

COMMUNITY CHECK-IN NOTES

Tuesday 9 June: NHS remote consultations

Organisations represented:

- Action for Pulmonary Fibrosis
- AKU Society
- Alex TLC
- Alström Syndrome UK
- Angelman UK
- Archangel MLD trust
- Ataxia UK
- Behçet's UK
- Cerebra/Cardiff University
- Duchenne Family Support Group
- Gauchers Association
- Max Appeal
- Medics for Rare Diseases
- Pitt Hopkins UK
- Ring20 Research and Support UK
- Same but Different
- The Smith-Magenis Syndrome Foundation UK
- UK Mastocytosis Support Group
- Unique – the rare chromosome disorder support group
- Wolfram Syndrome UK

Genetic Alliance UK staff attending:

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

NHS Remote Consultations

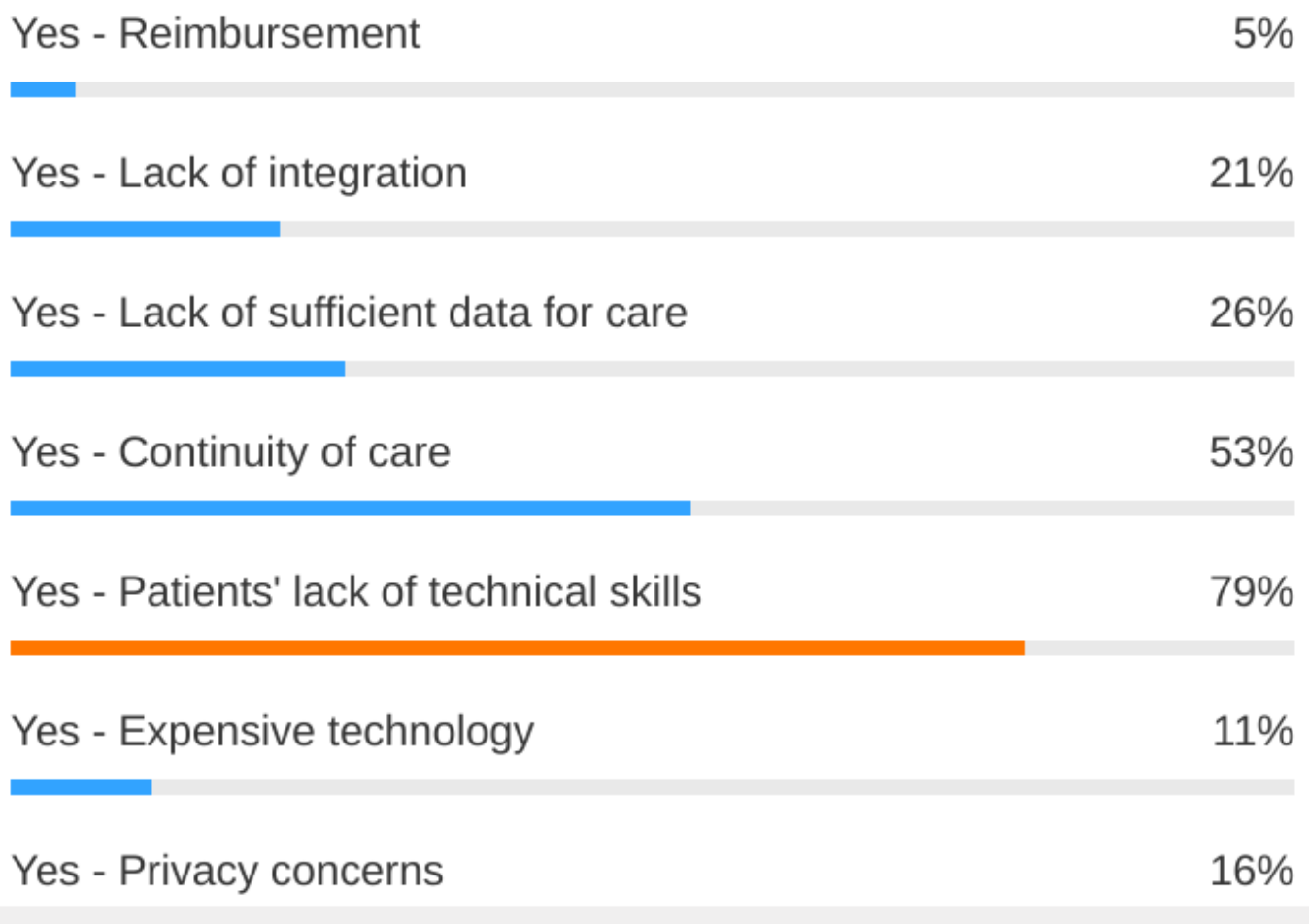
The biggest concern identified as a barrier was the lack of technical skills of patients

Genetic Alliance UK

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Registered charity numbers: 1114195 and SC039299
Registered company number: 05772999

1. Do you have any concerns about telemedicine? If yes, select top three (Multiple Choice)



Zoom poll results

Presentation from Kerry Leeson-Beevers, Alström Syndrome UK on a brief overview of finding of telemedicine clinics and Alström Syndrome UK:

- Clinic in Birmingham – attendees see 11 clinicians in full day clinic (for children).
- Impact of Covid-19 – all highly specialised clinic postponed since March (will have knock on effects throughout year), many local appointments also cancelled.
- Telemedicine clinics give contact with experts and assurances, fills a gap until clinics return so Alström Syndrome UK is supporting this – planning (specialties, interpreters, accessibility). They have also developed a telemedicine information sheet and advice for what families could do to prepare for the appointments, help families get used to technology, attended clinics to support families.
- As an interim measure telemedicine clinics are really beneficial. This helps with family anxiety, especially as families do not want to visit hospital. No bloods etc can be taken but families were able to receive diet and nutrition advice.

- Difficulties include connection/tech issues, they were not able to weigh/measure at home due to lack of equipment and there were limited opportunity for one-to-one interaction.

Kerry said: 'As an interim measure, [telemedicine consultations] offer reassurance, but they do not replace specialist clinics'. She thinks telemedicine clinics are here to stay and this brings challenges and opportunities. They are not as good as face-to-face clinics, but can reduce regular travel, could allow more contact with health professionals between annual clinics, may help with transitions and may help with links with GPs.

Comments following Kerry's presentation:

- There would be huge amount of value to having a GP and/or social work also present at telemedicine clinics, and they are often the most difficult to get in the room.
- For many rare families there is no care coordination at the best of times. Unique have asked their families who have been attending about their experiences – about half of respondents are very positive about telemedicine, some say felt listened to for the first time. There is also a lot of negative feedback, for some they haven't had a chance to meet their paediatrician in person – it is very difficult when your child hasn't even been examined by the person you are talking to. For many, appointments have just been cancelled by text message. Some have had to fight to get results over the phone. One lady is deaf and can't use telemedicine, but her doctors are not willing to engage by email/social media which would suit her needs better. It has been a mixed reception – but thinks a specialised clinic might be a better standpoint (due to coordination) for telemedicine.
- Telemedicine was considered for Duchenne to reduce stress of travel before, but ran in to issues with reimbursement for this from the clinics – perhaps this has been resolved due to the Covid-19 situation? Population size may also be an issue and existing difference in clinics across UK and the already existing postcode lotteries. Some tests, such as the six-minute walk test, cannot be done by telemedicine.

Issues raised on chat relating to telemedicine:

- Some of our parents are deaf or on the autism spectrum which makes telemedicine difficult for them.
- Important to consider the loss of body language cues during physical consultations.
- Telemedicine does not work terribly well for dermatology-related concerns.
- Some consultations need physical interactions / exams such as blood tests.
- Video sessions would be preferable to telephone calls (Especially if there is no speaker phone for parents/carers to join call too).
- Poorer families may not have access to technology.
- There is disparity between consultations - some clinics are only on phone and some are on video.
- We are grateful for the telemedicine clinics, but most concerned about those patients who aren't able to initiate new treatments because that isn't being done at a distance. Of greatest concern are those with advanced forms of mastocytosis, whose life expectancy may be shortened by delayed treatment.
- We also have patients who are really pleased with telemedicine. They've been hoping for it for years because travel is so problematic for some because of their condition. So for some it's a great relief to finally have this option and they'd love to have the option going forward.
- Would there be a merit in an opt-in for face-to-face consultation system. So you automatically get a telemedicine appointment unless the patient/family/doctor request face-to-face?

- Could the GP join the telemedicine online MDT meeting?
- I think for our families we've heard mostly positives, because it cuts the travelling down, the issues with travelling for disabled children, the long days for an hour's appointment and the time delay and poor waiting facilities can trigger seizures for our children. I think there should be options depending on the condition, what the appointment is for, and what it includes. If a blood test is needed if the tertiary centres could link with community nurses etc that would be amazing. You could have a community nurse or a specialist nurse at the appointment in the home to take bloods for example or physical checks? I'm talking longer term here past shielding etc.
- Before Covid-19 started we had mooted telemedicine for some appointments but the consultants raised the issue of reimbursement so has that been put in place for this time? and would that continue after...? otherwise clinicians might have issues.
- We have access to phone meetings or video but only since Covid-19.
- Many of our patients have access to telephone appointments, that seem to be working well since Covid-19.
- Telemedicine only available since Covid-19 – personal experience is only by phone directly.
- We didn't have [telemedicine] before but since Covid-19 most appointments have either been cancelled (early on) or via telemedicine. People had asked for it before but it wasn't considered possible before.
- Same here - only phone and video meetings and consultations since Covid-19.
- We have access to phone and video consultations now since Covid-19 but not before either. Most consultants and patients want to keep a mix going forward.
- Some families are having telemedicine calls; the clinical lead is using Zoom consultations since Covid-19 kicked in.
- I have experience of it in Switzerland where doctors and patients have far more direct contact with each other. For me it was really helpful and helped me be a partner in my care.
- Some of the specialist centres for metabolic/LSDs were already do some telemedicine prior to Covid-19.
- We're starting to organise with some clinicians who have been slow to use telemedicine ... adult clinicians are using telephone but not video.
- We have no access to video or telephone consultation at this time. We too have a specialised service that has been cancelled since end of March affecting 22 people so far. I've asked about telemedicine but the Trust are slow at setting anything up.
- Child and Adolescent Mental Health Service consultant feedback is that it is harder on Zoom as cannot see family interactions.
- There are two specialised centres for ataxia in the UK (Sheffield and London) Sheffield has unfortunately completely closed as the clinicians have been redeployed to the wards. However, London has been doing all their clinics virtually. I haven't heard any feedback on how this has been ... yet! It has been a long ambition of Ataxia UK to set up virtual clinics. The clinicians are willing but various streams within the NHS have been a stumbling block. Given this it is amazing to us how quickly it has been set up when it had to be. Quite frustrating but very positive for the future.

Comments from the chat relating to shielding:

- I've been told shielding dates have changed in Scotland and been extended until July.

- I work with families affected by any rare disease. I have found that most of our families have not been offered any form of communication from medical sector at this time, more that they should wait until the pandemic is over for any communications.
- I believe that Wales will be shielding until 16 August. Letters are meant to be sent out from the chief medical officer.
- The Royal Society of Medicine are hosting a webinar about Covid-19 and rare diseases. Shielding is coming up because of the rare genetic diseases tool that has been published. It would be great if you all could sign up for free. Sign up here: rsm.ac.uk/events/medical-genetics/2019-20/mgn51/.
- Some GPs seem to be reviewing their patient records and telling patients not to continue to shield.
- We have patients very concerned that they will now be forced back to work if shielding is ending.
- In Scotland we are participating in discussions with Scottish Government to inform decision making around shielding. I am hosting a zoom chat on this next Monday (2.00pm-3.30pm) please email natalie@geneticalliance.org.uk if you'd like to join.
- We have concerns about reactions to the cleaners and hand sanitisers for our members when they go back to work/school.
- Further to earlier concerns about reimbursement and comments, in Duchene, as carers parents cannot simply return to the physical workplace and risk infection given that it is not possible to socially distance within the household.

A.O.B

JS highlights that Scotland, England and Wales news update videos will be online at the end of the week on the hub: covid-19.geneticalliance.org.uk/news.

Next week is small charities week so this will be the focus of the community check-in.

Genetic Alliance UK will be launching a survey for CEOs to assess the impact on of Covid-19 on charities/organisation in the genetic, rare and undiagnosed community.