

LEARNING FROM THE EXPERIENCE OF CO-CREATING AN ONLINE ASSESSMENT AND SUPPORT RESOURCE FOR TEENAGERS AND YOUNG ADULTS (TYA) WITH CANCER.

Sue Dolby, Macmillan Consultant Clinical Psychologist & Jen Cheshire, Macmillan Psychology Support Project Manager
On behalf of the On Target Team, Bristol, UK.

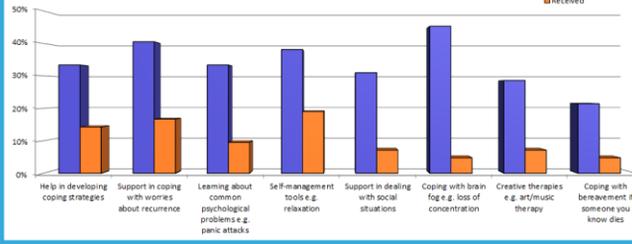
Recognising the need to design assessment and support resources that reflect the differentiated developmental needs of TYA's with cancer from diagnosis through to aftercare, informed the development of a new online holistic needs assessment which could act as a portal to evidenced based self management resources allowing young adults to become active partners in their care. Adopting a co-creation approach, the On Target team took the South West TYA Service's Integrated Assessment Map (IAM) to an online platform linked to a new Help!! Website offering level 1-2 psychological wellbeing information and advice. www.tyaiam.co.uk www.tyahelp.co.uk

Why an online resource?

From the co-created On Target survey with TYAs as part of the requirements analysis stage of the On Target programme, 55% of patients reported no psychological support and a significant gap between their needs and the availability of information/advice. This led to a programme workstream to:

- Co-create a solution that would be available to TYAs when they need it (i.e. 24/7).
- Enable access to level 1-2 multi-media information that would develop supported self assessment and self management
- Sign post to targeted resources when their needs required it

Psychological / Emotional Support



Gap in what young people said they wanted, and what they felt they received – On Target Patients' Workstream – Findings Report 2013

Why co-creation?

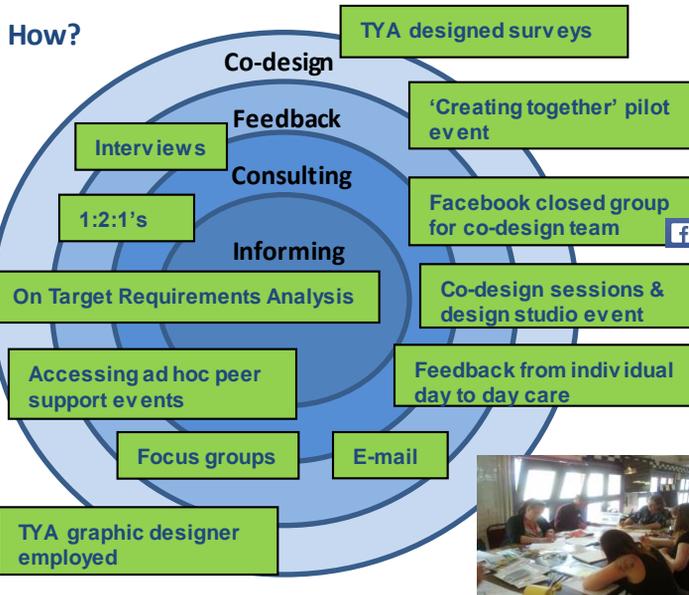
TYA South West and the Macmillan On Target programme utilises the principles of co-design with service users & staff, because we believe:

- Engagement in service design will enhance the use of services & resources.
- Co-creation will result in better patient experience.
- There is a therapeutic benefit to taking part in service improvement in this way.

<http://www.healthcodesign.org.uk>

Bate, P. & Robert, G. (2009). Bringing user experience to healthcare improvement: the concepts, methods and practice of experienced based design. Oxford: Radcliffe Publishing.

How?



What are TYA and staff telling us about their experience of co-creation?

"I loved the experience and it really helped me develop some confidence after treatment"
TYA Patient

"It was really therapeutic to be part of something that could help others, but at the same time was helping me"
TYA Patient

"I really enjoyed helping the TYA team to help other young people like me"
TYA Patient

"The process has challenged our own assumptions about what TYA want, and how they will engage in their own healthcare"
Project team member

What does the data tell us?

The initial IAM / Help! Pilots finished on 30/01/2015.
Over the Help! pilot period (12/05/14 – 30/09/14) :

- The website was accessed 686 times using 295 devices.
- 4370 page views occurred with an average of 6.37 pages per session.
- Return to site rate of 42.3 %.
- Feedback was collected via a star rating per page process and free text. 61% of the pages received 4-5 stars out of 5. The Help! website is now open access.

IAM / Help! is now online and moving to an App to increase access. In the period November 2014 -October 2015 :

- 102 TYA's have received logons, for supported self assessment.
- 80% (N=82) have accessed the site.
- 66% (N=54) submitted ≥1 IAM.



Learning to date

- A co-creation approach is engaging staff and young adults with cancer in the development of their services.
- TYA and staff increasingly utilising the resources as part of everyday care.
- The co-design events can offer a therapeutic peer support opportunity as well as delivering authentic multi-media resources designed with TYA as 'experts by experience'.
- Evidence is emerging to support the principles associated with co-creation to continue underpinning the TYA South West approach to service improvement.

The On Target Team wish to acknowledge and thank all the young adults, their networkers and the staff who work with them for their contributions to this work.

