

Cross Party Group on Rare, Genetic and Undiagnosed Conditions

Wednesday 28 October 2020 (11.30am-12.30pm)

MINUTES

- **Welcome and introductions**

Bob Doris MSP welcomed all in attendance. The meeting took place on Zoom.

- **Minutes of the last meeting**

The minutes of the meeting held on 26 May 2020 were agreed.

- **Impact of Covid-19 on the rare, genetic and undiagnosed community**

Nick Meade, Genetic Alliance UK's Director of Policy, provided a presentation on the findings of Genetic Alliance UK's 'The Rare Reality of Covid-19 Report'. A copy of the presentation has been provided.

- **Discussion: Impact of Covid-19 on the rare, genetic and undiagnosed community in Scotland**

CPG members acknowledged the impact COVID-19 has had on the community.

Telehealth: The use of telehealth has increased considerably as a result of Covid-19. This has been welcomed by many members of the community. It was noted that for those who have care provided by many specialists across the country, being able to move to appointments online has aided the coordination of care, reduced the burden of time and costs of travel and has been helpful in supporting those shielding. One example highlighted the potential of telehealth to speed up decision making by bringing consultants from different centres together with patients to agree a care pathway.

There are limitations to telehealth however. It cannot replace face-to-face care and this is most significant for people who are meeting their clinician for the first time and for people with cognitive impairment who may usually attend their appointments with a carer or advocate. There are also challenges around accessibility of technology, the cost of equipment and broadband connection, the quality of internet connection and the person's ability and confidence in using digital technology. Examples were given of whether third sector organisations had provided support in the form of information on how to use technology, or through allocating small grants for the purchase of iPads (An example being the PSP Association who supported those living with PSP in a care home/supported living environment with an iPad, and their family member who would usually attend an appointment with them, so both could continue to be present at consultations.)

It was agreed that telehealth developments have provided opportunities for better coordinated care, but patient choice must be respected and support must be available to assist patients in maximising the opportunities for telehealth. Work should be undertaken to

understand what scenarios are best suited for telehealth, as telehealth is not appropriate for every circumstance (first appointment, receiving a diagnosis etc)

ACTION: NF to feedback views on telehealth to Scottish Government's Rare Disease Oversight Group

Impact on carers: Many members shared their experiences of how the Covid-19 situation had placed a significant burden on carers. Many carers have found that their care or respite packages have been suspended due to the Covid-19 restrictions, or have been significantly changed. There was recognition of the impact this will have on carers mental health, with some noting that parents of children with considerable support needs reporting that they have had no break or support during the duration of lockdown. Further, where support does exist, it has in many cases been necessary for this to change. For example, personal assistants may not have been able to take a person they support to a place, or for an activity, that they particularly enjoy. This has been detrimental to the routines and, ultimately the mental health, of many.

ACTION: NF to identify relevant CPGs and write to secretariat to consider if there is scope for joined up action.

Impact on services for rare conditions – It was noted that elective, and even some quite urgent surgeries, have been significantly delayed as a result of Covid-19. There was a general consensus that delay and cancellations were unavoidable at the height of the crisis, however there is a concern about the extent of the backlog NHS Scotland will face. There was comment that perhaps services for rare conditions will not be seen as a priority as NHS Scotland is remobilised. It was noted that although telehealth appointments meant some people were able to continue to receive regular care and/or their annual consultations, for many appointments had been cancelled and they were still waiting for rescheduled appointments to be issued. It was noted that the extent of delay, and impact on waiting times, has not been clearly communicated.

ACTION: NF to raise concerns with Rare Disease Strategic Oversight Group and ask for update on NHS Scotland's remobilisation priorities.

Impact on clinical trials for rare conditions: It was noted that, with such focus and attention on Covid-19 vaccinations, clinical trials for rare conditions had been suspended and the development of new trials likely to have been delayed. It was also noted that there is opportunity, as the public perception and understanding of research has increased significantly – this may be beneficial for increasing participation in research in the future.

ACTION: NF to identify relevant CPGs and write to secretariat to consider if there is scope for joined up action.

Impact on children and education: Nick Meade's presentation highlighted that there had been challenges for children with additional support needs in England returning to schools, noting that guidance relating to the reopening of schools in a Covid safe manner had not taken due consideration of children with Additional Support Needs. There was acknowledgement from CPG members that there had been some challenges for children

with additional support needs and that this had extended to higher education too. It was noted that online learning for colleges was not appropriate for people with additional learning and support needs, but this was being encouraged.

ACTION: NF to identify relevant CPGs and write to secretariat to consider if there is scope for joined up action.

- **CPG Care Coordination Report**

Natalie Frankish explained that work was ongoing to collate the Cross Party Group's views and recommendations on improving care for rare conditions in Scotland. A summary will be provided at the next meeting in November. Patient organisations were invited to attend a meeting on 2nd November 2020 to discuss the proposals for the report. A draft version of the report would be shared with CPG members in due course.

- **Date of next meeting**

The next meeting will take place at 11.30am on 25 November 2020 on Zoom. The meeting will focus on care coordination with a presentation from the CONCORD research team and an opportunity to review and agree the proposals in the CPG report on improving care coordination.

Attendance – Cross Party Group on Rare, Genetic and Undiagnosed Conditions – 26 October 2020

Bob	Doris MSP	Convener
Mark	McDonald MSP	Co-Convener
Natalie	Frankish (Secretariat)	Genetic Alliance UK
Nick	Meade	Genetic Alliance UK (Presenter)
Mike	Cain	HSP Support Group
Harriette	Campbell	Sickle Cell Support Group
Susanne	Shanks	PCD Family Support Group
Edel	Clough	PCD Family Support Group
Amy	Comrie	EDS UK
Andrew	Deans	NHS Lothian
Gill	Dickson	PSP Association
Jessica	Jones	Cystic Fibrosis Trust
Rae	McNairney	Primary Immunodeficiency UK
Catherine	O'Hara	Behcet's UK
Karen	O'Hara	Alpha 1 UK
Arlene	Smyth	Turner Syndrome Support Society
Lynn	Stewart	MyAware
John	Wallace	Autoinflammatory UK NLRP12
Lindsay	Weaver	Metabolic Support UK
Dan Michelle Gillian	Farthing Erskine Newman	Haemophilia Scotland Aarskog Syndrome Foundation Highland Children's Forum