Views of Parents About the Use of Neonatal Real World Data for Research Purposes

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Introduction

Parents are central to research. Real World Data (RWD) is increasingly used for research purposes but there is a lack of data about parental views on the use of data collected in routine practice for research purposes. Accordingly, we aimed to explore parents' knowledge and awareness of, interest in contributing to, and willingness to learn about, real world data.

Methods

We conducted an online survey among parent communities by asking family organizations to circulate a link to the survey among their contacts in March 2018. All participation was anonymised. There were 328 respondents from 4 regions: Africa, Australia/ New Zealand, Northern America, Europe. 100% of respondents were parents.

Results

Knowledge of Real World Data (RWD) / Real World Evidence (RWE) Among Parents:

Have You Heard of RWD/RWE? [%]

91 No / 9 Yes
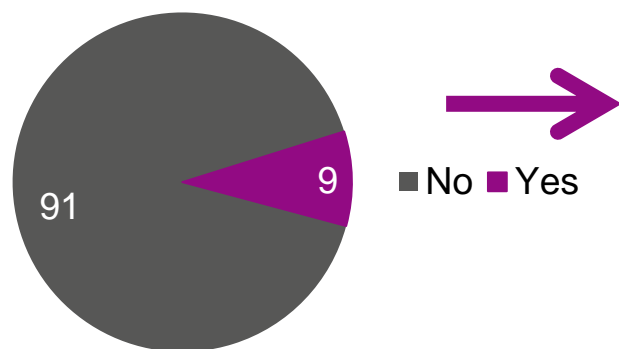
Understanding of RWD/RWE:

- Participation in follow-up phases of trials
- Participation in studies on follow-up
- Qualitative studies
- Data is already generated through visits to doctors' offices or hospitals

Discussion

This preliminary survey indicates that the use of real-world data in research is likely to be acceptable to the majority of family members and suggests areas that need attention to make the most of family interest in real-world data.
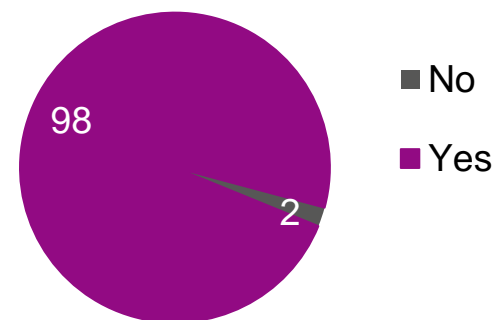
Interest of Parents to Learn More About RWD/RWE:

Should Parents of Preterm Babies Receive Information on RWD? [%]

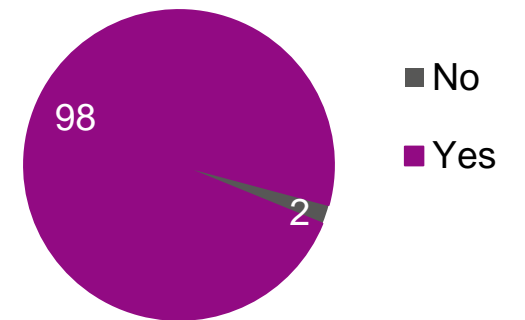|	%
Yes	72
I don't know	13
Not parents, but their representatives	13
No	2
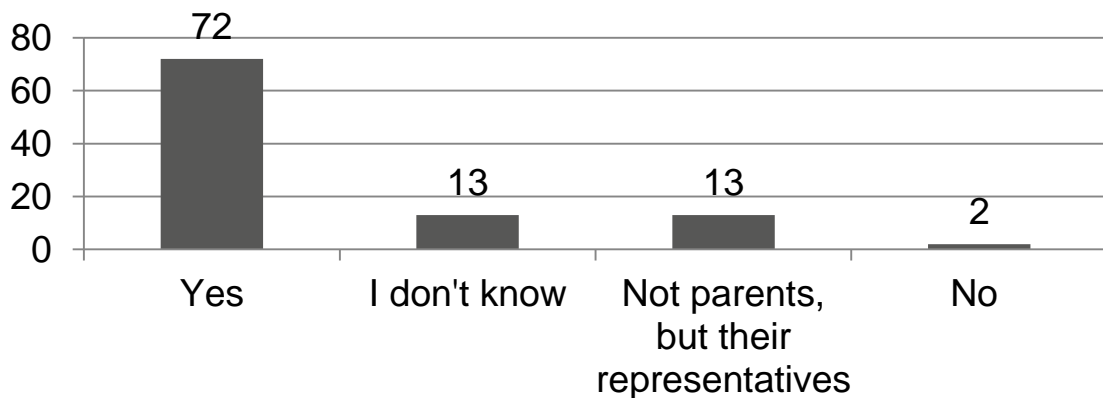
Wish to Know the Purpose of the Study and to Get Results After Participation in Study :

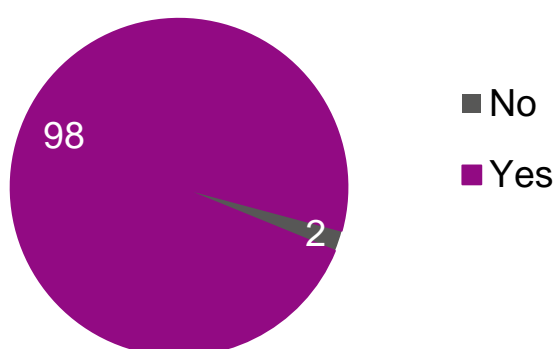**Would You like to Know the Purpose of the Data Collection? [%]**

98 Yes / 2 No

Would You like to Have Access to the Results of the Study? [%]

98 Yes / 2 No

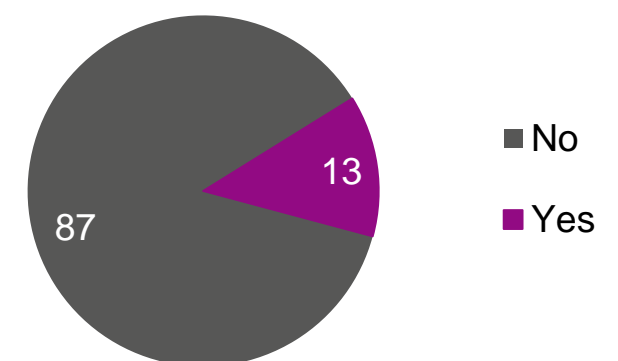### Interest of Parents to Participate in Real World Studies:

Would You Be Willing to Give Your Child's Data Anonymised [%]

98 Yes / 2 No

Reasons for Declining:

- Participation in too many trials already;
- More clarity and clear guidelines for use of data

Would You Be Willing to Provide Your Child's Data for a Longer Time*? [%]

87 No / 13 Yes

*3 years or more

Preferred means of data collection (ranked from 6,preferred, to 1, not preferred)

Mean of data collection	Score	Mean of data collection	Score
Insurance claims (billing)	**5,46**	Patient registries or databases	4,35
Electronic health records	4,77	By visits to the doctor's office	4,06
Apps / mobile devices	4,73	By visit to a hospital emergency room	4,02
E-health tracker	4,65		
Surveys	4,59		

Ackowledgements

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