

The challenges and reality of patient and public involvement (PPI) with teenagers and young adults

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"No matter how complicated the research, or how brilliant the researcher, patients and the public always offer a unique, invaluable insight...." Professor Dame Sally Davies, 2009

Background

- BRIGHTLIGHT is a cohort study evaluating specialist care for 13-24 year olds newly diagnosed with cancer in England.
- Patient and public involvement (PPI) is central to health research, considered imperative to improve the quality and relevance of evidence-based studies (Thomson et al, 2013).
- Most literature stresses the benefits of PPI with young people; in reality working with this population presents many practical challenges, which requires alternative strategies.
- We have adopted a multi-pronged approach to our Patient and Public Involvement (PPI) strategy.
- To advocate a young voice in all study design and management, we involve young people in a variety of ways at all stages to maximise engagement.

Results

The following challenges were identified as key barriers to involving young people in study development and management:

- Supporting PPI takes unexpectedly large amounts of time and resources
- Identifying appropriate methods of contact and engagement
- Explaining and understanding the difference between participation and involvement
- Measuring impact to the study and to young people
- Incorporating diversity- hard to reach populations
- Low or unpredictable engagement rates
- Reporting PPI activities

Aims

Based on our experience of involving young people in research, optimising recruitment to PPI events and response via online methods can often be challenging and slow.

Our poster will discuss practical strategies employed to overcome some of these challenges.

Conclusions

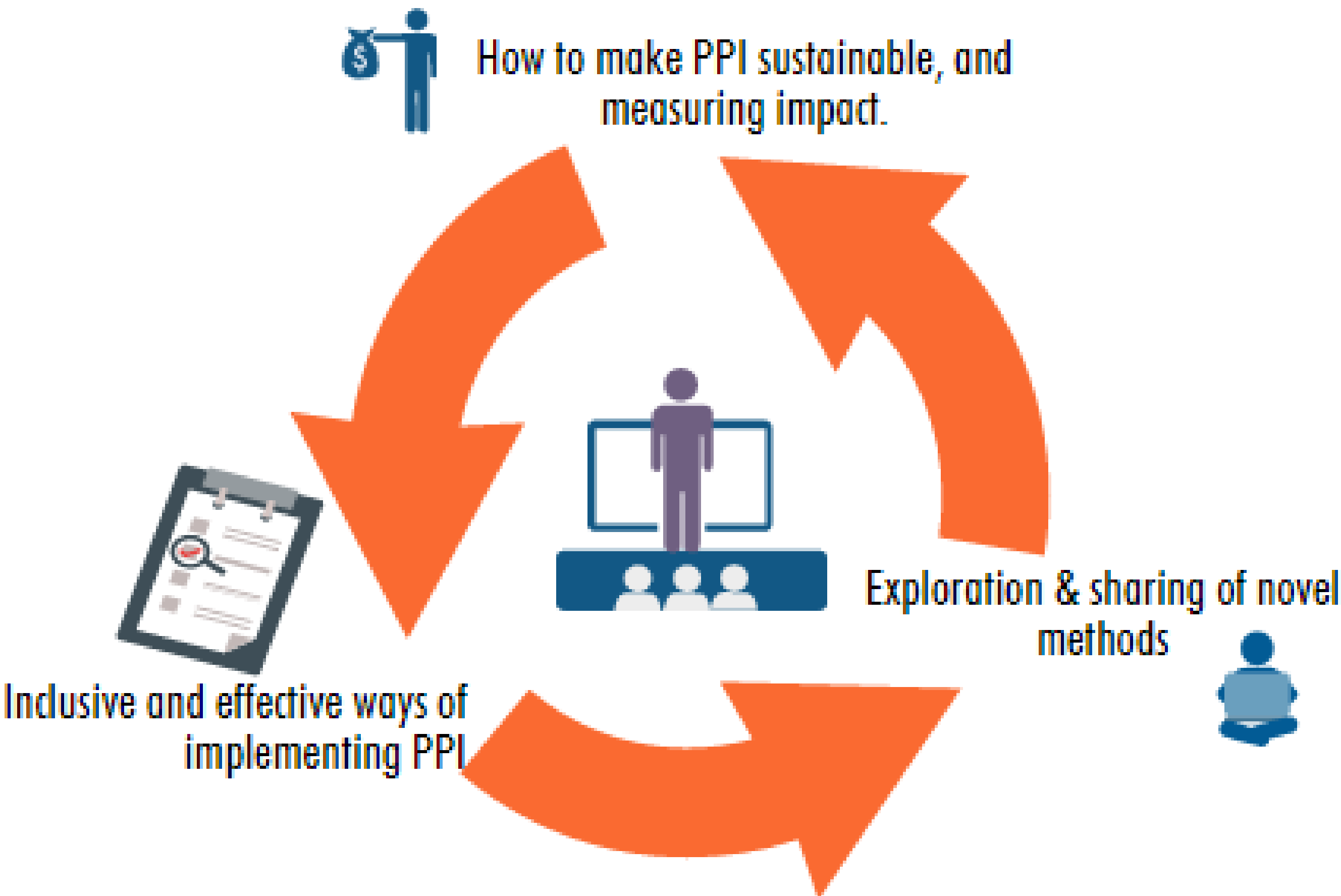
Working with young people is rewarding but requires significant resources to overcome the challenges we have encountered. We argue the need for increased dissemination of peer-reviewed PPI articles to enable other researchers to overcome barriers and improve the academic credibility of PPI activities.

Participants

- The Young Advisory Panel (YAP) are BRIGHTLIGHT's current patient and public involvement group made up of 18 young people.
- The Core Consumer Group made up of 5 young people were the previous user group that advised on the feasibility work- **Essence of Care Study**.

Methods

Online methods of recruitment to PPI opportunities such as social media advertising alone has proven difficult. In addition to this, we have had to employ several other methods such as directly contacting each young person, or use healthcare professionals from treatment centres to help recruit young people.



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