

Young people's priorities for a teenage and young adult specialist cancer unit

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Introduction

- Health policy in England recognises the needs of teenagers and young adults (TYA) with cancer¹.
- Key recommendations reflect the age specific needs and unhindered access to age-appropriate environments.
- Recommendations are made in the absence of a definition of what an age appropriate environment is.
- Furthermore, little research exists about TYA preferences of key features of an age appropriate environment.

Aims

- To identify the priorities for a specialist TYA cancer unit.
- To invite TYA who have experienced cancer to work as co-researchers

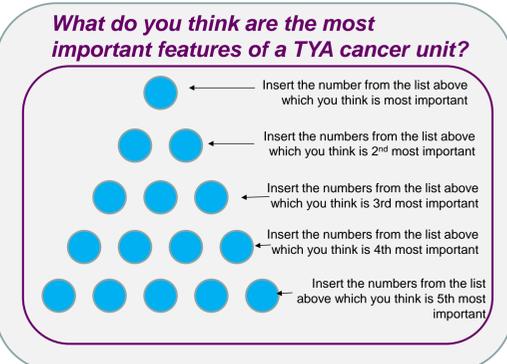
Study design

This was a mixed methods study with data generated from two sources: an interactive workshop and a survey

Study 1

- Young people were recruited through Teenage Cancer Trust Facebook page and Jimmyteens.tv to attend a one day workshop.
- 15 core characteristics of specialist TYA cancer care were identified from the literature and placed on cards.
- In two groups, young people ranked the cards through consensus on a pyramid (most important at the top, least important at the bottom).
- Spare cards were provided so young people could substitute the pre-printed cards for other features they thought were more important.
- Notes were made of the discussions between young people about card placement.

Figure 1: Pyramid included in the FYSOT survey



Study 2

- Young people who attended 'Find Your Sense of Tumour' (FYSOT) were given a self-report version of the cards & pyramid (Figure 1).
- The completed cards were returned to the NCRI TYA Core Consumer Group (CCG).

Analysis

- Cards were ranked within the pyramid².
- They were scored from 1 – 5 based on the position in the pyramid (5 points for items at the top down to 1 point for those at the bottom).
- A rank score was calculated for each item.
- Scores were standardised through dividing by the sample size.
- Data for the workshops and FYSOT survey were integrated through ranking the final standardised scores.

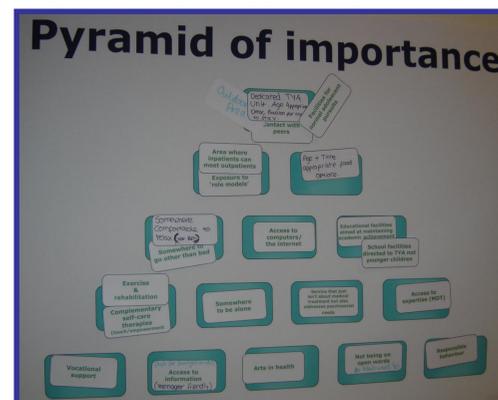
Results

- Eleven young people diagnosed with cancer aged 14 – 25 years participated in the workshop.
- An example of one pyramid is shown in Figure 2.
- The top 3 priorities were:
 1. Dedicated unit ("we are treated like adults but we get the privileges and time that other children do").
 2. Contact with peers.
 3. Somewhere to be alone.
- Young people wanted the cancer unit to be like home (carpets not wooden floors), with a mixture of side rooms and bays (ways of ensuring privacy), and an outdoor space that was not populated by smokers ("fresh air does the world of good").
- Young people did not meet any peers on an adult or paediatric ward but it was important for them to see other young people who were surviving, especially seeing that hair grows back!
- There was nowhere to go on an adult ward but young people desired somewhere comfortable to relax.

Results

- Pyramids were returned from 64 young people aged 13 – 24 at diagnosis.
- The top 3 priorities were:
 1. Dedicated unit.
 2. Contact with peers.
 3. Somewhere to go other than bed.

Figure 2: Example of a pyramid of priorities



Integrated results

Overall, the top ten priorities of a specialist TYA cancer unit were:

1. Dedicated unit.
2. Contact with peers.
3. Somewhere to be alone.
4. Somewhere to go other than bed.
5. Facilities for normal adolescent pursuits.
6. Area where inpatients can meet outpatients.
7. Contact with peers.
8. Access to information
9. Access to computers (& the internet).
10. Access to expertise (the MDT).

Conclusions

- There were wide variations in young people's priorities for a specialist TYA cancer unit.
- While the physical unit was rated #1, the discussion in the workshop concluded that the priority was not decor but the quality and ethos of care.
- Involving young people in the development of specialist TYA services is an important step towards improving the patient experience.

References

- ¹ National Institute for Health and Clinical Excellence. Guidance on cancer services: Improving outcomes in children and young people with cancer. London: NICE 2005
² Zebreck B, Mills J, Weitzman TS, Journal of Cancer Survivorship, Vol 1, Issue 2, pg 137-145 2007

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