

Patient and public involvement work with parents of children with life-limiting conditions and bereaved parents

Best practice when working with:

A PARENT AS A MEMBER OF AN ADVISORY BOARD

COMMUNICATION IS KEY Use plain language for well-timed and relevant communications.



- Ensure **language** used in meetings and other communications is clear (e.g. avoid jargon) and sensitive.
- Allow time for **rapport building** and time for parents to talk about their child.
- Give parents **opportunities to ask questions** and share concerns throughout. Offer various methods to do so (i.e. chat box or private messaging) so it is not only those who are confident to speak up who are heard.
- Maintain **sensitivity** and flexibility if parents digress/ go off topic.
- Share **feedback** with parents regularly on the impact of their involvement in the advisory board.

BE INCLUSIVE

Offer opportunities that are accessible and reach a diverse mix of people and groups.



- Ensure a **diverse** mix of parents are involved or invited (i.e. different ethnic groups, fathers as well as mothers etc).
- Ask parents which days of the week and times would work well for them and work around their time commitments such as childcare arrangements.
- Get to know the needs of the parents and **adapt plans** to meet their needs.
- If members of their child's clinical team are involved, discuss the appropriateness of this with the parent and ask if they have any concerns.
- Consider what **training** the parent may need or want for the role.
- Ensure **adequate funding** is in place and parents are reimbursed for their time and expenses promptly. If parent will be involved in co-chairing sessions, consider what payment and support is needed for this level of responsibility.
- **Do not assume everyone can use technology.** Reassure parents of what you are able to offer as an alternative (i.e. allowing them to feedback verbally rather virtually).



BUILD RELATIONSHIPS

Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.



- **Clearly communicate** what the role entails, including the purpose and frequency of the meetings.
- **Allow parents to prepare** in advance so they feel confident in the session, however, keep pre tasks to a minimum and give parents plenty of time to do them.
- Give parents **flexibility and choice** depending on their schedule (i.e., option to take time out of sessions or change plans last minute).
- Offer parents an **informal chat before** the meeting (especially for the first meeting) and a **debrief afterwards**.
- Do not rely on just one parent; it may make more sense to involve two or more in case one cannot make it at last minute.
- **Address the power dynamic** and ensure that everybody feels they have an equal part to play in meetings (i.e. consider asking parents what their motivations are for taking part and ask professionals to share something personal).
- **Offer opportunities for parents to be involved in leading the work** (i.e., sessions could be co-chaired with parents) and make sure parents are prepared and supported in the role.



Patient and public involvement work with parents of children with life-limiting conditions and bereaved parents

Best practice when working with:

A PARENT AS A SPEAKER AT AN EVENT

COMMUNICATION IS KEY Use plain language for well-timed and relevant communications.



- Maintain **sensitivity** and flexibility if parents digress/ go off topic. Arrange a sign beforehand to remind parents to get back on topic if they feel this would be helpful or offer to help with timekeeping.

- Share **feedback** on the talk with parents so they are aware of the impact it has had.



BE INCLUSIVE

Offer opportunities that are accessible and reach a diverse mix of people and groups.



- Ensure a **diverse** mix of parents are involved or invited (i.e. different ethnic groups, fathers as well as mothers etc).
- Consider parents' **practical needs**, i.e. whether a translator is required, level of literacy, and other potential commitments such as childcare.
- If the child is coming along to the event, consider who will care for the child while the parent is speaking and provide the necessary practical support/ **accessibility requirements** (i.e. hearing loops, wheel-chair access, details on where the nearest Changes Places toilet is etc).
- Ask the parent if they have any concerns about members of the clinical team being there or if people show up unexpectedly, and plan for how to manage this.
- Ask if parents would like any **training or support**.
- Ensure **adequate funding** is in place to cover parent's time as well as expenses (i.e. travel, accommodation, internet, childcare/caring, or conference ticket costs).
- **Keep administrative jobs to a minimum**, don't ask Parents to fill out long and complicated forms for their expenses, and have a person of contact for queries.



BUILD RELATIONSHIPS

Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

- **Let parents decide whether taking part would be in their best interests**, do not assume involvement would be too burdensome or too soon after a bereavement for example.
- **Be clear** about what parents should expect (i.e., how long to talk for, who will be in the audience etc).
- **Agree some clear messages** which relate to the aims of the event. Share/explain the preceding speaker's talk beforehand so parents understand the broader context of the session.
- Ask parents if they would like help putting together/**feedback** on their presentation slides or do a practice run.
- If more than one parent is involved, offer **group meetings** to enable parents to get to know each other beforehand.
- **Ask parents if they would prefer to co-present** with a professional or with another parent.
- Provide **practical support for travel** to in-person events (e.g. venue information, directions and locating/paying for parking. Arrange to meet parents outside the venue on arrival and offer refreshments to welcome and reassure them).
- Consider when during the event the parent will be asked to speak, e.g. would it be more appropriate for them to speak earlier on in the day?
- If staying for the duration of the event, **consider arranging a buddy** so parent's feel included throughout the day (i.e. during the breaks/lunchtime etc).
- Meet the parent before the event, immediately after, and in the days following to **provide support and a space to debrief**.