

Research recommendations for review question: How can the views of babies, children and young people be best represented by independent advocates?

Research question

How can the views of babies, children and young people be best represented by independent advocates?

Why this is important

The involvement of children and young people in decisions about their healthcare can help to optimise their experience of healthcare, but there may be children who are unable to advocate for themselves or do not have parents or carers to support them. For these children and young people, support can be provided by independent advocates. However, the literature review to determine how children and young people can be best represented by independent advocates did not yield any evidence. Understanding how children and young people can be best represented by independent advocates is important to enable them to have an opportunity to express themselves and empowerment to make decisions.

Table 6: Research recommendation rationale

Research question	
Why is this needed	
Importance to 'patients' or the population	Children and young people who have difficulty advocating for themselves may find the support of an independent advocate very helpful to improve their experience of healthcare.
Relevance to NICE guidance	High. The use of independent advocates in healthcare was a topic identified as important by stakeholders during scoping for this guideline.
Relevance to the NHS	The relevance to the NHS is high, because improving support to children and young people has the potential to improve their experience of healthcare, quality of life, engagement with services, and thus potentially outcomes
National priorities	The National Service Framework for children, young people and maternity services aims for long-term and sustained improvement in children's health, and sets standards for health and social care services for children, young people and pregnant women.
Current evidence base	No evidence was identified for this review question.
Equality	Children and young people who do not have parents or carers to support them, such as unaccompanied asylum seekers or care-leavers, and those with communication difficulties or learning disabilities may have particular need for independent advocacy services and so this topic is of particular concern to ensure equality in healthcare provision.
Feasibility	This study would need to encompass the use of independent advocacy in a range of healthcare settings, and would need to access children and young people in all these settings.

Table 7: Research recommendation modified PICO table

Criterion	Explanation
Population	<ul style="list-style-type: none"> • People <18 years-old who have experience of healthcare • Studies that use the views of parents or carers as proxies will be included only if they are responding on behalf of their child or charge, and <ul style="list-style-type: none"> ○ The baby or child of the parent or carer is under 5 years, or ○ There is a clear rationale provided as to why the study is using parents' or carers' view
Phenomena of interest	Experience of healthcare, in particular how babies, children and young people feel they can be represented by independent advocates
Context	<p>Themes will be identified from the literature. The committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified):</p> <ul style="list-style-type: none"> • Access to records of healthcare staff discussions • Adequate training for independent advocates including knowledge about developmentally-appropriate approaches • Appeal to, or use of, advocacy groups • Availability and accessibility of appropriate advocacy services • Awareness of independent advocate services • Encouraging and supporting self-advocacy when possible • Sensitivity and responsiveness of independent advocate to feedback from child or young person • Views on timing of support provided from the independent advocate, establishing views regarding where and when advocacy is beneficial, including continuity of support
Study design	Qualitative – using semi-structured interviews or focus groups
Timeframe	1 year
Additional information	Consider preferences in a variety of healthcare settings, and for mental health and physical health

Insert abbreviations