

Palliative care for children and young people with life-limiting conditions and life-threatening illnesses is a relatively new discipline, and one where current practice in services has developed beyond the evidence base available. Barriers to conducting research in this area are numerous, and span the entire length of the research process.

CLAHRC researchers from the BRAVES project, based at the Louis Dundas Centre, are working to identify these barriers to recruiting children with life-limiting conditions to research, and to develop solutions.

“Establishing robust evidence is going to require concerted effort on everyone’s part: clinicians, parents, patients, and researchers.”

Professor Myra Bluebond-Langner, principal investigator on the BRAVES project, has recently recorded a [podcast with the journal Palliative Medicine](#), discussing the need for an increased understanding of barriers to research in paediatric palliative care, findings from the project so far, and outlining the future research planned by the team.

Initial findings from the study, and previous work at the Louis Dundas Centre, have suggested that fundamental barriers exist at both the individual level, e.g. clinicians’ attitudes to involving young people in research, as well as at the institutional level, e.g. ethics committees and resource constraints, even though children and young people *want* to participate in research.

“So, *why*, if we no longer accept paternalism in clinical practice, are we willing to accept it, indeed demur to it, in research practice?”

The overall goal of the BRAVES project is to develop guidance based on the experience of all stakeholders, which in turn will help to develop the evidence base in the field of paediatric palliative care.

Based on the findings outlined in the podcast, the research team has since conducted a study investigating the experiences and difficulties of chief investigators recruiting children and young people with life-limiting conditions and life-threatening illnesses to research. The findings from this study are expected to be published soon. The next step for the CLAHRC researchers is to analyse data collected from a nationwide research groups’ applications to

Research Ethics Committees, and to interview members of these committees to develop further insights.

[Click here](#) to read the journal article on which this podcast is based.