

# Lets play Twister™! Novel methods to facilitate understanding of complex research methods and generate secondary research hypotheses with young people

Rachel M Taylor, Ana Martins, Sarah Lea, Jeremy S Whelan, Lorna A Fern  
Cancer Division, University College London Hospitals NHS Foundation Trust

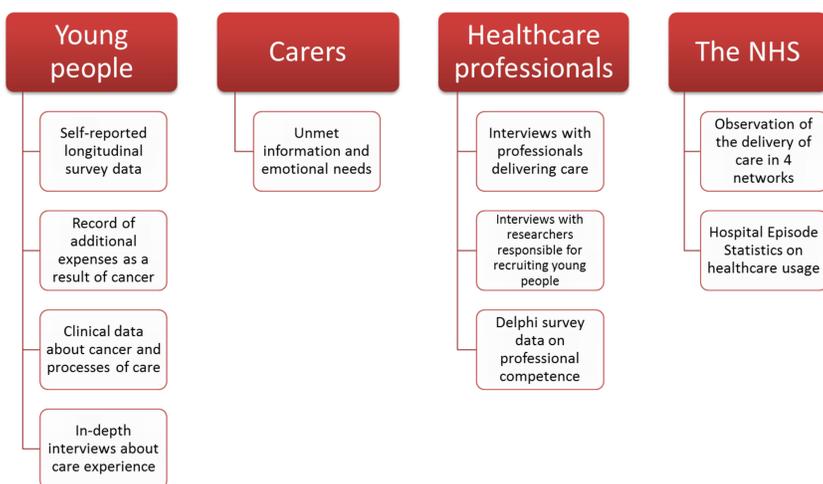
## INTRODUCTION

- Teenagers and young adults (TYA) with cancer have poorer outcomes than children and older adults, which led to the publication of the *Improving Outcome Guidance for Children and Young People* [1].
- Based on the guidance, cancer services in England were reconfigured so young people aged 15-18 years were referred to one of 13 principal treatment centres and those aged 19-24 had 'unhindered access' to specialist TYA care.
- While specialist and 'age-appropriate' care have been advocated, there is no definition of age-appropriate care. Furthermore, there is no evidence of the benefit of specialist care.

## WHAT IS BRIGHTLIGHT?

- BRIGHTLIGHT is the national evaluation of cancer services for TYA aged 13-24 years in England.
- BRIGHTLIGHT is a programme of research evaluating services from multiple perspectives, including the environment of care, professionals delivering care and central to the programme, young people and carers experiences of care (Figure 1).
- In addition to the primary data analysis, such a wealth of information lends itself to further exploration.

Figure 1: The BRIGHTLIGHT Data Bank



## METHODS

- To facilitate young people's understanding of 'hypothesis' or 'research question' the board game *Twister* was adapted so each movement represented a different aspect of data (Figure 2).
- Young people were divided into the BRIGHT Team and LIGHT Team. Two members from each team were on the mat at any one time; the other members spun the wheel (Figure 3).
- Teams made alternate spins until all four players had made a move. The links between each teams moves were recorded, for example, left hand green by team member 1 and right foot yellow by team member 2 would be reported as: "My cancer – How cancer has affected my friends and family"
- Each team then discussed how they thought the two domains were linked.
- The process continued until one of the players on the mat collapsed. Young people then swapped so spinners became players and vice versa.

Figure 2: BRIGHTLIGHT Twister movement and data linkage



Figure 3: BRIGHTLIGHT Twister



## AIM

Young people who are part of our Young Advisory Panel (YAP) have been central to study design, protocol development, study management and dissemination [2-5]. Extending the YAPs involvement further we wanted to identify what they thought was important to investigate further in secondary data analysis.

## PARTICIPANTS

- The BRIGHTLIGHT YAP comprises of 20 young people who were diagnosed with cancer aged 13-24 years. They were invited to a one day workshop through a notification on their closed Facebook page.
- Eight young people (1 male, current age 15-24 years) attended the workshop. Two were on treatment, the other six were 6 months to more than 2 years off treatment.

The BRIGHTLIGHT YAP participating in the workshop



"The events get better and better each year. You guys actually take the suggestions on board and improve accordingly :)" (Post workshop feedback)

## RESULTS

Thirty-six links were discussed, which were refined into 21 hypotheses or research questions. These were circulated to participants to individually vote for their top 3. The nine that received a vote are outlined in Table 1.

Table 1: Areas proposed for secondary data analysis that were rated as important

Area for secondary data analysis	Number of votes (%)
Is the impact of cancer affected by how much support you get from people in similar situations?	6 (75)
How I feel about my body after a cancer diagnosis affects my ability to form new relationships	3 (38)
Am I less likely to be involved in decision making if I am younger?	2 (25)
How much information I received from my treatment team affects how I feel about myself when treatment finishes	2 (25)
Young people who have cancers that are treated with surgery only and do not receive chemotherapy or radiotherapy have less support from other young people with cancer	1 (13)
Fatigue affects the type of job I have or can apply for	1 (13)
The number of healthcare professionals involved in my care affects the impact of cancer on my daily life	1 (13)
Stress and anxiety about my treatment affects how I get on with my family	1 (13)
If I am feeling depressed I am more likely to miss appointments, treatment and not take my medication	1 (13)

## CONCLUSIONS

- Young people can actively be involved in generating ideas for secondary data analysis if they are given the appropriate tool and these are not necessarily those viewed as important by healthcare professionals.
- While we have the YAPs opinion of what we should analyse, a James Lind Alliance priority setting exercise is currently underway to underpin the research agenda for TYA with cancer so secondary data analysis will also be informed by the results of this.

## REFERENCES

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