

COMMUNITY CHECK-IN NOTES

Tuesday 23 June: Royal College of Paediatrics and Child Health Shielding Guidance

Organisations represented:

This week we must apologise for no list of organisations represented – the first portion of our chat failed to save, and we do not want to share an incomplete list.

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

Shielding guidance

Presentation from Nick Meade, Genetic Alliance UK on changes to shielding guidance in England and Northern Ireland:

- NM notes that the UK Covid-19 alert level has reduced from four to three and provides an overview of current shielding policy.
- England: Today, announcements on further easing of lockdown will be made. On 6 July, a further update on shielding guidance will be made – the gap in between announcements will allow for any monitoring of changes in risk level resulting from the most recent easing of guidance. Those shielding can already take exercise outdoors and from 6 July, the extremely vulnerable will be able to meet in groups of up to six outdoors and ‘support bubbles’ could be opened up to those shielding. The shielding programme will pause from 1 August 2020 and support packages in place will continue until then. From 1 August 2020 those in the shielding group will be able to return to work if their workplace is safe. There will be 25 days of continued support following shielding to allow for transition out of shielding. Secretary of State for Health has acknowledged the hardship faced by those shielding and thanked those who have shielded.
- Wales: There has been no change to the shielding guidance since 4 June, which allowed those shielding to take exercise outdoors. Shielding guidance will remain in place to 16 August.

Genetic Alliance UK

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Registered charity numbers: 1114195 and SC039299

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- Northern Ireland: Shielding restrictions will stay in place to 31 July 2020 then guidance will pause and social distancing will be advised.

Presentation from Natalie Frankish, Genetic Alliance UK on changes to shielding guidance in Scotland:

- NF provided an update from Scotland - shielding guidance was updated on 18 June 2020 advising those shielding to take outdoor exercise, participate in non-contact sport and meet with one other household (maximum eight people) in their garden. Guidance will remain in place until 31 July 2020 although may be updated before then.
- NF shared key messages from a zoom meeting on shielding in Scotland that took place with 22 patient group representatives:
 - Not clear that shielding guidance is advisory
 - Some still don't have letters issued
 - Confusion as other lockdown restrictions ease and different guidance across UK
 - Consensus that decision to shield or not to shield was a matter of personal risk and opinion. Need for information to inform this, such as local case numbers, high risk activities
 - Agreed that shielding was not a viable position long term
 - Very supportive on easing of restrictions on outdoor exercise, many already doing this - but concern from those in very busy areas (many having to exercise very early or late)
 - Dedicated hours deemed unrealistic - won't suit everyone and won't be adhered to by non-shielders. Better to consider 'safe spaces' like local authority parks and playgrounds that can be booked/monitored.
 - More support required - energy costs, IT and technology grants and support
 - Shielding impact on household not considered - education, employment impacts
 - Accessibility in post-shielding world - space in shops, toilet access, pavement space
 - Concern for future provision of health and social care services

Presentation from Dr Mike Linney, Registrar, Royal College of Paediatrics and Child Medicine:

- Dr Linney explained that initial shielding guidance was not informed by RCPCH and not, in all cases, appropriate for children. Since then, RCPCH has been working to produce updated guidance appropriate for children.
- Dr Linney noted a limited impact of disease from Covid-19 on children, but that children were being affected by anxiety, reduced wellbeing, inequality, social and emotional development and interruption of education. There is also an impact from the likely rise in domestic violence and impact on child safeguarding, delayed presentation, reduced health care access
- Dr Linney said RCPCH issued first guidance on 16 April and produced new guidance on 7 June, which was highlighted by Dr Jenny Harries during the no10 press briefing on 22 June 2020.
- Dr Linney noted that shielding will only PAUSE from 1 August in England. Shielding may return if the virus does not stay suppressed and so it is important that shielding lists and guidance are maintained.
- RCPCH has discussed guidance with all 4 CMOs to ensure consistency - the guidance applies to children across the UK.

- At the heart of guidance is that the decision to shield should be as a result of discussion between clinicians and families about their own circumstances and the potential impact of activities such as going back to school.
- Dr Linney was hopeful that children will go back in August/September.
- Dr Linney explained the difference between 'Group A' and 'Group B' as outlined in the guidance.
- 'Group A' are conditions that will require continued shielding – those at risk due to primary or acquired immunodeficiency, children with very specific immunosuppression as part of cancer therapy.
- 'Group B' - list groups of conditions which will require a case by case discussion to decide whether, on the balance of risks, a child should be advised to continue to shield. <link here>
- Dr Linney noted that various Royal Colleges and professional bodies had been consulted and contributed to the guidance.
- RCPCH guidance was also informed by:
 - Covid-19 Database - which provides information on covid-19 patients with co-morbidities across UK
 - Research Evidence - looks at research published across the world.
 - Evidence - details of admitted patients (non-mandatory so not complete, but captured 20-25%) - expected that around 1000 children have been admitted to hospital with a positive covid-19 test
 - Evidence was also gathered from research from global admissions of children to PICUs
 - Dr Linney notes that rates of complications from Sars-CoV2 infection do not appear to be disproportionate to those from other respiratory viruses affecting children.
 - Most common co-morbidity respiratory or complex neurodisability - groups which are otherwise at increased risk of complications from all respiratory viruses.
 - ISARIC-4C (Coronavirus Clinical Characterisation Consortium)
 - OpenSAFELY - review of factors associated with Covid-19 related hospital - risk of death linked with age and more linked with male, obesity, ethnicity and deprivation.
- Dr Linney noted that there were additional useful resources available on the RCPCH website including FAQs on shielding, shielding guidance, Covid-19 resources for parents and carers (including a selection of communication books)

Comments following Dr Linney's presentation:

- JS wonders whether evidence of whether children admitted because of Covid or because of underlying conditions - ML says hard question to answer, suspects likely because of Covid but very few of the admissions required significant respiratory support.
- Angelman UK asks a series of questions regarding expanding the bubble programme for parents of disabled children more generally; the future of NHS volunteers; reasons for changing RCPCH guidance.
- ML confirms CF and interstitial lung disease still included in Group B - this hasn't changed.

- Angelman UK asks where does responsibility for issuing this guidance lie? ML notes that letters that have come out so far may not have been very helpful - new letters are due out soon (RCPCH haven't been able to input into letter) ML says every child needing shielding will be under secondary or tertiary care - likely that those cared for just by GP won't need shielding.
- ML anticipates that clinicians/specialists will speak to their patients/parents to discuss risk and whether they should shield. ML expects that every family will be awarded a consultation with their clinical team
- Unique notes there is no mention of complex comorbidities with a background of learning difficulties or behavioural problems. Notes coming out of shielding will have an emphasis on social distancing – but not possible for many children. ML understands the concerns and emphasises the need for the discussion between parent and clinician.
- Unique ask what is the actual risk to our children? Notes that the statistics presented wouldn't reflect the community that was already shielding by that time. ML notes that this is why they remain cautious - but thinks the risk is proportional.
- Angelman UK asks, if the intent is to get kids back to school - what does this mean for the reinstatement of the requirement for local authorities to provide ECHPs. EG makes the point of inability of many children to adhere to social distancing and requirement of close contact for staff – this will be a barrier for kids going back to school. ML says understandable concerns and that there is already dialogue with DfE. ML shares concerns about SEND, notes that the goal is to ensure virus remains suppressed/suppressed further to reduce social distancing requirements. ML says it is important that they can continue to try and demonstrate with the science that the risk is low.
- ML asks if people are on the right track – there are thumbs up from participants.
- JS asks people to share questions offline.

Genetic Alliance UK will collate questions to the RCPCH and share them at the end of the week.