



A participatory study of teenagers and young adults views on access and participation in cancer research



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ARTICLE INFO

Article history:

Received 19 December 2014

Received in revised form

6 July 2015

Accepted 16 July 2015

Keywords:

Adolescent

Teenagers

Young adult

Access

Gate-keeper

Choice

Research

ABSTRACT

Purpose: The purpose of this study was to elicit young people's views on access and participation in cancer research.

Methods: Eight young people aged 18–25 years with a previous cancer diagnosis aged 15–24 participated in a one day workshop utilising participatory methodology. The workshop consisted of four exercises: role play/scene setting; focus group examining thoughts and opinions of research access and participation; individual reflection on access to different types of research; and creative interpretation of the workshop. Further consultation with 222 young people with cancer was conducted using an electronic survey.

Results: Three themes emerged:

- **Patient choice:** Young people thought it was their right to know all options about available research. Without knowledge of all available studies they would be unable to make an informed choice about participation.
- **Role of healthcare professionals as facilitators/barriers:** Young people suggested non-clinical healthcare professionals such as social workers and youth support coordinators may be more suited to approaching young people about participation in psychosocial and health services research.
- **Value of the research:** The what, when and how information was delivered was key in relaying the value of the study and assisting young people in their decision to participate.

Further consultation showed approximately 70% wanted to find out about all available research. However, one third trusted healthcare professionals to decide which research studies to inform them of.

Conclusion: Effective ways to support healthcare professionals approaching vulnerable populations about research are needed to ensure young people are empowered to make informed choices about research participation.

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1. Introduction

The United Kingdom (UK) claims the highest rate of cancer trial participation in the world (Singh, 2007). Despite this, there are

inequalities in access to research. Patient demographics such as age, socioeconomic status and ethnicity are all recognised as contributing factors (Fern et al., 2008, 2014; Ford et al., 2008; Furlong et al., 2012). Investigations into lower rates of participation for young people with cancer have frequently focused on structural and organisation barriers, lack of available trials and restrictive age eligibility criteria (Fern et al., 2008, 2014; Ford et al., 2008; Furlong et al., 2012). The potential role of 'professional gate-keeping' as a barrier to access to research has received little or no attention.

Young people present with a range of cancer types and exhibit unique psychosocial needs which require specialist age appropriate

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cancer care. The environment of care is believed to be particularly influential to patient experience but not yet quantified. In August 2005, the National Institute of Health and Care Excellence (NICE) issued *Improving Outcomes Guidance* advocating specialist teenage and young adult (TYA) cancer care delivered in 13 'Principle Treatment Centres' (PTC) (National Institute for Health and Care Excellence, 2005). Despite bespoke TYA cancer units and healthcare policy which advocates specialist cancer services for young people, the outcomes and costs associated with such care are yet to be fully described.

Increasing pressure on financial resources together with the UK's position as a leader in providing specialist cancer care for young people has brought the need for an evidence base for specialist services to the forefront. The 'gold standard'—a randomised clinical trial comparing outcomes and costs of specialist care versus non-specialised care is neither ethical nor feasible in a country where implementation and access to TYA services already exist. Following a period of extensive feasibility work, methodology testing and engaging multiple stakeholders including patients (Fern et al., 2013), parents, charitable organisations, TYA, paediatric and adult oncology communities (Gibson et al., 2012; Taylor et al., 2011), National Institute for Health Research (NIHR) Cancer Research Networks and relevant National Cancer Research Institute (NCRI) Clinical Studies Groups, a national study 'BRIGHTLIGHT-Do specialist cancer services for young people add value?' was opened in October 2012.

BRIGHTLIGHT is a longitudinal cohort study evaluating specialist cancer care for young people aged 13–24 years, newly diagnosed with cancer in England (www.brightlightstudy.com). BRIGHTLIGHT aims to determine to what extent specialist cancer care for young people affects outcomes and costs to both young people and the NHS. To ensure maximum recruitment of TYA to the study we developed BRIGHTLIGHT within the context of our five 'A's conceptual model for increasing participation of young people in cancer research: 'Available, Accessible, Aware, Appropriate and Acceptable' (Table 1) (Fern et al., 2014). BRIGHTLIGHT is open to recruitment in most NHS Trusts in England thus geographical access is ensured. An age eligibility criterion which spans the TYA age group and broad inclusion criteria also ensure maximum potential for participation. By September 2013, over 400 patients were recruited, making BRIGHTLIGHT the largest cohort of 13–24 year olds with cancer in the world; however this was a quarter of the anticipated recruitment target. An explanation for initial recruitment rates being less than anticipated were delays in gaining approval in many Trusts; often BRIGHTLIGHT was being scrutinised with the same regulatory rigour as a Phase I clinical trial. Opening the study in multiple Trusts, including all thirteen PTCs, was not accompanied by significant improvements in recruitment.

Optimising recruitment and facilitating access to research is complex; we engaged with the clinical community and our Young Advisory Panel (YAP) for advice on the lower anticipated recruitment rate. A number of protocol changes were implemented to improve recruitment. The protocol amendments, also framed around our five 'As' model were mainly related to improving study awareness, access and acceptability to patients and healthcare professionals (Table 1). However, recruitment rates to the study showed no notable improvements.

Subsequently, screening logs returned from 65 of the 97 open centres were analysed and showed a refusal rate of just 18% amongst those approached against an anticipated 35% versus an anticipated 35% which was based on refusal/consent rates in other published TYA cancer studies (Burns et al., 2009; Carpentier et al., 2008; Kondryn et al., 2009). This high acceptance rate possibly reflects the success of feasibility work to develop BRIGHTLIGHT with young people, for young people, ensuring relevance of study

questions and design. Nevertheless, analysis of screening logs also illustrated the main contributing factor for lower than expected accrual was that around a quarter of young people with a new cancer diagnosis were not being approached despite fulfilling the eligibility criteria. Factors such as limited resources were contributory; however, we identified a proportion of patients where healthcare professionals did not feel it was appropriate to approach the patient. Having identified the potential role of 'professional gate-keeping' contributing to lower than anticipated recruitment rates to BRIGHTLIGHT, we sought to elicit young people's views about access to and participation in cancer research.

2. Methods

A qualitative study using participatory methods during a one day workshop in September 2013 was carried out with eight self-selected young people who are part of the BRIGHTLIGHT YAP, the study's patient and public involvement representatives. Their remit is to advise on: methodological issues, such as recruitment; create and comment on the content of newsletters and other means of publicising the study; advise on topics for future survey content. They will also be integral in interpreting results and suggesting potential implications and interventions for young adult cancer care.

Information about the day was distributed prior to the workshop, written consent was obtained from workshop participants for audio and visual recording and to use these for multiple purposes, including being placed on the BRIGHTLIGHT website. The workshop was held in a non-clinical office facility. BRIGHTLIGHT is approved by London–Bloomsbury Research Ethics Committee (reference 11/LO/1718).

Four male and four female YAP members attended the workshop, currently aged 18–25 years and who were diagnosed with cancer aged 15–24 years. One young person was still receiving treatment; diagnoses included four haematological malignancies and four solid tumours. Data were collected through role play, focus group, and individual reflection. Four researchers were in attendance at the workshop.

2.1. Exercise 1: role play and scene setting

The workshop began with role play carried out by four researchers who enacted scenarios illustrating reasons for non-approach, which were outside of the exclusion criteria of the protocol but were cited in the BRIGHTLIGHT screening logs. Additional dialogue reflecting comments that recruiting teams had made were also incorporated into the scenarios. See Table 2 for BRIGHTLIGHT inclusion and exclusion criteria and examples of the scenarios depicted. These included pregnancy, learning disabilities, or the surgeon/doctor did not think participation was appropriate (no other reason supplied).

2.2. Exercise 2: focus group examining thoughts and opinions of access and participation in research

One researcher (LF) led the focus group, which opened with a question to elicit young people's views on the scenarios they had just observed. Discussion within the Group was encouraged with the researcher being reflexive with additional questions. However, there were a number of prompts in the discussion guide to ensure all points were covered or discussed.

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