



‘Does Patient and Public Involvement (PPI) with young people add value?’ Ten years of PPI, the BRIGHTLIGHT experience

Taylor RM¹, Martins A¹, Lea S¹, Gibson F^{2,3}, Whelan JS¹, Fern LA¹

¹Cancer Division, University College London Hospitals NHS Foundation Trust ² University of Surrey

³ Great Ormond Street Hospital for Children NHS Foundation Trust

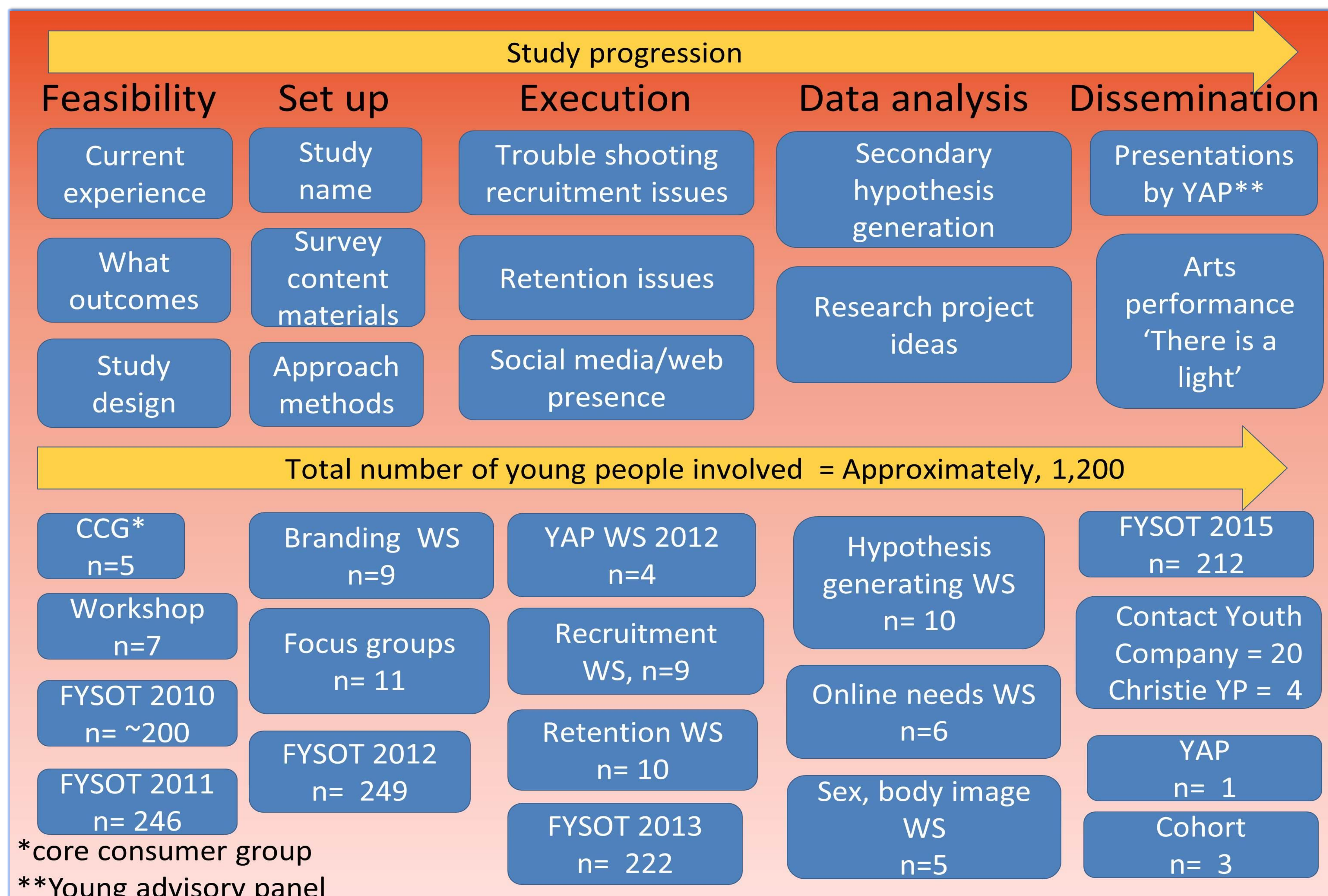
INTRODUCTION

Involving young people in research design and conduct is now considered integral to good research practice. Young people with cancer are a unique group as they are faced with potentially life-limiting disease against a back drop of monumental physical and psychological changes. They are often viewed as vulnerable and difficult to engage, therefore user involvement for this group is often described as challenging. BRIGHTLIGHT is a national evaluation of cancer services in England: we aimed to involve young people from inception through to dissemination. Here we describe multiple novel and innovative involvement methods to involve young people in research.

METHODS

Young people participated in a number of participatory methods: workshops, focus groups, individual reflection, role play, interviews, electronic surveys, presentations and an arts-based creation and performance of results. Workshops adopted novel methods including a brand transformation model, field-force analysis and BRIGHTLIGHT twister.

Figure 1: BRIGHTLIGHT user involvement



RESULTS

Between 2008 and 2017, approximately 1,200 young people contributed to the design, conduct and dissemination of BRIGHTLIGHT (Figure 1). This including study design, approach materials, naming and branding the study, troubleshooting recruitment and retention issues, secondary hypothesis generation and dissemination. All methods are detailed in our peer reviewed publications available <http://www.brightlightstudy.com/resources/>. Measuring PPI impact is difficult. However, BRIGHTLIGHT refusal rates were 20% against an anticipated 35%. Retention rates at Wave 3 (18 months into the study) improved from 30% to 58% following interventions suggested by young people. The arts based performance 'There is a light' has performed to over 600 professionals, patients, and public audiences.

CONCLUSIONS

Involving young people in study design, operation and dissemination positively impacts study relevance and design. Our experience demonstrates improvement in up-take and increased retention of participants. Adequate resources must be allocated to allow innovative creative methods to be employed. Challenges still persist in involving ethnic minorities and those less willing to share their voice.