

Creating an online PPIE group for perinatal research in a UKCRC-registered Clinical Trials Unit: experiences from Bump2Baby

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Background



- large portfolio of perinatal studies at NCTU
- varied PPI involvement across different trials
- aim to streamline PPI across the portfolio
- move from local PPI to a national focus
- pandemic accelerated transition to online platforms
- focus on developing a community space for parent chat about maternity and newborn research
- input of ideas to existing studies and new research

How we run the group



- regular multidisciplinary group meetings during set-up
- Facebook page and closed group
- Why Facebook? - allows engagement whilst juggling busy family lives
- Why a closed group? - environment where parents can openly share their views and experiences on topics of a sensitive nature
- joining questions and group rules agreed by all
- branded advertising materials
- online advertising by national maternity and newborn groups
- posters and postcards displayed by parent groups and maternity units across the UK



simple animation accessed online by QR



Lessons Learned



- Facebook algorithms - work hard to get posts seen
- Facebook records - don't expect to find everything
- lurking - not necessarily a bad thing?
- can you ever switch off?

Where we are now?

- 225 Facebook group members (Sept 2022)
- interaction mostly between 10-11am and 10pm
- 2 way interaction



- online survey confirmed
 - members enjoy sharing stories and experiences
 - members enjoy learning about research relevant to their interests
 - members want to help shape future research

What do we do?

Facebook group posts

- latest newborn and maternal health research
- general research
- general interest
- Polls - quick engagement

Study specific discussions

- 4 funded studies



- 6 studies in development

Discussion topics

- acceptability of proposed study designs
- when and how to seek consent
- outcomes and data collection

Live sessions - Zoom or live chat

- clinicians
- academics
- lay co-investigators

Data collected

- membership numbers
- active membership
- popular posts using the Facebook analytics

Bump2baby was initially funded by East Midlands NIHR Clinical Research Network to set-up the group

Conclusion

- PPIE input is more coordinated, and streamlined across the NCTU's perinatal research portfolio
- Parents gained a platform for dialogue, a place to share experiences, an avenue to access learning in perinatal research
- Significant time, resource and planning is required to manage regular group input, feedback, and keeping posts interactive

