


Professor Faith Gibson



To find out **what research questions are important** to **young people** who have experienced cancer, their **families/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.



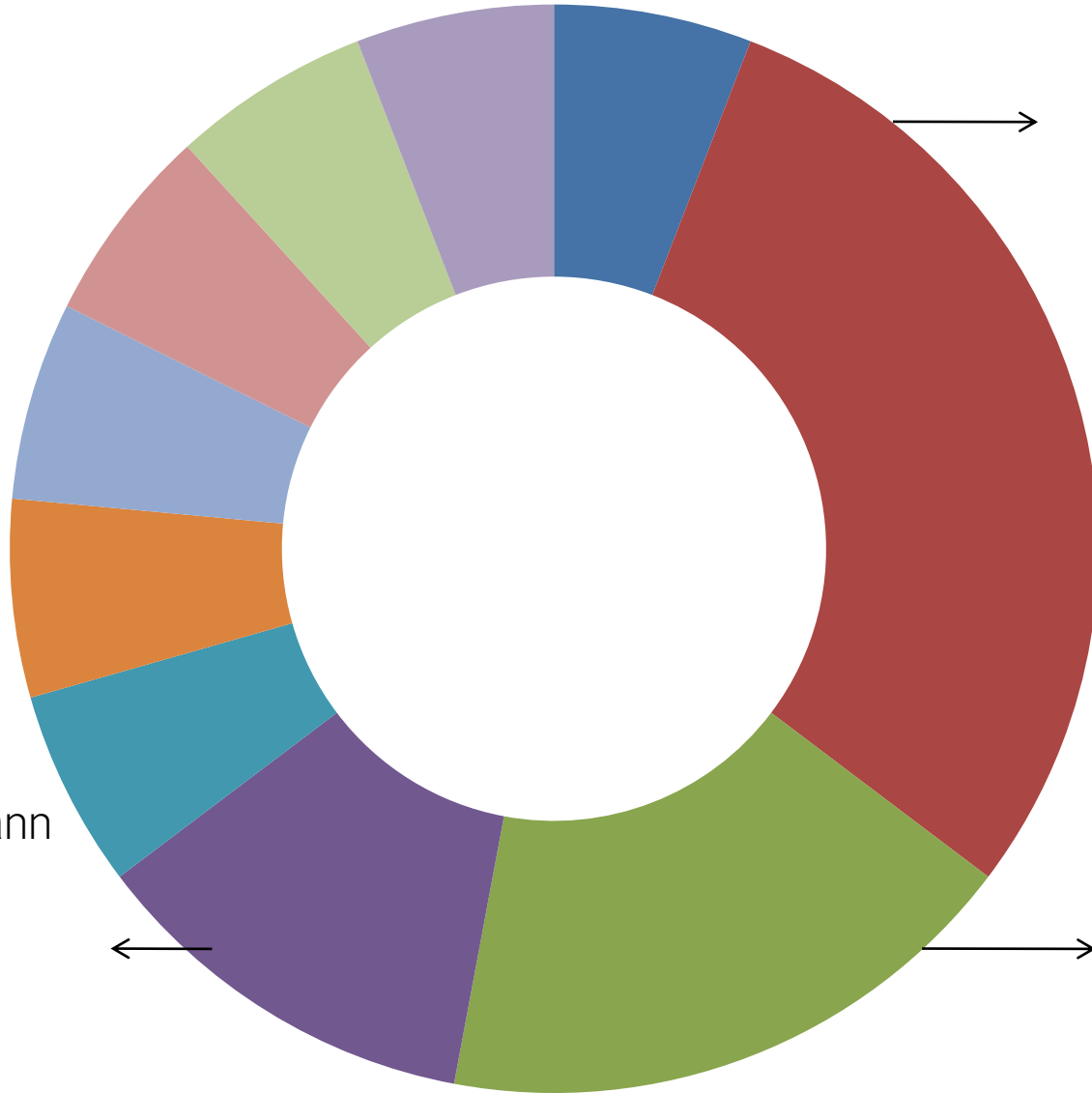






“To identify gaps and unanswered questions in research, the answers to which may reduce the individual and societal burden of young peoples’ cancers.”





Karen Dyker

Rachel Hough

Mike Grozsmann

Sue Morgan
Sam Smith



326 'out of scope questions' removed
(e.g. about availability of services, personal questions, ambiguous questions)



Duplicates combined, questions worded into 'researchable questions'



Evidence checking:

- Has the question already been answered?
- Is there a study currently looking at this question?

Found 7 questions already answered, 16 ongoing studies

= 185 unanswered
questions

1. It did not fit the scope of reducing the individual and societal burden of young peoples' cancer or could not be answered by research.

'Can a cancer sufferer become an organ donor?'

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.



7 young people.

4 parents.

14 professionals.

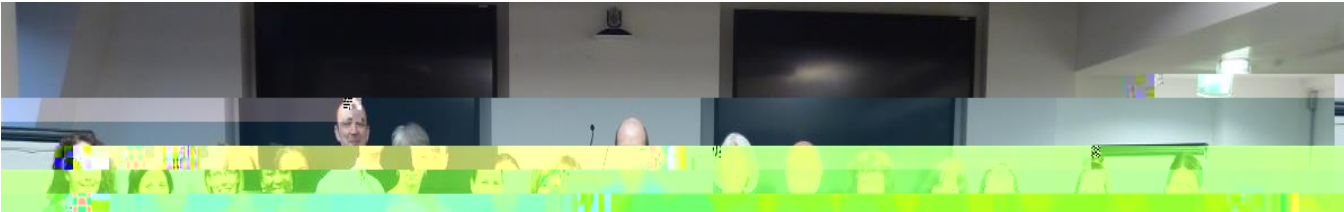
3 James Lind Alliance Advisors.

Homework, then group work to discuss, debate and order questions.

Ensure everyone's voice was heard.

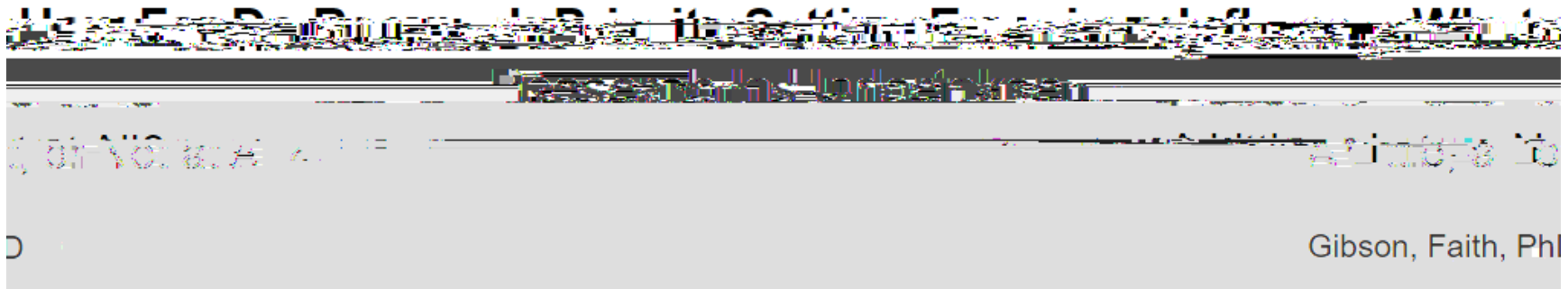


1. What psychological support package improves psychological well-being, social functioning and mental health during and after treatment?
2. What interventions, including _____, can reduce or reverse adverse short and long-term effects of cancer treatment?
3. What are the best strategies to improve access 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 _____ 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 and physical harm, while ensuring relapse/complications are detected early?
10. What targeted treatments are effective and have fewer short and long-term side-effects?



JOB DONE.....NO.....







ONS

Office for National Statistics

Research priorities for people with dementia: 2019
The 2019 research priorities survey for people with dementia was held on 15 September 2019. It was the first time that people with dementia themselves were consulted on their research priorities. The survey was held on the day that the Alzheimer's Society's 2019 Dementia Research Day was held. This was a significant moment for the dementia research community as it marked the day when patient-led research was first implemented in the UK. The survey was held in partnership with the Alzheimer's Society and the Dementia Research Service. The survey was held in partnership with the Alzheimer's Society and the Dementia Research Service. The survey was held in partnership with the Alzheimer's Society and the Dementia Research Service.

Research priorities for people with dementia: 2019

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Research



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