



# The 7<sup>th</sup> ‘D’: Don’t decide for me

Rachel Taylor, Anita Solanki, Natasha Aslam, Jeremy Whelan, Lorna Fern.

University College London Hospitals   
NHS Foundation Trust



### Background

BRIGHTLIGHT is a cohort study evaluating specialist care for 13-24 year olds newly diagnosed with cancer in England.

Since October 2012, a total of 510 young people have been recruited by 133 NHS Trusts. BRIGHTLIGHT is now the largest cohort study of young people with cancer in the world.

Feasibility work with young people to develop BRIGHTLIGHT has contributed to a low refusal rate of just 18%. However accrual is only at one-third of the anticipated figure.

Analysis of returned screening logs to explore low recruitment indicated one in four young people are not being approached.

Optimising recruitment to research is complex. We engaged with the clinical community, and implemented various protocol changes. Simultaneously, we aimed to elicit young people’s opinions about access and participation in research.

To date, no study has examined young peoples’ views on access, approach and clinical gate keeping in cancer research. We found that young people considered it their right to be informed about all research studies for which they were potentially eligible. This is in keeping with the current ‘its ok to ask’ campaign in the UK, which aims empower patients to ask their treatment team about all research studies. It is also in keeping with healthcare policy in the UK; ‘no decision about me, without me’.

### Aims

During a one day workshop we sought to explore young peoples views on approach and access to research.

### Participants

As part of the patient and public involvement strategy, eight cohort and non cohort members aged 18-25 were recruited via a BRIGHTLIGHT social media campaign.

### Methods

Using participatory methods, data were collected through role play, focus group and individual reflection.

The facilitator-led role play illustrated examples of reasons cited in the BRIGHTLIGHT screening logs which did not classify as exclusion criteria for entry to the study. For example, pregnancy, or non-English speaker.

Following an open discussion, young people expressed their opinions on the scenarios, and provided individual reflection. The workshop ended with creative audio-visual young person led interpretation of the day.

### Results

Data were transcribed verbatim and analysed using thematic analysis. Three main themes emerged: **patient choice; role of healthcare professionals; value of research** (see Table 1: Row 1 shows themes, rows 2 and 3 illustrative quotes)

Table 1

Patient Choice	Role of Healthcare Professional (HCP) as facilitators/barriers	Value of the research
<ul style="list-style-type: none"><li>Right to know all available research options</li><li>Unable to make an informed decision if information was withheld</li><li>Being approached about research studies not felt as a burden</li></ul>	<ul style="list-style-type: none"><li>Clinically trained staff such as doctors were considered paramount to discussions and decisions about drug and research treatment. However, social workers and activity coordinators were felt to be well placed to discuss psychosocial and health services research</li><li>Time constraints of clinical HCPs’ were identified, strengthening the argument for including other MDT members in consenting to research</li></ul>	<ul style="list-style-type: none"><li>The way in which the information was presented by HCPs’ was important</li><li>If the HCP conveyed the value of the study, the benefit to other young people, and displayed enthusiasm, young people felt they were more likely to participate</li></ul>
<i>“At the end of the day, its your decision isn’t it? If they give you the option its up to you to say yes or no”</i>	<i>“From what I see the problem doesn’t lie with the young adult, it lies purely with the health professional”</i>	<i>“If they [HCP] were able to see the value of the survey... what kind of outcome and impact this survey would have for patients, then they would be very proactive about it”</i>
<i>“You should have the right to partake in studies”</i>	<i>“social workers deal with your environment and that’s why I think they are the best people to actually push this survey through”</i>	<i>“I think the patient has to get something out of it because they are making the investment of their time”</i>

### Conclusion

To date, no study has examined young peoples’ views on access, approach and clinical gate keeping in cancer research. We found that young people considered it their right to be informed about all research studies for which they were potentially eligible. This is in keeping with the current ‘its ok to ask’ campaign in the UK, which aims empower patients to ask their treatment team about all research studies. It is also in keeping with healthcare policy in the UK; ‘no decision about me, without me’.

### Acknowledgements

This poster presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research Programme (Grant Reference Number RP-PG-1209-10013). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health. The *BRIGHTLIGHT Team* acknowledges the support of the NIHR, through the Cancer Research Network.