklist-type assessment, and very difficult for them to find the time within that to develop relationship-based practice.

This is, therefore, a very complex issue, with lots of different elements. I think that, when it comes to implementation, we have to understand the workforce issues in their entirety and holistically as part of the system, but we definitely have to do something to help improve workforce competency.

Ruth Maguire: Good morning, panel. Thanks for your answers so far.

I want to talk a little bit about the long-term care commission. Last week, Alzheimer Scotland was in Parliament, talking to colleagues. The commission’s report focuses on long-term care; obviously, a feature of that is residential care, but it also encompasses quite well a lot of the themes that we have been talking about such as the real cost of care, how it is paid for, alternative care models and improving commissioning.

The improvement plan does not discuss the underlying issue of funding. We have just been talking about the challenges facing social workers, and I imagine that operating or trying to operate in a human rights-based way in a time of austerity is soul destroying. Obviously, local authorities determine how much of their budget goes into social care, as does, I believe, the NHS, with regard to what goes to integration joint boards. Should—or could—the broader question of the funding of long-term care be addressed by the collaboration?

Pauline Lunn: I am not sure how much of that lies within our sphere of influence. How local authorities disseminate their budgets would not be something that we, as funded partners, would have much sway over. We would certainly have opinions, though.

What we can do is try to influence. For example, a particular interest of mine is commissioning; I used to write tenders for a living, I manage tender teams and I am really interested in reforming commissioning. We can have an influence from that perspective.

We hear worrying stories of local authorities moving to price-only tenders—that is, with the quality component stripped out—and I agree with the part of the long-term care commission report that highlights that an unintended consequence of the underinvestment in community care services is more folk going into residential care. As a result, they do not get access to self-directed support, because it does not apply to residential services; however, such services are significantly more expensive, so it is a false economy.

There are certain parts that we can influence. As for whether the national collaboration should be involved, I am not sure how many organisations comprise the collaboration, but the majority are in the voluntary sector, with people on the ground delivering services.

Dr Kellock: I suppose that this speaks to the broader enabling context in which self-directed support sits. In order to have that choice and control, we need a better-funded infrastructure around it. However, that infrastructure would support not just self-directed support itself; a balance would be struck across all of the organisations' duties and responsibilities.

We would certainly want the opportunity to ensure that what we understood by self-directed support implementation, quality and practice was understood better by those in the position to make such decisions. That brings me back to my earlier points about ensuring that a deep understanding of self-directed support is wedded to the policy context.

From what I have heard from colleagues in local authority areas working in self-directed support, it is not necessarily high enough up the agenda, and certainly not in health and social care partnerships. We would therefore welcome more direct visibility of self-directed support to ensure that those who are charged with its implementation at a local level can speak directly to the most senior people within the organisation. Such an approach will allow the local position to be reflected and some understanding to be built around what is required at that level.

Ruth Maguire: In your answers to Emma Harper and just now, you touched on the issue of wider understanding, which I guess is a matter both for the public and for policy makers. What has to change in that respect? I was struck by the phrase "cornerstone delivery vehicle", which was used, I think, by Pauline Lunn. I think that we see this almost as a separate project or thing, not as that kind of vehicle. I know that it is quite a big question, but what has to change to ensure that we get that visibility?

Pauline Lunn: We deliver a lot of training on self-directed support, have lots of programmes and speak to people about it all day, every day, and one of the things that we tell people—and which often comes as a surprise—is that SDS is not something that you get. Instead, it is a way of working; in fact, it is the only way of working for the vast majority of social care. Because it is a way of working, its values and principles are all about showing flexibility and making sure that there is choice and control in people's lives.

SDS is not a thing that you get; it is a thing that you do. That connection is not often made, even by local authorities and organisations delivering services, and I think, therefore, that we need to start right at the very beginning. People phone us up all the time and say, "I'm getting support, but I want SDS instead," and we are like, "Okay, cool—let's dial it back." Having to explain that is fundamental to the whole thing. I do not know whether others have a position on it, though.

Kaylie Allen: You do not know about it unless you are in the system. It is the same with social care; people probably do not really understand it until they need it. I think that that is the conversation that needs to be had. It can be quite complicated or quite simple, but it is all about the way in which social care is delivered.

Just to pull the threads together, I come back to the role of the voluntary and community sectors here. They are key players, and they need to be resourced better to help people live independently in their communities. The way in which they work is to ask, "What does this person need, and what can we put around them?", regardless of whether they are in the system.

I have been thinking about the conversation about prevention, the role of the voluntary sector and the community in supporting people and the language that gets used when explaining self-directed support. It is not something that you are going to retain, unless it is actually and practically where you are at and you need it. We can have better definitions and national consistency in how we talk about self-directed support—and that would be good—but I think that it is all embedded in how we work with people. We say to them, "What matters to you? You have a choice, and here are some options." That is what the voluntary and community sectors are very good at delivering.

Ruth Maguire: Forgive me if I go over some things that we have already discussed, but it is not always the budget that restricts choices. This is also about models of care. We will all have examples from our constituency work of someone who, having been assessed by an allied health professional or social worker as requiring a level of support to live their life, will then be told that that support is not available. It is not all about money; in fact, in the committee's inquiry into rural healthcare, we found that sometimes the issue was availability of service.

Dr Kellock: It is not all about money, no, and I think that you were right to talk about the practice model, as that is really important.

Perhaps I can look at this very simplistically through a care management lens, if what you are asking about is care management. What is seen as success in a care management process is paid-for care at the end of the day. You carry out an assessment that tells you what level of care is required; you cost that up; and that is your success factor at the end of the day. In a relationship-based practice model, success looks like what matters to the person. That could mean enhancing their natural, family and community supports, which goes back to the question about early help and prevention, early intervention and having those supports available locally.

One of the things that we addressed, which we heard quite a lot about when we reviewed the SDS standards, was the need to protect natural supports for people. At the point of crisis, what was being made available was sometimes something that got in the way of the person's natural supports and rendered those supports difficult to deliver.

12:00

Ruth Maguire: By natural supports, do you mean someone's network—their family and friends and so on?

Dr Kellock: Yes, their network, their family and their community supports—things that matter to them in the community. The best self-directed support that we have seen builds on and values those as core to the person's sense of wellbeing. It is not all about money. We need more resources in the system but, if we had a different way of practising, we would make best use of what we already have in the system and what people already have themselves.

Ruth Maguire: May I have one brief final question? I am testing the convener's patience a little bit.

Obviously, speaking simplistically, the challenge in moving to prevention from patching things up—if we think about hospitals and investment in community care—is the process of moving money away from fixing stuff to the relationship and preventative stuff. Is that a similar situation? I am trying to understand what the blocker is in moving from, "Here's what you need and here's how we're going to give you it," to the relationship that we are talking about.

Dr Kellock: Maybe the question is about understanding what unmet need looks like. The assumption that you can move money from the acute end of the system upstream is predicated on there not being unmet need that comes in and uses all that resource.

Ruth Maguire: It is being predicated on that.

Dr Kellock: Yes. It is difficult to predict.

Paul Sweeney: On the impact of funding on future service design, local authorities have, on average, had a 10 per cent cut over the past decade. Around 80 per cent of local authority funding is central Government grant and 20 per cent is raised through council tax and local charges. In Glasgow, the percentage of funding that is spent on education and social care has risen from 60-odd per cent to over 70 per cent. Clearly, the council's focus has been pared down to two big areas of policy delivery, which puts subsequent pressure on delivery.

How do we break the cycle of annual budgets that are under increasing pressure, which is being ratcheted up, for health and social care partnerships and integration joint boards, which we then see being backed up into the NHS? I am trying to figure out how we break this prison of accountancy, if you like, and build the case for cost avoidance. We just heard about people presenting at A and E departments with late-stage cancer. Those are obvious business cases that show that, if we deal with something earlier, we will avoid a lot of costs to the public in the longer term and have better outcomes for people. What are your insights into how we better design that model for the future?

Dr Kellock: That might be above our pay grade. However, I am sure that we have some opinions on that. It is very complex. I used to be involved in systems to tackle health inequality, in the days when there was funding in the system. Sometimes, it is about knowing what is the right thing to unblock systems. You need to have a really good understanding of whole-system dynamics. That is where we look towards implementation science, which is a much wider field of understanding about complex social policy and health policy, rather than thinking, "Oh, yes, there is a simple solution to this. We do this bit over here." It is about the unintended consequences and understanding how to mitigate those.

Our approach is to start small, test small and test in different environments so that you can understand what is happening out there. One thing that have we picked up in our recent engagement with people is the arbitrary decisions that are made to help to protect local authority budgets or prioritise how local authority budgets are being spent. Rules will come into effect that say, “We’ll only do this,” or, “We’ll only do that,” or, “We’ll only spend it here.” Those rules seem to make sense if you are looking from a financial perspective but, when those rules are applied to real-life instances, all sorts of strange things happen and there are all sorts of unintended and really unwanted consequences.

What we have been hearing about people’s natural supports being interfered with comes from those sorts of decisions and rules being put in place to try to control spend and manage within budgets. A whole-system approach is about understanding that, if you put a rule in somewhere, it will do something further down the line and impact on the rest of the system.

We need to think things through well, not rush to make decisions. We need to think on a whole-system basis to understand what good implementation looks like, not just what, in this case, good self-directed support looks like. We need to work in a co-productive learning way with the whole range of stakeholders. That is quite difficult to do. Through the national collaboration and the work that we do—at the level that we do the work—we would say that we have gained a huge amount from working collaboratively with people who use services. That has to play out across Scotland in order to get the kind of systems at that macro level that we need.

The Convener: I thank the witnesses for their evidence.

Next week, the committee will continue phase 2 of its post-legislative scrutiny of the Social Care (Self-directed Support) (Scotland) Act 2013 with an evidence session with integration joint boards.

That concludes the public part of our meeting.

12:07

Meeting continued in private until 12:25.

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