Information Provision for Adolescents With Cancer

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Presentation overview

- Relevance to medical informatics
- Motivation
- Information sources & content
- Guidelines for information provision
- Take home message
Relevance to medical informatics

- We are good at problem solving and providing highly detailed evidence based outputs – that few can understand.
- The power of our work is realised only when it is applied.
- There is little analytical capacity directed towards this group and few improvements seen in two decades.
- This group requires different information presented in different ways & we produce the information.
- Outlier analysis.

Motivation

Information provision is not tailored for this audience & there are few ‘experts’ to guide.

Adolescents are not always good communicators. We need to understand what they want and not expect cooperation in requirements gathering.

Adolescence is a time when looks and acceptance are critical to social survival. Cancer alienates and often prevents any chance of a normal appearance.

Adolescents are almost always treated in either child or adult focussed centres and only 5% of patients are adolescents.

Clinical outcomes and ability to cope are directly affected by the quality and appropriateness of information received.

Adolescents are treated with protocols designed for children or adults. Upon turning 16 their chance of survival is halved.

Information sources & content

What sources are used and trusted?
- Doctor. Only 30% take the time to build trust and relate appropriately.
- Other patients – must be matched. Not always supported by doctors.
- Social media & targeted websites. Must be appropriate & mediated but few available for cancer patients.

What do they want to know?
- The truth not reassurance.
- What will happen to them not everyone else.
Guidelines for information provision

- Accessibility – any time and place – anonymous, without consent, confidential and private.
- Ensure it is delivered through the right medium. Strangely they don’t read the Lancet, know of the Cochrane library or know other teens with cancer.
- Language – teen specific and on topic. Cut the terminology.
- Qualified and reliable.
- Low cost.
- They need to take control, connect, share, inspire, support and hide.
Take home message

- Not only teens and not only cancer – information should always be tailored to the user – patient, clinician, analyst, media reporter, computer system.

- Citizen centred e-Health should mean we tailor informatics processes for all citizens – including the outliers. How we request information to ensure we have high quality data and how we share the results of analysis to ensure people have high quality information that can become high quality knowledge relevant to the individual is the next frontier for MI.
Thank you

Please speak with me personally or email to anna.shillabeer@au.ey.com if you are interested in sharing opportunities to engage in collaborative research in personalised healthcare and/or health information provision.