OFFICIAL REPORT
AITHISG OIFIGEIL

Standards, Procedures and Public Appointments Committee

Thursday 18 May 2017

Session 5

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STANDARDS, PROCEDURES AND PUBLIC APPOINTMENTS COMMITTEE

10th Meeting 2017, Session 5

CONVENER

*Clare Adamson (Motherwell and Wishaw) (SNP)

DEPUTY CONVENER

*Patrick Harvie (Glasgow) (Green)

COMMITTEE MEMBERS

*Tom Arthur (Renfrewshire South) (SNP)
*Emma Harper (South Scotland) (SNP)
*Daniel Johnson (Edinburgh Southern) (Lab)
*John Scott (Ayr) (Con)
*Alexander Stewart (Mid Scotland and Fife) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Bob Doris (Glasgow Maryhill and Springburn) (SNP)
Fulton MacGregor (Coatbridge and Chryston) (SNP)

CLERK TO THE COMMITTEE

Douglas Wands

LOCATION

The Adam Smith Room (CR5)

Scottish Parliament

Standards, Procedures and Public Appointments Committee

Thursday 18 May 2017

[The Convener opened the meeting at 10:00]

Cross-party Groups

The Convener (Clare Adamson): Good morning and welcome to the 10th meeting in 2017 of the Standards, Procedures and Public Appointments Committee. I remind everyone to switch electronic devices to silent, although I might indulge Mr MacGregor and allow him an occasional glance at his phone in the course of the proceedings.

Agenda item 1 is evidence taking on two proposed cross-party groups, the first of which is the proposed CPG on the future of football in Scotland. I welcome Fulton MacGregor MSP, the proposed convener of the group, and invite him to make an opening statement about the group's purpose.

Fulton MacGregor (Coatbridge and Chryston) (SNP): Thanks for the welcome, convener, and thanks for giving me the opportunity to come to the committee today. It feels very different being on this side of the table.

Thanks, too, for allowing me to use my phone. Members might not know this, but yesterday was our due date, hence the convener's permission to check my phone.

I do not plan to speak for long, because the proposed group's merits largely speak for themselves. Football is Scotland's national game, yet, for years, our national team has underperformed on the national stage. Countries that have substantially smaller populations and in which football is not as much part of the social fabric are performing way beyond us on the world stage. Iceland is just one such example. I am not suggesting for a minute that the cross-party group should take over the running of the Scottish Football Association, but it could provide a platform for all organisations and stakeholders to come together with fans and associations to discuss and promote the game.

In all other areas of civic life in Scotland, it is everyone's job to do the best that they can. We are all on other committees and, as we know, we talk about the Government, councils and voluntary and private sector organisations working in partnership to get the best outcome for Scotland's institutions. In my discussions with the SFA about setting up the group, it has been open to that kind of working as well. Football should not be any different in that respect.

There is also a problem with access to the game in this country. I have had conversations with the Scottish Disabled Supporters Association—which, I am delighted to say, will be part of the group if it is approved—in which it has revealed some troubling information about the struggle that many disabled people face when they attend their chosen club's games.

Young people's access to the game is also an issue. Again, one example to look at is Iceland, which has made it very easy for young people to get involved and to get the support that they need to develop as players. In many areas of Scotland, however, we have moved to third and fourth-generation pitches, which are far too pricey for young people; booking them costs hundreds of pounds. Many members around the table have discussed that issue in the chamber. It makes sense to have all-weather pitches, but the charges are far too high.

I remember them, as will other members, but gone are the days when you would go out and play football in the street or on a wee bit—any bit—of grass. There would be health and safety issues with such an approach now—and I am not suggesting that we return to it—but we need to capture some of the random-play aspects that we had before, through working either with local authorities or with other organisations to reduce costs. As for the group's aims, you will have read them: we hope to provide a platform for discussion with a view to improving all aspects of our national game.

I will conclude by touching on the MSP membership of the group. I am disappointed that no female MSP has joined it, but I believe that its wider membership will ensure that issues that are faced by women and girls in football in Scotland are kept in sharp focus. The proposed group's secretary is a former Scotland women's international who is very highly regarded in the game. The Scottish Women's Football Association has also agreed to play a full part in the group, too, and has been very supportive. I will continue to encourage all members to participate in the group and to become involved, but I just wanted to put on record that I am aware of the all-male make-up of the group and that it is something that we will seek to challenge within the group if it is set up.

The Convener: Thank you very much, Mr MacGregor. Do members have any questions?

Tom Arthur (Renfrewshire South) (SNP): This proposed CPG on the future of football is very timely, given that it is now 50 years since 1967 and what was perhaps the high-water mark for Scottish football.

I want to focus on the grass-roots aspect in particular. I am a member of the Health and Sport Committee, and access to sport more generally is an issue that we have been looking at. Have you made any approaches to some of the lower-level football teams that are engaging in social enterprises? Their activity goes beyond simply facilitating youngsters to play football to the much more positive and constructive role that they play in their communities. Is football as a social enterprise and a social good an area that the group will be considering?

Fulton MacGregor: Thank you for that question. It is an area that we would look to develop. Obviously, as the group has not yet been set up, we have not had a meeting other than the one to discuss our aims and objectives. However, it is an area that I am passionate about, too, and speaking as the group's convener, I would say that, if the group goes ahead, it is something that I want to do more on.

My own club, Albion Rovers in Coatbridge, has a rich history in that respect. Recently, it has been providing during the summer and other school holidays a training camp for youngsters. The club is right across from my offices, and I get to see what happens because a lot of the time it happens during recess. There are hundreds of kids involved; they get dropped off early in the morning, are picked up at about 3 o'clock and have that interaction all day. It is definitely an area that I would like to look more at.

Alexander Stewart (Mid Scotland and Fife) (Con): I am delighted to see that you are looking at access and affordability, because those issues can be a real barrier to a number of individuals who want to get involved and participate. The whole idea of community engagement and the social and community-based aspect, which Mr Arthur touched on, are very important. If the group is set up, what will be your main drive with regard to what you will try to achieve in the early days?

Fulton MacGregor: It will be about widening access in relation to the areas that I mentioned. I have already had some provisional discussions with the disabled supporters association, which has been very forthcoming and very welcoming of the group. I would like to do a bit more work in that area.

Some stadiums and clubs in Scotland are more accessible than others and there might be an opportunity to look at that a bit more and to try to encourage all clubs to be at a similar level. When I spoke to the association, I think that Dunfermline Athletic was mentioned as one of the better examples, and we could invite Dunfermline to a meeting to learn what it has done to achieve what it has achieved and see whether there are any lessons to be learned elsewhere.

I mentioned women's football and the role that the organisations that represent women's football will play in the group. I am hoping that that will help to extend access. I note, too, that those championships are coming up; we are all proud of our team, and I hope that they will do well.

The Convener: One of the SFA centres of excellence for football is in Braidhurst high school in my constituency. Indeed, the school has just won the under-18s Scottish shield, and I was delighted to attend the game at Hampden in support of them.

Schools play an important role. I remember that when I was a youngster—a long, long time ago now—the school estate was open, not closed, and we had access to the football pitches in the summer months. All of that changed, for very reasonable reasons; the pitches are now fenced off and that access is not there for people. Have you engaged with local authorities on this matter? Have you invited them to be part of the group? They could play an important part in terms of the curriculum and access to the school estate.

Fulton MacGregor: Yes. This is definitely an area that we propose that the group looks at. As I mentioned in my opening statement, all of us have probably experienced issues with 4G pitches in our constituencies. There are brand-new 4G pitches at St Ambrose high school in Coatbridge, but when you drive by them during the summer, that massive area of land lies unused. Do not get me wrong—on a Saturday morning and at other times, you will see various teams using the pitches, and they have probably been charged quite a lot to be there. Sometimes, however, there is no one on it. Anyone who knows the area will know that the site used to known as the Espieside pitches—we all used to play there.

We definitely need to work with local authorities to make such areas more accessible to young people, and I would definitely want the group to look at the matter. As I am sure members know, I have raised the issue in the chamber when we have discussed the issue of play and at other times.

Patrick Harvie (Glasgow) (Green): Good morning. It is obviously for the group to decide its work programme—and you should probably not take advice from someone who knows as little about football as I do—but I recall that in the previous session, the Scottish Government tentatively took forward proposals on fan ownership. Have you discussed the status of fan ownership in Scotland? Do you intend to follow up on the Scottish Government's moves on the back of cross-party pressure to see what further opportunities there might be to expand fan ownership and to look at the governance of private ownership in the sport and whether that is working well in the interests of fans or communities?

Fulton MacGregor: That issue has not been discussed yet but, again, it could certainly be an agenda item at a cross-party group meeting.

The issue links to Mr Arthur’s point about what clubs are doing to manage their own situations. The issues of social enterprise and fan ownership are interlinked, and we need to consider such models, particularly with regard to the smaller clubs and ensuring that they can survive in the modern climate.

We talk about football being Scotland’s national game, but a wee fact that a lot of people are not aware of and which is probably worth noting is that, per head, more people in Scotland go to games than any other country in Europe, but that does not help the smaller clubs that are struggling with attendance rates. As I have said, that is definitely a matter that we would want to look at.

You have said that you do not know a lot about football. The purpose of the group is to be inclusive to all, whether or not they have a direct interest in football. Football plays a big part in Scottish civil life, so it impacts on all our constituencies.

Emma Harper (South Scotland) (SNP): Good morning. I am curious about your registration form, which says that the group would discuss attempting

“to make the game affordable, accessible and safe.”

Part of that relates to people participating in the sport. I am interested in looking at how we can make football affordable to people so that they can go to watch games, whether or not they be big season games. I am aware that ticket prices can be high. Is that a matter that the group might consider?

Fulton MacGregor: Yes. The cross-party group would be able to make only suggestions; however, it would provide a forum for discussing the issue, and I hope that it would—gently—influence clubs’ behaviour. Obviously, the price of match tickets is down to the clubs but, through the group, I would like to look at positive examples. I have mentioned Albion Rovers; a couple of seasons ago, it had a pay-what-you-can season ticket. Some people gave a wee bit of money, and others who could not afford so much could buy the ticket for a penny or a pound. I think that Motherwell operated a similar scheme. The best way of looking at the pricing structure might be to bring in clubs that have put in place successful initiatives to reduce ticket prices and to see whether that can be replicated elsewhere.

John Scott (Ayr) (Con): I, too, think that the group is a good idea. Given your involvement in the future of football in Scotland, you will be aware that there is a level of unhappiness with some of the legislation on crowd behaviour at football matches. Will that be one of the things that your cross-party group will consider?

10:15

Fulton MacGregor: We do not propose to discuss the legislation on antisocial behaviour at football matches, because there are already parliamentary processes for that. A bill has been passed, and I know that James Kelly is introducing a member’s bill on the matter. I think that, given the group’s remit, if its members and other people were to say that it had become more of an issue, we could reconsider discussing the legislation, but the initial discussions on setting up the group have been more about accessibility and other things. It must be acknowledged that difficult behaviour at football matches can affect accessibility, because people might choose not to take young children to games where that kind of behaviour might be happening. At this point, though, it is not an issue that the group will consider; if the group evolves and wants to look at it, it can do so, but I am aware of the parliamentary processes that are happening around the issues.

Daniel Johnson (Edinburgh Southern) (Lab): I have no questions. All I will say is that anything that seeks to promote being active to people is good, as is anything that seeks to return Scotland to the top flight of international football. I therefore wish you very well.

Fulton MacGregor: Thank you very much.

The Convener: As we have finished our questions, I thank Mr MacGregor for attending. Our decision will be taken later in the meeting, and we will inform you of it as quickly as possible.

The second proposed cross-party group that we have to consider is on rare genetic and undiagnosed conditions. I welcome to the meeting Bob Doris MSP, who is the proposed convener of the group, and invite him to make an opening statement.

Bob Doris (Glasgow Maryhill and Springburn) (SNP): Before I start my opening statement on why we are seeking to reregister the group—under, I readily acknowledge, new terms of reference—I want to thank two individuals. One is Alastair Kent, who is stepping down from his role at Genetic Lives UK. Over the years, he has made a huge effort, not just in Scotland but across the United Kingdom, to draw to people’s attention the plight of those who live with rare genetic and undiagnosed conditions. The other is Malcolm Chisholm, the former MSP who was co-convener of last session's cross-party group, along with me. Although I was co-convener, it is fair to say that Mr Chisholm is a force of nature and did a massive job of leading the cross-party group. I hope to follow in his footsteps, at least partially, should the group be reregistered.

I want to talk about one of my first experiences of the issues that relate to the cross-party group. In the previous parliamentary session, I was deputy convener of the Health and Sport Committee. The committee received a number of petitions from the Public Petitions Committee, and one of those petitions, on rare diseases, led to a Scottish Parliament inquiry into access to medicines. Importantly, that committee did that work in a non-partisan, non-political way. The Scottish Government responded in a similar fashion, and we drove real change. That was possible because of the cross-party group and the effect of those living with rare conditions, their families and campaign groups getting together and networking. That drove momentum in the area.

I want briefly to put some facts on the record, if time allows. The cross-party group on rare diseases existed in the previous session and undertook important work relating to issues affecting the rare disease community. It covered topics such as access to new medicines for very rare conditions, which I have already mentioned; improving research opportunities for rare diseases; gaps in specialist nursing provision; and improving the co-ordination of specialist care services.

The group played an important role in monitoring the implementation plan for rare diseases in Scotland and facilitated an opportunity for stakeholder involvement in the development of work undertaken by the Scottish Government in the area.

The cross-party group on rare, genetic and undiagnosed conditions will build on that work, but will have an expanded remit that includes genetic and undiagnosed conditions—that is the difference that I referred to in the terms of reference. In Scotland, over 2,000 babies are born with a genetic condition every single year, which equates to one in every 25 babies. In addition, there are over 6,000 recognised rare conditions, which are estimated to affect more than 300,000 people in Scotland.

Although there are many different rare and genetic conditions, patients and their families face many similar issues. Regardless of their specific conditions, many people who are affected by genetic and rare conditions report similar challenges, including difficulties in obtaining timely diagnosis; difficulties in accessing appropriate specialist care and support; difficulties in accessing appropriate information; difficulties in accessing treatment; and a lack of co-ordination of care. Although there are a number of condition-specific cross-party groups, none of those groups adequately addresses the challenges that face patients who are affected by rare, genetic and undiagnosed conditions.

In that context, I seek permission from the committee to reregister the cross-party group, with different terms of reference.

The Convener: Thank you. I invite questions from members.

Tom Arthur: One of the stated purposes of the group is to

> "Act as a channel of communication between the Scottish Parliament and families affected".

I am aware of the work of the cross-party group in its incarnation in the previous session. How do you envisage the group's relationship with affected families and individuals functioning? Will that be through meetings between individuals and families and members of the group or other means? Will you elaborate on that?

Bob Doris: Absolutely. I can give a specific example, which I hasten to add comes from before the group's reregistration. In the hope of becoming convener of the cross-party group, I sponsored rare disease day in the Scottish Parliament. On that day, a rather inspirational lady spoke about her experience with EDS—I will stick to the acronym rather than mispronounce the syndrome. She made a powerful speech about deficiencies in managed clinical networks, issues with diagnosis and a variety of other issues. The Cabinet Secretary for Health and Sport was at the start of that meeting but she missed that speech because she had to leave due to other diary commitments. The person who made the speech therefore worked through me and other members of the yet-to-be-registered cross-party group to contact the Scottish Government, and there have now been meetings and engagement to improve that situation. That is a specific example.

Clearly, we are not seeking to be another Health and Sport Committee of the Scottish Parliament, but there are time constraints on all members and all standing committees of the Parliament. That was an example where we could pick up an issue with a genetic condition and move on it quickly. Individuals will be entitled to join the cross-party group in their own right, or they can join through one of the various organisations that are listed on the registration form. There is nothing to preclude any individual from seeking to be a member in their own right. The philosophy on the membership of the cross-party group is inclusive—the aim is to openly engage and work in partnership where we can with committees of the Parliament and the Scottish Government.

Tom Arthur: In your opening statement, you referred to work that the previous group did on access to medicines, and your registration form states that

> "Access to new medicines for orphan and ultra-orphan medicines in Scotland"

will be a key aspect of your work. Given that we are approaching one year since the Montgomery review of the Scottish Medicines Consortium and given the challenges that we face on that issue, how will the group seek to advance that agenda during this session of Parliament?

Bob Doris: The core way to advance that agenda is through the Health and Sport Committee working in partnership with the Scottish Government, which I am sure it will do in this session as its predecessor did in the previous one.

The challenges that we face are worth while. People with various conditions in this country, including rare and genetic conditions, have never had such significant access to new medicines. The issue is that, because technology and science advance so quickly, expectations increase speedily, and rightly so. There is a challenge for Government and for the Health and Sport Committee and other stakeholders in relation to the Montgomery review. We need a continuous review of access to medicines in this country.

History shows us that, if we are not careful, those who have conditions that affect only three, four or five families in Scotland can be squeezed out of the debate. The debate about rare diseases was pretty silent until Rare Disease UK, by marshalling and bringing together various inspirational families, allowed them to realise that there is nothing rare about having a rare condition. That was the purpose of that organisation, and it is the purpose of the proposed cross-party group—it is not to lead the political debate; it is to provide a communication link and to create a network of families and groups that seek to support those who live with rare, genetic and undiagnosed conditions. We must do anything that we can to make sure that, when the review is progressed, they will not be squeezed out. I am sure that they will not be—I know that the Scottish Government has its eye on the ball—but we must not take anything for granted. I want to make sure that the cross-party group has a role to play in that regard.

Tom Arthur: I agree absolutely. Many of the processes for the decisions that are taken on access to medicines can be highly complicated and challenging. It has struck me from engagement with my constituents that there can be a disconnect and a lack of understanding of what the motivations are for certain decisions. It is clear that there is an opportunity for a platform to be provided for information, communication and participation, and that is to be commended.

Patrick Harvie: Good morning. I would like to ask about the group's external membership. I am happy to see the group being recreated. Drug treatment is an area in which there is sometimes a tension between evidence-based decisions and lobbying efforts by companies involved in the field. Are any of your external members private sector organisations such as drug companies, or are any of them funded by such companies? As a group, have you discussed what your approach would be if private sector organisations such as drug companies wanted to become external members?

Bob Doris: That is a really important question. I do not know whether I have all the answers, but I can make an initial comment.

If you look back at the workings of the Health and Sport Committee in the previous session, you will see that my relationship with the pharmaceutical companies was one of constructive scrutiny. When I thought that they overcharged for their medicines and overpromised on what they could deliver, and that the people of Scotland were not getting the best deal from them or were not being best served by them, I said so.

To varying degrees, the pharmaceutical companies fund various patient groups, although that is subject to very strict rules of engagement. I do not know to what extent that is the case in relation to each of the patient groups and organisations that are listed, but I think that it would be good practice—although I do not think that it is required—to have a statement about that, for the sake of transparency. I intend to check with the organisations concerned and to make that information available on a centralised public record. Each MSP or member of society should not have to look at each organisation that is a member and cross-reference that with other public record information, so let us get it centralised in one place. I am happy to provide that.

I am not sure whether we need a policy or a protocol on how we deal with pharmaceutical companies, because we will not be there for them; we will be there for the patients and the families of those with rare, genetic and undiagnosed conditions. However, I would be happy to put that on the agenda for our first appropriately constituted meeting.

Mr Harvie has given me the opportunity to say again that I think that drug companies have to do a lot more in relation to affordability. Maybe what they are paid should be based less on the outcomes of clinical trials and more on the real-life outcomes of their medicines once they have been taken by patients in wider society. It should be a case of cash on delivery, rather than cash up front, for the outcomes that they claim from their clinical trials. I am happy to put that on the record again today.

Patrick Harvie: That is very helpful. The committee has discussed the issue of private sector organisations being external CPG members. There is no rule against that—it does happen—but we have acknowledged that some thought is needed in that area. I am happy to hear Bob Doris's response; I think that he is taking a very constructive approach.

John Scott: I declare that I have an interest on two fronts, as a member of the proposed cross-party group and as someone who has a rare genetic condition. I am therefore interested in genetic and genomic research. Do you see a way of encouraging such research, Mr Doris? Do you also see a way in which your proposed cross-party group can work collaboratively—or undertake joint working—with other cross-party groups that have an interest in the same area?

10:30

Bob Doris: I will deal first with your question on joint working. Frankly, I think that the proliferation of cross-party groups in the Parliament necessitates joint working. The committee has been grappling with the problems of CPG duplication and overlap over a number of years. I do not think that our proposed CPG would pose such a problem, but I think that it would be incumbent on the group to mainstream its work so that we could identify an issue that would be of interest to another CPG and undertake joint working on it.

Can you remind me of your first question?

John Scott: It was whether the CPG could be a way of trying to encourage genomic research.

Bob Doris: Ah! I was trying to dodge that bullet. I wish that Malcolm Chisholm was sitting beside me, because he knew a lot more about that matter. However, I saw an inspirational presentation by NHS clinicians on the human genome project as part of the rare disease day reception at the Scottish Parliament. That is amazing work that is both publicly and privately funded in Glasgow and Edinburgh. I do not always get the science of it, but I am a politician, so I do not have to get the science of it: I just have to get that it provides huge opportunities to transform the lives of people the length and breadth of Scotland.

I have to increase my knowledge base about the subject. I know that there is a proposed visit to one of the project sites, and I hope to go along and find out more. However, anything that the cross-party group could do to promote that research and raise awareness of it would be important.

For various health-related issues, whether it is the human genome project, clinical trials or whatever, Scotland is probably the best country in the world for collecting data. Some would say that we collect too much data, particularly in relation to health. However, if we consider the data that we collect on Scotland's DNA footprint, we are best placed and world leading by default in terms of the opportunities of doing things with that data. The human genome project is just another example of that.

In my earlier answer to Mr Harvie, I was slightly critical of pharmaceutical companies. However, if pharmaceutical companies are looking for the best place to do real-life clinical trials, Scotland, given the data that we collect, is world leading.

John Scott: Thank you for that comprehensive answer. I record my appreciation for the work of Malcolm Chisholm, who was co-convener of the previous cross-party group and is, indeed, a much-missed member of the Scottish Parliament.

Alexander Stewart: I very much welcome the fact that the previous cross-party group will be reformed. Mr Doris came here today to sell that proposal and I think that he has done that extremely well.

The proposed CPG intends to examine the areas of health and social care provision with regard to rare and undiagnosed genetic conditions, which is a complicated issue to make progress on. The CPG would also have to deal with the scientists and clinicians, and you touched on how Scotland is world leading on data in some health areas. How would your group progress its work along the lines that you have indicated? Does the group have plans to do work along any other lines? Will you talk to similar groups in other UK Parliaments? Will you look at what is happening elsewhere, particularly in Europe? There is a broad base to the issues that your CPG proposes to address, which will give many others the opportunity to examine health and social care provision.

Bob Doris: I think that the answer is yes to all those questions, but I will give a slight health warning. I am to be the convener of the proposed CPG, but although it has to be parliamentary in nature, the point is to engage with and listen to stakeholders, and allow them to shape some of the CPG's agenda. I therefore do not want to set a hare running by saying that among the things that we will look at, the priority will be how health and social care services meet the needs of those who are living with rare and undiagnosed genetic conditions. There are various matters for the CPG to address—for example, monitoring and contributing to the implementation plan for rare diseases in Scotland. If stakeholders decided that they wanted to scrutinise that area more rather than the services that are provided across Scotland through the new integration joint boards, for example, I would be partly led by the patient groups involved.

Looking at how health and social care services meet the needs of those with rare and undiagnosed genetic conditions seems like a good idea, but perhaps Alexander Stewart might want to raise that at the next meeting of the cross-party group. I would certainly welcome you on board, Mr Stewart, and would love to have the benefit of your experience. We are open minded about exploring your idea further.

Alexander Stewart: Thank you.

Emma Harper: Last week I participated in a members’ business debate on myalgic encephalomyelitis, and yesterday Ash Denham led a members’ business debate on neurofibromatosis. A lot of awareness raising is conducted in Parliament through members’ business debates, which is a great way to do that. I welcome the reregistering of the CPG so that we can continue to raise awareness and bring everybody together, given that there is inequality in the provision of care.

Last night, I met a genetic nurse. She is based in greater Glasgow but she covers the south-west of Scotland—Ayr and Dumfries and Galloway—so her role is really rural and really challenging.

Would the group link with general practitioners and the British Medical Association? Raising awareness among GPs is often a good way to start because they are people’s first stop but we have challenges with GP numbers already in Scotland. What are your thoughts on engaging with medical practitioners?

Bob Doris: I assume that when we want to look at that area, we will bring in certain key professionals, such as the Royal College of General Practitioners. As I said in my opening statement, one of the issues with EDS is the length of time that diagnosis takes because of the level of GP awareness. There are managed clinical networks and guidelines in relation to these matters. Sometimes you can take it from the grass roots, making sure that GPs on the ground are familiar with different diseases and getting the information out there, but sometimes it is about making sure that the clinical pathways and the managed clinical networks are fit for purpose.

I think that engaging with GPs is a very good idea. I am just conscious that we throw a lot at them—they are generalists by nature, so sometimes it is about making sure that, when they see a potential issue, they have the confidence to move through the appropriate referral pathway.

Emma Harper: I absolutely agree—it is not always the GP who is the specialist on diagnostic and treatment pathways. Advanced nurse practitioners might be included, as part of the managed clinical network, in assessing and diagnosing people and helping them to get on the right treatment pathways.

Bob Doris: I absolutely support that. Not only will patients get a quicker, speedier service, but they will get a far superior service because a nurse specialist becomes a real expert—they are doing something every single week, whereas clinicians such as doctors may do things just once in a while. The nurse specialists get quite slick and are at the top of their game, so the service is often better; it is also much cheaper for the national health service so it is certainly something that we have to expand. I think that that is the direction of travel.

The challenge in this area is the general challenge with preventative spend and service redesign: we have to invest to save down the line. There has been a significant expansion of nurse specialists but who are we to sit here as MSPs and say that to groups that as yet do not have nurse specialists while others are campaigning for an expansion of their nurse specialist service? Therein is the rub. Within that context, rare, genetic and undiagnosed conditions could be squeezed out if we are not careful. Emma Harper raises a really interesting point, as did Mr Stewart. We need to make sure that, as care and treatment pathways are being designed, they are there for those who live with rare conditions.

The Convener: That is the end of the questions. I should declare an interest as someone who is likely to be a member of the CPG if it is established. I thank Mr Doris for his attendance.

Bob Doris: Thank you, convener.

The Convener: Agenda item 2 is consideration of the two proposed CPGs. There are no comments from members on the proposed CPG on the future of football in Scotland. Are members content to approve that CPG?

Members *indicated agreement.*

The Convener: The second proposed CPG is on rare, genetic and undiagnosed conditions. There are no comments from members. Are members content to approve that CPG?

Members *indicated agreement.*

Annual Report

10:39

The Convener: Agenda item 3 is consideration of our draft annual report. I invite general comments from members.

I thank the clerks for their work in producing the draft report, which comprehensively covers what we have done. Would it be possible to include a paragraph that notes our engagement with the work of the Presiding Officer's review of parliamentary procedures? We have had a couple of witness sessions covering that area. Are members content to agree to that?

John Scott: I am sorry, convener, but I was not paying sufficient attention.

The Convener: The report does not recognise the work that we have done in engaging with the Presiding Officer's review of parliamentary procedures. I asked whether a paragraph on that could be added in.

John Scott: I agree. I was going to raise that point myself.

The Convener: Are we content for the clerks to draft something that can be approved by email?

Members *indicated agreement.*

The Convener: Is the rest of the report agreed to?

Members *indicated agreement.*

10:41

Meeting continued in private until 10:52.

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