

## Thursday 25<sup>th</sup> November 5-6pm Meeting Minutes

Discussion Topics	What was raised and what we will do
<p><b>Annual Questionnaires</b></p> <p>We wanted to know how long you would be willing to spend filling out our next annual questionnaires</p>	<p>Generally, the SCG spent around half an hour completing the IMAGINE 2021 annual questionnaire. This was agreed to be an acceptable length of time.</p> <p>Whilst the SCG said they wouldn't mind spending up to 40 minutes on the survey, ideally survey-time should not be extended beyond this.</p> <p>The SCG highlighted the importance of the 'save and return' function, which allows parents to complete the survey in their own time and at their own convenience.</p> <ul style="list-style-type: none"> <li>→ <i>We will ensure that the next annual survey does not take more than 40 minutes to complete</i></li> <li>→ <i>We will continue to use 'save' and 'return' buttons, allowing participants to stop and start the survey as they wish</i></li> </ul>
<p><b>DAWBA and ABAS</b></p> <p>We wanted to know if there was anything we could do to make filling out the DAWBA and ABAS, our longer questionnaires, more manageable and appealing.</p>	<p>The SCG agreed that, from memory, the DAWBA and ABAS were not too challenging to complete during IMAGINE 1.</p> <p>The IMAGINE 1 DAWBA reports were considered 'quite helpful' and provided a good incentive to participating.</p> <p>The SCG agreed that offering families a voucher for taking part would not motivate them to complete the surveys. The most powerful incentive was the hope that the study might benefit somebody in the future.</p> <ul style="list-style-type: none"> <li>→ <i>We will continue to provide families who have completed the DAWBA with a personalised report summarising their responses</i></li> </ul>
<p><b>Questionnaire order – together or separate?</b></p> <p>We wanted to know whether families would rather be sent the DAWBA and ABAS questionnaires together or one after the other (with a time gap).</p>	<p>The SCG didn't mind whether the DAWBA and ABAS are released separately or together. As long as families have enough time to complete both surveys before the deadline and can work through them at their own pace, it doesn't matter when they are released.</p> <ul style="list-style-type: none"> <li>• <i>Families will be sent the DAWBA and ABAS 5 years after they first completed it. During the DAWBA and ABAS year, parents/nominated adults will not be asked to complete an annual survey.</i></li> </ul>
<p><b>Webinars</b></p> <p>Next year we would like to start running some expert webinars. We were interested</p>	<p>The SCG thought that webinars summarising the study's key findings so far would be useful.</p>

<p>to know what topics and format would be most useful for families.</p>	<p>A webinar looking at transitions in our cohort over time might be of particular interest. Many of the children who were part of IMAGINE 1 are now transitioning into puberty/adulthood, which brings with it differing needs and challenges.</p> <p>A webinar or Q and A with an expert on autism spectrum disorder, or neurodiversity more generally, could provide reassurance for families. Additionally, information on accessing services, seeking support, communicating children’s needs and understanding timescales for assessments/diagnoses, would be very relevant.</p> <ul style="list-style-type: none"> <li>• <i>We will continue to generate webinar ideas, and feed these back to the SCG. We hope to have our first expert webinars running next year.</i></li> </ul>
<p><b>The bigger picture</b></p> <p>We wanted to know how IMAGINE could have the most impact in the future. What would have been the most helpful support families could have received when their child was first diagnosed? What would have been the most helpful support families could have received when their child was growing up?</p>	<p>The SCG emphasised the need for consistency and long-term support from services for families and children with rare genetic conditions and intellectual disability. Whilst support is available, it is usually short-term and not specific to the needs of each individual child.</p> <p>The SCG highlighted the common experience of being considered the ‘expert’ by professionals, but then not being taken seriously or listened to when the have concerns.</p> <p>When it comes to rare genetic conditions, it can be very challenging to manage the uncertainty of not knowing what the condition might mean for your child as they develop. The SCG highlighted the need for more publications around puberty, transitions and support for post 16/18 age group.</p> <ul style="list-style-type: none"> <li>• <i>Throughout IMAGINE 2 we intend to collate and publish information about experiences of puberty in children/young people with genetic conditions and will signpost via our social media outlets and website to useful services and support groups for 16/18+</i></li> </ul>