BRIGHTLIGHT: Do specialist cancer services for teenagers and young adults add value?

Dr Rachel Taylor
On behalf of the BRIGHTLIGHT Team
Reason for the research

Do specialist cancer services for teenagers and young adults add value?
Four points remain unclear

1. What is specialist care?
2. What are the core parts of this service?
3. How much does this cost?
4. What outcomes are associated with specialist care?
Challenges

- **What study design?**
  - Ideally randomised controlled trial, BUT
    - Services are already in place
    - Unethical to randomise to specialist care vs. not
    - Variation in services across country

- **What sample?**
  - Too much variability to be single centre
  - National cohort, BUT
    - How do you identify ALL young people?
    - How do you recruit ALL young people?

- **What outcomes?**
Essence of Care: Phase I

Phase 1
Commenced June 2009

Understanding TYA cancer services

- Non-participant observation & interviews with TYA & HP
- Interviews with commissioners & documentary analysis
- Workshops with YP & HP
- Review of longitudinal & panel surveys in England

Management & Organisation of Phase 2

- Literature reviews of TYA cancer services, outcomes & measures
- Interviews with young people
- Evaluation of NHS datasets & registries

Methodological issues related to Phase 2

- Interviews with commissioners & documentary analysis
- Non-participant observation & interviews with TYA & HP
- Workshops with YP & HP
- Review of longitudinal & panel surveys in England
A scoping exercise of favourable characteristics of professionals working in teenage and young adult cancer care: ‘thinking outside of the box’

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A scoping exercise of favourable characteristics of professionals working in teenage and young adult cancer care: ‘thinking outside of the box’
WHERE is care provided?
WHAT are young people’s experiences of care?
Aims of BRIGHTLIGHT

- Workstream 1: What is specialist care?
  - Explore the culture of care
  - Identify the competencies of specialist professionals
  - Develop a bespoke metric to quantify specialist care

- Workstream 2: Outcomes are associated with specialist care?
  - Impact of specialist care on outcomes, experience and processes of care
  - Socio-demographic and geographic inequalities in access to specialist care

- Workstream 3: How much does specialist care cost?
  - Estimate the cost of care (cost effectiveness and cost benefit)

- Workstream 4: Formulate opportunities for change
Study design

**Workstream 1**
- **Modified e-Delphi Survey**: 158 HCPs from 5 continents
- **Case Study**: 4 networks, 21 hospitals, 120 hours observation, interviews 30 YP and 40 HCP
- **Secondary analysis of HES data**: 1,076 YP; >27k hospital admissions

**Workstream 2**
- **Longitudinal cohort study**
- **Carer survey**

**Workstream 3**
- **Health economic analysis using retrospective cost questionnaire, prospective diary, NHS Data**
  - Cost questionnaire >50%
  - Diary = 13%
  - NHS data ≈1,100
Young person involvement

The Essence Echo

Essence of Care study:
Phase 1 complete
Researchers, including a team of young people with cancer, who have been working towards making young people’s lives better when they have cancer, are pleased to announce the results.

Read on if you would like to know more...
Focus on the BRIGHTLIGHT Cohort Study

Aims

▪ Examine the association of level of care to outcome
▪ Examine geographic & socio-demographic inequalities
▪ Evaluate cost & cost effectiveness of different levels of care
▪ Examine carer’s experience of the different levels of care.
Overview

- Longitudinal, cohort study recruiting every young person aged 13 – 24 years diagnosed with cancer from July 2012 to December 2013
- Target sample = 2,012 young people
- Study opened to recruitment 17th October 2012
- Data collection through a bespoke survey
Eligibility criteria

- **Inclusion criteria:**
  - Diagnosed between July 2012 and December 2014
  - Aged 13 – 24 at the time of diagnosis
  - Resident in England at the time of diagnosis
  - Recruited within 4 months of diagnosis

- **Exclusion criteria**
  - Not capable of completing the survey
  - Recurrence of previous cancer
  - Death is imminent
  - Receiving a custodial sentence at time of treatment
  - Does not consent or assent
BRIGHTLIGHT Survey

Step 1 • Literature review

Step 2 • Workshop with young people

Step 3 • Conceptual framework

Step 4 • Identify validated questionnaires

Step 5 • Develop descriptive questions

Step 6 • Validation
Development and validation of the BRIGHTLIGHT Survey, a patient-reported experience measure for young people with cancer

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Challenges

- Identify all young people:
  - National cancer registry (Cancer Waits dataset)
- Recruit all young people:
  - National Cancer Research Network (circa 2012)
- Data collect (face-2-face interview) with young people in their home:
  - Ipsos MORI
Challenges continued

Regulatory approval

- Research Ethics approval
  - Annual reports
- R&D approval (n=109)
- CAG approval
  - Annual reports
- NHS Digital approval
  - Annual reports
  - Audits [expense]
- PHE Approval

Recruitment

[Graph showing recruitment progress over time]
BRIGHTLIGHT Data Bank

**Young people**
- Self-reported longitudinal survey data
- Record of additional expenses as a result of cancer
- Clinical data about cancer and processes of care
- In-depth interviews about care experience

**Carers**
- Unmet information and emotional needs

**Healthcare professionals**
- Interviews with professionals delivering care
- Interviews with researchers responsible for recruiting young people
- Delphi survey data on professional competence

**The NHS**
- Observation of the delivery of care in 4 networks
- Hospital Episode Statistics on healthcare usage
Implications for practice

Based on current evidence:

• Product for workforce planning/training
• Evidence to expand on the 5As recruitment model (Fern et al. Lancet Oncol 2014; 15: e341–50)
• Evidence based support for carers

Based on future evidence

• Direction for commissioners on specialist care
• Evidence for informed choice
• Transferability to young people with other long-term conditions
Implications for research

Companion studies

• When Cure is Not Likely (Marie Curie)

Current

• S-PROM (SUK/BCRT)
• RELEASE_ME (NIHR HS&DR)
• Extended cost analysis (NIHR PhD fellowship)
• REFER_ME (tbc – NIHR PGfAR)
• RECRUIT_ME (tbc – NIHR PDG)

Future

• James Lind Alliance
• Long-term value of specialist care
• Interventions to improve care
Implications for policy

- NICE Surveillance Team, July 2014
  ‘The improving outcomes for children and young people with cancer service guidance should not be considered for an update at this time. The guideline should remain on the active list and be considered in light of results emerging from existing trials such as the BRIGHTLIGHT study.’

  #43: Establish clear criteria for designation and de-designation of treatment centres for TYA patients
  #45: ...consider ways in which access to clinical trials for teenagers and young adults with cancer could be significantly increased
  - NHS England/NIHR working party
Summary

- Complex evaluation of healthcare need complex study designs
- Involving young people in study design and study management
  - Acceptable to participants
  - Results that are meaningful to young people
  - *Evidence into practice quicker?*
Cont.

- Demonstrate the value of specialist care
- Identify the more important parts of specialist care and how they may be improved
- Help improve training for TYA staff
- Understand the cost of TYA cancer to young people and the NHS
- Inform the planning of future services
Dissemination

**BRIGHTLIGHT-TYAC conference**

6th & 7th July 2017

**National Cancer Research Institute Annual conference**

5-8th November 2017

**2nd Global AYA Cancer Congress**

5-7th December 2017
Special thanks to...

1,114 young people consented to the Cohort
25 young people acting as co-researchers
Research staff in 109 NHS Trusts supporting BL
Healthcare professionals in TYA cancer care
Teenage Cancer Trust Lead Nurses
NCRI TYA CSG HSR subgroup
BRIGHTLIGHT Executive Team

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