

HOW to engage families in paediatric emergency research FROM THE START



PROPOSAL

Develop a clear (plain language) summary to share with families

Ask families to comment on readability and the importance of the research question and primary outcome

Ask families to review the proposal i.e. The summary, patient engagement, budget and dissemination plan

PROTOCOL AND ETHICS

Meet regularly with families to explain the study and discuss study design

Ask for feedback on recruitment, the consent process, acceptability of procedures, materials to be given to families

Incorporate the findings from discussion with families in the protocol – this will assist your ethics committee review

CENTRAL TO ALL FAMILY ENGAGEMENT

Establish ground rules for working together from the beginning:

- Clarify roles, responsibilities and expectations
- Schedule meetings in advance, with consultation
- Give clear timelines and options for how families can respond or participate
- Families are not clinicians or researchers, don't use language that will exclude or intimidate
- Ensure meetings are chaired carefully to enable input from all participants and inclusion of all points of view

Evaluate how things are going:

- Reflect on how meetings went and check in regularly
- Consider asking members to complete an anonymous survey

Acknowledge contributions:

- Timely payment for involvement
- Written acknowledgement via email
- Formal acknowledgement in publications eg. in acknowledgements section or as co-authors

DURING THE STUDY

Communicate regularly (meeting or email) to discuss progress and analysis of findings

SHARING THE RESULTS

Get families involved in how your study results can best be communicated and disseminated to other members of the public

Work with families to co-design patient/parent information for future use in the Emergency Department

RESOURCES FOR MORE

How can parents be involved in research?

Writing a TOR for a committee

Compensation for family partners

VCCC Alliance Consumer Engagement

2022 - 2023 MSEI Equitable Remuneration Guidelines

Glossary