

A qualitative study to understand the barriers to recruiting adolescents and young adults with cancer to BRIGHTLIGHT, a national cohort study

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BACKGROUND

BRIGHTLIGHT is an evaluation of teenage and young adult (TYA) cancer services throughout England. Despite national support from clinical teams and the Clinical Research Network, BRIGHTLIGHT recruited 55% of its target sample. We sought to understand healthcare professionals' perspectives of the challenges to recruitment to this low-risk observational study and thus to provide guidance on recruitment processes for future studies.

Methods

Semi-structured telephone interviews with 23 healthcare professionals who had indicated, on an anonymised questionnaire, their willingness to participate (Table 1). Participants included Principal Investigators and other staff recruiting to BRIGHTLIGHT. Data were analysed using Framework Analysis. Interviews and analysis were carried out by an independent researcher.

Results

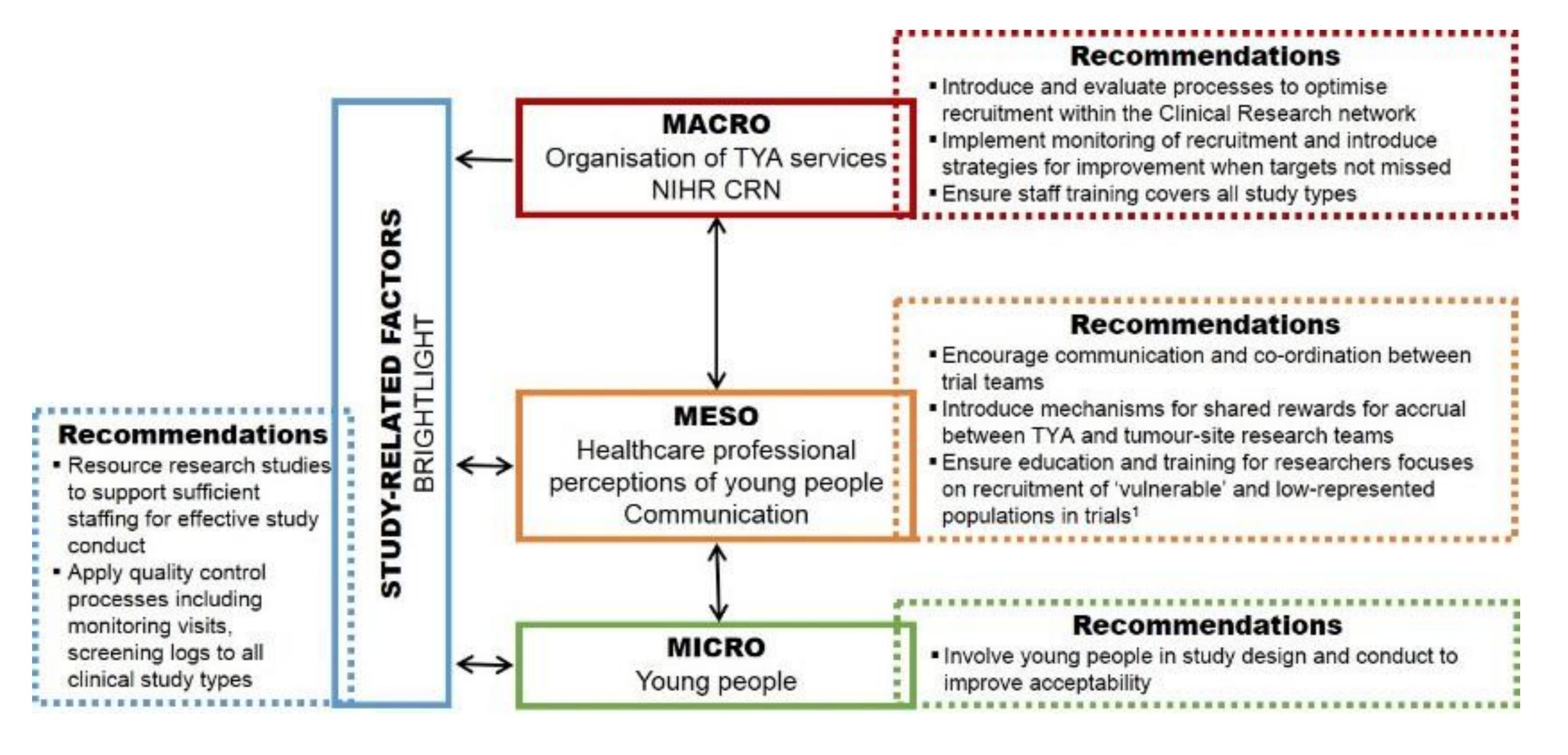
The emergent themes were linked to levels of research organisational management, described here using the levels of social network analysis (Figure 1): micro-level (the individual: in this case the target population - young people with cancer); meso-level (the organisation: this related to site of recruitment and those staff responsible for recruitment); and macro-level (the large-scale or global structure; relating to the wider research function of the NHS and associated policies).

Table 1: Participants

Characteristic	Number	%	
Professional Background			
Research Nurse – Adult	15	66	
Research Nurse – Paediatric	3	13	
Clinical Nurse - TYA	3	13	
Other	2	8	
Type of Hospital			
TYA Principal Treatment Centre	5	22	
TYA Designated Hospital	14	61	
Other Cancer Unit	4	17	
Role in BRIGHTLIGHT			
Principal Investigator	12	52	
Recruitment role	11	48	

"So most of our research department, and most of NHS research, is set up in terms of oncology, people with breast cancer, lung cancer, colon cancer and so forth. So it's, kind of, tumour site specific and the whole cancer service is based around being some specialist, you know, specific research department. You've got nurses who work on neurology studies, or breast studies, or lung studies and it was a completely different mind shift when you start looking at age rather than tumour site specific"

Figure 1: Challenges to recruitment by the level they occur, and recommendations to improve recruitment to research



Conclusions

This study has identified significant barriers relevant to all studies which aim to recruit patients across multiple tumour types. We suggest that interconnected whole-system changes are required to facilitate the success of interventions designed to improve recruitment (Figure 1) Interventions targeted at study design/management and the micro-level only, may be less successful.

Reference

The full report of this study is available at: http://bmjopen.bmj.com/content/7/11/e018291

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