

Participants' impact on OTARC research

We asked our researchers "What do participants mean to your research?"

Knowledge

Time

Generosity

Understanding

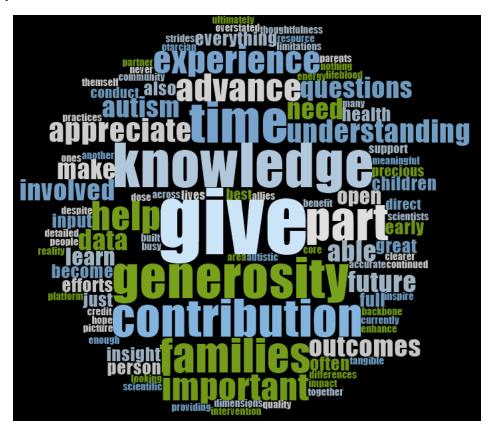
Experience

"Participants inspire and sustain our research. Without their voice and willingness to share their experience, we would not have the knowledge and understanding we do. Participants are why we do what we do."

"Everything, research wouldn't be possible without them. They also bring a dose of reality to research."

"They are the most important part of our research. Without them we would have nothing and would not be able to help others. They are full of generosity, thoughtfulness and (are) wonderful."

"Without participants we would have no autism research. The contribution participants make to our research can't be overstated- we value their time, efforts, and input. I hope we are providing enough to thank them for their contribution."



"When someone participates in our research, they don't just give us their time; they give us an insight into parts of themselves that we could never know just by looking at them. And when one person after another is generous with their time and insights, we can start to piece together a clearer, more detailed and ultimately more accurate picture of who we are and what we need."

So, what impact have research participants had on early identification and diagnosis of autism?

"Engagement with autistic children and their families in this program of research has meant that future generations of autistic children can be identified as early as possible, to facilitate their health and wellbeing through access to supports and services. It has also helped thousands of families better understand their child and how to best communicate with them and meet their needs."



And for interventions for children with autism and their families?

Participants have "allowed us to investigate the impact of intervention on the individual and their family; this allows us to build an evidence base for the intervention; it also helps us refine these interventions to make them maximally effective."

<u>Professor Cheryl Dissanayake</u>, Chair of the Olga Tennison Autism Research Centre



Thank you so much! We couldn't do it without you

"Invaluable. Generous. Selfless."

"Participants who I meet in the Research Unit are so generous in sharing their journey, and often want to help other families by contributing to research. Every single child, teenager and adult, makes a difference to our understanding of Autism. There would be no data, and no research without them. Each participant brings their own unique experience and knowledge to our Research Unit. Thank you!"

"Participants make our research meaningful and relevant. By helping us they are helping others in the community. Their participation helps to provide further understanding and to drive change"

"I am in awe of the generosity of participants, who, despite living full and busy lives, make time to be involved in studies. Often, they're helping future generations with no direct benefit to themselves and their families. Without them, there would be no research. We often give credit to scientists for creating new knowledge and understanding, but participants are the ones sharing their knowledge and experience and so are core to the scientific process."

"Participants are the lifeblood of research. Without their generous dedication of time — which is a precious resource for many of our parents — we would not be able to make such strides in informing early intervention practices."

"To me participants become part of the OTARCian family - They partner with us to advance our knowledge of [autism] and to ask the future questions for research. They become the platform for future families to learn from and to put their hand up for research."

Join us...

This presentation was created by Alexandra Haschek.

- For more information about what OTARC does, please visit our website.
- Register to participate in research: sign up here.
- Donate to OTARC: tax-deductible donations gratefully received here.



