Quality Standards for Youth Participation

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About

Goal

To develop a set of standards to underpin ethical and effective youth participation in all aspects of clinical trials and research
Audiences

• Funders
• Researchers
• Those supporting young people to be engaged in clinical trials and research ethics committees
• Trial Managers
• Patient and public engagement leads
Parameters of the standards

Working assumptions on the Standards

Tailored to the clinical trial context

Meet the audiences needs

Align to ethical standards & expectations

Holistic – all aspects of working well

Option for developing accreditation for meeting standards
Approach
Project initiation and co-creation

Purpose:
To ensure a shared understanding of the intended outcomes and collate ideas for influencing

How
• Project initiation workshop with core project staff, potentially other key stakeholders.
• Youth engagement in project design through virtual workshops
**Approach**

**User needs assessment**

**Purpose:**
To understand the needs of the intended audience for the standards

**How**
- 12 semi-strictures interviews with a wide range of perspectives: trial managers, research ethics committees, youth participation specialists, policy makers & funders
  - Understanding of youth participation and key concepts
  - Goals they want to achieve through engagement activity
  - Their needs and experiences of using standards
  - Issues around accreditation
Approach
Mapping of current standards & accreditation

**Purpose:**
To document current standards for inspiration and coherence

**How**

- Desk based mapping of all relevant current standards frameworks
  - Clinical Trials
  - Research with children and young people
  - Youth participation

- Identified 36 Standards frameworks or guidelines with over 350 individual statements or topics
Approach
Young people’s insight on standards

**Purpose:**
Ensure that the standards and themselves grounded in the views and experiences of young people

**How:**
Interactive workshops to understand young people’s priorities on the standards
Approach

Drafting the standards

User needs assessment

Mapping of current standards

Young people’s ideas for standards framework

Working first draft of standards
Approach
Consultation on draft standards

**Purpose:**
Build support for the standards
Check the standards are fit for purpose

**How:**
- Opportunity for comment and engagement on the standards
Approach
Finalise and communicate

**Purpose:**
Finalise standards and ensure tools which enable people to get their

**How**
- Final standards documents
- Outputs such as: key messaging document, leaflets, social media assets and an associated webpage.
- Guidance on its use