

Research Priorities for the Future Health of Multiples and their Families: The Global Twins and Multiples Priority Setting Partnership

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For which topic were research priorities identified?

health research for multiples

In which location was the research priority setting conducted?

international

Why was it conducted at all?

Although several studies have highlighted developmental difficulties for multiples and the mental impact on their parents, research is lacking on modifiable risk factors, protective factors, interventions and the expertise of healthcare professionals^{14,15}. It is clear that, in order to improve the outcomes of multiple pregnancies, we must focus on the specific needs of multiples, their parents and health professionals who work with them.

What was the objective?

to bring together multiples, parents and carers of multiples, clinicians and researchers from around the world in order to identify the top 10 unanswered questions in health research for multiples

What was the outcome?

a list of 10 research questions

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: forming steering group, developing survey to identify important unanswered research questions relating to the health of multiples and their families. Step 2: collecting research questions: survey, participants were asked to suggest up to three unanswered research questions covering important topics related to multiples' health, 2891 questions submitted, additionally guidelines reviewed, a further 37 questions added. Step 3: data processing: removing duplicates and out of scope questions, merging similar questions, check against evidence, resulting in 89 indicative questions. Step 4: interim ranking: survey, participants were asked to select the two questions from each of the five established categories (antenatal care, intrapartum and postpartum care, neonatal and pediatric health, child psychiatry and development, and parental and family health) which they thought were the most important, participants then asked to rank their selected 10 questions in order of importance to them, the three indicative questions ranked as most important in each of the five categories moved forward. Step 5: final prioritization: workshop: two groups were formed, comprising equal numbers of parents of multiples, clinicians and researchers, each group was asked to prioritize the 15 indicative questions, group rankings were then combined into an aggregate ranking, two new small groups were formed, process was repeated once more, resulting in plenary consensus on top 10

Which stakeholders took part?

Multiples or parents of multiples, healthcare professionals (dietitians, educationalist, fertility specialists, GPs, midwives, nurses, neonatologists, obstetricians, physicians, psychologists), researchers. Survey: 1120 participants (84% multiples or parents, 3.1% obstetricians, 2.6% midwives). Interim ranking: 528 participants (82% multiples or parents, 3.8% obstetricians, 3.8% researchers). Workshop: 26 participants: 13 parents of multiples or parent representatives, 13 clinicians or researchers (26.1% obstetricians, 17.4% fetal medicine experts).

How were stakeholders recruited?

The steering group publicized the survey through a PSP webpage, the websites of their own organizations, social media and e-mail. The survey was open to all multiples, families of multiples and those with experience in treating or caring for multiples and their families.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group. The steering group consisted of representatives of organizations for multiples or parents of multiples, clinicians (such as obstetricians and neonatologists) and researchers with expertise in multiples. Overall, the steering group consisted of 32 members from 23 institutions in 18 countries.