



Penta

Child Health Research

Quality Standards for Youth Participation

Tom Burke

tom@amplify.org.uk

16th December 2021



About



Goal

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

Audiences

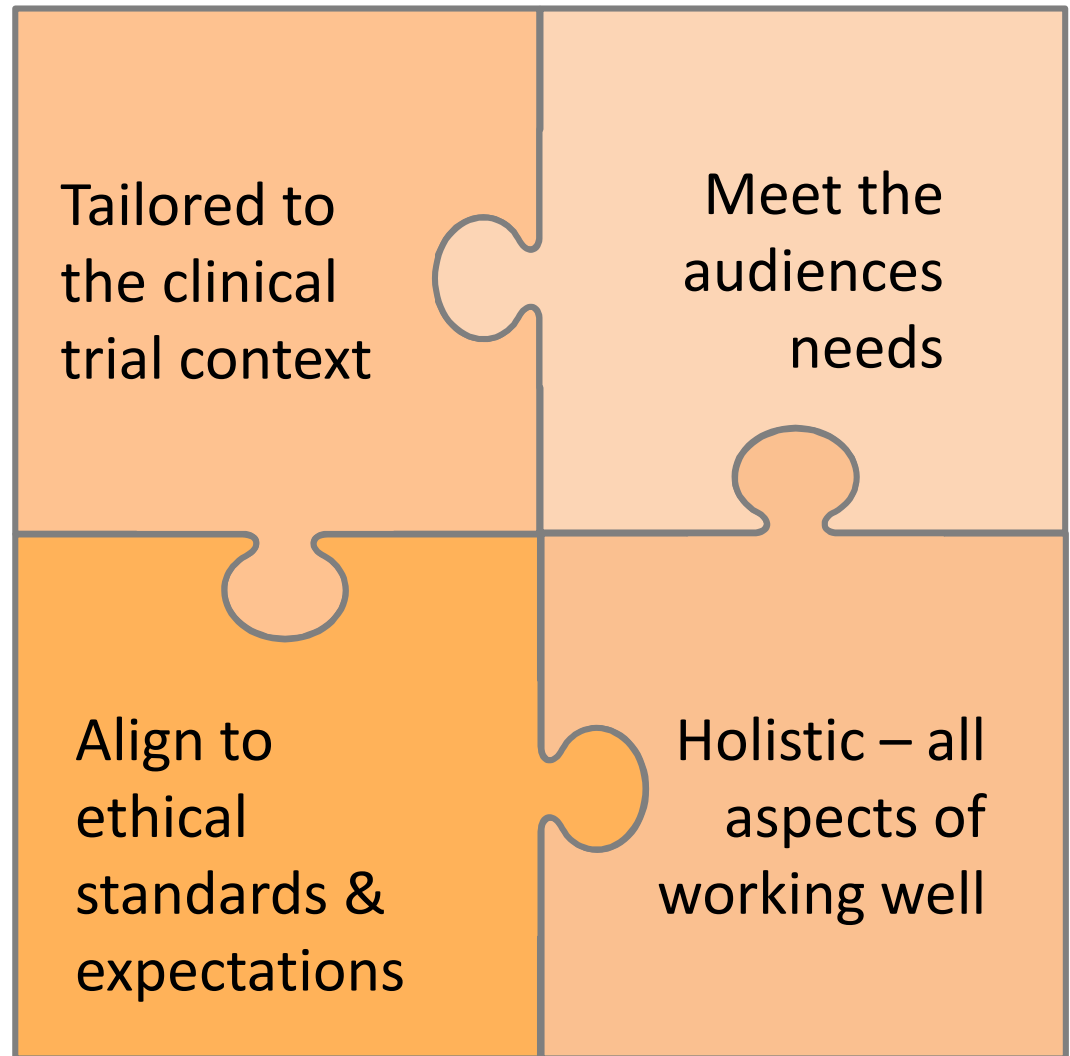
- Funders
- Researchers
- Those supporting young people to be engaged in clinical trials and research ethics committees
- Trial Managers
- Patient and public engagement leads



Parameters of the standards

Working assumptions on the Standards

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-structured 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

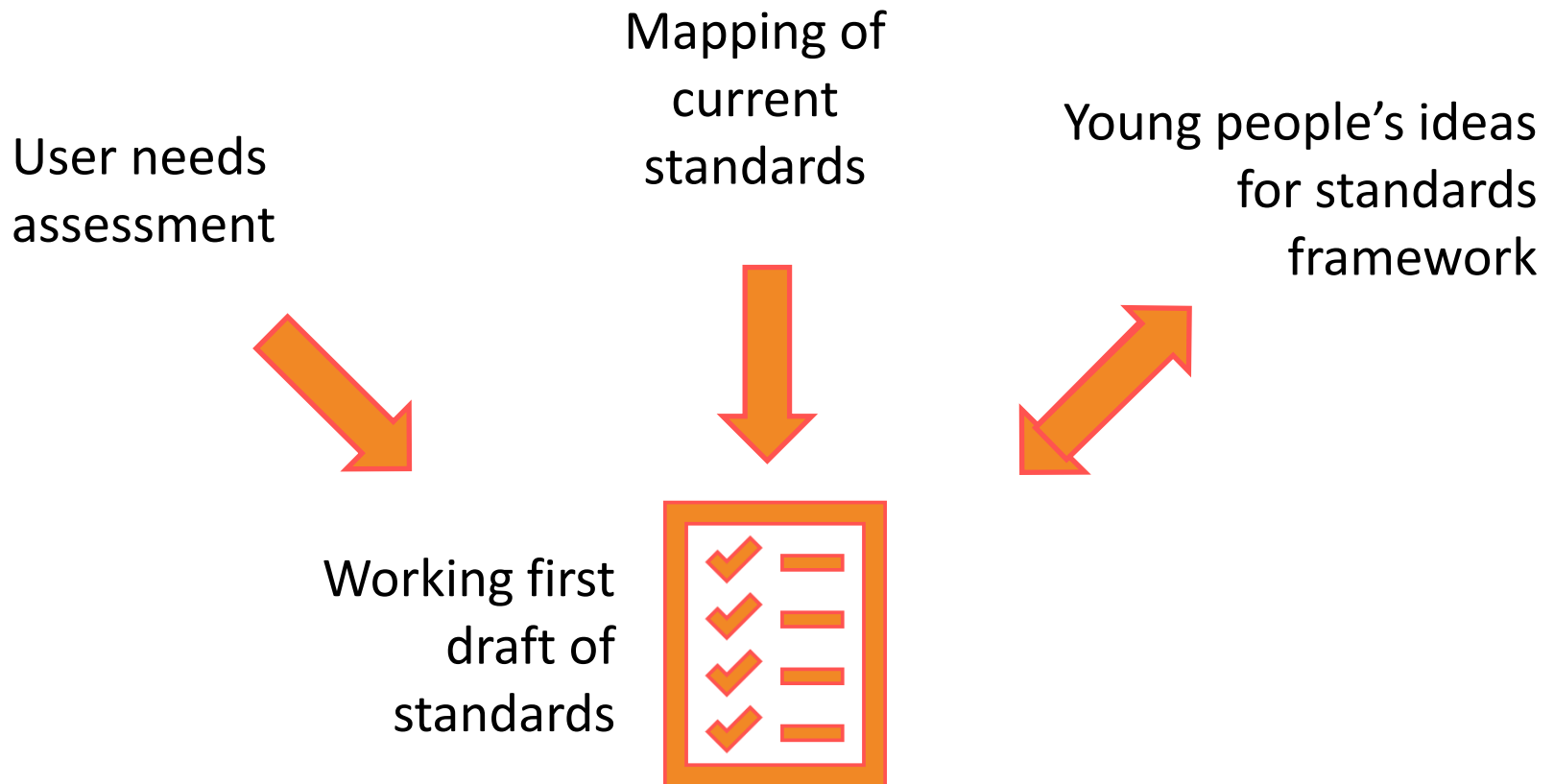
How

Interactive workshops to understand young people's priorities on the standards



Approach

Drafting the standards



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





Penta

Child Health Research