

Wave 2 Feedback

Jo provided a research update and a summary of the Wave 2 data. Some of those involved in the study provided feedback:

- **Video upload:** Some caregivers had difficulties uploading the videos to OneDrive. They liked the idea of using WhatsApp to send videos instead.
 - **Outcome:** We are going to ask the Ethics team about this.
- **Instructions for videos:** Instructions for creating home videos were useful and straight forward. Some caregivers were concerned about whether they had recorded “the right thing”. They suggested that the instructions could state the importance of ‘the before & after’ or “lead up” to communicative acts – highlighting that they don’t need to just focus on capturing the ‘important’ bit (i.e., a vocalization), as there is huge value in the ‘dead time’ of the video.
 - **Outcome:** We are going to add this to the instructions, alongside a guide for the ideal minimum and maximum length for videos.
- **Questionnaires:** Positive feedback was provided about the questionnaires, including clear instructions and good focus. The use of free-text comment boxes was seen as essential – they allow caregivers to provide an explanation of responses. In some cases, this might be the difference between choosing to answer questions or not.
 - **Outcome:** We are going to look at where more comment boxes could be added to sets of questions.

Thoughts on in-person assessments at Wave 4

- There was a consensus that in-person assessments at Time 4 would provide a valuable comparison to Time 1 data. Group members suggested that if families were happy for us to visit at Time 1, they would likely be fine with it for Time 4.
- It was suggested that we could observe changes to the home environment which might not be captured by the questionnaires. These could also be included in future surveys (i.e., changes to the family dynamic – new sibling, parent now working part-time instead of full-time, etc.).
- Another suggestion was that it would be useful to look at differences between children’s communication with the researcher vs. caregivers. This may demonstrate which children can generalize their communication skills.

Outcome: We would like to pursue this option for 2026/27. However, we will need to secure additional funding and get ethical approval. We will keep you updated.

How can we maximize engagement for Wave 3?

1. Phone calls & visits:

- The group agreed with the idea that some people might benefit from completing questionnaires over the phone.
- They also felt that visiting families who are struggling to make the videos – due to technical difficulties or confidence – would be helpful.
- However, it was also pointed out that some caregivers might not want us to go to their homes, so we should consider offering alternative locations, such as a club or school. Getting the videos during school time could also be ideal as it doesn't take up evenings/weekends.

Outcome: We plan to offer a phone call or visit to those struggling to complete the questionnaires or videos (as a last resort).

2. Short version of questionnaires:

- We could create a very short version of the questionnaires for those struggling to complete the main one, or a shorter compulsory questionnaire with additional questions if caregivers have time.

Outcome: We plan to offer a shortened version of the questionnaires to those struggling to complete them (as a last resort).

3. Reminders:

- Gentle reminders were described as really helpful - some caregivers just forgot about the task. These could be via email or text.

Outcome: We plan to send gentle reminders via email/text around the deadline for completing questionnaires/videos.

4. Additional benefits:

- *Financial incentives:* The group liked the idea of being entered into a lottery for an additional voucher. It was also suggested that the voucher amount for more deprived families could be increased.
- *Signposting:* Providing links to support for caregivers, even at a national level, could be helpful.
- *Parent network:* The group was keen on the idea of establishing a WhatsApp group or private Facebook group for families involved in the study. Allowing them to connect would create a sense of community. If a caregiver was struggling with a study task (i.e., uploading videos) they could ask for help from others.
- *Child-specific feedback:* Another suggestion was to provide feedback for individual caregivers on their child's progress between waves of the study.

Outcome: We are considering all the above options, but we need to consult with the Ethics team about each of them.

How should we ask about communication?

The overall message from the group was that defining a child's language level / reporting on their communication methods is very complicated.

Things to consider:

- **Changes over time:** It would be important to give people the opportunity to say if/how different communication methods have changed over time.
- **Context:** Setting is important (i.e., children may communicate differently at school vs. home). There are also several factors which may affect a child's communication methods (e.g., how the child is feeling, what the child is requesting, how well they are understood, who they are communicating with).
- **Different methods:** Communication in this group is multi-modal. More options need to be added to the list of communication methods, including physical communication (different from gesture e.g., hand leading / pushing), signs, using objects of reference, noises, typing, and stims. The importance of physical communication in particular was discussed, including the negative impact that this can have on caregivers e.g., when children get stronger
- **Interpreting communication:** Some group members highlighted the nuance of specific child behaviours and how so much can be communicated in a simple or unique act (e.g., different types of screams mean different things). They also discussed how it is hard to know if their child is trying to communicate – when a child does something, is the adult just picking up on it, or is the child intentionally communicating?

Outcome: We are going to continue working on this aspect of the questionnaire, with the following takeaways in mind:

- We could include a question with each communication method, asking for percentage use, and how this use has changed over time (e.g., same, decreased, increased, N/A over the last year).
- We should include an optional free-text comment box for caregivers to provide more details.
- We should ensure that the setting is specified (i.e., how the child communicates *at home*).

We will also keep you updated on our plans to conduct interviews on this topic.

Thoughts on additional Wave 4 measures

Parent language:

- **Difficulty:** Group members found the vocabulary measure quite difficult. This could prevent completion, affect retention, or cause feelings of guilt/shame. Suggestions included; a warning at the start that it is intentionally difficult, a downloadable document for answers at the end, and adaptations for those with additional needs.
- **Different measures:** Several group members agreed that a measure of *communicative confidence/ability* might be more important. This could include communicating with professionals / implementing recommendations for their child's development. The importance of English language skills was also discussed (i.e., self-report for caregivers on beginner/advanced/fluent in English).

Sensory profile:

- **Importance:** This was identified as a very important topic, particularly focussing on what may dysregulate children.
- **Comment box:** Questions can be difficult to answer as a child's sensory needs depend on several factors e.g., mood, context, type of input. A free-text box could be useful. Without this option, respondents may be tempted to just tick 'sometimes' for lots of items.

Caregiver support:

- **Negative impact:** There was general concern about how the *informal support* survey might negatively impact caregivers. Suggestions included; making it optional, adding a trigger warning, clarifying the purpose of these questions, signposting to support, and reducing the length of the survey.
- **Answer options:** Additions to the *formal support* survey included; adding a "I don't know about this" column, splitting up the "I can't access this column" to reflect different reasons (i.e., not entitled to it vs. not available), and adding a comment box next to each one for further explanation. The form should also capture what support people want most.
- **Sources:** Other sources of informal support were discussed, including national schemes/benefits (i.e., blue badge, radar key), local offers or one-off benefits (i.e., SEN hour, jump the queue, discounts), and advisory support (i.e., CAMHS, local offer website).
- **Focus on caregiver:** These discussions highlighted the need for the questions to emphasize that this is about support that benefits the caregiver (not the child).

SDQ:

- **Difficulty answering:** This measure was deemed to be unsuitable for this population due to limited language. A warning could be added about this at the start, alongside 'N/A' or 'Not sure' options for items. Alternatively, respondents could just respond to relevant items, and/or use a comment box to provide further details.

Motor & Imitation:

- **Importance:** This was identified as an important topic linked to the learning and use of speech sounds. It also links to apraxia/dyspraxia observed in everyday activities e.g., difficulties blowing out a candle / blowing bubbles.
- **Response options:** It was suggested that the 'never' and 'rarely' options should be separated - *never* might be 'can't' whilst *rarely* might be 'they can but they don't do it much'.
- **Quality:** Group members asked how good the imitation would need to be. Some respondents might put 'never' if it's not full/perfect (e.g., if they stick out just the tip of their tongue). The questions should capture whether a child a) does not attempt, b) attempts but not well, or c) does a good imitation.

Outcome: These questionnaires would primarily only be included in Wave 4, which will commence in Autumn 2026. We will continue to develop these measures and seek further feedback at future meetings.