OFFICIAL REPORT
AITHISG OIFIGEIL

Health and Sport Committee

Tuesday 27 March 2018

Session 5

The Scottish Parliament
Pàrlamaid na h-Alba

Tuesday 27 March 2018

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HEALTH AND SPORT COMMITTEE
11th Meeting 2018, Session 5

CONVENER

*Lewis Macdonald (North East Scotland) (Lab)

DEPUTY CONVENER

*Ash Denham (Edinburgh Eastern) (SNP)

COMMITTEE MEMBERS

*Miles Briggs (Lothian) (Con)
*Alex Cole-Hamilton (Edinburgh Western) (LD)
*Jenny Gilruth (Mid Fife and Glenrothes) (SNP)
*Emma Harper (South Scotland) (SNP)
*Alison Johnstone (Lothian) (Green)
*Ivan McKee (Glasgow Provan) (SNP)
*David Stewart (Highlands and Islands) (Lab)
*Sandra White (Glasgow Kelvin) (SNP)
*Brian Whittle (South Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Dr John Paul Leach (Association of British Neurologists)
Pamela Mackenzie (Sue Ryder)
Professor Malcolm Macleod (NHS Forth Valley)
Tanith Muller (Neurological Alliance of Scotland)
Mairi O’Keefe (Leuchie House)

CLERK TO THE COMMITTEE

David Cullum

LOCATION

The James Clerk Maxwell Room (CR4)

Scottish Parliament

Health and Sport Committee

Tuesday 27 March 2018

[The Convener opened the meeting at 10:00]

Preventative Agenda (Neurological Conditions)

The Convener (Lewis Macdonald): Good morning and welcome to the 11th meeting in 2018 of the Health and Sport Committee. I ask everyone to switch mobile phones off or to silent mode. While the use of mobile devices for social media is welcome, I ask people not to photograph or record the proceedings. That is the role of our committee staff.

Our first item of business is an evidence-taking session on neurological conditions, which is part of our inquiry into the preventative agenda. It is a pleasure to welcome to the committee Pamela Mackenzie, the director of neurological services and Scotland for Sue Ryder; Tanith Muller, vice-chair of the Neurological Alliance of Scotland; Professor Malcolm Macleod, professor of neurology and translational neuroscience at the University of Edinburgh and clinical lead for neurology at NHS Forth Valley; Dr John Paul Leach, consultant neurologist and a council member representing the Association of British Neurologists; and Mairi O’Keefe, the chief executive officer of Leuchie House.

We have time for a range of questions from committee members. Questions and answers should go through the chair. If you feel that you would like to chip in or provide additional answers to those given by your colleagues, please feel free to do so.

I will start by asking about the aim to produce a national action plan and revised standards for neurological health services in the course of this year. Are the right activities being undertaken towards the development of the national action plan?

Mairi O’Keefe (Leuchie House): Everybody would agree that it is right to have a national action plan. Standards for neurological health services were produced fairly recently—in 2009, I think—but there has been a disappointing lack of take-up of them. We would very much welcome having national standards, but there has to be a commitment to taking them forward.

Pamela Mackenzie (Sue Ryder): I echo what Mairi said about the 2009 clinical standards. The document that contained them was very good, but the standards were not mandatory, and my understanding is that the new standards are not mandatory either. We need that piece of work to be followed by a good inspection regime that will enable us to scrutinise shortfalls in services and make sure that there is clear action planning, so that we do not end up with something that does not have priority, as happened with the 2009 standards.

The action plan is fantastic news for us. It is what we have all been asking for. The pieces of work that are going on around that will really help. We hope that the national advisory committee for neurological conditions will be given the authority and resources to support the implementation of that action plan.

Professor Malcolm Macleod (NHS Forth Valley): There are two or three issues here. I was involved in trying to oversee the implementation of the previous audit standards. One of the difficulties was how many there were—operationally, there were about 108 or 109 different ones. If we ask people to do everything, they will not be able to focus on doing anything to any great extent, so the first thing is to have a core set of priorities that we seek to have people look for. The second thing is to make a distinction between audit for accountability and audit for improvement—I hope that we are engaged in an exercise in audit for improvement.

The third issue is the difficulty that we have because services for people with neurological conditions are immersed and interspersed in every part of what the health service does, from primary care through to secondary care. Neurology services touch perhaps only 5 or 10 per cent of that activity. Our patients use services in primary care and elsewhere that are also used by other patients whose disabilities are not neurological but cardiological, oncological or whatever. It might be sensible to try to separate those out, because there is a kind of apartheid going on if we are interested in our neurology patients but less so in cardiology or oncology patients.

Dr John Paul Leach (Association of British Neurologists): The first thing that I want to say is that we do not want to reinvent the wheel. We have a national advisory committee for neurological conditions. Unfortunately, it is not represented here today, but I have sat on some of those committee meetings. I absolutely echo the call to empower and invigorate that committee and allow it to take the agenda further forward in all respects, and we have to recognise the range of neurological conditions. We are not talking only about people with severe disability who require residential care; a massive percentage of acute admissions to hospital have neurological conditions, ranging from intermittent paroxysmal disorders through to progressive degenerative disorders.

In many ways, neurological services in the past 15 to 20 years in Scotland have blossomed. In some ways, we have become victims of our own success. We are managing to deal with epilepsy, first seizures, multiple sclerosis and Parkinson's disease in specialist clinics in a way that we could not even dream of in the 1990s. All people with first seizures will now be seen at some point by a neurologist. That might feel like poverty when they have to wait three months but, as opposed to 20 years ago, when first seizure patients were seeing accident and emergency doctors, psychiatrists and general physicians, we are in a better place. Yes, there is room for improvement, but the best group to tell how much further improvement we need would be the national advisory committee for neurological conditions, so re-invigorating and empowering it will be key to where we go in the next 10 or 20 years.

Emma Harper (South Scotland) (SNP): I am interested in the development of new standards, and in supporting the development of standards that are up to date compared with the 2009 ones. I know that a scoping report on general standards for neurological care and support was published in March this year by Healthcare Improvement Scotland. It lists standards that have been developed for many neurological conditions, but Professor Malcolm Macleod has just described how a lot of the core processes around neurological care are the same, so rather than reinventing the wheel, how do you think we can develop core standards that can be separated when we need to look at different neurological conditions such as Parkinson's and epilepsy, which might involve different needs than motor neurone disease? I am thinking about people doing non-invasive ventilation at home at night, for example.

Professor Macleod: We are talking largely about specialist nursing support. Some of the needs are generic and apply to all patients, and some are specific to the disease in question. However, non-invasive ventilation might apply not only to patients with motor neurone disease but also to those with myasthenia gravis and other neuromuscular conditions.

I have been concerned for a number of years about what I call diagnostic apartheid. If you come to my neurology service in NHS Forth Valley and you have one of five conditions, you can get access to a specialist nurse. However, until very recently, if you did not have a condition that was on that list you would get nothing. The growth in generic neurology specialist nurses—we now have two in post in NHS Forth Valley—is very important.

In terms of audit standards, there is process audit and outcome audit. Outcome audit is quite difficult, because the outcomes that we do not want to see are, thankfully, quite rare. If you measure a service against valproate-exposed pregnancies, for instance, those are very rare events so you might not get enough information to feed back to the improvement process.

Process audits are difficult, and the experience, both from the cancer-tracking audits and from the Scottish stroke care audit, is that they require a bit of admin to work. When I see a patient in the transient ischaemic attack clinic in Larbert, I fill in a form that goes to an audit data controller, who inputs the information, which then gets fed to the Information Services Division of the NHS in Scotland, and that information comes back on a monthly basis so that we can see how well we are doing. If you want to do a similar thing for neurology, you will need audit workers in every neurology centre to capture that information.

I echo John Paul Leach's point that the patients who we see in our clinics are a very small proportion of the patients who have neurological conditions, and a focus just on neurology services, to the exclusion of primary care, is not going to resolve the bulk of the problems with services for neurological patients.

Pamela Mackenzie: The new standards that are being applied are quite different from the 2009 clinical standards. There are some similarities, as has been said, but the new standards encompass the whole person. They do not take an acute-hospital approach to things. They involve a pathway approach to people with a variety of neurological conditions, to help them to live life to the fullest and to get the best outcomes from a health perspective, a wellbeing perspective and a family perspective. We would hope to see that being driven through the standards, so that we are looking at the whole person rather than purely at clinical outcomes.

Mairi O'Keefe: I echo some of the comments about the commonality of a lot of the nursing care for people with neurological conditions. At Leuchie house, we look after people with 35 different conditions, provide just under 6,500 respite days and look after people from 26 local authorities, so we are able to talk effectively about the situation throughout Scotland.

We developed our service—not just respite care but what we call the Leuchie MOT, which you have probably read about—so that we can fully assess our guests' physical and emotional requirements when they are with us. Every guest gets a wheelchair assessment and gets weighed, which is difficult in the community. Everybody gets a wheelchair alignment, which can change because of degeneration. Everybody gets pressure mapped and gets a full body map. Everybody gets an oral assessment. We are working with volunteer pharmacists to spot polypharmacy.

We are a nurse-led and physiotherapist-led service. We are able to impact not only on the guests but on their carers, because carers can come and stay with their partner if they so wish. We can work with them as couples or individually on both their physical and emotional requirements. Last year, we did more than 800 anticipatory or preventative interventions. It could be beneficial to use the third sector a lot more.

Tanith Muller (Neurological Alliance of Scotland): Specialist nursing is quite a complex area. There is a range of nursing interventions at different stages of different conditions and a lot of variety in the role that specialist nurses perform in different conditions. An epilepsy specialist nurse will offer a very different package of support from an MND nurse specialist.

It is important to consider the whole journey—not just the in-depth, advanced neurological care but the stuff that is provided up front. For example, in the condition that I work in for my day job, a Parkinson's nurse specialist advises people at diagnosis about the risk of impulse-control disorders from the medication that they are taking. Dealing with the mop-up of that is an important part of the support that they provide that is not relevant to other conditions but is distinct.

The point about specialist nurses is broad. One of the opportunities in the action plan work is to deal with the breadth of experience that there is and try to ensure that we have pathways and general rules that apply where there are general points but also recognise the fact that there are significant differences in the needs of different people in the community.

Emma Harper: In 2009, when the standards were written, we did not have health and social care integration. Other members will ask more detailed questions about that. Community care—your home being the best place to have your care for your health, wellbeing and family—will be part of new standards being developed. The witnesses should feel free to comment on that.

Mairi O'Keefe: We all welcome integration. There is nobody in the room that would not want it. However, it is embryonic and, just now, a lot of people are falling through the cracks. I am not saying that, in 10 years' time, it will not be fantastic but, until we manage to get out of the silos and get much more joined-up thinking, a lot of people will fall down between the silos.

Pamela Mackenzie: The health and social care partnerships are embryonic at the moment. To get it right, they need strategic commissioning guidance. They are inexperienced in the delivery of the pathway approach for neurological conditions, so I would welcome some commissioning guidance for them so that we get away from generic tendering and commissioning that does not offer clients with complex neurological conditions the right service at the right time.

Sandra White (Glasgow Kelvin) (SNP): I am pleased that Tanith Muller mentioned epilepsy because I have been given a pie chart and epilepsy is not mentioned in it under neurological diseases.

I note that the 2009 standards mention epilepsy, but only its specific indicators. I wonder whether you could expand on that, because, after all, you would expect the new standards to look more at the situation with epilepsy. I might ask about specialist nurses later, but what are your thoughts on that matter? Other conditions were not mentioned in the 2009 standards, which just gave specific indicators for epilepsy, and epilepsy itself is not even mentioned in the chart that I referred to.

10:15

Dr Leach: The older standards mentioned rapidity of access to care for epilepsy and first seizure. We know that the epilepsy sub-group in the national advisory committee on neurological conditions is one of the more active; indeed, it has been very proactive in setting out its ambitions for how epilepsy care in all areas of Scotland should shape up. This is very much at the heart of what the NACNC will be doing, and the epilepsy sub-group representative is very prominent on that committee.

I am surprised that the chart that you have referred to does not mention epilepsy. As you know, it is one of the most common neurological disorders; it is, if you like, at the other end of the spectrum from the severe, degenerative, progressive conditions that require residential care and which many witnesses will talk about. Most people with epilepsy will be able to lead a full and seizure-free life, but they need good medical care and intervention from doctors and nurses.

Tanith Muller: Epilepsy Scotland is represented on the standards development group, and, as I understand it, the condition-specific standards for epilepsy are deemed to be continuing while the generic standards are resolved. However, I have no doubt that colleagues in Epilepsy Scotland will be making the case for having the best possible support.

I am also aware of a Scottish intercollegiate guidelines network guideline on the management of epilepsy that was published fairly recently, and I know that that has formed a great part of the work of the epilepsy sub-group that Dr Leach has referred to.

The Convener: As has been said, the issue with the existing standards is the lack of application and implementation. Who will be responsible for monitoring the effectiveness of the forthcoming national action plan and the implementation of the standards? What will happen if the standards do not come up to scratch? Does the national advisory committee, which has been mentioned, have the authority to play an active part in the matter? We have heard about its importance, but we have also heard that it needs to be reinvigorated and re-empowered, which must obviously give some cause for concern.

Tanith Muller: It is safe to say that the third sector community has on-going concerns about the implementation and monitoring of new standards. Healthcare Improvement Scotland is stepping back from that scrutiny role, which is leaving a gap. As lessons from history show, the neurological standards lost energy when Healthcare Improvement Scotland loosened the reins, and after the boards got the £1.2 million investment for carrying out local improvement work, which has been referenced, it became much more difficult to hold them to account. The former national advisory group attempted to do so, but it was not really resourced to do it properly. As Pamela Mackenzie has said, there is a case for giving the national advisory committee more resources if it is to be the body that takes on that role, and I will be interested in seeing the work that emerges.

Mairi O’Keefe: Sue Ryder’s recent work on plans in the 31 integration joint boards was very worrying, as it highlighted that some areas had no plans at all. If there are no teeth behind the approach, when difficult decisions have to be made on budgets, people say, “Well, we don’t have to adhere to that.” It is a shame to say that, but it is the case.

Pamela Mackenzie: As I said, it is essential that we have sufficient resource to implement and scrutinise the standards. Whether that resource lies with Healthcare Improvement Scotland or the national advisory committee is another question altogether, but it must be scrutinised. Every health authority was supposed to have an action plan for neurology. However, as Mairi O’Keefe said, our report in 2017 showed that only four authorities had a plan, but those were not active and were due to expire. It is absolutely critical that we get it right, so that we do not continue with the current situation.

Professor Macleod: In NHS Forth Valley, we got some of that money, but short-term non-recurrent bits of money are not much good, because you cannot make long-term investments with them. When we are measuring services and auditing for accountability, which is what it sounds as though we are talking about—a minimum set of standards that must be achieved—the problem is that, if a board does not have the resource to recruit staff or provide the service, we end up setting people up to fail, because all that they will be able to do is report that they cannot achieve what they have been asked to do. Nobody wants to be involved in that kind of activity if there is nothing that can be done to sort it.

The elephant in the room is that the reason why people are concerned is that neurological services in Scotland are not optimal. That is not because we do not audit them enough; it is because we do not resource them well enough. If the attempt to create an audit and standards system is some kind of sop—a way to say that we are doing something, because something must be done—it is a waste of everybody’s time. The resource and activity should be invested in the primary services that we are trying to audit.

Dr Leach: I echo some of what has been said. I do not like to speak for the NACNC, but we have to make sure that it is well-enough resourced and empowered so that it can speak truth to power and say when things are not going well. That requires the resource for it to work out what is not going well and the mechanism by which it can report upwards.

One of the recurrent themes in the advisory committee, in its current and previous form, is that we have not been encouraged to talk about workforce. The W word should not be mentioned because, if we start talking about workforce, we might have to talk about recurrent money to spend on more staff at the front line and in chronic care for neurological conditions. A committee like the NACNC cannot be bidden to keep away from politically sensitive issues. If people want the truth, they have to be prepared for some uncomfortable news about workforce.

The Convener: Is that about priorities at board level or in the Government?

Professor Macleod: If you mean priorities for funding, boards are underfunded. Most of them are running a deficit and scrabbling hard to save what money they can by not filling posts if they can avoid it to create a salary gap and all that stuff, because they are skint. If you had chief executives in here, they would tell you that they are largely skint.

The Convener: We do, and we hear that.

Pamela Mackenzie: We cannot get away from the fact that there are budgetary pressures. However, in planning for neurology services in the future, we need to think about where resources are currently allocated. They are not necessarily allocated in the right way but they could be, if we had a pathway approach.

We have already talked about low-level services that can support people in the community for longer, be that with benefits or by managing their condition through specialist nurses or advisers. We do not invest in that level, which means that we hear from people only when they go into crisis. That means that they go into the acute sector with an expensive hospital stay, which can be avoided with the right preventative services.

The pathway approach to neurological care in its entirety is not resourced in the right way. We need a radical reshape of the current services to free up resources so that we can deliver things in a different way, bringing care closer to home—which is what we all want—and avoiding costly hospital interventions, which are not great for the economy and certainly not great in terms of outcomes for individuals or their families.

Mairi O'Keefe: I echo what Pamela Mackenzie said, because a lot of the work that we do at Leuchie does not require a lot of time with the guest or a lot of resource. One of the major things is pressure mapping. When a guest sits in their wheelchair, we put a tiny little mat underneath them that is linked to a computer, and we can show them the red areas where the skin is likely to break down. We work with the guest on how to avoid that, using core exercises and physiotherapy.

The amount of money that the national health service saves if that skin does not break down is huge. It is difficult to quantify, but we are working with high-resource individuals and their carers. We can work together with them on things that will make their quality of life better. Coming to Leuchie is not just about having a fun holiday or the respite aspect; the real miracle of Leuchie is what we equip our guests to go home with, which is about their quality of life.

Professor Macleod: In the past, one of the frustrations has been that, because the money in our glorious Scottish health service does not follow the patient, the savings also do not follow the patient. Over the past 10 years, we have reduced the bed days that we use in Lothian by about 75 per cent, which is a substantial saving, but those funds have just disappeared; they have not reverted to the neurology service to allow local reinvestment to support the activity, and that is a difficulty.

If we can get beyond the point where we are saying, "We'd like more money, please," we can begin to ask how we can be more efficient and effective and how we can prioritise better with the funds that we have. That is where we are. We have to decide what our priorities are, because we cannot have everything being a priority. We have to think about key areas for improvement, rather than say, "This is the minimum standard, which everyone should aspire to," when everyone knows that it is hopelessly optimistic and that we are just setting ourselves up to fail.

My emphasis is on having a small number of areas where we think that it would not take much resource to make quite a major difference to the experience of people with these conditions. We should try to get some kind of local or national consensus on what those areas should be and how to measure them. That is how we can get most out of the process.

Jenny Gilruth (Mid Fife and Glenrothes) (SNP): Pamela Mackenzie's written submission states:

> "Health and Social Care Partnerships (HSCPs) are under no compulsion to specifically include neurological services within their remit—unlike other service areas such as palliative care—and there is little or no mention of care and support for people with neurological conditions in any HSCP strategic plans."

Why do the partnerships not recognise that it is part of their responsibility to deliver neurological services? Is that just because it is not compulsory? What is going on there?

Pamela Mackenzie: There are a couple of things. In each authority area, the numbers will not be big enough for neurological services to be seen as a priority. Older people will always take precedence, because there is a growing number of older people and there needs to be a shift in the balance of where care is provided.

The numbers have something to do with it, but it is also because there is just no requirement in relation to those services, so people with neurological conditions get lumped into other categories. For instance, neurological conditions are normally categorised under physical disability. The joint commissioning plans for the integration bodies currently make loose mention of neurology under physical disability, but they do not mention it in its own right. As I said, we need to get commissioning for neurological services right, so there needs to be guidance and expertise.

The issue is not being consciously ignored, but it has fallen off the political radar and everybody's radar, and it is only in the past 18 months that the real inadequacies that people with neurological conditions are living with on a daily basis have been highlighted.

Mairi O'Keefe: The neurological conditions that we are talking about are all palliative—they will not get better. Unfortunately, it is just beginning to be recognised in the palliative care strategy that neurological conditions are a palliative situation. We do not get parity in funding. We do not provide end-of-life care—although unfortunately that does happen—but all the conditions that we deal with are palliative; they are not going to get better.

Tanith Muller: I want to switch back to the question of why neurology is not included. Way back when the integration legislation was going through, the Scottish Government did an exercise about which services would compulsorily be part of integration, and neurology was not one of those. That is partly where the split arose. Neurology is seen as an acute specialty, and there is no recognition of the huge amount of work that health and social care partnerships do to support people to live day to day with neurological conditions. People do not separate it out in that way, because neurology is seen as an acute specialty.

Pamela Mackenzie: One way round that is to give the partnerships delegated authority to be able to develop plans for commissioning neurological services.

10:30

Jenny Gilruth: Pamela Mackenzie's written evidence highlights that disconnect at the local level and the disparity across the country in how services are provided. In 2017, you asked health boards and local authorities whether they had a specialist neurological rehabilitation team, which would include specialist occupational therapy, and you found that only a third of health boards and only five of the 32 local authorities had such a team. Your submission states:

> "Many local authorities and health boards believed a service or partial service was available locally but did not necessarily provide it themselves. This paints a picture of a complex and piecemeal system".

What impact does that piecemeal system have on service users?

Pamela Mackenzie: It is a postcode lottery. You mentioned the shortfalls in the provision of community rehabilitation teams. If someone happens to live where there is such a team, they might have access to it, although only if they have been pointed in the right direction. A lot of general practitioners will not know that it exists.

In collecting that data, we found real confusion in that local authorities thought that health services provided the teams, and health services thought that local authorities provided them. That was in the same geographical areas, so there was a real disconnect there.

We know that good rehabilitation services—both preventative services and those for acquired neurological conditions—can have a huge impact on people's wellbeing. Although progressive neurological conditions cannot necessarily be prevented, the health complications that can ensue can be prevented through rehabilitation.

The Convener: What are the neurologists' views of what IJBs should be doing in that space?

Dr Leach: Again, I stress that we are talking about a spectrum of conditions. There is always a danger of unintended consequences. If we divert all neurology services, or a majority of them, to the chronic and degenerative conditions, we will ignore much of the acute work that needs to be done. We cannot take the people who deal with presentations of acute neurological problems away from the front line to do other things and expect no adverse events.

I stress that what Sue Ryder and Mairi O'Keefe's care home do is absolutely vital and will be state of the art, but there are other aspects of neurology care. To be honest, I was slightly concerned when the Sue Ryder report came out and said that Scotland is failing neurological patients. We are failing some patients at one end of the spectrum of neurological disorders and we have to look at the whole spectrum.

The big problem is that an unintended consequence could be a derogation of acute neurology care through focusing too much on the long-term conditions. We need to look at all of the issues that have been raised—I am not saying that anyone should be ignored or that we should ignore the pressing matters of long-term care—but we cannot forget what neurology means in its totality.

Professor Macleod: There is a slight danger that we think that one size fits all and that we need a specialist occupational therapist for every patient in the community. If you are dealing with outreach from the Astley Ainslie hospital for people who have acquired brain injury, clearly, you will need those high-level specialists. However, if the patient is repatriated to Achiltibuie or wherever they live, it might be more reasonable to have someone who has more generic skills and can cover a range of patients in that population area. It is not necessarily the most cost-effective approach for every board and every service to have a full set of services. There should be an allowance for flexibility and local implementation according to local needs and local patterns of disease, which can vary in different parts of Scotland.

Tanith Muller: If I wanted to know what was happening in neurological services, I am not sure that I would ask either health boards or local authorities, as they would not necessarily know what is happening on the ground. That is one of the big issues. My suspicion is that, although the data looks bad, if someone has survived a stroke, there will be some specialist support for them locally. In most parts of Scotland, there will be support for people who have MS or Parkinson's, and it will be provided in the community. That is not reflected in the answers that Sue Ryder got in its report.

One of the challenges is that the picture is really complex and is difficult to measure and audit. We need to agree what we think there is. We can use all the intelligence that we get from different agencies to map what is where and where it is going. That is one of the good things that the national advisory committee is doing, because only when we really know that will we be able to move forward and work out what needs to change.

Pamela Mackenzie: Just to give some reassurance, our "Rewrite the Future" reports in 2016 and 2017 did not set out to discredit acute services in any way, shape or form. Indeed, we acknowledge that there is some great work going on. Sue Ryder is not involved in just high-end care for people; we also provide very low-level services involving self-management and care at home. We cover a wide gamut of care provision, offering individuals choice.

On Malcolm Macleod's point about specialism, one of the conclusions in our 2017 report is about educating more generalist providers so that they can provide a high-quality service. We do not have to have a specialist nurse in Achiltibuie, for example, but we may be able to educate and support the providers who currently deliver care-at-home services or community services there to deliver a better service so that people can stay at home for longer, their conditions are managed better and they have fewer health impacts.

Brian Whittle (South Scotland) (Con): Good morning, panel. You have touched on the potential lack of data to inform development of an action plan. Some of the written submissions point out that, in relation to neurological conditions, prevalence data is lacking and service provision data is hard to identify or is missing. Professor Macleod called for the

> "incorporation of Community Health Index (CHI) tagging of activity in primary care"

and across social care activity. How does the lack of data hamper provision of services for people with neurological conditions, in particular since most of those people's diagnoses are known to the health service and social care services? Why is there a lack of data and what data is required?

Professor Macleod: We do not have disease registries. We see patients in our neurology clinics, we write their GP a letter, the GP gets the letter and then we perhaps need to see them again. However, we do not feed that information into a central database of who has what condition. There are good reasons for that, which are to do not only with the burdensome nature of the task but with privacy and so on. That means that, when people ask us how many patients we have with myasthenia in our patch, we do not know unless we trawl through the 10,000 letters from the past year to try to work out what the numbers are.

It is, potentially, feasible to have a registry of patients who are seen in neurology clinics and who have neurology diagnoses and what those diagnoses were, but that would miss the large number of patients who have previously been seen in neurology clinics and discharged for care in the community. Patients with epilepsy, for example, might not have been seen in a clinic for many years, for the good reason that they do not need to be seen. That approach would also miss the large part of the iceberg that sits under water: the patients with neurological impairments who have never been seen in a neurology clinic because they are managed in primary care.

Therefore, although it is a nice idea to have a list of where people are, what services they are using and what their needs are, it is complicated to implement that. That said, the idea that where people impact on publicly provided health or social care services that activity should be recorded through the CHI number, would at least allow us to see where patients are. For instance, for valproate—which is one of our epilepsy drugs and which is a risk in pregnancy—we have CHI linkage of information on patients picking up valproate prescriptions from their community pharmacy with information on people who interact with our obstetrics services. By matching the numbers, we can see the people with epilepsy who are using obstetrics services. The more CHI data we collect, the richer that source of data will become in terms of enabling us to understand where our patients are and what services they are accessing.

Mairi O'Keefe: I have been working with the ISD. There is a lot of data on the NHS, but the ISD's work to collate figures on social services and local authorities is still very young. It is working on getting a bigger picture of what is happening in the community as well as what is happening in acute services.

I am not sure what the effect will be of the Scottish primary care information resource, or SPIRE, which is the data service that is used with GP surgeries. We hope that it will bring in a lot more data, but it is still very young—it is just being rolled out in the west of Scotland.

Brian Whittle: I am interested in collection of data. Is there potential for anonymity for the patient? I assume that you do not attach a name to the data. Also, how will the targeting of activity across primary and social care through a person's CHI number benefit the development of services?

Professor Macleod: If, for example, a patient is seen in a neurology clinic and we discharge them because we think that we have sorted their headache, it would be interesting to know whether after that they were seeing their GP once in a blue moon or once a week. A CHI tagging for each GP visit would give a sense of that. Neurology services are in difficulty just now, but primary care is in great difficulty: many practices are really struggling, so that data is really important in terms of those of us in secondary care being able to help to alleviate some of the burden on primary care. Just chucking the people whom we see back to the GPs, thereby creating a burden on primary care for GPs or practice nurses, is not a good thing, but we do not know what the amount of such activity is in primary care.

However, those are low-level process or activity measures. We can do little bits on getting outcome measures on quality of life—which is the main thing—premature death or accident and emergency department attendances, for example, but it is difficult to get agreed measures and it is quite burdensome for patients, not the service, for that information to be collected recurrently unless people can be convinced, and we can be confident, that we will be able to do something useful with it.

One of the problems with the previous data and audit group was that we were collecting lots of information but there was the workforce issue, to which John Paul Leach alluded, of there being no prospect of getting much more in the way of services or neurologists. Therefore, the question was what was going to change for the patients by our merely demonstrating that there was a problem. Across neurology services, there was a lack of confidence that it was going to be much more than an elaborate window-dressing exercise, I am afraid. That is one of the reasons why the energy fell away.

Miles Briggs (Lothian) (Con): I will touch on community-based services and community care. The Sue Ryder submission identified the point that 86 per cent of people with neurological conditions are in residential care homes for the elderly, which I think includes about 250 younger adults. What can be done to address people being in inappropriate care places?

Pamela Mackenzie: We do not know whether that is correct: we think that the number is much more than that. The national care home census has included neurological conditions as part of the analysis of data so, in October, we will have more accurate information about the number of younger people who are in facilities for older people.

There will not be specialist provision for everybody, but as I said earlier about community services, there are ways in which we can support older people's care homes to enable them to support people with complex neurological conditions. I am not saying that the environment is necessarily right, but we could support staff to be better educated about complex conditions and to manage them better. We could do that quite quickly. It would need to be resourced, but we could manage it well. More community provision—for example, physiotherapists and occupational therapists—could go into nursing homes for people who have complex conditions so that their needs were being met.

When we highlighted that in our report, many people came to us saying that they had a relative in their early 50s in an older people's care home and that they were in despair because that was the only place where they could put them. On the back of that, we have one such case for whom things have very much improved. The person is still in that care home but is now having chest physiotherapy and postural management. Their quality of life has been significantly enhanced, although their placement has not changed.

We will not have specialist services everywhere. It would be wonderful if we did, and we should be aspirational enough to think that we can have more specialist residential provision, probably under a regional approach. There are things that we could do that could improve the situation.

10:45

Mairi O'Keefe: A lot of Leuchie house's guests are inappropriately in residential care. We work closely with residential services: for example, when we weigh our guests and discover that they have lost or gained weight and their pressure mattress setting is wrong but that is the setting that is being used in their care home. We are also able to liaise with residential services about wheelchair replacements or modifications, and about diet and what they require for healing for pressure areas.

We do a lot of work with people who perhaps come to us for four-night breaks, but are in residential care somewhere else. However, we have some people with primary progressive MS who are in their early 30s and are in the psychogeriatric care home. It is very upsetting. We had one guest who came from Wick. The local community funded her coming down and Loganair provided the fights. The difference to her quality of life in the two weeks when she was with us was amazing, as was what she took back to the care home.

Tanith Muller: The question of what happens to younger people with neurological conditions who need residential care is complex. We are aware of younger people who have found it difficult to find a place even in an older people's care home because such care homes will not take them. That creates a real barrier.

A number of the national and local charities provide training along the lines that Sue Ryder provides. The Scottish Huntington's Association and Parkinson's UK cascade learning for care home workers to help them to understand what they need to do to support younger people with neurological conditions. The Parkinson's UK scheme also works with home care workers to support people better at home. There are solutions, but they tend to be condition specific rather than generic, because there are no generic charities to provide such schemes.

Professor Macleod: The group of patients to which we are referring is small but complex. There are young teenagers and adults with neuromuscular problems such as Duchenne muscular dystrophy who have complex physical needs. There are patients with multiple sclerosis, as has been mentioned. There are patients with Huntington's, which involves physical and emotional or psychological problems that need management. Perhaps the greatest well of untapped need is young head-injury patients who have physical and behavioural difficulties after their head injuries, and for whom there is very patchy and limited provision.

One of the tangible difficulties is that, if I were to open a facility for young chronically sick patients with 10 beds in Forth Valley, it would be full in about six months and, because those young people will live for decades, it will remain full for decades and no more space will be available. Therefore, when we provide such facilities, we need to think about how empty we want them to be. We always want them to be a little bit empty, but how does that fit with the business model of whoever is providing the care? They would have to run at 70 per cent capacity all the time just so that they would have space to take people when they need it.

I do not know what John Paul Leach's view is but, for me, one of the tragedies of working as a clinician is seeing people in the wrong care setting—usually an acute hospital—because services are backed up down the line because there is no appropriate place where those people can maximise their quality of life. There is always a balance to be struck between such people being near their home and family and being in a centre of expertise and excellence. However, just now, most people have neither, which is very disappointing.

Dr Leach: I will reflect on the different—for good reason——perspectives that we have on neurological disorders. An estimate has been given that there are throughout the country 200 or 250 young patients in older people's care homes. Pamela Mackenzie thinks that there are far more than that and has other data. Is that one of the pieces of data that we really need to firm up? Does the problem affect hundreds or dozens of patients? We need to know. If we are to come up with firm recommendations about how we provide residential care, we need to have that properly scoped.

Miles Briggs: We have mentioned permanent care places. I want to consider respite care. I was lucky enough to visit Leuchie house last year, and I was blown away by the services that it provides. I could not meet some of its guests because they were out on a microlight flight. That is the sort of break that everyone wants their loved ones to experience.

In other parts of Scotland, a local old people's home becomes the respite option, and many people do not want to put their loved ones in that setting. Do you have a picture of the current provision across Scotland and where there is a real need for better investment in respite care, or for linking services to what we currently have? Mairi O'Keefe mentioned 26 local authorities, so what are the others doing and what quality of respite care do they offer?

Mairi O'Keefe: It is a postcode lottery, but we do not have enough data, so I would not like to give a definitive answer to that. However, we know that some local authorities with which we deal do not send people to respite care, or if they do they send them to a care-of-the-elderly environment, because that is cheaper than their coming to Leuchie. The guests at Leuchie are charged only 50 per cent of the actual cost; we raise the funds to pay for the rest of it. Because it is so person centred and we do so many anticipatory preventative interventions, it is slightly more expensive than a care home, but that is a short-term perspective. If you look at it in the long term, taking into account the preventative aspect, we are actually saving money for many people and giving them better quality of life.

We also provide emotional support and counselling. A lot of people are quite angry about their condition, and their carers, even though they do not have the condition, find that their lives have changed unbelievably. We need to look at the whole picture, but it is difficult to cost it. I take John Paul Leach's point that we tend to look after the high-end dependency people, but that is only two-thirds of the people. Another third of our guests are at what we would term the lower end, so we are able to work across the sector in all aspects.

However, respite is incredibly patchy across local authorities. Self-directed support is a great thing in concept, but when you are dealing with cognition and fatigue it can be difficult for a person to make decisions about an SDS package if they cannot compute all the details that they need: carers are already stressed when they go through the SDS assessment, so it tends to end up with them doing the easiest thing, which might not be the best thing for them.

Professor Macleod: For patients with a high level of disability who require and benefit from respite care, there is a danger of apartheid. My understanding of the new recommendations is that traumatic brain injury is not included on the list of neurological conditions, but the needs of such patients are almost identical to those of patients with Huntingdon's and other conditions. There is a real danger that we are siloed in our approach to audit, when we should be saying that this is about services for people who would benefit from periods of respite regardless of whether they have an underlying neurological condition. It is important to bear that in mind.

Tanith Muller: One of the things that people report to us, across the complex conditions, is that it can be difficult to get a respite place at all because complex needs can mean that there are a limited number of places where that will be taken on. I echo Malcolm Macleod's point about the scope of need and the lack of suitable respite across all the conditions.

We have not really touched much on the impact that living with somebody with a neurological condition has on families and carers, and how essential respite is to give them a break from caring for people who typically, at the more complex end, have needs across all aspects of their lives and require pretty much constant supervision, as well as the practical tasks of dressing, feeding and that kind of thing. That has an immense impact on carers, who worry very much about whether those needs will be met when the person for whom they care goes into respite. In my experience, some people resist respite because of those concerns, despite the effect that it has on their health and their ability to cope with their workload.

Mairi O'Keefe: I agree with Tanith Muller.

Pamela Mackenzie: The panel has described the lack of respite well. There is a postcode lottery. I agree with Tanith Muller's point, as people will resist respite placements, even to the detriment of their health. They will not have their loved ones go somewhere that they deem to be inappropriate.

We have been working with Angus health and social care partnership over the past couple of years on an interesting project involving respite at home. People are far more comfortable with that because they can, for example, have a round of golf or a couple of drinks with a mate. They prefer that to going somewhere to have respite through an older people's service. There are therefore alternatives to traditional residential respite, although that is still necessary and hugely beneficial. There are other ways that afford people choice.

Emma Harper: On that point, there are models of respite that are being developed. I know that, for example, NHS Dumfries and Galloway is looking at delivering respite in people's homes. However, there are challenges when there are specialist needs, particularly for children with neurological conditions, which is where Acorn house in Dumfries comes in, as has been said.

Mairi O'Keefe: I agree that there is a lot of flexibility in how people determine how they would like to spend their respite, which is right. However, there comes a point when it is just too stressful for many people: if people are coming into their house, they have to train them and help them to understand the situation. A lot of people find that to be more stressful than going into residential respite that they trust. We tell our guests and other carers that it is sometimes a daunting experience to come into respite, but we usually say "Give us two sleeps and everything'll be fine after that."

A person who comes to us is one of 20 people who are dealing with disability at home, compared to their being one person on their own at home. We have check-in and check-out and try to have the ambience of a country house hotel. We look after people with complex conditions, but we have that relaxed atmosphere that makes it so much easier. It takes 24 hours for us to get to know them and for them to get to know us, but we are all fine after that. We are experienced in doing that, compared to a team that goes into someone's home and is perhaps not completely au fait with the situation.

Sandra White: I have to correct what I said earlier about epilepsy not being included in the chart, because it is. I was trying to make a point about epilepsy because a head injury can cause brain injury that can cause epilepsy, which is outside what the chart deals with and is not recognised, as Professor Macleod said. I apologise if I misled anyone on that point.

I am wondering what the panel's thoughts are on the issue of respite with regard to voluntary workers and health and social care professionals. I might know what they are, but I would like you to answer my question. Is further investment needed in specialist nurses for people with neurological conditions? I fire that out, although I am sure that you will all answer yes. Perhaps you can say why more investment in such nurses is needed and what they bring to people with neurological conditions that others cannot.

Mairi O'Keefe: We have touched on the fact that although there is a generic aspect to much of the nursing care, there are also specific aspects. We need a two-pronged approach, one part of which is the generalist part that covers a lot of needs aspects in training. However, as Tanith Muller has explained, there is also a need for specialist nurses. People can be seen by specialist neurological nurses, and we deal with people with Parkinson's and MND and those who need non-invasive ventilation. We need to have a broad spectrum of ability available, and at certain stages on the pathway there is a need for specialist nursing care.

11:00

Pamela Mackenzie: The simple answer is yes, but the situation is much more complex than that. This morning, we have been describing people's journeys from acute illness right through to the ends of their lives. At various points, they will need to access specialist advice and support. Although it would be great to have more resource, that might not necessarily be the best use of it, as there are other ways of supporting people.

The reason for my saying so is that, at the moment, across the United Kingdom, we have test areas in which we are providing lower-level services involving self-management, which are nurse led. One community nurse specialist oversees that project, but it is healthcare advisers who support people in living with and managing their conditions. There are more cost-effective ways of using the limited resources that we have in order that we can benefit people. Although specialist nurses are fantastic—I absolutely advocate their use—I would not want to say that they are the only solution to people's problems.

Dr Leach: When asked whether we need more resources, my first response as a health professional is, of course, to say yes. However, the extent of that need is important, and working out that extent will require more data. That is where the NACNC's bid to scope services across the country will be so important. For instance, if we could work out how many patients with a new diagnosis of epilepsy do not get to see a nurse, we would have a measure for how many more epilepsy specialist nurses we need. If we could work out how many people with Parkinson's do not have regular reviews of their medication with a nurse and do not get help at home with anything that they need from the nurse, we could answer that question properly. Therefore I will say yes, but I will not know how big a yes that will be until we get the data. We should be charging the NACNC with completing its scoping of services so that I could then tell the committee how big that yes should be.

Professor Macleod: I agree with Pamela Mackenzie that the issue is not just about nurses. Some of the role is disease specific, but there is also some signposting about services. For example, life-skills coaching and counselling go on, and various healthcare professionals can have such skills.

I will make a couple of observations. First, across our diseases, we have different acceptable case-load burdens for nurses. For example, a community psychiatric nurse might look after 20 or 30 patients, a motor neurone disease nurse might have 20 or 30 patients on their patch and it might be the same for a Huntington's disease nurse. However, an epilepsy nurse or a Parkinson's disease nurse will deal with hundreds of patents, or sometimes a thousand. It is interesting that the nurses with fewer patients tend to integrate much better across the primary and secondary care divide than those who deal with hundreds of patients with epilepsy and who see themselves as hospital-based epilepsy specialist nurses. If we have increased numbers of specialist nurses, there will be opportunities for better integration with social care.

The second point is that for most neurology units that have very small numbers of specialist nurses there is a problem for continuity of service when a nurse retires or moves on. For example, we have two multiple sclerosis nurses, which is good because, if and when our senior nurse decides that she has had enough and will retire, we will have a ready-made replacement to step into her shoes. For other conditions, we have only one specialist nurse, so if that nurse retires we will have to train another nurse from scratch.

There is not really a career structure for neurology specialist nurses. To my mind, a career structure that started off with someone deploying generic neurology specialist skills and then, later into their career, moving into a specialisation in a particular condition would allow us to have continuity. Not long after I started in NHS Forth Valley, our epilepsy specialist nurse left and we went eight months before we could appoint another one. That was very difficult for patients and for us. The situation was partly because there is such a small number of those individuals: they are like gold dust.

Tanith Muller: The Neurological Alliance of Scotland would say yes—we would highlight the role that specialist nurses often have in relieving the burden on their consultant colleagues by identifying people who really need to see consultants. We would probably also highlight the fact that it is not just about nursing support and that physiotherapy and occupational therapy are two of the other allied healthcare professions in which people would look at using professionals with insight into specific neurological issues rather than musculoskeletal and general ones, because they are so crucial to helping people to retain function and to do well. That applies across all conditions, not just degenerative ones.

Sandra White: That was very interesting. Thank you.

Ash Denham (Edinburgh Eastern) (SNP): Before the meeting, I was interested to read in the Sue Ryder written submission that the organisation is

> "working with New Economics Foundation ... to develop an economic model of neurological care"

in the hope of demonstrating the positive impact that it could have on the public purse. Will you please tell us a little more about that?

Pamela Mackenzie: This is hot off the press—I got the data only yesterday. We have kept on saying that investment will produce a saving, but that has all been anecdotal—we have not been able to demonstrate it—so we have done a piece of work on that with the New Economics Foundation. We have taken three case studies: one involves someone with an acquired brain injury, one involves someone with motor neurone disease and one involves someone with Huntington's disease. They are real people whom we know. We have mapped their lives to date against a reactive pathway and a proactive pathway. Some of them have had a proactive pathway and some have had a reactive pathway.

Once we have our report, I will be happy to share it with the committee. I have not yet analysed the information in great detail, but I can give percentages today. If a person with acquired brain injury follows a proactive rather than a reactive pathway, that produces savings of 75 per cent to the health economy. That means that the person goes through a proper rehabilitation programme and their condition improves, as opposed to not getting the right rehab or the continued rehab that they need. I was shocked to see that massive percentage.

If a proper pathway for the management of people with Huntington's disease is followed, the cost benefit to the health economy is 45 per cent. The committee will not be surprised to hear that the position is the same for people with motor neurone disease, for which the saving would be 56 per cent.

There is a lot of detail about how those costings have been produced. We have costings per year and we have extrapolated them for the average lifetime. Once we have had time to digest the information, we will share it with the committee. I brought these pieces of paper that are sellotaped together so that I could demonstrate those savings today.

Ash Denham: That sounds interesting and positive. Is the panel aware of similar cost benefit analyses that might help with national planning? Is that the only such study?

Mairi O'Keefe: As I said, we have worked with ISD and we reckon that, if a guest comes to Leuchie at a cost of, say, £2,000 for a fortnight instead of going into hospital—a lot of our guests have to go into hospital for high-dependency care if they have non-invasive ventilation, because care homes will not accept that responsibility—that probably saves about £5,000 a week.

Dr Leach: For people with refractory epilepsies that may require medium-term residential care, we have the William Quarrier Scottish epilepsy centre in Glasgow, which is a state-of-the-art world-class epilepsy centre. We know that, although admitting patients to that centre might involve a short-term cost, exactly as Mairi O'Keefe described for her clients, there is a definite pay-off in reducing the need for acute care, emergency admissions, assessments at accident and emergency, and ambulance journeys. All those things are saved, so there is a definite net saving. I do not have the figures to hand, but that was in a bit of work that Gerard Gahagan and Maria Oto at Quarriers did.

Ash Denham: So that work has been done and the figures are available.

Dr Leach: Yes.

Professor Macleod: With my professorial, rather than neurological, hat on, I am always slightly dubious about data that I get from drugs companies about how good their drugs are, so we need to be careful that we have independent cost utility or cost benefit analyses of services, because it is clearly in the interests of people who provide services to show how valuable those services are. I do not doubt that such services have value, but I think that those who make public resource allocation decisions want to do so on the basis of the best information.

Our theme running through today has been that we do not have good starting-point information on how many patients there are, what the demand is, what the impact of the various services might be and, therefore, what the cost saving might be. Of course, we have to proceed on the basis of the best information that we have available. However, if committee members were to read some of the business cases that I make to my employers—I hope that they are not listening—about how a little bit of money spent on something will transform the whole of NHS Forth Valley, they would say that I was putting an optimistic gloss on what might be possible. We need to be careful about that.

Alison Johnstone (Lothian) (Green): This has been a very interesting session. The staff whom we have in place are obviously key to the delivery of the best neurological services. I have certainly experienced that when visiting Leuchie house and other facilities across Scotland.

Malcolm Macleod's submission states that

> "most if not all neurology services in Scotland struggle to meet performance targets both for urgent and routine new patient referrals"

and mentions delays for follow-up appointments. It also says that there is a problem with recruiting to neurology posts. I would like to understand how those delays affect patients and what we can do to solve the recruitment problem.

Professor Macleod: We have recent experience of the recruitment problem in NHS Forth Valley. As I was saying to John Paul Leach on the way in, when I were a lad, the idea that a vacant consultant neurology position in Scotland would not have a single applicant would have been incredible—and yet we had a post for which we did not get any applicants. I would like to think that we are a reasonable place to work, with a nice environment and all of that. There are recruitment issues, for sure.

In terms of the harms that might come to patients, I would like to think that, on receipt of a referral from a general practitioner, if it was clear that a patient needed to be seen urgently, we would push the boat out to do that. Often, that means phoning them up to say, "Come at 8 o'clock and we will see you before the clinic starts". However, although we should see people on our waiting list for urgent out-patient appointments within 10 working days, it takes more like three or four weeks. The target for seeing routine out-patients is 12 weeks, but it takes nearer 18 weeks just now. The same thing applies in most places.

On the question about what harm comes to patients while they are on the waiting list, I am not sure that there is a great deal of what might be called biological or medical harm, but there are lots of associated anxieties for patients who are waiting to be told that their condition is not anything to worry about, to have a scan that may show that everything is all right or to find out what treatment is needed. For people who have conditions that prompt their primary care physician to advise them not to drive until they get a neurological opinion—warning strokes, possible epilepsy and the like—it is most frustrating if they do not drive for that waiting period and then, when someone sees them after five weeks, they are told that they never needed to stop driving.

The recruitment issues are multitudinous. We should remember that real-terms salaries across healthcare have fallen by 15 to 20 per cent over the past seven years, so it is a less attractive proposition. I know of junior doctors leaving to work in finance, consulting and other areas, because they do not see medicine as the career for them—they can earn more doing something else that is perhaps almost as enjoyable.

We have particular issues in Scotland that relate in part to our ability to recruit from overseas, because of concerns about what might happen with Brexit. I am not aware of any major differences between Scotland and England, although I suspect that the situation is slightly worse here. Nobody likes to speak about this very much, but undoubtedly it must be affected by the difference between Scotland and England in the availability of higher awards, which used to be called merit awards.

We have tried to work out the lifetime chance of getting a higher award for a neurologist in England, which must be about 30 or 40 per cent. If someone who is leaving training and choosing where to work as a consultant elects to work in England, their chance of getting a higher award by the time they retire is about 30 or 40 per cent. In Scotland that chance is zero, and I think that that impacts on our ability to recruit.

There are a variety of reasons, and we need to do everything that we can to maximise the number of applicants. I would like to have five applicants for every job, so that I can choose the very best. Just now, I will take anyone who applies and makes it through to interview. I do not think that that is good for patients with neurological diseases in Scotland.

Tanith Muller: People who present with neurological symptoms in particular have high levels of anxiety because a lot of those conditions are very serious. Of course, fortunately, most of them do not have such a condition, but their worry is still profound.

The measures that health boards are taking to deal with the recruitment crisis are sometimes unhelpful. We use locum neurologists who do not know the local systems, which means that people get a diagnosis of multiple sclerosis, Parkinson's or whatever and are then chucked back into primary care without being referred to the services that exist to support them, so they struggle without the information that they need to manage their symptoms well. They are just not getting the information that they need, which is an additional problem for health boards as they try to respond.

11:15

Alison Johnstone: You said that people are sometimes put back into primary care without the appropriate information following them. Could greater multidisciplinary working in primary care improve support for people with neurological conditions?

Mairi O’Keefe: Yes. I will touch on the recruitment aspect, but there should be better communication between health and social care. It is really about the knitting together of health and social care; as that gets more mature and efficient it will make a huge difference.

At Leuchie, we are nurse led and physio led. I can talk only about the nursing aspects. It is no surprise that there is a national shortage of nurses, which will get worse. That is not an easy thing to solve.

There is also the care assistant side of things. It is a lot easier to work in Lidl or Tesco for not much difference in salary but with a heck of a lot less responsibility. The Scottish Social Services Council has introduced quite a lot of learning and development, which is absolutely fine, but a lot of care providers think that things have gone too far the other way. People might want to spend their career in care, but they do not necessarily want to have a level 4 Scottish vocational qualification in management to be a care assistant. We need to strike a finer balance there, because that is putting people off. Some people embrace learning and want to do it; others do not, but that does not mean that they are not good care assistants. We are in a rural area, too, which does not help. However, there are many ways to skin a cat. We have upgraded our senior care assistants to take on more responsibility, so the trained staff are doing what they are trained to do, although that is not necessarily a nice thing.

The use of agency nurses is a huge element. Agency nurses are paid really well. They can pick and choose which days they want to work and they will earn just as much as they would in a substantive post, but they have very little responsibility. I am not just talking about nursing but locum vets and pharmacists, too. We have allowed that culture to come in because we are not funding the positions as they should be funded. That applies not just to nurses and doctors but across the spectrum. The agency and locum aspect is extremely worrying.

Dr Leach: I seek your indulgence, convener, to return to Malcolm Macleod’s point about the data on Quarriers. That data about cost effectiveness is in the public domain and it has been peer reviewed, so I thank Malcolm Macleod for the opportunity to bring it up again—that was fabulous. [*Laughter*.]

The recruitment and workforce issues are important but, at the other end of the journey, we also have a retention problem. We have a difficulty with disillusioned, overworked, hard-pressed senior staff—I am talking about not just medical staff but nursing staff. Unless we do something imaginative to make sure that staff have a reasonable working experience, we will struggle to retain people beyond their mid-50s. That is a big issue.

I echo Tanith Muller’s point about using short-term locums and agencies, and bringing in consultants for a weekend to see patients at 20-minute intervals, so that they see 10, 14 or 20 patients a day. That is no way to deal with a condition such as epilepsy, Parkinson’s or MS, which are lifelong conditions. Just giving someone a label and sending them packing back to the GP is expensive and it is not useful.

Professor Macleod: I detest that idea of bringing in people from outside. It is driven by a desire for boards to meet their waiting time targets but it is very disruptive. We had people coming in to do clinics over the weekend and we audited what happened. The rate at which they requested investigation was much higher than the rate of our in-house neurologists; the rate of complaints was much higher; the rate of return appointments made was much lower; and the chaos that ensued was much, much worse. It would have been quicker for me to see those 100 patients, given the time that it took to try to clear up the mess afterwards. It was very disruptive.

Alison Johnstone made a point about closer working with primary care. Some years ago, for about a year or so, I did neurology clinics in primary care practices around the Forth Valley patch—out in Callander, Sauchie and so on. Although it was great fun, I do not think that there was any great added value for the patient in being seen by a consultant neurologist in a different environment. I do not think that we need to think about pushing out that kind of diagnostic interaction into the community, but the other part of what we do—particularly in relation to care and specialist nurses—could very reasonably be pushed further out into primary care.

Ivan McKee (Glasgow Provan) (SNP): This has been a very interesting session so far. I want to follow up Ash Denham’s questions about the economics and the cost benefit analysis. I very much look forward to seeing the work that the New Economics Foundation has done for Sue Ryder.

I take Professor Macleod’s point on board—I have spent a lifetime being cynical about the purported benefits of spending on one thing to get a saving elsewhere. However, the reality is that if you do things better and spend money in the right place, you will make a difference—we have had many concrete examples of that this morning, including the point that we have just heard about consultants.

I want to explore that a wee bit further. First, what mechanisms are in place to allow us to analyse such things? I think that the answer is probably that there are not very many and that such activity is very ad hoc, which is bad. However, it is also good, in the sense that there is a lot of opportunity there. Secondly, what changes to structures have to be made? I think that we have touched on that, in relation to the savings not following the patient. What changes do we need to make to how we measure and track money in the decision-making processes, so that the person who makes the decision about investment is in the part of the organisation that gets the benefit from the saving and is able to reinvest? Could you explore those areas and give us your thoughts on ways forward?

Professor Macleod: There is a problem with inter-board transfers. There are probably four boards that have in-patient neurology services and the rest avail themselves of those services as and when they need them. The cost of transfers between boards is reconciled in accordance with what are called blue book agreements. At the end of three years, people tally up who moved in which direction across all their services—the cross-boundary flows—and they work out an overall number. They can then say that Lothian owes Forth Valley £X or Forth Valley owes Lothian £Y.

It is almost impossible to unpick the costs—I have struggled with that over the years. However, one of the great benefits of having a socialised healthcare system is that you do not have to count every penny in every area to generate a bill that goes to a patient at the end of the day. There is a substantial cost saving—we see that in the difference in the cost of the administration of healthcare between here and the US, for instance.

The downside is that you do not have access to that information to manage your services adequately. It should not be beyond our wit to be able to avail ourselves of new information technology and the like so that we can capture things in much finer detail, understand what is happening where and try to allow those funds to follow that activity.

However, my experience of NHS finance is that it is a big, massive thing and nobody really understands the big picture. Trying to get money to flow from one bit of the NHS to another is incredibly complex. Either you bite the bullet and say, “We are going to understand every penny and what it was spent on,” or you say, “Actually, we trust you to do just about the right thing but we would like you to do a bit more of this,” which is how it works—or does not work—just now.

Ivan McKee: Mairi O’Keefe talked about specific examples, such as pressure sensors, which would deliver savings further down the line. Such things are very small but obvious, and they all add up. I will be interested to see the detail behind the New Economics Foundation evidence, which will include similar examples of where doing X saves Y. Are there not many small dots that could be joined at a micro level to make things easier?

Professor Macleod: The saving never goes into the budget from which the expenditure was made. A bit of money is saved in one area, by spending a bit of money in another area, but you end up spending more. There is no way of matching that up, even if the saving is identifiable. For example, if I have a great neurology service, which means that my patients with epilepsy have 5 per cent or 10 per cent fewer attendances at my emergency department, that money is expenditure foregone—it is money that is not spent, but it is not in a briefcase for someone to deliver to my neurology service so that I can employ another epilepsy specialist nurse.

That is the difficulty with trying to attribute savings to allow expenditure, which is what we would all like to be able to do.

Pamela Mackenzie: We took a stab at trying to demonstrate that, because the data is not available and we cannot say, “If you do this, you will get that”. The way in which resources are allocated is hugely complex. We had a perhaps naive hope that the integration of health and social care and pooled budgets might help resource allocation. That might come and it could be very helpful, but we are a long way off.

The detail in the stories in the case studies will make interesting reading, particularly in relation to some of the interventions that have clearly provided cost savings. We wanted to be able to demonstrate that to commissioners in particular, so that they could think about things in a different way.

Ivan McKee: Is the Government not doing that at all?

Pamela Mackenzie: No. We commissioned that piece of work ourselves.

Ivan McKee: Are you aware of the Government doing any work in that area?

Pamela Mackenzie: No, I am not aware of any work.

Brian Whittle: I have a particular interest in the preventative agenda. You mentioned the difficulty in allocating money that we have not spent. Is there a way in which we could look at that in relation to the preventative agenda—taking the money that we do not spend and allocating it somewhere?

Mairi O'Keefe: You could give it to us. [*Laughter*.]

Professor Macleod: I gave the example of the savings that would be made if someone did not attend A and E, so let us break that down. There is an opportunity cost of A and E attendance—someone has had to use a syringe to draw blood and the blood has to be sent away to the lab. Some costs would be incurred anyway, because the patient has to be seen by a doctor for half an hour, but if the patient does not turn up, it is not that the doctor will not be paid for that time; the doctor will do something else instead.

The costs could be saved if we could change the way in which accident and emergency is run so that it does not incur those costs. There is an issue there about the link between the ability to reduce our reliance on, for instance, well-staffed accident and emergency departments, and that reduction leading to savings. Reducing the number of people with epilepsy who attend accident and emergency is not going to make accident and emergency's bills go down by very much. The costs are not going to change very much at all.

Trying to get into the detail of where those savings are and what they might be is difficult. Collecting more information might be helpful but I am not altogether confident about that.

Mairi O'Keefe: When guests come to Leuchie, we have a unique opportunity to do a 24-hour assessment—something more than just five or 10 minutes in a GP surgery or a social worker visiting the house. From that, we are able to ascertain a lot more detail and information, which we feed back to the community teams.

Sometimes the community teams do not want to listen to that information. It might mean that a guest will need to be hoisted in the evening while, in the morning, they can transfer because they are more fit or whatever. To the local authority, that means double handling, with two people going in to a patient at night, rather than just one person.

We can be the advocates for the people who come to Leuchie for those 6,500 respite days because we can do that 24-hour assessment. However, we also have our struggles with wheelchair assessments, ROHO cushions, pressure mapping, stand aids and all the other stuff that we do. There is resistance to what we want to tell people.

11:30

Pamela Mackenzie: I want to pick up on Brian Whittle's point about the preventative agenda. We have to do some small tests of change in order to realise the benefits, and we need to be able to demonstrate them.

We have talked about small pockets of money becoming available for innovation. For example, the three-year self-management programme that we are doing at Dee View court has short-term funding. We have three years of funding and we are doing a full evaluation of that service so that we can demonstrate the financial benefits and the benefits in terms of outcomes for people. However, we need people to be receptive to what we are trying to demonstrate, and therein lies the problem. You can demonstrate something but, once the money is gone, the money is gone. Unless it goes into a commissioning strategy and people see it as a really good, holistic pathway and they want to invest some money at that level, nothing will change.

The Convener: David Stewart will lead our final area of questioning.

David Stewart (Highlands and Islands) (Lab): I thank the witnesses for their excellent evidence today.

We have touched briefly on carers in the evidence that we have heard so far. What assessment have the witnesses made of the new Carers (Scotland) Act 2016? It comes into force on Easter Sunday, although I do not think that there is any religious significance to that. How will that help people with neurological conditions?

Mairi O'Keefe: We welcomed the 2016 act. We were part of the consultation process. We try to look after carers just as much as we look after our guests with our keep well, keep caring campaign. The standards are very good but, again, I do not see much evidence of any resource behind the act. For local authorities, it is something else to adapt to, and it might put quite a strain on some local authority budgets.

Tanith Muller: I absolutely agree with that. My assessment is that support for people who care for people with neurological conditions is a quite neglected area. In some cases, it is about the gradual development of insidious need over a period of time, which means that we do not get a tipping point where we can identify that care is needed.

One of the key measures in the 2016 act is proper carer identification strategies. However, those will need to be properly resourced so that, once we have identified that somebody has caring needs and needs support, that support can be provided. I am concerned that there will not be enough resource in the implementation of the act in the wider community, where resources are essential to the provision of support. We know that projects for carers and so on are among the areas that are at risk of having their funding cut by cashstrapped local authorities. People’s needs are being identified but there is no support to meet those needs. That is the real risk as we move forward. The intention is great; we just need it to be realised.

David Stewart: The young carer statement is an important aspect of the 2016 act, which I support. To amplify your point, the statement identifies the carer’s needs and how they are to be funded. How important will the statement be?

Tanith Muller: Young carers play a massive role in supporting lots of people who have neurological conditions across the board—people of child-bearing and child-rearing age. Those children are under a great deal of stress.

However, in general, neurological services are less good than some other areas of the health service at providing that family and holistic support. Oncology is probably much better at identifying those family needs, picking them up and moving things forward. Historically, neurological services have perhaps been a bit more atomised and focused on acute need and diagnosis, and have not been able to provide that family support. There is real opportunity here for carers of all ages to have their lives improved, as long as the 2016 act is properly resourced.

Pamela Mackenzie: We deliver to more 500 people in the community across Scotland, and we see that the struggle of young carers—and older carers as well—is a huge issue. In the past year, we have had to flag up safeguarding issues, particularly for young vulnerable adults whom we support. We have never really had to do that before, but we felt that there was significant risk to those young people. I welcome the 2016 act but, as everyone else has said, it is the resourcing that will make it happen.

Mairi O’Keefe: In the past, when we were funded by the MS Society, we had a fortnight every year when families could come along—the person with MS, their partner and their children. The person could have been living in a nursing home already, and might never have had the opportunity to have a family holiday. We saw how young children interacted and worked together and supported each other—and they still do, even though they do not visit us any more. As we worked with them each year, it really highlighted the problems that arose. The problems when they were under 10 were different from those when they were 14, 16 or 17, but that is not being tracked. Just because a young person is 16, that does not mean that they are not experiencing issues. Actually, there can be more issues as they grow older.

Professor Macleod: A key aspect is Tanith Muller’s point that carers function very well for a while but then, gradually, things get worse and worse. Often, people get to the stage of having to go away for a weekend and induce a crisis in order to get the professional caring services involved. If you can fix one thing, it should be anticipatory support for individuals and their carers so that things are put in place immediately before they are needed, not two weeks afterwards. That would make a huge difference to the lives of people with neurological conditions.

David Stewart: Another important aspect of the 2016 act is the involvement of carers in discharge from hospital care. What do you think about that?

Tanith Muller: It does not always happen. There needs to be a real move forward to get away from people being discharged from hospital in the middle of the night and arriving back at home thinking, “How did that happen?” If the act leads to people being discharged properly, that would be a real strength.

At the end of the day, if there is a need for someone to get out of a bed, they are going to be hoiked out of it, almost regardless of what the 2016 act says. Perhaps my acute medical colleagues could give a perspective on that.

Professor Macleod: The reason why patients are discharged at 3 o’clock in the morning is that there is an emergency at the front door that needs a bed and the hospital does not have enough beds. That is why it happens, so the solution is pretty straightforward.

Dr Leach: What David Stewart talked about is the formalisation of what we would consider to be best practice—that is, that carers and families are involved. However, for the reasons that have been highlighted, it does not always happen.

The Convener: I thank our witnesses for a very full and informative session. Your evidence is much appreciated, and we will follow up on it in due course.

11:38

Meeting continued in private until 12:49.

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