



Participatory research: using board games to guide secondary analysis of big data

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Introduction

- Teenagers and young adults with cancer have poorer outcomes than children and older adults
 - *Improving Outcome Guidance for Children and Young People*
- Reconfigured services
 - 15-18 years refer to TYA Principal Treatment Centre
 - 19-24 years 'unhindered access' to specialist care



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





What is BRIGHTLIGHT?

- National evaluation of cancer services for TYA in England
- Programme of work comprising 3 workstreams
 - Workstream 1: environment of care and competence of professionals delivering care
 - Workstream 2: young people and carers experience of care; impact of care on outcome
 - Workstream 3: cost effectiveness and benefit



What makes BRIGHTLIGHT unusual?

- Young people involvement and engagement from the onset
 - NCRI TYA CSG CCG
- Developed with young people, for young people to make results meaningful to young people
- Young Advisory Panel (YAP)



CCG & protocol development

Taylor et al. 2011, 2013

Fern et al. 2013



Identify research area

Design the research study

Publish research results



James Ashton Katie Brooman Carol Starkey



Hannah Millington Tom Grew

Analyse research results

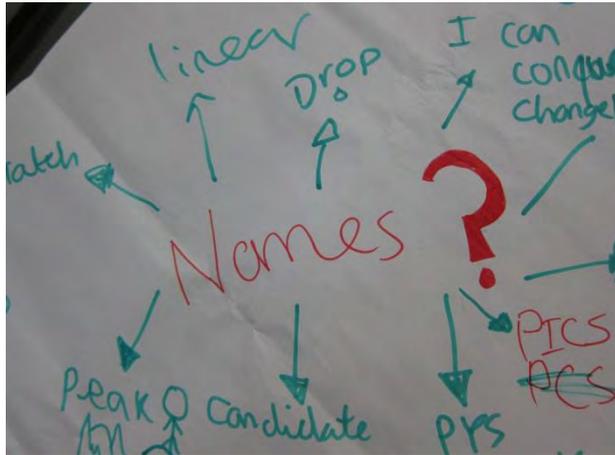


Carry out the research

- Life changing impact of diagnosis
- Provision of information
- Place of care
- Role of health professionals
- Coping:
- Peer support
- Psychological support
- Life after cancer



Branding BRIGHTLIGHT

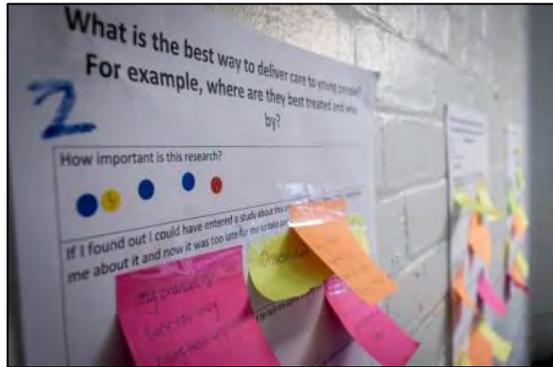


Taylor et al. 2015



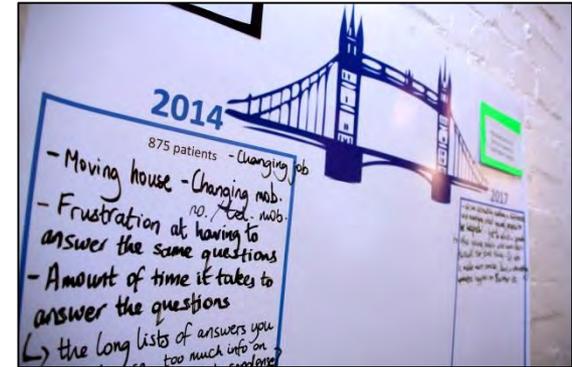
YAP & study management

Recruitment



Taylor et al. 2016, 2017

Retention





YAP & dissemination

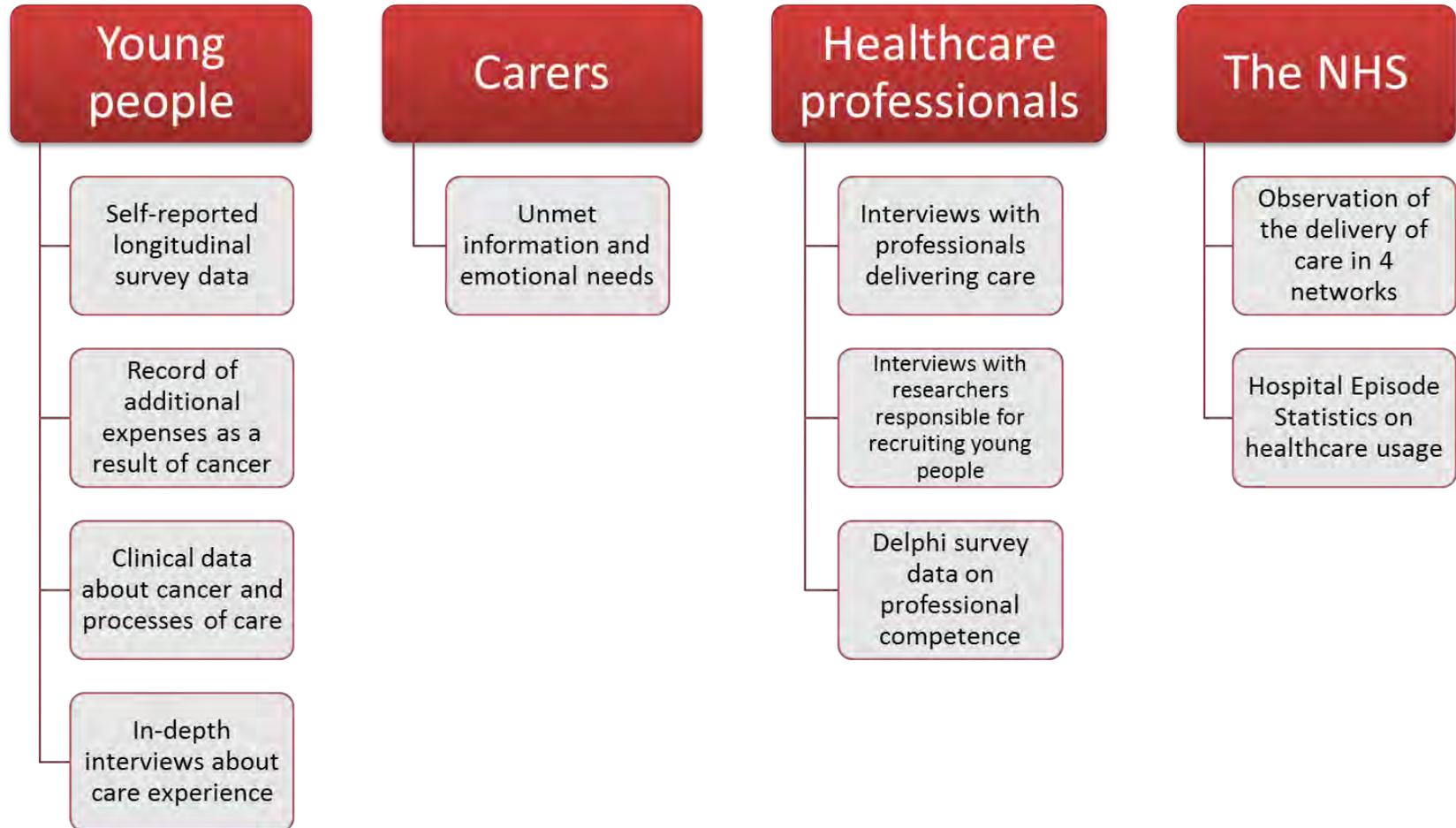


There is a Light: BRIGHTLIGHT





BRIGHTLIGHT Data Bank





Aim

Identify what young people thought was important to investigate further in secondary data analysis



Participants





Methods

- Two teams: BRIGHT Team & LIGHT Team
- Two members from each team were on the mat at any one time; the other members spun the wheel
- Teams made alternate spins until all 4 players had made a move
- The links between each teams moves were recorded
- Each team then discussed how they thought the two domains were linked

Right Hand



How I feel

-  How much my cancer affects my life
-  How I feel
-  Who supports me at home
-  Who supports me with my treatment

Left Foot



My body

-  How the cancer has affected my body
-  What traditional treatment I have had
-  What alternative therapies I have had
-  What treatment, medicines, appointments I have missed





Results

- Thirty-six links were discussed
 - 21 hypotheses or research questions
- Circulated to the YAP to individually vote for their top 3
- Is the impact of cancer affected by how much support you get from people in similar situations?
- How I feel about my body after a cancer diagnosis affects my ability to form new relationships?
- =Am I less likely to be involved in decision-making if I am younger?
- =How much information I received from my treatment team affects how I feel about myself when treatment finishes?



Conclusions

- Young people can actively be involved in generating ideas for secondary data analysis if they are given the appropriate tool
 - Not necessarily those viewed as important by healthcare professionals
- YAPs opinion plus James Lind Alliance priority setting exercise is currently underway
 - Secondary data analysis will also be informed by the results of this.



Value of involving young people

“The events get better and better each year. You guys actually take the suggestions on board and improve accordingly :)”

Post workshop feedback



Thank you for your time

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