

Cross Party Group on Rare, Genetic and Undiagnosed Conditions

Tuesday 26 May 2020 (10am-11am)

Zoom Meeting

Note of Meeting

- **Welcome and introductions**

Bob Doris MSP welcomed all to the virtual cross party group and invited members to share their names and organisations using the zoom chat feature (list of attendees attached).

Bob welcomed Professor Jason Leitch, National Clinical Director for the Scottish Government.

- **Professor Jason Leitch, National Clinical Director, Scottish Government**

Professor Leitch provided a short introduction to his role and took questions tabled by CPG members.

Questions asked at the meeting, and a summary note of responses are provided below.

Q#	Theme	Asked By:	Question:
1	Shielding	Bob Doris, MSP	<p>Is Scottish Government confident that every person that should be in receipt of a shielding letter has received one? What should people do if they still think they are eligible, but have not received a letter?</p> <ul style="list-style-type: none"> - Professor Leitch explained that the shielding letter does not 'require' people to shield, but advises them to do so. He noted that people can chose to shield if they feel that it would of benefit for them to do so. - Professor Leitch explained that one of the main purposes of the shielding letter was to ensure people who required support had access to it (for example access to getting medicine, food deliveries etc). This support is supplied through local authorities. - Professor Leitch explained that there is no medical benefit in receiving a shielding letter – it will not entitle you to any specific medical help or access to different doctors. - Professor Leitch explained there is a process in place to check whether a person who has not received a letter, should receive one. Anyone who believes they should have/need a letter should contact their primary health professional.
2	Shielding/Easing of lockdown	Natalie Frankish, Genetic Alliance UK	<p>Many of our members and families have reported feeling very anxious about the possibility of long term shielding and its effect on their emotional wellbeing and their personal health outcomes, or those of their child. This anxiety seems to have increased as we move towards easing of lockdown measures.</p> <p>For example, some parents are worried that their shielding child will be left behind, having to stay at home whilst siblings get to go to school or see their friends. Some who care for their partners have told me that they are worried about going back to work. Some are concerned about deterioration of their physical and mental health as they won't be able to go out for exercise or have interactions with others, and some are concerned about feeling isolated when their existing support networks go back to work.</p> <p>What conditions will have to be met before there is any relaxation in the advice to those currently shielding?</p> <p>How will the Scottish Government support families required to shield for longer? Will there be consideration given to introducing 'safe spaces' or 'social bubbles' for those shielding?</p> <ul style="list-style-type: none"> - The current guidance for those shielding is due to expire on 16 June 2020. - The CMO's of the four nations are considering future guidance. It is hoped that, provided transmission levels of the virus

			<p>within the community remain low, that the guidance for those currently shielding may be revised and eased.</p> <ul style="list-style-type: none"> - Professor Leitch offered a reminder that shielding guidance was not for the whole household, but for the shielding person. Others in the household must however follow guidance on hand washing, social distancing etc.
3	Auto inflammatory diseases in children and other Covid19 related conditions	Arlene Smyth, Office for Rare Conditions	<p>Have there been any reported cases of the auto inflammatory disease associated with Covid-19 in Scotland since the beginning of this outbreak?</p> <p>What symptoms should parent/carers/guardians be looking out for?</p> <ul style="list-style-type: none"> - Professor Leitch confirmed that there had been approximately 200 cases of this in the UK, with a very small number (too small to number due to patient confidentiality restrictions) in Scotland. - There has been no death of a child from this condition in Scotland, although a small number of deaths have occurred elsewhere in the UK. - Professor Leitch noted that Covid19 is a new virus and not enough is known about it, or this condition appearing in children, to definitively suggest the two are linked. Professor Leitch noted that there wasn't evidence to suggest that children with existing auto inflammatory conditions were of increased risk. - Professor Leitch explained that the symptoms were similar to <u>that of sepsis</u>. He emphasised the importance of going to hospital or contacting the health service if any parent had any cause for concern about the health of their child.
4	Return to Routine Care	Amy Comrie, EDS UK	<p>When will routine outpatient, screening and genetic testing services return and what measures will be put in place to reduce backlog?</p> <ul style="list-style-type: none"> - Professor Leitch explained that as restrictions begin to ease this week (w/c 25 May 2020), this would include a gradual reinstatement of national health services, including routine outpatient appointments. - Professor Leitch noted this would be a gradual step-wise introduction but was hopeful of a near normal return of NHS services in the near future. - Dental services are subject to a five phase plan for reintroduction. There are currently emergency dental hubs for emergency care. - It is less clear when those accessing care in other parts of the UK will see a return to normal. Although pre-Covid19 reciprocal health care arrangements across the four nations are still in place and will continue, the speed at which each nation is emerging from lockdown may be a factor in the resumption of cross-border healthcare services. Professor

			Leitch agreed that this would be looked into by Scottish Government.
5	Education and Return to School	Stacey McPherson, CHAMP 1	<p>I have a child with complex needs and who is considered vulnerable. What measures are the Government planning on putting in place to reassure parents like us, with children like ours, that it will be safe to send our children back to school?</p> <p>For those families who have ASN provision in school but cannot return to school, will it be possible for support to be provided for home-schooling in another way? E.g. remote 1:1 support or at home support as a designated 'key worker'.</p> <ul style="list-style-type: none"> - Professor Leitch explained that Scottish Government have released details of the phased return for schools, acknowledging that children with additional needs were unlikely to be in one of the first groups to return. - Discussions are still being had with regards to ASN provision and how this can be provided safely going forward. - There is likely to be considerable challenges around transport provision for children getting to schools, particularly bus services. - It will be for parents to discuss their child's needs with their local authority – local authorities will be given the responsibility for bringing schools services back.
6	Education and Return to School	Laura Smith, Children's Health Scotland	<p>Could Prof Leitch comment on the level of risk to shielding carers (for example, shielding parents, grandparents or kinship carers) of children either currently attending the hubs or on return to school? How should managing this be approached?</p> <ul style="list-style-type: none"> - Professor Leitch explained that shielding requirements were not for the household, but for the individual – he recognised that for some this would pose challenges but emphasised the importance of hand washing, social distancing, cleaning surfaces. - The current shielding period is due to end on 16 June 2020 – the four nations CMOs are working together to consider what guidance will then be issued to those in the shielding group.
7	Access to Treatment	Bob Doris, MSP	<p>What has the impact of the Covid19 situation been on the supply of medicines for other health conditions? When will the Scottish Medicines Consortium resume assessment of new medicines for rare conditions?</p> <ul style="list-style-type: none"> - Professor Leitch offered reassurance that medicines currently required for other conditions, that are also being used in Covid-19 related trials, were not subject to any shortage in

			<p>supply. Such medicines are being procured on a UK level through a different procedure.</p> <ul style="list-style-type: none"> - It is expected that the SMC will return to operation in the near future. It is hoped that there won't be a significant backlog as pharmaceutical companies have been concentrating on other matters during the Covid-19 crisis.
8	Facemasks	Natalie Frankish, Genetic Alliance UK	<p>We have been contacted by some organisations regarding guidance on the use of facemasks.</p> <p>Firstly, will guidance be provided for those who may be unable to wear facemasks, for example those with breathing difficulties or autism or people who may rely on lip reading?</p> <p>Secondly, will clear and easy to understand guidance be issued to children and young people to help them understand why the use of masks is being recommend, how they should be used and also that they are not a substitute to handwashing and social distancing.</p> <ul style="list-style-type: none"> - Professor Leitch confirmed that face coverings will be required on public transport and the guidance will remain for people to wear face coverings in confined spaces with others. Face coverings provide limited protection from getting the virus, but are considered potentially beneficial in stopping those with the virus from spreading it. - Professor Leitch explained that face coverings are suitable for short interactions in confined spaces (public transport, shops etc) but are not intended to be used as PPE or for use over a long period of time (as this brings risk from the covering being touched/getting dirty) – children for example, will not be required to wear them when at school and shop workers will not be expected to wear them.
9	Evidence and data collection	Bob Doris MSP	<p>Is Scotland contributing data to efforts by European Reference Networks to collect data at European level relating to Covid19?</p> <ul style="list-style-type: none"> - Professor Leitch explained that there is a concerted world wide effort to share and gain data relating to Covid19 – Scottish Government is participating in as many of these networks and forums for data collection as possible, not just European networks, but worldwide networks too.

Attendees

Bob	Doris MSP	Convener
Mark	McDonald MSP	MSP member
Natalie	Frankish (Secretariat)	Genetic Alliance UK
Salena	Begley	Family Fund
Claire	Black	SWAN parent
Marion	Butchart	Novartis
Mike	Cain	HSP Support Group
Harriette	Campbell	Sickle Cell Support Group
Edel	Clough	PCD Family Support Group
Amy	Comrie	EDS UK
Michelle	Conway	
Tom	Cranston	Scottish Government
andrew	Deans	NHS Lothian
Gill	Dickson	PSP Association
Rachael	Docherty	FOP Friends
Sarah	Griffiths	Scottish Government
Jenni	Hampson	Kyowa Kirin
Elisabeth	Hunter	ROHHAD Association
Pushpa	Hussain	Metabolic Support UK
Tanya	Jones	
Coreen	Kelday	Brittle Bone Society
Zoe	KM	Autoinflammatory Disease UK
Professor Jason	Leitch	Scottish Government
Hazel	McLachlan	Behcet's UK
Rae	McNairney	Primary Immunodeficiency UK
Stacey	McPherson	CHAMP1
Zosia	Miedzybrodzka	University of Aberdeen
John	Miller	Duchenne Muscular Dystrophy
Jodie	Mitchell Hyslop	Harper's Helpers
Ali	Murray	
Prince	Obike	Sickle Cell Support Group
Catherine	O'Hara	Behcet's UK
Karen	O'Hara	Alpha 1 UK
Carol-Anne	Redpath	Scottish Government
Martina	Rodie	Office for Rare Conditions
Tracey	Saunderson	On behalf of Emma Harper MSP
Laura	Smith	Children's Health Scotland
Arlene	Smyth	Turner Syndrome Support Society
Lynn	Stewart	MyAware
Katie	Thurston-Smith	Pfizer
John	Wallace	Autoinflammatory UK NLRP12
Lindsay	Weaver	Metabolic Support UK
Alex	Whitteker	Haemophilia Scotland
Anne	Wilson	Children's Health Scotland