

TOP 10 RESEARCH PRIORITIES FOR TEENAGE AND YOUNG ADULT CANCER IN THE UNITED KINGDOM: PARTNERSHIP BETWEEN YOUNG PEOPLE, CARERS AND PROFESSIONALS



@TYAPSP



FAITH GIBSON
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ON BEHALF OF THE PRIORITY SETTING PARTNERSHIP

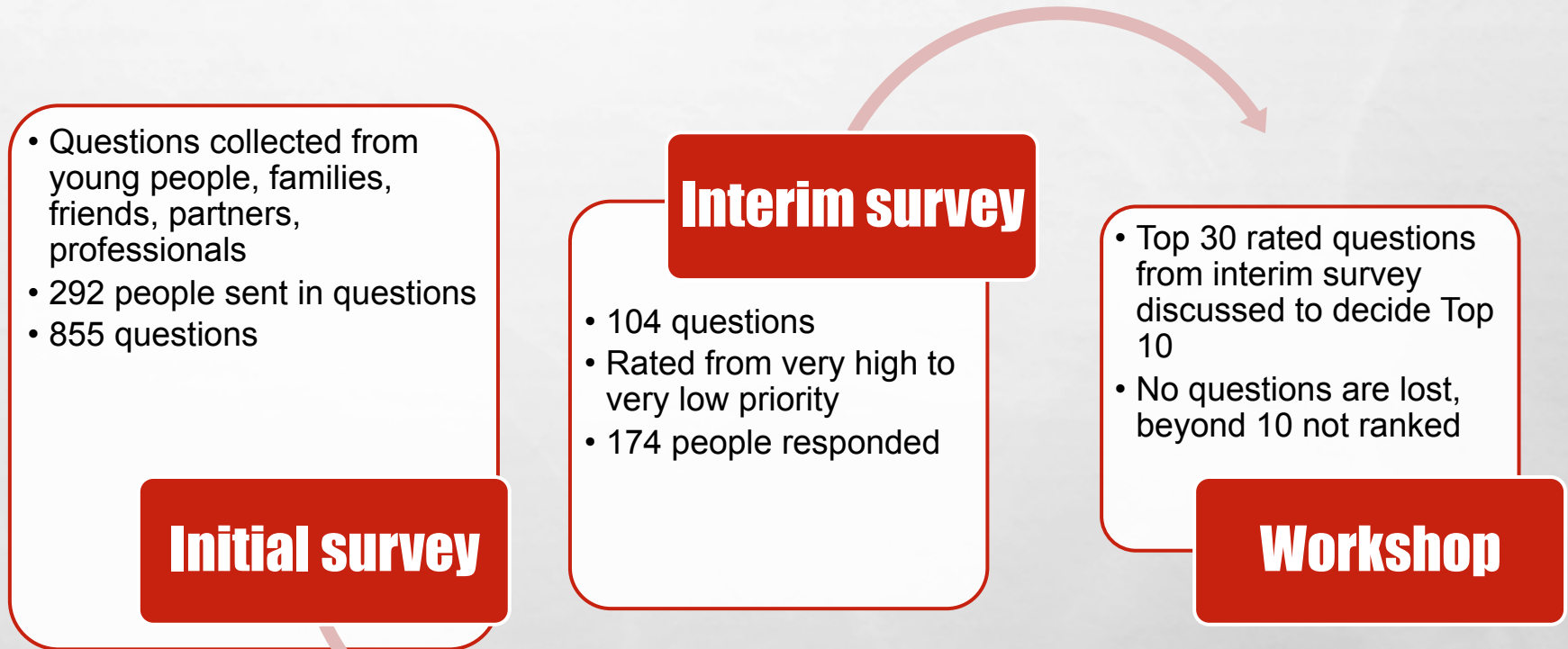
• **NOTHING TO DISCLOSE**

WHY DID WE DO THIS PROJECT?

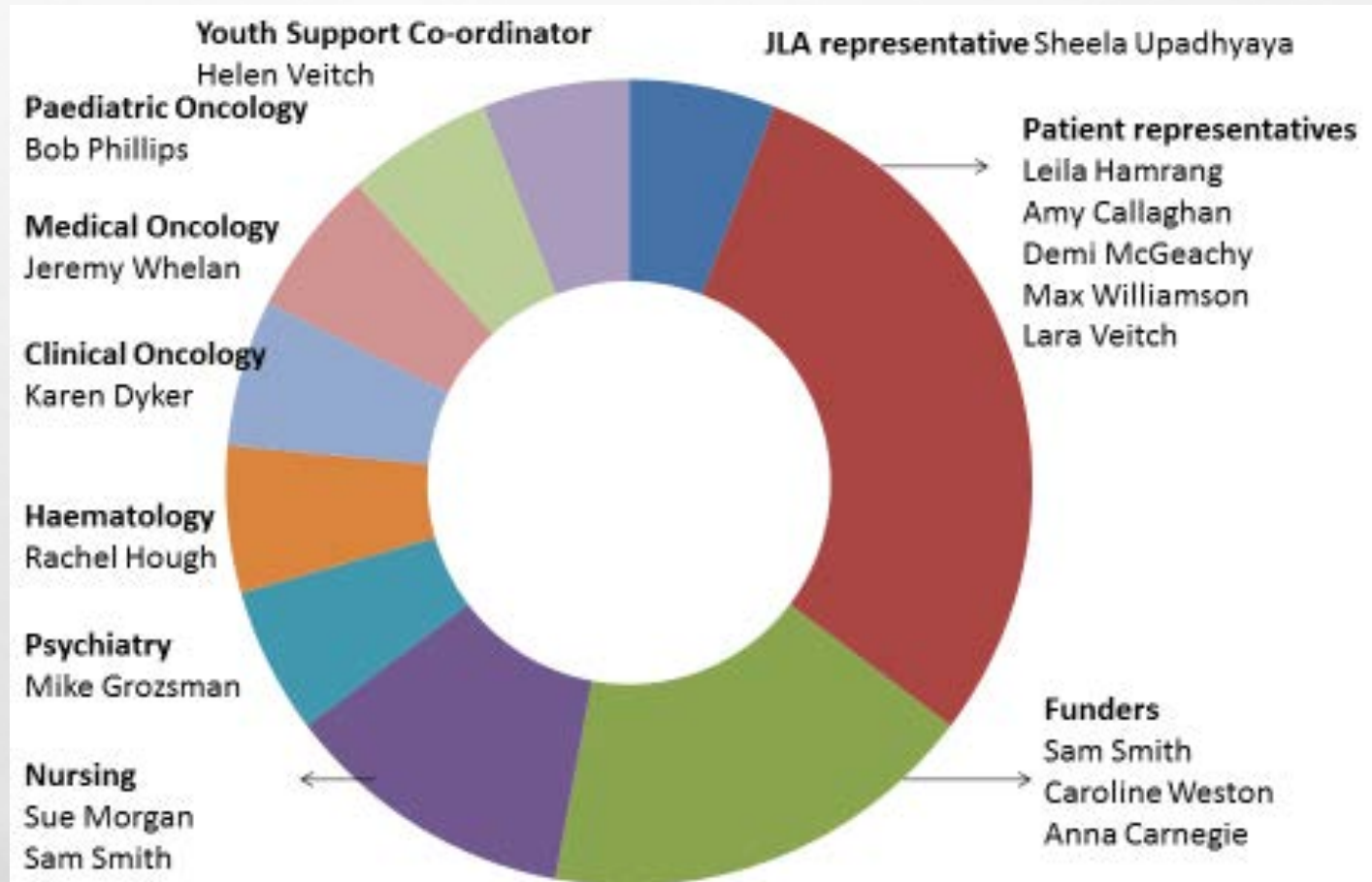
- To find out what research questions are important to young people who have experienced cancer, their relatives/carers and professionals.
- To align research priorities between young people, carers and professionals.
- To raise awareness of research needs/gaps within this field of cancer care.
- To inform funders of priority research areas for young people.

PROJECT OVERVIEW

Aim: 'To identify gaps and unanswered questions in research, the answers to which may reduce the individual and societal burden of young peoples' cancer.'



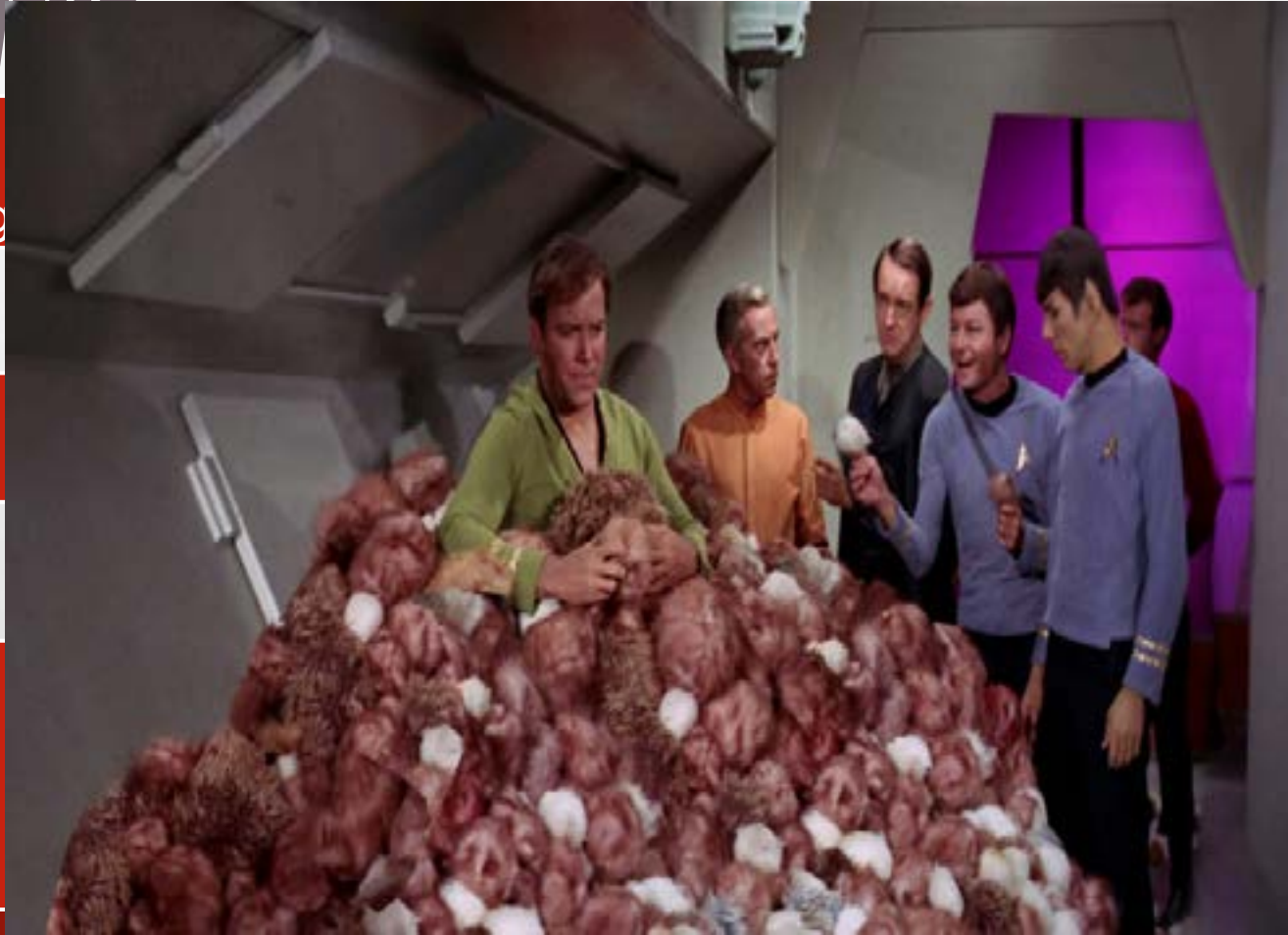
MULTI DISCIPLINARY STEERING GROUP



HOW DID WE REDUCE THE 855 QUESTIONS FROM THE INITIAL SURVEY

(e.g.

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= 185 unanswered questions

INTERIM SURVEY PREPARATION



- 185 questions – too many to ask people to vote on.
- Steering group decided to include all the questions asked by more than one person (64 questions).
- Steering group voted on the priority of remaining questions – top 40 added to survey.
- = 104 questions for interim survey.

INTERIM SURVEY



- Rate each question - very high to very low priority.
- 174 people responded:
 - 58 young people (33%)
 - 45 parents/relatives/friends/partners (26%)
 - 71 professionals (41%).
- We worked out the rankings of each question for each of the 3 groups then averaged these rankings to come up with top 30 questions for the workshop.



WORKSHOP

- One day workshop attended by:
 - 7 young people
 - 4 parents
 - 14 professionals.
- 3 JLA advisors, NO researchers, 6 silent observers
- Group work to discuss, debate and order questions.
- Ensure everyone's voice was heard.



TOP 10 QUESTIONS

1. What psychological support package improves psychological well-being, social functioning and mental health during and after treatment?
2. What interventions, including self-care, can reduce or reverse adverse short and long-term effects of cancer treatment?
3. What are the best strategies to improve access to clinical trials?
4. What GP or young person strategies, such as awareness campaigns and education, improve early diagnosis for young people with suspected cancer?
5. What are the best ways of supporting a young person who has incurable cancer?
6. What are the most effective strategies to ensure that young people who are treated outside of a young person's Principal Treatment Centre receive appropriate practical and emotional support?
7. What interventions are most effective in supporting young people when returning to education or work?
8. How can parents/carers/siblings/partners be best supported following the death of a young person with cancer?
9. What is the best method of follow-up and timing which causes the least psychological harm, while ensuring relapse/complications are detected early?
10. What targeted treatments are effective and have fewer short and long-term side-effects?

Thank you for listening, I leave you with some final words from Amy.....

A YOUNG PERSON ON OUR STEERING GROUP WHO SAID.....

'I think it speaks volumes we have psychological support as our top research priority. Physical health is so important but the impact mental health issues can have is monumental so I'm delighted we agreed this as our utmost priority.'

'Having patient input in this process is fundamental - we have a different perspective of what works and what doesn't and where there's room for research and improvements to be made.'

'Having a priority that names ways to improve GPs knowledge of young people's cancer is essential in empowering them to feel able to attend their GPs if they are noticing changes in their body.'

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