

Opportunities and barriers to the design of a self-management resource for young cancer survivors

Keywords: Web-based self-management, young cancer survivors, design of online support

Improvements to diagnosis and treatment mean that most British teenagers and young adults (TYA) with cancer now survive (Birch et al. 2002). With a growing population of survivors there is a need for alternative mechanisms to support the transition from treatment to survivorship (Zebrack 2011, Evan and Zeltzer 2006). The popularity of social networking sites, online forums and smartphones amongst young people potentially make the internet an ideal platform for self-management, e-learning and support following cancer treatment (Hulme 2010, Elwell et al. 2011).

This paper considers the needs of young people, and the feasibility of developing a web-based self-management resource. It considers the priorities and perspectives of a range of stakeholders and captures potential barriers to innovation.

A mixed methods approach included a rapid review of the literature, an online survey of young cancer survivors (n=24), focus groups and interviews with TYA patients, (n=7) and their parents (n=6) and interviews with information technology, medical, nursing and social work professionals (n=11).

All stakeholders were generally supportive of providing reliable and credible web-based self-management resources to augment face-to-face support. The teenagers and young adults indicated that they would like an on-line resource to provide clinical, informational and social support features. A number of governance issues emerged regarding whether all these functions could be provided by an NHS Trust IT system. There were some ethical and confidentiality issues, for example in the desire amongst young people for online contact

with health professionals and for accessing medical test results.

The research has led to design recommendations for a structured self-management resource to support the transition from treatment to survivorship. This would require close working between design, information technology and clinical staff to meet user, provider and governance needs. Computer use amongst this group is commonplace, and therefore it is an expectation that self-management needs will be met at least partially in this way in the future.

References

- Birch JM, Alston RD, Kelsey AM, Quinn MJ, Babb P, McNally RJ. 2002. Classification and incidence of cancers in adolescents and young adults in England 1979– 1997. *Br J Cancer* vol. 87, no 11, pp1267–1274.
- Elwell L, Grogan S & Coulson N. 2011. Adolescents living with cancer: The role of computer-mediated support groups, *Journal of Health Psychology* vol 16, pp236-249.
- Evan EE, Zeltzer LK. 2006. Psychosocial dimensions of cancer adolescent and young adults. *Pediatric Oncology Group of Ontario Symposium: Walking two worlds – Adolescent and Young Adult Oncology*. Ontario, Canada
- Hulme M. 2010. *Life Support Young people's needs in a digital age*. Institute for Advanced Studies, Lancaster University.
- Zebrack BJ. 2011 Psychological, social, and behavioral issues for young adults with cancer. *Cancer* vol. 117, pp2289-2294.