ISSUES RELATING TO COVID-19 AFFECTING PEOPLE LIVING WITH GENETIC, RARE AND UNDIAGNOSED CONDITIONS

Shared with the Rare Disease Policy Board

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The issues described in this document were communicated by Beverly Searle (Unique) and Kerry Leeson-Beevers (Alstrom Syndrome UK) to the Rare Disease Policy Board. The issues here have been compiled from Genetic Alliance UK's weekly calls with members, with input from Beverly Searle and Kerry Leeson-Beevers.

It is important to note that this is a compilation of experiences from our community of people living with genetic, rare and undiagnosed conditions. Their experiences are not universal, and may not reflect policy or intent from service providers. If there are specific announcements, new policy or changes that any service provider or government service would like to highlight that would mitigate these experiences, Genetic Alliance UK will be happy to publicise these.

Support and acute needs of carers and patients

A central pillar of the response for vulnerable people is the categorisation of being vulnerable, receipt of a letter indicating this, and addition to the register of vulnerable people. There have been issues with the implementation of this system for people living with genetic, rare and undiagnosed conditions:

- There has been variance in support available between the devolved nations, though this issue is being addressed. Patients who live in a different country from where they access their specialised services have had to contact their specialists, who have then informed the patients' GPs.
- Many of the patients with many of the more complex conditions are receiving declaration of vulnerability letters more slowly than others. In some cases this is directly from a specialist, which can mean that they have not been added to the register of vulnerable people. This can cause delays or problems in accessing other support, including priority for shopping and medication deliveries.
- Difficulties with self-registering for shielding when records are in several separate locations makes it easy for patients to 'fall through the cracks' and for there to be delays in decisions about vulnerability and necessity for shielding, so letters are often delayed.

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Registered charity numbers: 1114195 and SC039299
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- There is variability within condition-specific communities with some people receiving letters while others have not.
- Some patients being advised by their specialists that they are vulnerable and should be shielding but this is being ignored/denied by some GPs, some of whom are not familiar enough with the particular genetic or rare disease to make a clinical decision to allow shielding advice letters to be sent or who have not received any advice from the specialist to enable this.
- Some families whose affected child has received a shielding letter are then having problems with accessing reserved supermarket slots since they are being told their child needs to hold an account with the supermarket.
- Food parcels for shielded patients do not take into account clinically-driven dietary requirements. This is a general point, but once veganism, gluten intolerance and other basic requirements are catered for, how long will it take for food packages for specific genetic and rare conditions to be available? The middle ground appears to be dialysis friendly food - but this is a complex spectrum.

The impact of lockdown has been keenly felt by our community:

- There is a tension for key workers when they are vulnerable because of a genetic, rare or undiagnosed condition, or providing support to someone who is vulnerable.
- It has been challenging to manage isolation, especially when caring for someone who struggles with changes in routine.
- Impact on mental health and wellbeing of patient and carers being greatly impacted, as the combination of being vulnerable combines with being isolated.

Those with carers or personal budgets for care face specific challenges:

- Usual care and support has been withdrawn in some cases while in others, shielding requirements necessitate this.
- Care worker contracts are under threat or cancelled, with some families being threatened with having to reapply for support when they have asked for the in home care to be suspended due to vulnerability and shielding worries.
- There has been cessation of payments for families who have stopped care workers coming into their homes.
- Full personal protective equipment (PPE) for care workers helping shielded patients at home must be paid for out of the patients' own funds (this is not included in their regular budget to employ care workers). It is extremely challenging to purchase this equipment.
- New wheelchairs and maintenance/repair services for existing wheelchair are not being delivered because staff are not going into patients' homes.

Getting authoritative information can be challenging:

- Limited information is being provided to people who do not speak English as a first language. However, this is high level and complex. Patient organisations are working hard to provide information in an accessible format which often requires interpreters and one-to-one phone calls.
- Some communities feel overloaded with information while there is a dearth of information for other genetic, rare and undiagnosed condition communities regarding Covid-19 and their specific disorder.
- There have been concerns arising from interpretation of NICE guidance, isolated reports of do not resuscitate orders and rationing of access to intensive care. This has caused a lot of fear and

worry though these cases appear to be either misinterpretations or isolated incidents of incorrect announcements.

Patient support organisations

The organisations that support our community are under immense strain.

Workforce

- Simply put, genetic and rare condition charities are being asked to do more with less. Many teams are now smaller, while new, challenging requests are being made for support.
- Adaptions to digital and home-based working has been challenging for some small organisations and their impact has been lessened because of this.
- Some of the challenges might be mitigated by volunteering, but for many this poses new management challenges.

Financial impact on charities

- Every organisation we have contacted has been affected financially. Some are adapting less well than others.
- We do not believe the government's measures to protect charities support Genetic Alliance UK's members well. We fall between support for small local charities and large national charities. Our network provides a comprehensive and complex range of support and services to the genetic, rare and undiagnosed community that should be protected.

Impact on research

- One of our members reports preclinical research delays, with a line of study having to be stopped to be restarted.
- Clinical trial continuity threatened – some trials have stopped while others are managing to continue with changes to protocols.

Longer term information

- The genetic, rare and undiagnosed condition community would like to know which diseases constitute the widely referred to 'underlying health conditions' when reporting deaths due to Covid-19 in the news. Is this information being collected centrally and, if so, which genetic and rare conditions are represented? Specific death rates and survival rates linked to Covid-19 and specific genetic and rare conditions would be very helpful information for the community to have in order to guide their members.
- Many genetic, rare and undiagnosed condition patients and their families are concerned about the possibility of relaxing the lockdown. Until a vaccine is available, patients will remain at increased risk and many are afraid about jobs and the long-term impact.

Impact on 'business as usual'

Routine care for genetic, rare and undiagnosed conditions

- We are extremely concerned that our community are becoming frightened to go to hospitals and clinics, either for necessary routine care or for acute needs. This creates the grave risk of serious consequences from an untreated condition that would otherwise have been dealt with.

- We are aware of ‘Covid-free’ wards and clinics, but believe more should be done to promote these and this approach should be implemented more widely.
- Some clinicians and patients are adapting well to telemedicine and telephone consultations but many others need help them to feel more confident. Many would benefit from tools to enable them to help monitor and manage their condition including weighing scales, and equipment to measure blood pressure and oxygen saturation.
- Many people living with genetic, rare and undiagnosed conditions are having clinics cancelled or routine support reduced or withdrawn.

Policy matters

- We know that 'non-urgent' NICE assessments/evaluations/guideline development and genomic testing have been delayed. This appears to be understood by the community for the time-being, as we are in the early stage of the impact of Covid-19 on the health service and parallel activity. There is not yet an indication of when we can expect business as usual activities to pick back up.
- The classification of what makes a NICE assessment 'urgent' seems to be based on whether or not it is cancer (with a few exceptions.) For a short window, we believe the genetic, rare and undiagnosed condition community will be sympathetic to NICE's challenge, but it might not be long before this disparity begins to appear to be inequitable.
- UK Strategy for Rare Diseases - likewise - the community is sympathetic to short term delays, but uncertainty lasting for too long would be very detrimental to the long-term work to deliver better outcomes for people living with rare, genetic and undiagnosed conditions.