

Cross Party Group on Rare, Genetic and Undiagnosed Conditions

Wednesday 27 January 2021 (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 25 November 2020 were agreed.

- **Discussion: Access to Health Services during Covid-19**

Members noted concerns about the time it may take for routine services to return to normal. Communication of proposed timescales and managing the expectations of patients was considered important.

It was noted that the experiences of accessing services during the pandemic had been patchy – some people explained that their routine consultations and check-ups had been cancelled with no rescheduled date given or an indication of when normal services would resume. This was true both of primary care and specialist services.

There has been variation in how plans for care have been communicated to patients – with some reporting positive ongoing communications with their primary and specialist care providers. Others reported feeling alone and unsure about who to contact for information, relying on themselves to manage their, or their child's, care effectively.

Concern raised over patient fears about attending clinics and hospitals during the pandemic.

Telehealth has been very helpful and should be used regularly after the pandemic but only with the consent of patients who should be allowed to choose their preferred options.

A link for the Rheumatology Global Survey was shared in the meeting chat.

- **Discussion: Vaccinations**

Some concerns were raised about how information about vaccinations had been communicated – specifically their safety, what they contain, the advantages and disadvantages, how they interact with other vaccinations/medications and how safe they are for people with particular underlying health issues. It was noted that public service campaigns to dispel concerns were necessary.

Bob Doris MSP reassured members of safety and urged people to get vaccinated when invited for their own safety, and for that of others.

Natalie Frankish explained that a range of resources were available on NHS Inform's vaccination hub and would share this information following the meeting.

With regards people with underlying health conditions it was noted that anyone with concerns about their specific circumstances should contact their GP or specialist clinician to discuss. It was also noted that some professional bodies and some patient organisations had released statements on the safety of vaccinations for particular conditions – for example, the Association of British Neurologists had provided guidance to say that all Covid-19 vaccines were safe for neurology patients.

It was suggested that patient and professional confidence had been knocked by the decision to lengthen the time between doses against manufacturers guidance.

There were concerns raised about the apparent speed of the vaccine roll out in Scotland, particularly compared to other parts of the UK. It was asked whether there was a lack of vaccinators and whether the Army should play a role in supporting roll out. Bob Doris MSP assured that roll out was continuing at pace and delays were resulting from the decision to prioritise care homes first – he noted that he had received reassurances from the First Minister that there were sufficient vaccinators in post to deliver the vaccine. He also noted that he expected a ramp up in the rate of vaccinations in the coming weeks.

Some questions were asked about specific conditions not being considered 'clinically vulnerable' and therefore being excluded from the category 6 roll out of the vaccine. The JCVI guidance was explained and people concerned that they should be prioritised, but were not, should contact their GP or specialist clinician.

ACTION: NF to circulate the links to vaccination resources on NHS Inform

ACTION: NF to raise concerns with relevant teams at Scottish Government

- **UK Rare Disease Framework**

The UK Rare Disease Framework was published on 9 January 2021 and can be read here – <https://www.gov.uk/government/publications/uk-rare-diseases-framework/the-uk-rare-diseases-framework>

Natalie Frankish (Genetic Alliance UK) gave an overview of the themes and priorities of the new Framework and explained that the Scottish Government are expected to produce an Action Plan for Rare Diseases for Scotland by end of 2021.

- **Update on CPG Report**

The Minister for Public Health and Sport, and the relevant Scottish Government Team, were to be given advanced sight of the CPG report.

The report would be circulated before the next meeting and signed off during the meeting on 3 March 2021.

- **AOB**

An issue regarding the EDS toolkit being removed from the RCGP website was raised. Further information to be sought.

Rare Disease Day will take place on 28 February 2021. Rare Disease UK will be holding a UK-wide Parliamentary event on Wednesday 24 February between 10am and 12pm.

- **Date of next meeting**

The next meeting will take place at 10am on 3 March 2021 on Zoom.

This will be the last meeting of the CPG in this Parliamentary session.

Attendance – Cross Party Group on Rare, Genetic and Undiagnosed Conditions – 27 January 2021

Bob	Doris MSP	Convener
Mark	McDonald MSP	Co-Convener
Natalie	Frankish (Secretariat)	Genetic Alliance UK
Mike	Cain	HSP Support Group
Harriette	Campbell	Sickle Cell Support Group
Edel	Clough	PCD Family Support Group
Amy	Comrie	EDS UK
Andrew	Deans	NHS Lothian
Gill	Dickson	PSP Association
Rae	McNairney	Primary Immunodeficiency UK
Fiona	Watt	Primary Immunodeficiency UK
Catherine	O'Hara	Behcet's UK
Arlene	Smyth	Turner Syndrome Support Society
John	Wallace	Autoinflammatory UK NLRP12
Michelle	Erskine	Aarskog Syndrome Foundation
Michelle	Conway	CRD Consulting
Ali	Murphy	EDS UK