

# Exploring stakeholders' perceptions of teenage and young adult cancer ambulatory care

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#### **Project background**

The Teenage and Young Adult (TYA) Ambulatory Care (AC) service began at University College London Hospitals in 2012 as an alternative, mobile approach to the delivery of cancer treatment that was previously delivered in the inpatient setting. Its main driver was to promote independence and normalise lengthy cancer treatments within a family-centred context. It is the first service of its kind in the UK and Europe and, since its development, it has become nurse led, meaning that all supportive care and day-to-day treatment is performed and delivered by the nursing team and advanced nurse practitioner. Patients are only seen by a doctor at the start of their treatment cycle or if they become acutely unwell. To capture the development of this new service, a nurse-led group (STEER) was developed to work with patients, families and clinical staff.

#### Aim

This second-phase project aimed to build on the original introduction and development of AC. However, during the reconnaissance phase of the project, the membership of STEER changed significantly, leaving only the two project leaders. They therefore had to adopt a more pragmatic approach and amend their aim. The new project aim was to develop a deeper understanding of the service from the perspective of stakeholders.

#### Implications for practice

- To encourage empowerment of patients and to reduce anxiety when they are going home or into ambulatory care, some aspects of AC should be explored and adapted so patients could become accustomed to them while still the inpatient setting, in particular urine testing and, where suitable, medication administration
- Where possible, patients and families should be offered a visit to the AC service before deciding whether to select this treatment option
- Greater understanding of the AC service among nursing staff could be achieved through internal rotation of inpatient staff

This project was supported by the FoNS Practice Based Development and Research Programme in partnership with the General Nursing Council for England and Wales Trust

# Online

Further information about the project can be accessed from: <a href="mailto:fons.org/library/report-details?nstid=71868">fons.org/library/report-details?nstid=71868</a>

# **Key activities and outcomes**

Action research informed the project. A number of methods and approaches were used throughout the phases of the action research cycle.

#### • Reconnaissance

It was during this phase that membership of the nurse-led STEER group reduced and it became apparent that the aim of the project would need to be revisited. The project team used a creative approach to explore their values and beliefs about AC, and then shared these with nurses working on the inpatient ward. During this discussion, it emerged that the ward nurses held different views about AC, feeling that at times it increased their workload and stress levels. Creating this opportunity for discussion helped the project team to realise the need to explore the perspective of all stakeholders.

PROVEM

# • Planning

This phase involved identifying those people with an interest in the AC service, or those who could be affected by or have an affect on the service, either positively or negatively. With many stakeholder groups identified, the project team realised they would need to be pragmatic and adapt their approach to engage with different groups. Formal ethical approval was not required, but ethical issues were discussed with the trust's research and development team.

### Implementation (exploring stakeholder views)

During this phase, the project team used a number of approaches to engage with the stakeholders. This included: a focus group with a small number of AC patients (n=3), a parent and a carer; emotional touchpoint interviews (n=6) with AC patients; a claims, concerns and issues exercise with clinical nurse specialists; questionnaires with ward nurses (n=10) and doctors (n=5). Some of these approaches were new to the project team and so presented both challenges and opportunities for learning.

#### • Evaluation

The project team worked together to review all the evidence that had been collected. Initially they read through the data individually, capturing sentences and phrases that reflected stakeholders' perspectives, which were then grouped into themes. They then shared these to identify common themes from across the whole set of evidence. The FoNS practice development facilitator supported this process by asking critical questions. The key themes identified from the collected data were knowledge, empowerment, positive experience and anxiety. These findings helped the project team begin to identify implications for practice. In particular, they recognised the potential opportunities to enhance the empowerment of patients — a key aim of the Teenage Cancer Trust (teenagecancertrust.org) — across the whole service, including the inpatient service, by adopting some AC principles.

# • Begin the cycle again

In particular, the themes of empowerment and anxiety presented an opportunity to challenge the current philosophy of TYA care. Although it appears that many young patients are keen to participate in AC, professional anxiety has the potential to reduce the opportunities for independence and self-care this offers. Questions could also be raised as to why TYA AC is still only delivered in this one specialist cancer unit.