Specialist cancer services for teenagers and young adults in England: BRIGHTLIGHT research programme

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Plain English summary

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Background

In England, around 2000 teenagers and young adults aged 13–24 are diagnosed with cancer annually. There is evidence that the results of cancer treatment for teenagers and young adults could be better because children or adult services do not meet all their needs. National health-care guidance states that all young people should have access to specialist teenage and young adult services. In England, 13 specialist centres for teenagers and young adults exist, but they are all different and access varies. Despite recommendations for specialist services for teenagers and young adults, no definition of 'specialist care' or its 'core' parts existed. Professionals and patients said 'TYA [teenage and young adult] specialist care' is 'better', but it was unknown how specialist services affect outcome or how much this costs the NHS and patients.

What we asked

- What are the most valuable parts of specialist care for teenagers and young adults?
- How does specialist care affect treatment success?
- What costs are associated with specialist care?

What we did

We studied specialist services to identify the most valuable parts.

We recruited 1114 teenagers and young adults with cancer who completed five surveys over 3 years. We recorded their time spent in a teenage and young adult centre, and how much it cost the NHS and patients.

What we found

Some of the most important parts of specialist services are best treatments, professional knowledge, good communication, recognising teenagers and young adults as individuals, and the environment.

Six months and 3 years after diagnosis, we found that:

- Teenagers and young adults having treatment only at a children/adult centre had a better quality of life than those having all their treatment in a specialist centre and those who had treatment jointly in a specialist centre and children/adult centre.
- Those undergoing treatment only at a specialist centre had faster improvements in quality of life.
- Those receiving treatment in both a specialist centre and a children/adult centre had the lowest quality of life.

NHS costs were similar for all care in a children/adult or specialist centre, and NHS costs were most expensive for care in combined children/adult and specialist centres.

What this means

We identified the most valuable parts of specialist centres, which can guide future services.

Some patients may benefit from having all treatment at a specialist centre.

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