

How can we measure the value of specialist cancer care for teenagers and young adults?



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The NICE Implementing Outcome Guidance (IOG)¹ emphasises the need for specialist teenage and young adult (TYA) cancer care. The provision of 13 principle treatment centres (PTC) has been created to deliver this specialist care in England. In order to develop a proposal to evaluate this specialist care, a series of pilot and feasibility studies were conducted. The following is a summary of each project and how it has underpinned the methods of the 'Essence of Care' study.

What is the current service provision for TYA with cancer in England and what are the anticipated changes in the next 5 years?

Method: Semi-structured interviews with four commissioners of TYA cancer services & documentary analysis of nine implementation plans from Specialist Commissioning Groups.

Results: Current NHS care provision alienates TYA because it is targeted at children or the elderly. Services need to provide high expertise in physical, psychological & social care.

Challenges include: eliminating the idea of physician ownership (patient choice); timely implementation of the NICE guidance; lack of uniformity in shared care services; Resistance by some professionals to the introduction of specialist services.

What is the nature of specialist TYA cancer care?

Method: Non-participant observation in a PTC and semi-structured interviews with young people & health professionals.

Results: Seven core themes – the underpinning philosophy of empowering young people; developing as a specialist professional; defining TYA specialist care; the MDT; unit and physical place of care; peer support; young adult cancer care on adult cancer wards at the PTC.

What are young people's experiences of cancer care treated within England in the last 5 years?

Method: Semi-structured, peer interviews conducted by the NCRI TYA CCG.

Results: see poster C60 for details.

What are the key characteristics of a specialist TYA cancer unit?

Method: Workshops held with young people and health professionals, and a survey of young people at Find Your Sense of Tumour.

Results: see poster C62 for details.

Is there a framework available to address the methodological challenges of conducting a nationwide survey?

Method: A search of other longitudinal surveys and approached key people to provide information for the proposed study.

Results: Identified mechanisms for obtaining consent/assent from young people regardless of the geographical spread, and a way of delivering interviewer administered questionnaires, robustly, over five time points in 5 years, within the budget of the grant.

What are young people's preferences for the conduct of a longitudinal survey?

Method: Seven young people reviewed the outcome questionnaires and participated in a semi-structured interview exploring methodological preferences.

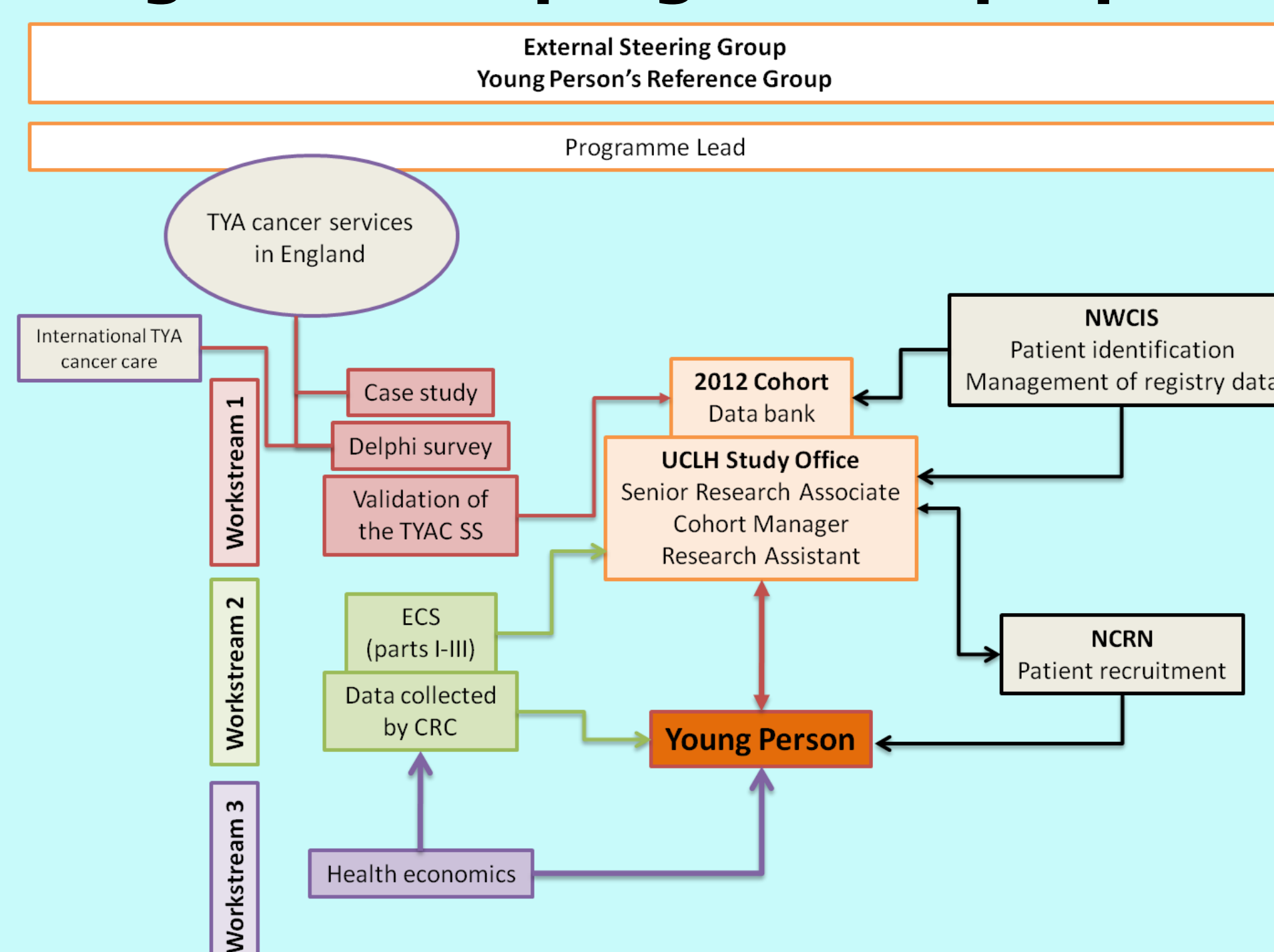
Results: The questionnaires were generally rated as acceptable and not burdensome. There was variation in preference for mode of administration but all agreed this should not be in the morning. Young people suggest that communication would be the key to retention over the longitudinal study

Can clinical data for all young people with cancer be obtained accurately and timely from existing NHS databases/registries?

Method: NWCIS examined national databases to determine whether diagnostic and follow-up data could be obtained from young people.

Results: The TYAC notification form has the most complete data but was only available from those referred from a specialist PTC. Additional information about diagnosis and treatment was available from the data repository, linked to Hospital Episode Statistic (HES) data.

Stage 2 NIHR programme proposal



What are the core skills, knowledge & attitudes of health professionals working in specialist TYA cancer care?

Method: Over two workshops, health professionals ($n = 22$) ranked 61 identified competencies on a diamond, the most important at the top and least at the bottom.

Results: Health professionals identified a pattern of communication unlike that of paediatrics (to parents) and adults (direct to the patient). TYA professionals needed to communicate with young people, parents & significant others. The most important competencies were identified as: expertise in treating paediatric & adult cancers; and understanding the impact of cancer.

Can we rapidly identify all new diagnoses of cancer in those aged 13 – 24 years?

Method: The North West cancer Intelligence Service (NWCIS) tested available cancer datasets to determine whether it was possible to identify all newly diagnosed young people in an appropriate time scale.

Results: Cancer Wait Time database provided the timeliest information, enabling 99% of young people to be identified within 90 days of diagnosis.

What patient-reported outcome measures are available and validated for young people aged 13 – 24 years?

Method: A review of the literature between 1980 – 2009 using key patient reported outcome terms (e.g., quality of life, symptom experience) to identify questionnaires used on 13 – 24 year olds.

Results: Identified questionnaires measured a variety of outcomes, including response to trauma, stressful life events, anxiety, hope, social support. The quality of the questionnaires is currently being evaluated.

How do young people rate their outcome after treatment for cancer?

Method: A review of the literature between 1980 – 2009 using key patient reported outcome terms (e.g., quality of life, symptom experience) to identify studies exploring self-reported outcome and experience in young people aged 13 – 45 years treated for cancer.

Results: A total of 69 studies have been identified, including 16 qualitative studies. These are currently being assessed using quality criteria (e.g. CONSORT).

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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