

COMMUNITY CHECK-IN NOTES

Tuesday 7 July: The Rare Reality of COVID-19

Organisations represented:

- Alex TLC
- Alstrom Syndrome UK
- Ataxia UK
- Cardiff University
- Cerebra
- Duchenne Family Support Group
- HMSA COMMS
- Pitt Hopkins UK
- PKD Charity
- The Gauchers Association
- UK Mastocytosis Support Group
- Unique
- Wolfram Syndrome UK

Genetic Alliance UK staff attending:

- Jayne Spink (JS), Chief Executive
- Nick Meade, Director of Policy
- Amy Hunter, Director of Research
- Natalie Frankish, Policy and Engagement Manager - Scotland
- Emma Hughes, Policy and Engagement Manager - Wales

Findings from Genetic Alliance UK's report: The Rare Reality of COVID-19

JS welcomes everyone.

EH invites comments by email (emma@geneticalliance.org.uk) ahead of a Welsh Government meeting on shielding to be held on 8 July 2020.

NM provides a presentation on Rare Reality of COVID19:

- Genetic Alliance UK launched new report on 2 July 2020
- An article on the report was published in Health Services Journal

Genetic Alliance UK

contactus@geneticalliance.org.uk

www.geneticalliance.org.uk

Registered charity numbers: 1114195 and SC039299

Registered company number: 05772999

- The report was shared with the Secretary of State for Health
- Shared letter through APPG and CPGs in Wales and Scotland
- The report combines information gained from Genetic Alliance UK community check in meetings with findings from the EURORDIS Rare Barometer Covid-19 survey
- The report is divided into two sections

Health services

- Business as usual stopped for rare disease patients. More than half of respondents felt that interruption related to the Covid-19 pandemic had been detrimental to their health and well-being. NM notes that the impact of the gap in treatment might be seen in the months to come.
- 1 in 5 report disruption in access to medicines
- In relation to telemedicine, online consultations have increased and email prescriptions have also increased
- NM notes almost half respondents found online consultations useful, but some (approximately 10%) found it not very or not at all useful

Wider Impact

Communication around shielding:

- Variation in the guidance is problematic
- Sudden changes happen without clear justification
- Basis for categorisation and risk levels are slow to be explained
- Letters came late or not at all and were allocated inconsistently
- Two tiers of vulnerable
- Many experienced feelings of isolation and lack of support
- Elements of real life not covered by the guidance

Education and access to support:

- Closure of schools has placed significant pressure on parents of children with SEND
- English obligations on local authorities reduced
- Reopening of schools happening without due consideration

Data and coordination of care elements of the 2013 strategy would have undoubtedly helped had they been implemented properly. Telemedicine and specific and comprehensive data on rare conditions would have facilitated the coordination of shielding information.

Recommendations

- In monitoring the spread of Covid-19, data should be collected that will enable assessment of the impact, in terms of morbidity and mortality, on people living with rare conditions
- People living with a rare condition who have a legitimate reason to ask for a test for Covid-19 should be given priority

- Access to PPE should be guaranteed
- Priority access for people with rare diseases for vaccination when available

Successful transition from crisis state

- For those who wish to continue protecting themselves through isolation support must be there to allow them to do so
- A clear and short timetable for reintroduction of services should be published

Learning for the future

- The challenges and failures in delivering letters giving shielding advice should be examined
- The development of the new UK framework for rare diseases has been delayed by the crisis and it is now more necessary than ever. Learning from this crisis must be included

Initial Priorities

- Risk assessment tool for future shielding communication needed to facilitate targeted, precise and accurate information
- Telemedicine to ensure access to the best possible rare condition healthcare is restored as safely as possible while maintaining the benefit of accelerated uptake in telehealth

Discussion:

Why do some find tele-consultations challenging?

- (NM) forming a new relationship with a clinician is difficult, it's easier to move to telehealth where there is an established relationship. In certain circumstances, value in being in the room for assessment etc.

Is there a relationship between socio-economic status and use of telehealth?

- (NM) access to technology is likely to be an issue
- (Participant) To complete online surveys, participants are likely to have access to equipment, are we missing those who don't have the opportunity to even answer the question?
- (Participant) Department of Health consultation on telemedicine was not truly representative of community, missing out a range of issues (accessibility, cultural, socio-economic)
- (JS) the Government is moving to encourage people back into hospitals for physical clinics
- (NM) tendency within NHS to have a one size fits all approach and notes payment for results process (in England) is a barrier. Message is that there needs to be a blended approach based on need/preferences of patients
- (Participant) questions have to be answered around telehealth, specialist services and care coordination - for example, locally provided tests - who pays for these?

- (Participant) reports from families that consultations are very quick with little action or information, for many families has been a negative experience
- (Participant) Have seen positive impact, increase in number of new referrals. Seems clinicians may have a bit more time to source information and support
- (Participant) feedback from a London based clinician 'normally there would be one to two deaths in a clinic in a year, but there have been four in June alone'. There is concern that the increase in deaths is because people have not been accessing support, have had appointments cancelled, depression from shielding etc. This is a stark reminder of other effects of pandemic
- (JS) This may be an issue for other conditions/groups but that we may not know the true extent of this for some time
- (JS) Health Service Journal covered the launch of the Rare Reality of Covid-19 impact report - looking to do follow up on stories from those who are shielding. JS invites contributions to this
- (Participant) Attended webinar on shielding last week. Most discussion was around calculated risk. About the balance of risk from virus vs risk from mental health impact. Notes some families still very unlikely to want to leave home and some desperate to get back to normal
- (Participant) Had similar experience, some parents are very uneasy about pausing of the shielding guidance
- (NF) provides an update from Scotland following a call with Scottish Government. Likely that decisions on whether a patient (children in the first instance) will continue to shield will be made following an assessment of risk and joint decision making between clinician and parent. Unsure whether this will also apply to adult patients
- (JS) Encourages everyone to share report. meetings will be dropped to once every other week (1st and 3rd Tuesday of the month at 10am). Next meeting will be 21 July, but people can still contribute between meetings

Comments throughout:

- We have found that for some of our families just receiving a phone call consultation, especially with geneticists, has been a very negative experience.
- We are having people reach out to us following diagnosis as telephone appointments are rushed and not personalised.