



Including the child's voice in research from a longitudinal birth cohort: insights from the ROLO Young Person's Advisory Group

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BACKGROUND

Public and patient involvement (PPI) enables children to provide input into research activities¹⁻³. PPI is an important characteristic of research, however, to date, most collaboration has been with adults. Practical resources and guidance for involving children in research have been published, however, the formation of Young Person's Advisory Groups in health research in Ireland is lacking⁴. The ROLO (Randomised cOntrol trial of a LOw glycaemic index diet in pregnancy to prevent macrosomia) Young Person's Advisory Group was established in July 2020. It is a unique group of healthy Irish children between the ages of 9-15-years-old who can provide views and opinions related to paediatric health research.

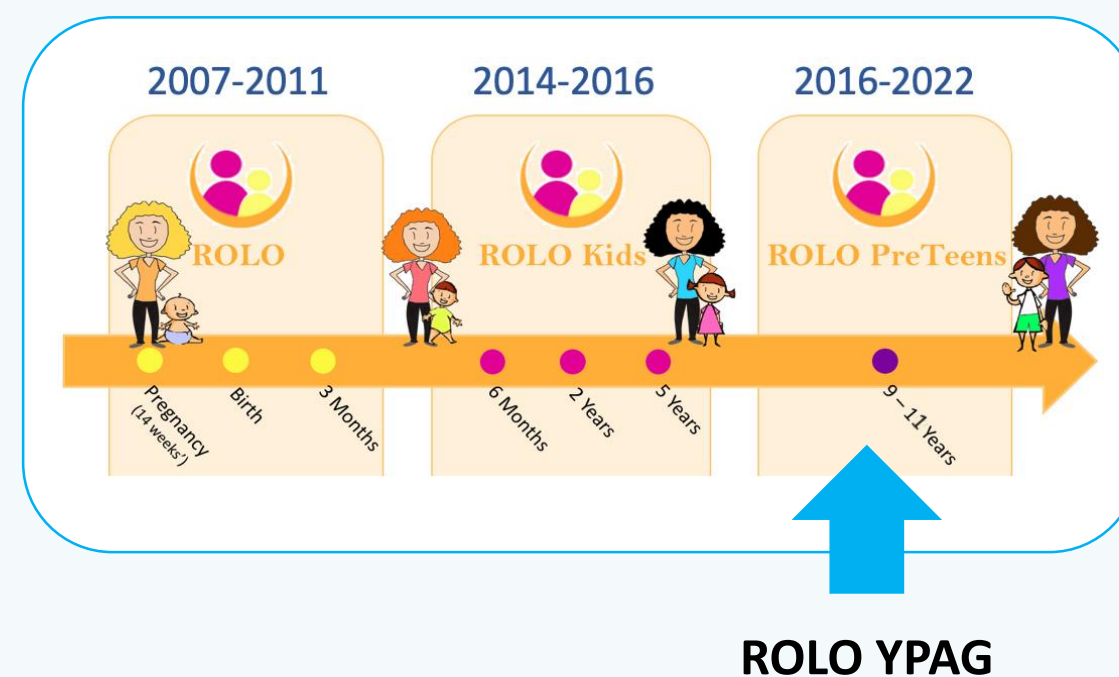
AIMS

1. The aim of establishing the ROLO Young Person's Advisory Group is to understand the key outcomes of importance for children relating to the health of themselves and their families, and to seek advice related to how the research agenda can be more relevant to the child's needs.
2. We aimed to describe the process of setting up the group and the key insights to date.



METHODS

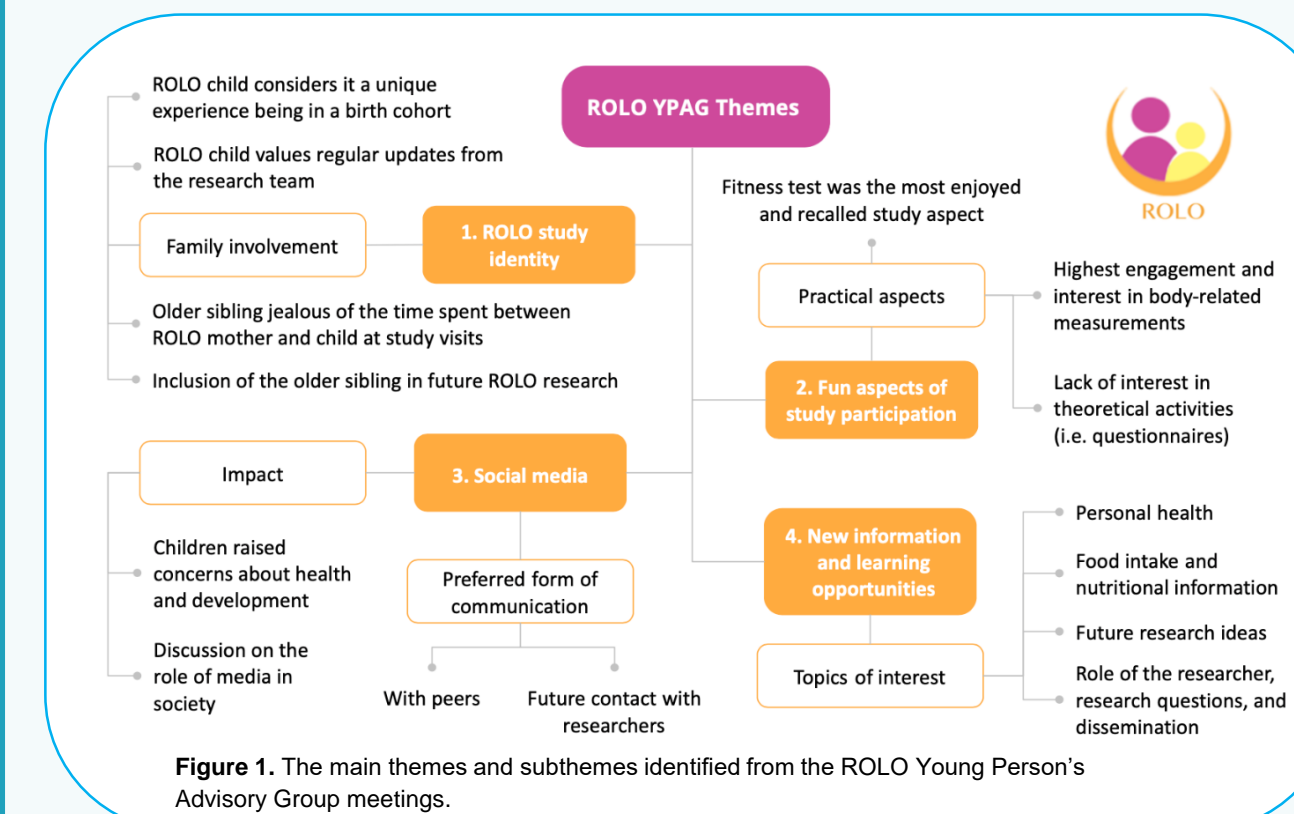
- The ROLO study is a longitudinal birth cohort of mother-child dyads over 10 years with a strong history of PPI⁵⁻⁹.
- In 2020, mothers who are actively involved in the study were contacted to invite their ROLO child and older sibling to participate in the Young Person's Advisory Group.
- Four meetings took place virtually on Zoom between July 2020 and February 2022 which were recorded, transcribed verbatim and analysed for themes based on the topics most frequently discussed and considered important to the children.



RESULTS

A total of 13 children have participated to date, aged 9-15-years-old. Four themes were identified from the conversations (**Figure 1**).

1. Study children viewed their identity as part of a longitudinal birth cohort as unique.
2. The fitness test and body measurements were viewed as fun aspects related to their participation in the ROLO follow-up visits.
3. Social media is considered an important form of communication.
4. Children expressed interest in attaining new health-related information.



"Usually, kids wouldn't get to know that stuff about themselves" (C1)

"And well, I remember from my last thing we did like the bleep test and I found that kind of fun" (C2)

"Em yes, it's the only way I contact my friends" (S1)

"Well, it's, it's kind of like fun to like find out stuff about yourself that you didn't really know" (C1)

Conclusion

The ROLO Young Person's Advisory Group offers promising scope for continued collaboration and places the inclusion of PPI as a fundamental aspect of the ROLO study. Our experience illustrates the establishment of a successful Young Person's Advisory Group in Ireland. Efforts to promote fun and opportunities for learning should be integral to the design and delivery of birth cohorts. Greater focus on effective recruitment and communication strategies may also ease the challenge of maintaining retention rates amongst young people involved in a longitudinal study. The main themes identified will guide our future research activities, particularly with children, in view of study design, relevance, and by communication strategies.