



**SOUTHAMPTON**  
CITY COUNCIL

*Better evidence, better decisions.*

# **HDRC Southampton**

**Young people engagement in  
health decision-making  
Evidence Review**

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## 1. Young people engagement in health decision-making

This review summarises the findings of a scoping review conducted to examine the deliberative methods used to engage young people in healthcare and health policy priority setting, and to identify the features of these methods that contribute to effective engagement.

### 1.1 Structure of Deliberative Processes and Procedures for Youth Engagement in Healthcare and Policy

Youth Committees and councils covering 5 studies

Young people worked alongside hospital and mental health stakeholders. The goals were to:

- Improve satisfaction with services
- Influence hospital strategies
- Empower young people with chronic illnesses

Key Recommendations included:

- Build long-term relationships
- Offer incentives and skill-building (for instance advocacy training)

Conferences, Panels and Stakeholder Meetings covering 3 studies

- Young people engaged with researchers and professionals in more formal consultation spaces.

Methods to Enhance Engagement with young people in health and social care priority-setting or decision-making processes covering 6 reviews. The techniques included:

- Education and coaching on the topic they are been engaged on including using youth facilitators or peer leaders.
- Therapeutic and emotional approaches to address emotional engagement and isolation particularly amongst vulnerable or marginalised group.
- Focus on trust-building.

Inclusive approaches, in one study, siblings were included in a Teen Advisory Board Committee which helped enrich discussions and foster more relatable peer conversations.

Creative and narrative-based techniques

- Vignettes: Used to simulate treatment decisions in paediatric oncology; youth and parents preferred receiving information at the same time.
- Photovoice and Storytelling: Used to explore youth priorities in sexual and mental health.

## 2. Digital Interventions

Digital tools were frequently used across studies to enhance youth engagement in healthcare and health policy priority-setting processes. These interventions were often introduced to increase accessibility, flexibility, and scalability, especially when engaging geographically dispersed or time-constrained young people.

Types of digital tools used include:

- Online decision aids:
  - Used especially for young people with depression during consultations.

The benefits include creating a safe, confidential environment for sensitive topics. And increased accessibility for youth with physical disabilities, living in remote/rural areas and no access to transport.

Stakeholder webinars including effective in engaging youth across multiple locations.

- Youth-friendly, but:
  - Parents struggled more with technology—termed a “generational learning curve.”
  - Use of Digital Media Tools including Videos, Photographs, “Decision Slider” tool – which allowed young people to record and adjust decisions multiple times, enhancing reflective participation.

Social Media Recruitment

- Platforms like Facebook support groups were used to recruit young people into deliberation activities.

Blended Approaches

- Some studies combined digital and face-to-face interactions throughout the deliberation process.
- Found to be most effective—but only possible where digital access is available.

### **3. Timing of public engagement in decision-making, levels of engagement and opportunities to share and foster mutual respect**

#### **3.1 Duration and contact time**

Engagement ranged from single-session activities (e.g., surveys, short workshops) to long-term involvement (e.g., youth councils and advisory committees).

- Short-term examples include:
  - One-off surveys (e.g., 50-minute depression aid session).
  - Two 30-minute rounds of an online Delphi survey.
  - 2-day workshops (e.g., using the ANGELO framework - analysis grid for environments linked to obesity).

Long-term examples include:

- The Youth Council is a national platform for youth empowerment and representation, enabling young people to contribute to policy discussions at home and abroad which impact on their lives – 18 months.
- Teen Advisory Committee – Monthly meetings from 2002–2014.
- Committees generally maintained deeper and longer contact with youth.

#### **3.2 Levels of engagement**

- Higher levels of engagement (committees/panels) were seen as more meaningful and respectful by young people compared to lower-contact methods (e.g. surveys).
- Engagement at all stages of decision-making was seen as most empowering and respectful.

#### **3.3 Opportunities for sharing and mutual respect**

- Respectful approaches included:
  - Maintaining anonymity when sharing personal stories.
  - Ongoing consultation roles (e.g., youth council shaping hospital trust decisions).
  - Involvement in evaluating impact and contributing to publications.
- Few studies allowed youth to challenge decision-making, which is an important indicator of mutual respect (per Abelson).

### **3.4 Power imbalances**

Three studies highlighted power imbalances between:

- Young people and researchers/parents.
- Research teams' decisions often held more weight than youth input.
- This led to youth being disempowered in processes meant to empower them.

### **3.5 Strategies to address power imbalances**

- Separate and shared consultation spaces for young people and families were used to help prepare before larger discussions.
- Some studies allowed youth to reflect and provide feedback on their ability to be heard.
- In one South African study, youth helped develop public engagement strategies and became ambassadors of project outcomes.

### **3.6 Social influences and expression**

- One study noted how social desirability and presence of adults or peers could influence how freely youth expressed their views.

### **3.7 Future recommendations**

- Build youth capacity for decision-making by:
  - Valuing their preferences, values, and emotions.
  - Acknowledging the impact of their interactions with adults and the power dynamics involved.

## **4. Quality of information given to participants**

### **4.1 Sources of information for priority setting**

- Studies used multiple methods to inform what priorities were considered, including:
  - Literature reviews
  - Qualitative data from experts
  - Qualitative data from young people themselves
- Some studies used both literature reviews and qualitative data to create comprehensive lists of change options.
- Uncertainty remains about whether literature or qualitative data was more useful in informing decisions.

## 4.2 Methods for selecting priorities

A range of tools and approaches were used to help youth select from possible priorities:

- Decision aids:
  - For young people with diabetes
  - For depression
- Discrete-choice experiments: For patients with hypodontia
- Delphi studies: Used to prioritize physical activity needs and general health issues
- Youth involvement in designing these tools improved acceptability and relevance.

## 4.3 Benefits of decision aids and shared decision-making toolkits

- Enhanced information quality for:
  - Young people
  - Parents
  - Health professionals
- Outcomes included:
  - Reduced decision conflict
  - Improved treatment adherence (especially for young people with chronic conditions).

## 4.4 Visual and creative communication methods

Visual tools were particularly effective in supporting young people's understanding and participation:

- Vignettes with pictures and narratives (e.g., childhood cancer decision-making).
- Life grids: To explore significant life events and interactions with doctors.
- Pie charts: Highlighted gaps between youth's desired role in healthcare decisions and actual experiences with doctors.

## 5. Outcomes and decisions

The scoping review used the Abelson's framework to evaluate deliberative processes for youth engagement and these outcomes are:

- Achievement of consensus
- Participant satisfaction
- Legitimacy and accountability

## 5.1 Achievement of consensus

Consensus was a core goal across all deliberative methods. Methods to reach consensus included:

- Delphi methods (multiple consultation rounds with aggregated feedback).
- Workshops: e.g., asking children to submit questions which were ranked to identify top priorities.
- Surveys and structured ranking exercises were used to reduce conflict and promote group agreement.

## 5.2 Participant satisfaction

Higher satisfaction was reported when:

- The process was genuinely inclusive of young people's opinions.
- There were longer duration and frequent contact.
- Youth were involved in all stages, including designing decision-making tools.
- Panels and discussions boosted confidence and leadership skills.
- Youth felt the decisions had impact beyond themselves, benefiting others.

However, a systematic review found that although shared decision-making tools (e.g., videos, info sheets) improved knowledge and reduced conflict, they did not improve satisfaction.

## 5.3 Legitimacy and accountability

Legitimacy was linked to the extent youth input influenced final decisions:

- Some hospital trusts implemented advisory input from youth councils into strategy and information materials.
- In other studies, youth input was ignored or excluded from final decisions, reducing legitimacy.
- A few studies granted young people decision-making authority, especially in mental health, hospital strategy, and obesity prevention.
- Power imbalances between youth, parents, and researchers continued to be a challenge.
- A shift towards youth-led approaches was recommended to enhance legitimacy.

Accountability (tracing how youth input affected outcomes) was rarely addressed:

- A South African study offered a rare example by holding a community forum to report and disseminate youth priorities.
- Most studies did not show how decisions influenced healthcare delivery, even though many suggested youth input could improve interventions.