

PRESS RELEASE

Embargo: Immediate

Contact: Monica Rankin, ICOMBO Chair, chair@icombo.org

Future of scientific discovery bright as new survey shows twins and their families are still willing to play a fundamental role in research

At the beginning of International Multiple Birth Awareness Week (5th-12th November), the International Council of Multiple Birth Organisations (ICOMBO) has just issued the results of a ground-breaking study into twins' willingness to participate in research. 2,643 twins and their families from 38 countries completed the survey. It found that almost half (49%) would be willing to participate with 44% unsure and only 6% would definitely not. For those willing to take part, a majority would be happy to do it regardless of the topic area, while a significant number wanted it to relate to the understanding of twins themselves.

These findings are of significant interest to the scientific community who regularly ask twins to participate in research because they can play an important role in understanding the interplay between genes and environment. By studying the differences and similarities between and within twin pairs, crucial insights into complex diseases have been discovered.

Research with twins can:

- Estimate the impacts of genetic and environmental factors on why people differ in health and disease
- Perfectly control for age and sex with a shared rearing environment
- Investigate difference in disease or environment with a matching control; co-twin control study
- By naturally matching on variables such as age, gender and environment, twin studies can more readily identify the causes of diseases and health
- Facilitate projects involving gender and disease with opposite sex pairs
- Analyse issues relevant specifically to twins
- Provide a powerful model for epigenetic studies

Commenting on the findings, Monica Rankin, Chair of ICOMBO said,

“It is great to see how selfless our families are when it comes to offering their time, and fundamentally themselves, to moving forward the discovery of new treatments and cures. It's of note that whilst they are often willing to do it for free, it is important to them that researchers also take time to explore and explain insights into their own twin relationship too.”

Research Director for ICOMBO, Carolyn Lister, who led on the survey said,

“It is clear from the feedback that twin registries and researchers from across the world should work with organisations that support twins and their families to make it as easy as possible for them to take part. There is an appetite to take part but many have not. Similarly, it is vital for researchers to have a clear patient involvement strategy or they’ll risk losing the support of this group.”

Assoc Professor Jeff Craig, President of International Society of Twin Studies (ISTS), and internationally acclaimed researcher, said,

“Twins have already helped in our understanding of brain development, cancer, obesity, aging, memory, addiction, behaviour and much more. Therefore, their willingness to continue supporting studies is welcome for the whole population. If anyone is interested in taking part then they should look at signing up here.”

The full findings of the survey will be shared with twin groups, and researchers at the International Society for Twins Studies and World Twin Pregnancy conference in Hong Kong in November 2019.

ENDS

Notes to editors

The Survey results in more detail:

- 2,643 twins and their families from 38 countries completed the survey, which was conducted between 22nd June – 31st August 2018 and collected online.
- Just under 8% had participated in one multiples-related research study previously and another 8% had participated in more than one study (84% had not participated in any studies).
- 30% of responders would be willing to participate in research studies in the future (multiples specific or not) and another 19% would participate only in studies that provide information of direct benefit/relevance to multiples themselves. 44% were unsure if they would participate while only 6% were a definite no to participating in any research studies.
- 32% of those willing to participate in studies said they would not need any incentive to do so. For others the most common incentive would be reimbursement of any expenses, e.g. petrol/travel costs followed by meal vouchers.
- People want to be informed of the outcome of the research with nearly half the respondents wanting full details of the results not just lay summaries.
- People started to feel more uneasy when it came to taking biological samples (this is where people started skipping questions so the numbers may actually be higher for those unwilling to provide samples). 16% of people who answered did not want any samples to be taken (i.e. could only measure things such as weight, height or ask questions) and 31% were unsure. Of those willing to give samples, cheek swabs were the most accepted biological sample with 53% willing to give these followed by saliva at 43%. At the bottom of the list only 5% would give muscle tissue and 3% sperm.
- Some respondents were also uncomfortable about samples being taken at birth with 27% not wanting any samples taken. Around 50-60% were willing to have cheek swab, cord blood, placental tissue, umbilical cord tissue or meconium samples taken.