University College London Hospitals NHS
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BRIGHTLIGHT
Do specialist services for TYA with cancer add value?

Empowering young people to participate in research: young people’s views about research access and participation

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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 740 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 three 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.

Aims

During a one day workshop we sought to explore young people’s views on access to and participation in research.

Participants

- The Young person’s Advisory Panel (YAP) are BRIGHTLIGHT’s patient and public involvement group.
- Eight members of the YAP (4 male, 4 female), aged 18-25 years attended the workshop.
- Diagnoses included four haematological malignancies and four solid tumours.
- Follow the workshop, further consultation was sought with 222 young people who were attending a national patient conference.

Methods

- Using participatory methods data were collected through role-play, focus group and individual reflection.
- .Role-play, by the research team, enacted scenarios illustrating reasons for not approaching young people cited in screening logs outside of the eligibility criteria. For example, pregnancy or non-English speaking.
- Following open discussion of the scenarios young people provided individual reflection on access to eight types of cancer research.
- Consultation with participants of the patient conference was through an interactive electronic survey.

Results

Three main themes emerged from the focus group: **patient choice, role of healthcare professionals as facilitators/barriers, value of the research**.

Patient choice

- Young people felt they had the right to know all their options and available research.
- Without knowledge of all available studies they would not be able to make an informed choice about participation.
- Being approached about research was not felt as a burden.

“At the end of the day it is your decision isn’t it? If they give you the option it is up to you to say yes or no.”

“You should have the right to partake in studies so long as they don’t physically clash.”

Role of healthcare professionals as facilitators/barriers

- Clinically trained staff, such as doctors and nurses, were considered paramount to information giving and decisions around drug and treatment research. However, social workers and activity coordinators were felt to be well placed to discuss psychosocial and health services research.
- Young people acknowledged and sympathised with the increasing time pressures for clinical staff and this was recognised as an indirect barrier to recruitment.

“From what I can see the problem doesn’t lie with the young adult, it lies purely with the health professionals.

“Maybe it makes more sense for the youth worker to do it because you are more likely to talk to them about the experience of being treated.”

“…the better route would be through the social workers. Because my experience is that health professionals have to have professional conduct, they can’t be too personal with you because they have to protect themselves as well. Whereas the social worker.”

Value of the research

- The way in which information was presented by the person gaining consent was important.
- If the healthcare professional conveyed the value of the study, the benefit to other young people and were enthusiastic in the delivery of information, young people felt they were more likely to participate.

“If they [healthcare professionals] 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 think the patient has to get something out of it. Because they are making the investment of their time they will want something out of it.”

Conclusions

To date, no study has examined young people’s 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 ‘It’s OK to ask’ campaign in the UK, which aims to empower patients to ask their treatment team about all research studies.

Access is critical to improving recruitment rates; this study illustrates that access can be blocked through healthcare professional gate-keeping. We also highlight the need to find effective ways to support and empower healthcare professionals in approaching vulnerable populations about research. Thus ensuring potential participants are given transparent information to make an informed choice, improve recruitment rates and ultimately the number of studies reaching completion.

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