

Using creative methods of engagement to facilitate the inclusion of children and young people with diverse needs in research.

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Using creative methods of engagement to facilitate the inclusion of children and young people with diverse needs in research

There is a growing recognition of the need to include children and young people (CYP) in health research. Increasingly, funding bodies emphasise early engagement with those with lived experience, and to recruit participants who represent the diversity of the remit of the study. People with life-limiting conditions are typically underrepresented in research because of their perceived vulnerability and as such, key voices are not represented in the research on which practice is based. While effective recruitment strategies can begin to address the breadth of CYP participating in research, data collection methods must meet their diverse needs, experiences, ages, stages of development and values, to maximise the likelihood of engagement and involvement. We will outline participatory research methods aimed at facilitating CYPs contribution to studies, drawing on our research and experiences of working with CYP with life-limiting conditions.

Engaging CYP with life-limiting conditions in research

Together for Short Lives and the Association for Paediatric Palliative Medicine established a joint research group to promote evidence-based practice for CYP with life-limiting conditions.¹ The group promotes how ethics committees and editorial boards should consider the approaches researchers take to undertaking research and the methods they employ with this group. It is a moral and ethical imperative that CYP are enabled to participate in research, and that the findings and their implementation represent their unique needs.

What research methods can be considered when collecting data from CYP?

Participatory research methods enable CYP to engage, participate and express themselves in a supportive, typically fun, environment.^{2,3} A range of interactive data collection methods have been used to engage with CYP (Table 1). While the methods themselves support the generation of robust

data to meet study aims, they can also help build effective relationships between participants and researchers, shape the narrative developed and enable the co-production of knowledge.

Table 1: Advantages and disadvantages of participatory data collection methods

Participatory data collection methods	Advantages	Disadvantages
<i>Visual arts</i> e.g. drawing, painting, crafting, lego/modelling	<p>Appropriate for CYP with varying levels of literacy.</p> <p>Can support researchers to explore CYP's thinking about the topic under investigation.</p> <p>Can be combined with traditional approaches, increasing engagement and understanding.</p> <p>Can enable CYP involvement in dissemination, making findings more tangible.</p>	<p>Not all CYP enjoy the visual arts or have the physical ability to participate.</p> <p>Planning and conducting activities are time-consuming.</p> <p>Depending on the activity and output, interpretation can be challenging without further discussion.</p>
<i>Creative arts and physical activity</i> e.g. drama, play, puppetry, dance, sport, exercise	<p>CYP typically enjoy physical activities, which can promote relaxation through body movement/physical expression.</p> <p>Activities can be used as a backdrop, or distraction technique to enhance rapport and CYP openness.</p>	<p>Can be difficult to plan physical activities without specialist knowledge or experience, or lack of safe spaces.</p> <p>Potentially adds costs and time to a project.</p>
<i>Written accounts or diaries</i> e.g. written or video diaries	<p>Being able to undertake activities in their own time can empower CYP to express themselves.</p> <p>Having time to think about questions or to reflect on experiences can add depth to the data produced, and reduce anxiety about expectations.</p>	<p>Some CYP do not enjoy writing.</p> <p>Completed diaries may result in minimal content, particularly if motivation not sustained.</p> <p>Some CYP may require physical/technological support to participate, and this may provoke anxiety.</p>
<i>Photovoice</i> e.g. photography/filming	<p>CYP often excited and enthusiast about having the opportunity to use different mediums.</p> <p>Can shift the power/control to CYP as they can have autonomy over what to photograph/film.</p>	<p>Without CYP involvement in the analysis the meanings behind the images captured can be lost or reflect the interpretive voice of the researchers rather than the meaning intended from the CYP.</p>
<i>Digital platforms</i> e.g. discussion platforms, social media, and gaming	<p>Online methods of data collection provide researchers the opportunity to both recruit and undertake data collection with CYP who may otherwise be underrepresented.</p> <p>Online participation can enable</p>	<p>Some CYP may have limited access to social media due to their condition, age, poor internet connectivity, socio-economic backgrounds / financial barriers.</p>

	<p>communication via assistive technology.</p> <p>Digital platforms can help CYP feel more at ease, as their identity can remain hidden.</p> <p>Online data collection can expand inclusivity and be cost effective: geography is not a limiting factor and scheduling time can be easier/</p> <p>Can result in low income and less mobile CYP to be involved.</p>	
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These ‘enabling methods’ can be valuable, supporting the sharing of rich experiences. They allow those who find it hard to express themselves to reveal more detailed and emotional stories than would be captured using traditional methods.⁴

What have we learned from undertaking research with CYP in palliative care contexts?

Although more studies are emerging that engage with CYP, there are still many studies within the palliative care field relying on proxy involvement of professionals and parents or other carers to represent the views of CYP with life-limiting conditions. Indeed, the voice of CYP with neurodegenerative conditions, who could offer insight into their experiences, in research is lacking.⁵ In our own work, early engagement with CYP in the research design process enabled trust with families and CYP to feel comfortable in sharing their perspectives. Building rapport took time, commitment, and engagement in activities outside of the study itself, to share information and explain our perspectives, in order for CYP to feel able to be involved and share their views. We benefited from the support of a young person with life-limiting conditions as a research team member and from an advisory group of young people, their siblings and parents. These foundations have supported the development of our studies, demonstrating our commitment to research that is of real-world relevance and importance to the CYP target population.^{5,6} We spent time undertaking consultation activities and delivering workshops to explore research foci and how various methods of engagement could be used.^{6,7} The workshops and activities undertaken used a range of data collection methods that have included digital TRELLO boards, closed Facebook group, twitter, ZOOM and TEAMS discussion/activities.

Participatory methods can be used to scaffold or enhance results gained from more formal methods. Making data collection relevant to the developmental stage of the CYP, their personality and preferences is important. Not all CYP enjoy art, or have the confidence to join discussion groups or the latest technology or unlimited access to Wi-Fi, and methods must be relevant to the developmental

stage and ability of CYP. Therefore, a mosaic approach, using a range of data collection strategies, can allow researchers the flexibility to meet the needs and preferences of participants. For example, children will often prefer to communicate with a range of senses, whereas young people may prefer to engage with more formal interview techniques or photograph where they some degree of autonomy. Measures validated for the population/age group are important but asking CYP questions about the suitability and burden of completing such activities and if the mode of delivery is suitable will help researchers to shape future studies. Participatory methods can also be used to scaffold or build upon the results gained from more formal methods.

Conclusion

We have outlined some research methods that can be used with CYP. For these methods to be successful, building rapport and trust with participants prior to data collection is needed. It is important that researchers consider not only CYP participation in research, but supporting CYP to engage with, shape and understand studies that affect them. The use of creative activities alongside more traditional research methods can reduce barriers, enable CYP to feel comfortable and encourage their participation. Future research exploring the mechanisms and outcomes of CYP research incorporating creative participatory methods in different healthcare contexts would prove insightful for researchers considering research designs and particularly their methods of meaningful engagement.

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