

Saturday 27th March 3:00-4:30pm Meeting Minutes

Discussion Topics	What was raised and what we will do
<p>Consent Process</p> <p>We wanted to know if the consent process was user-friendly.</p>	<p>Generally, the SCG were happy with the format of the online consent process and found it easy to use.</p> <p>They would like more clarity on consent for participants turning 16 through the course of IMAGINE 2</p> <ul style="list-style-type: none"> → <i>We will provide advice on what it means to consent on behalf of a child over 16 if they aren't able to consent themselves. We will contact families as their child is turning 16 to help with this process.</i> → <i>We have produced an easy read information video for the young person that explains the study so they can make an informed decision about participating. We will highlight and test the information video we made to make sure it's accessible for over 16s that are able to consent for themselves</i>
<p>2021 Survey</p> <p>We wanted feedback on our online questionnaires</p>	<p>Generally, the SCG felt the survey was quick and easy and to log in and out of. Most people completed the questionnaires using their smartphone.</p> <p>Some of the questions didn't have tick box options that appropriately captured the ability of the children/young people in the study.</p> <ul style="list-style-type: none"> → <i>Some, but not all, of the questionnaires that we use are 'validated'. Unfortunately, this means that we can't change the wording or add 'can't answer/not applicable'. However, we can add in extra instructions to explain that some of the questions may be difficult to answer and reassure that a 'best guess' is appropriate.</i> → <i>We will also add an open text box for additional descriptive information to be provided and ask participants to rate their 'confidence' in their responses to these questions.</i> <p>Would like a space to highlight the strengths of children/young people</p> <ul style="list-style-type: none"> → <i>We will add questions that formally captures these strengths.</i>
<p>IMAGINE Study Reports</p> <p>We wanted to know how families used the personalised DAWBA reports from IMAGINE ID and how to make IMAGINE 2 reports useful</p>	<p>The majority of IMAGINE 1 DAWBA reports were used to assist in getting additional support at school. It was felt that the reports would have more impact if they had 'more clout' or looked 'accredited'.</p> <ul style="list-style-type: none"> → <i>We are looking into changes we could make and will circulate drafts to the SCG group via email for feedback</i> <p>Discussed experience of professionals labelling children. Would like the feedback report to reflect the child's difficulties and what could change with support.</p>

	<p>→ <i>We'll investigate how to best to signpost for further support. However, as this is not a clinical assessment for your child, we won't be able to suggest specific interventions/tailored recommendations.</i></p> <p>An important research question for the study is to understand the impact of services and support on the children's development.</p> <p>→ <i>The Data Linking aspect of IMAGINE 2 will allow us to link our data to education and health records and address this question</i></p> <p>Would like a section that summarises the difficulties that are commonly associated with rare genetic disorders for professionals reading the report.</p> <p>→ <i>We will try to implement these changes and circulate drafts to the SCG group via email for feedback.</i></p>
<p>“No research about me, without me”: Involving the children and young people</p> <p>Although the online questionnaires will be filled out by the parent/nominated adult it is important that the children and young people are meaningfully involved.</p> <p>We wanted to know how the young people would like to be involved in research and what's the most accessible way to involve them in IMAGINE 2</p>	<p>Important that the young people can have a platform to share their experiences. This would need to be done in a thoughtful way that builds trust.</p> <p>→ <i>We will continue to have this discussion with the SCG group. Once the study has launched, we will explore funding opportunities to develop this further.</i></p>