

The meaning and measurement of outcomes in survivorship





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BACKGROUND

The Transforming Care after Treatment programme in Scotland (TCAT), funded by Macmillan Cancer Support, oversees the implementation of different local approaches to achieving 'good survivorship' through enhancing follow up and assessment. A multi-disciplinary team at Edinburgh Napier University is conducting the 5-year national evaluation that includes exploring cost-effective solutions and changes in use of resources.

METHODS

Tailored health economic evaluations for nine local projects. Quantitative and qualitative data collection was designed to inform cost effectiveness, cost benefit and cost minimisation analysis as appropriate.

RESULTS

Outcomes included patient derived measures of increased self-reported quality of life; improved self-reported health and wellbeing; increased self-management and reduced self-reported unmet concerns. Service outcomes measures included reduction in routine follow up and changes in resource utilisation.

Implementation processes at a local level meant that the expected data was not available or sufficient for the application of the proposed health economic techniques

DISCUSSION AND CONCLUSION

Understanding both the benefits and the costs of newly developing local models survivorship services for the growing number of cancer survivors is of critical importance. However we found that the transferability of findings is undermined by a number of factors.

Our work highlights the challenges in evaluating the health economic value of survivorship services. It evidences the need for further work to determine the meaning of outcomes for services and patients and to develop consensus as to how best to measure them. It makes an important and timely contribution to the development of a robust evidence base for cancer strategies that encompass the whole system and the holistic needs of people affected by cancer.

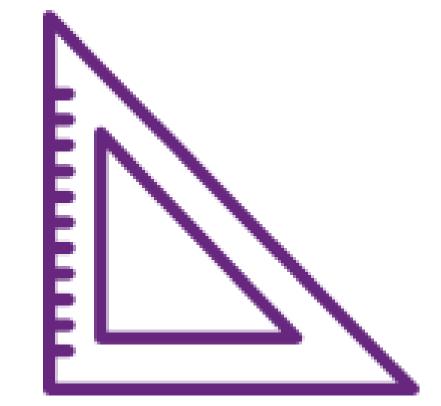
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FACTORS AFFECTING THE MEANING OF OUTCOMES IN SURVIVORSHIP

SCALE OF EVALUATION ACTIVITY

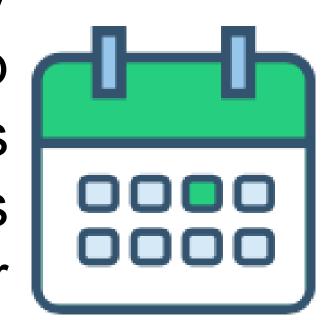
available from the Data local projects reflected the small numbers of participants, which possibility affects the of the samples being sufficiently powered to show an effect.



Significance in statistical terms was not possible to determine and the risk of presenting false positive or false negative statements was therefore high.

SHORT TERMISM

Local projects only had the capacity and time available to focus on snap shot, self-reported measures. This focus on short term outcomes limits understanding of the time required for the intervention to have an effect.



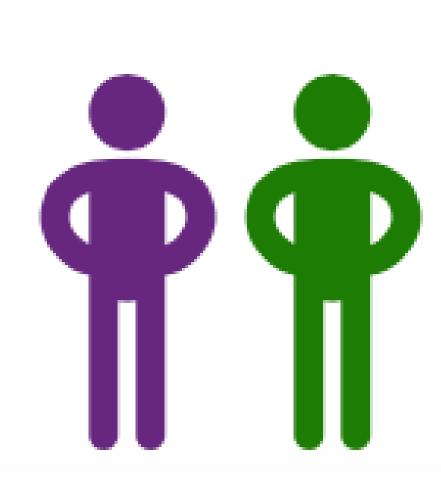
FOCUS ONLY ON PARTICIPANTS



Patients could opt in or opt out of the 'service' and within many, significant numbers declined or did not attend the new service. The number or characteristics of people who 'declined' or opted out were not universally recorded or analysed.

LIMITED EVIDENCE OF IMPACT

Quantitative baseline or comparator group measures (a control group) were attempted only within a few projects. Where they were, they lacked scale and/or sophistication to assure accurate comparisons.



ABILITY TO TAKE CREDIT FOR ANY IMPACT

Scale, sample selection and duration of local evaluations all combine to reduce the likelihood of a local project being able to attribute any measured or observable change accurately or solely to their new service. This issue of understanding and ultimately 'proving' cause and effect is compounded by the multi component aspect of many of the TCAT projects.