### Youth Engagement in Research

# Why do we need to engage children and young people as research partners?

Within the field of health research, there is a growing body of evidence that emphasises the importance of including the views, experiences and actions of those who are the focus of research (Black et al., 2018; DelNaro et al., 2017). It has also been stressed that this should include the engagement of children and young people, who should also have the right to participate in shaping their own healthcare (Clarke 2005; Daly, 2009; Larsson et al., 2018).

#### Are there good examples of engaging children and youth in this way?

INVOLVE is an organisation in the UK funded by the National Institute of Health Research (NIHR) which runs a number of young person's advisory groups (YPAGs). These groups are for young people aged 8-24 and meet every two months to provide feedback and shape research ideas. More information can be found at the following website https://generationr.org.uk/.

Despite the presence of organisations such as the YPAGs and the apparent enthusiasm for involving children and young people as research partners, it is reported that 'real engagement' is rarely evidenced in practice. Larsson et al. (2018) identified just three studies over the past decade that met the highest standards for involving children and young people in the research process; that is where the children and young people acted as informers, designers, innovators, evaluators and testers. (Garofalo et al., 2012; Kime et al., 2013; Wärnestäl et al., 2017).

#### What are the possible barriers to child and youth engagement?

When asked about engaging in research, children and young people highlighted a number of potential barriers (Hill 2006).

**Time and commitment:** Children and young people reported being very happy to partner in research in school time, but less willing to give up their leisure time.

**Power dynamic:** Children and young people highlighted the power imbalance between them and the adult researcher, which is reinforced when the researcher assumes the 'teacher' role within a school environment.

**Fairness and inclusivity:** Children and young people were very keen to ensure everybody had a chance to have their voices heard; stressing that it should not be the same people chosen every time.

## What are the benefits of using social media, specifically Instagram, as a platform for engagement?

Instagram is a social media platform where profile owners post visual content (photos, infographics, videos, etc) from phones or tablets that can be seen by followers of their profile or by those who follow simple keyword phrases called hashtags. The demographic for Instagram is skewed towards younger people with approximately 70% of global users being under age 35 (Clement 2020), and 73% of American youth between 12 and 24 using Instagram (Edison Research 2017).

Instagram's public timeline feature allows health organisations to share visually rich and diverse information to many millions of potential readers (Boulos et al., 2016). Examples of this include official accounts run by the World Health Organisation (WHO) the UK National Health Service (NHS), Health Education England (HEE) and the US Centers for Disease Control and Prevention (US CDC).

Emerging studies have also shown that Instagram may be a useful tool for study retention of and knowledge transfer to youth (Thomas et al., 2020; Vakili et al., 2020).



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