



ICOMBO
INTERNATIONAL COUNCIL OF
Multiple Birth Organisations

Research with twins & families

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Project aim

- Research with multiples contributes to our knowledge of issues relevant specifically to multiples but also has the potential to contribute transformative insights to our understanding of health, disease, behaviours and welfare for the whole population
- In conducting research it is critical the needs of multiples and their families are considered
- In 2018 ICOMBO developed a questionnaire to gather information to present to researchers about what multiples and their families would like if they are involved in research



Methodology

- Questionnaire developed with input from researchers
- Used Survey Monkey and conducted in English, French, German, Japanese and Spanish
- This survey was for both multiples themselves (if they were old enough to make decisions about their involvement in research) and the parents of younger multiples
- The survey was shared globally via social media and ICOMBO member clubs plus various partner organisations and individuals





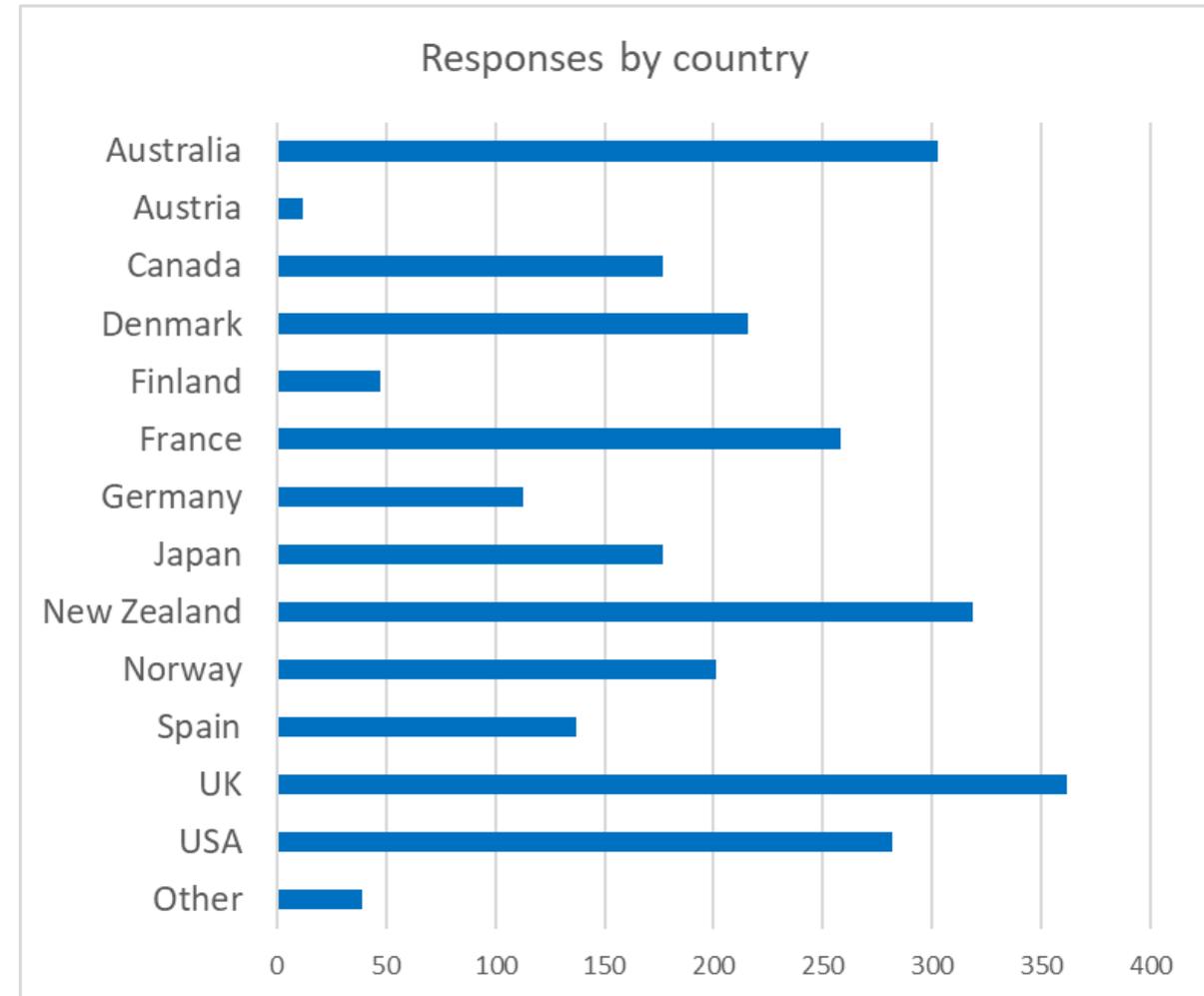
Questions

- Background Information
 - Background information gathered to help us interpret the responses and see if there are any differences between different groups (e.g. by country, age group)
- Participation in research
 - These questions provided more details about the types of studies people would be happy to be involved in and expectations from the researchers
- Non-participation in research
 - Optional questions designed to provide insights as to why people may not be willing to participate in research



Respondent characteristics

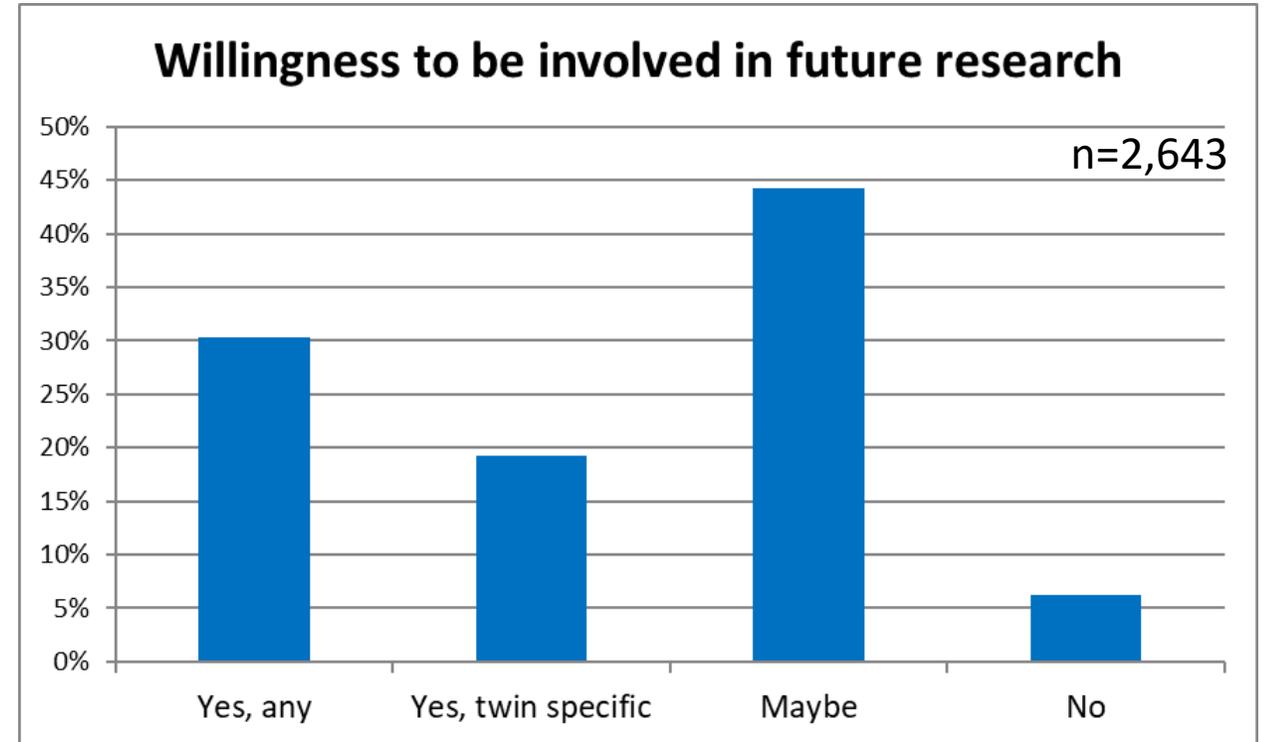
- Total of 2,643 responses from 38 countries
- Respondents:
 - 85% parent of twins (more than half had twins < 5 years old)
 - 8% twins
 - 5% parent of triplet or higher order
 - 2% were both a multiple and a parent of multiples





Participation in research

- Just under 8% had participated in one multiples-related research study previously
- Another 8% had participated in more than one study
- Nearly 50% are definitely willing to participate in research but will depend on nature of the study



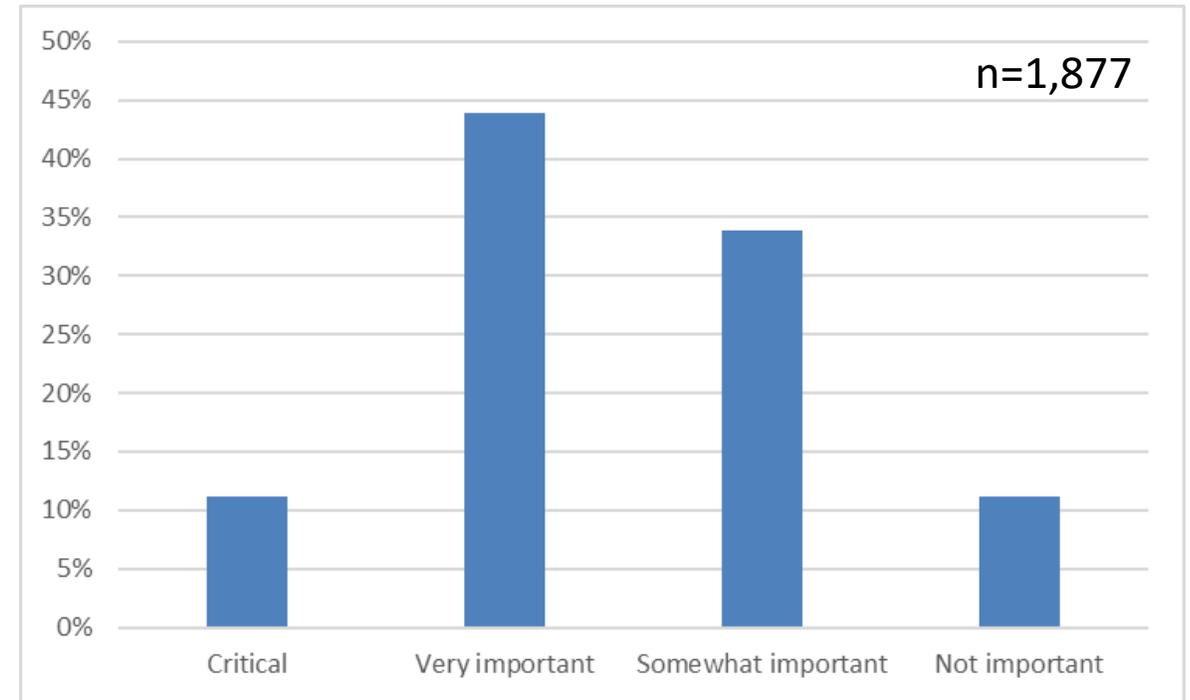
“I believe research is important and impacts decision-making”

“I’m not interested in participating in research for profit alone”



Multiples specific research vs general

- How important is it to you, when deciding to participate in research, that it helps you/your multiples and others to learn more about the unique challenges and benefits of the relationship between multiples?



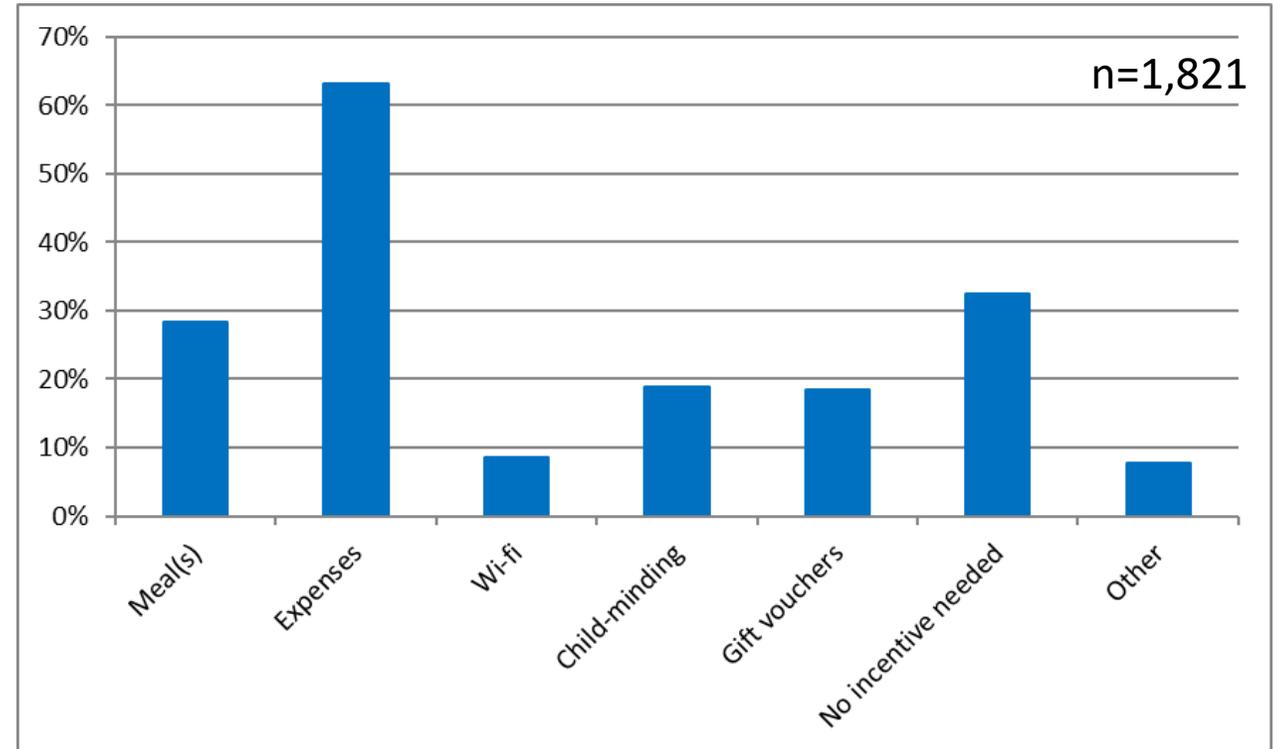
“If it helps multiples AND OTHERS it influences my decision completely”

“I enjoy learning more about multiples”



What incentives are needed?

- 32% of those willing to participate in studies said they would not need any incentive to do so
- Most just wanted any expenses covered, e.g. petrol costs, childcare
- 63% of people willing to travel outside their own city if expenses covered



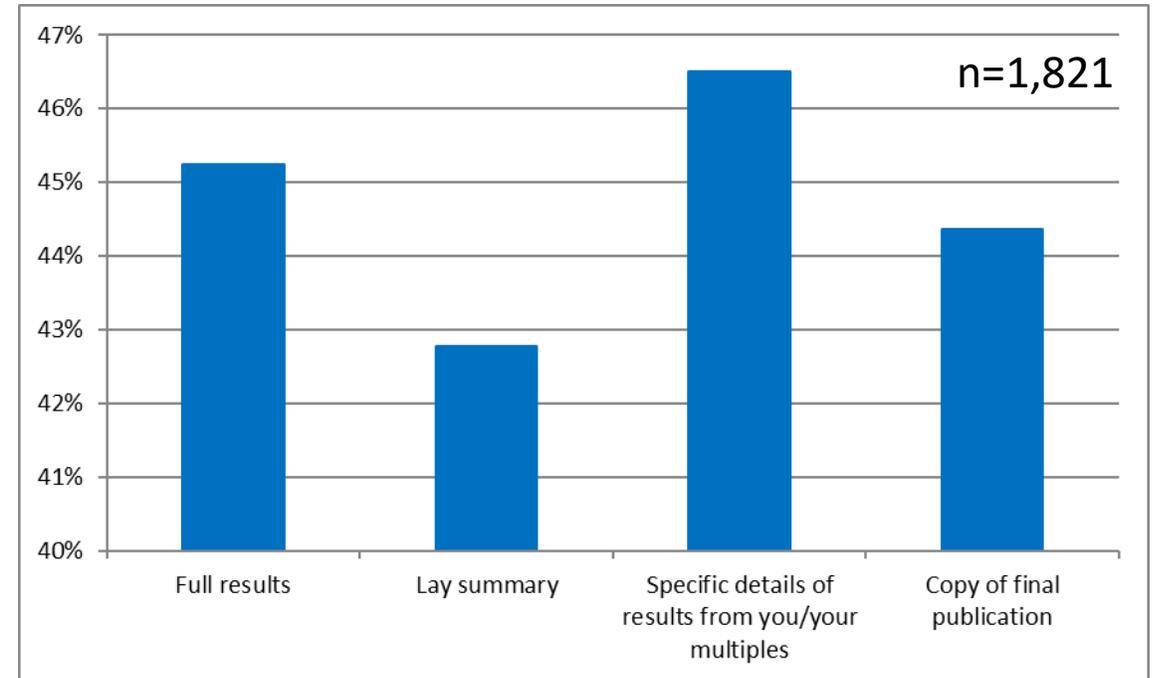
“Don't NEED these, but they sound nice! They would make it seem more appealing and easier”

“DNA test would be a plus”



Research outcomes

- 45% of respondents prefer access to full details of the results not just lay summaries
- 46% want details of their own/their multiples results
- 82% want to be informed if the researcher found something significant about themselves/their multiples



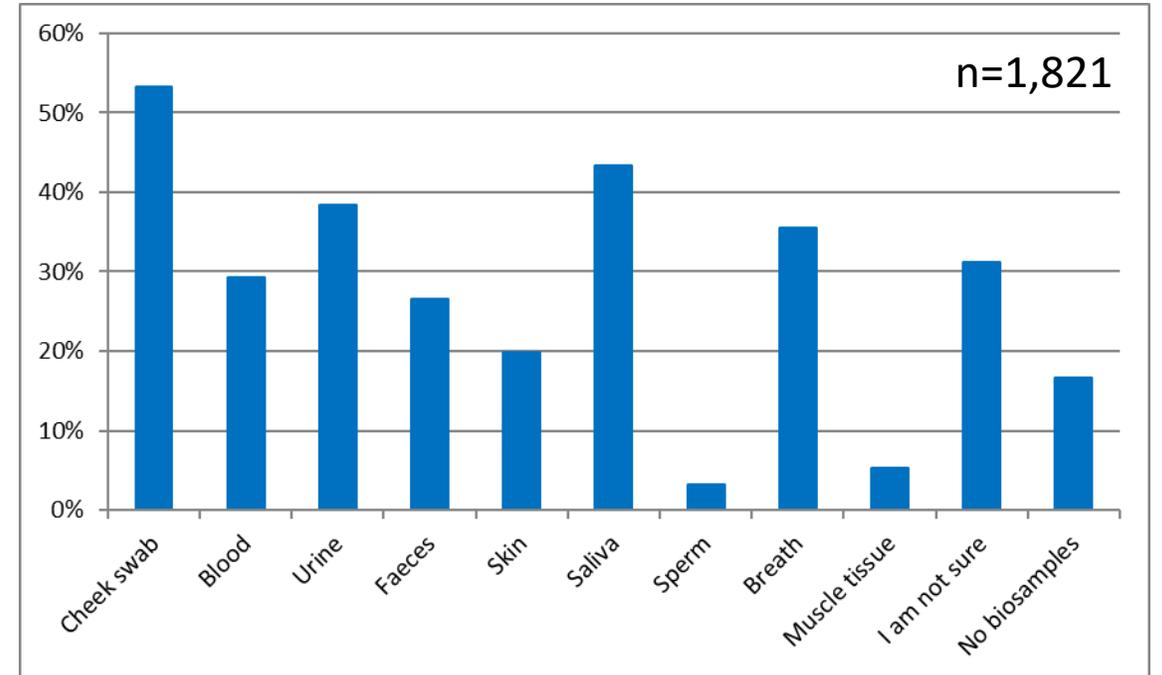
“I don't mind if I don't get anything, but I'm always interested in getting as much as possible”

“Any medical results sent to my GP”



Taking biological samples

- Respondents were happiest with questionnaire based studies or where simple measures taken (e.g. height, weight)
- There was significant uncertainty when it came to taking biological samples and a need for clear controls



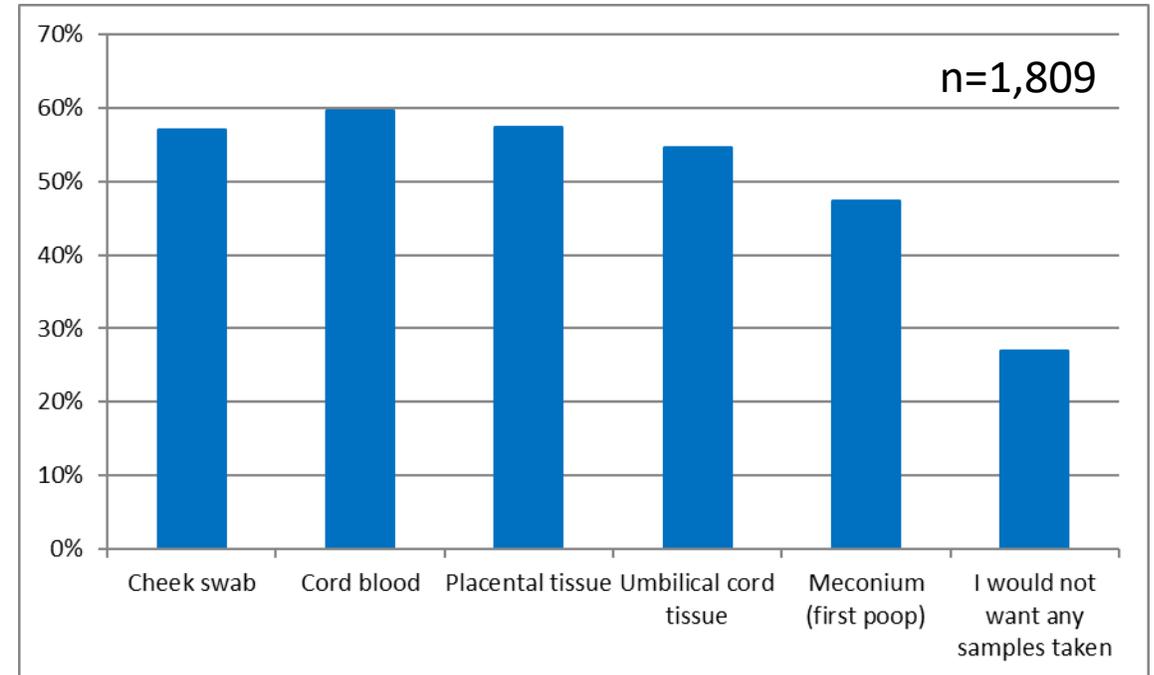
“Yes, probably. But only if I were given full information of test results”

“I would have to be truly assured of the destruction of samples and how they are collected, used, stored or shared”



Taking biological samples at birth

- Any biological sampling needs to be clearly explained with robust reasons for taking the samples (needs to happen well before birth)
- Concerns about risks and pain/discomfort to babies
- Researchers must clearly outline what happens to the samples



“If I knew the purpose or the potential purpose”

“If the collections are anonymous”

“Yes, subject to strict data regulations”



n=370

Questions for researchers

- *“I am curious to know where my multiples samples end up - research or donated to someone”*
- *“What is the purpose/ objective of the study. Are my child’s personal details protected at all times?”*
- *“How many individuals would need to supply a sample for the study to be beneficial/true representation of population?”*
- *“How does this research help others?”*
- *“What and more importantly WHY are you sampling?”*
- *“Who would be seeing the results and what would the results be used for?”*



Reasons why participate in research

n=737

- *“I find it very interesting”*
- *“If the info would be beneficial to parents of multiples to make them happier, healthier and better functioning people”*
- *“I believe it's important and impacts knowledge, action and change”*
- *“Research studies are vital to further our understanding and being a part of such studies is an honor”*
- *“Medical improvement, quality of life”*
- *“Aware that identical twins can provide unique study/control opportunities to researchers”*

Reasons won't participate in research



n=40

- *“I know my twins would not co-operate with this research”*
- *“Don't really want my 2 year olds subjected to it, tests or exams”*
- *“My children can decided if they want to participate when they are old enough to understand”*
- *“I don't feel that my children should be part of research”*
- *“Life is hard enough as it is, I would leave it up to the boys if they wanted to participate in research when they got older”*
- *“We simply won't have time, we barely manage to take care of the kids and take a shower :) maybe when they are older”*



Conclusions

- It is important that researchers understand how parents of multiples and the multiples themselves want to be treated when it comes to participating in research studies
- This study provides many valuable insights that if implemented should guide study design and improve study participation in the future
- There is a genuine desire from parents of multiples to contribute to research projects that benefit society not just multiples
- To ensure participation things should be as easy as possible especially for parents juggling multiples



Acknowledgements

- Assistance with development of survey from ICOMBO board:
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Thank you

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