Research Question

1. What motivates a participant's decision to complete a clinical trial?
2. How can trials make better use of routine clinical care and/or existing data collection to improve retention?
3. How can trials be designed to minimise burden on staff and participants and how does this affect retention?
4. What are the best ways to encourage trial participants to complete the tasks (e.g. attend follow-up visits, complete questionnaires) required by the trial?
5. How does involvement of patients/the public in planning and running trials improve retention?
6. How could technology be best used in trial follow-up processes?
7. What are the most effective ways of collecting information from participants during a trial to improve retention?
8. How does a participant's ongoing experience of the trial affect retention?
9. What information should trial teams communicate to potential trial participants to improve trial retention?
10. How should people who run trials plan for retention during their funding application and creation of the trial (protocol development)?

Top 10
Priorities for research into trial retention

"Would a donation of a pre-specified amount of money to a charity of the participant's choice on completion of the clinical trial improve retention?"

(Patient or public member)

"How often are clinical research teams consulted regarding the man power/ costings required to ensure appropriate staffing to ensure continued data follow up?"

(Frontline staff)

"What clinicians think is important to measure probably differs from what patients regard as important - there needs to be a mechanism for discussion and agreement on combining these different views"

(Patient or public member)

Previous Priority Project Overlap

	PRioRiTy I Ranking	PRioRiTy II Ranking	Research Question
A	6		What are the key motivators influencing members of the public's decisions to take part in a randomised trial?
		1	What motivates a participant's decision to complete a clinical trial?
B	1		How can randomised trials become part of routine care and best utilise current clinical care pathways?
		2	How can trials make better use of routine clinical care and/or existing data collection to improve retention?
C	3		Does patient/public involvement in planning a randomised trial improve recruitment?
		5	How does involvement of patients/the public in planning and running trials improve retention?
D	10		What are the advantages and disadvantages to using technology during the recruitment process?
		6	How could technology be best used in trial follow-up processes?
E	2		What information should trialists communicate to members of the public who are being invited to take part in a randomised trial in order to improve recruitment to the trial?
		9	What information should trial teams communicate to potential trial participants to improve trial retention?

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In association with:

James Lind Alliance Priority Setting Partnerships | PRioRiTy II | The Queen's Anniversary Prizes for Higher and Further Education 2017

Health Services Research Unit | Chief Scientist Office | MRC Centre for Medical Mycology | Health Research Board TMRN Trials Methodology Research Network 2017 | Trial Forge

MS: ITS WL0419

Trial Forge | MRC Centre for Medical Mycology | Health Services Research Unit | Health Research Board TMRN Trials Methodology Research Network | Chief Scientist Office

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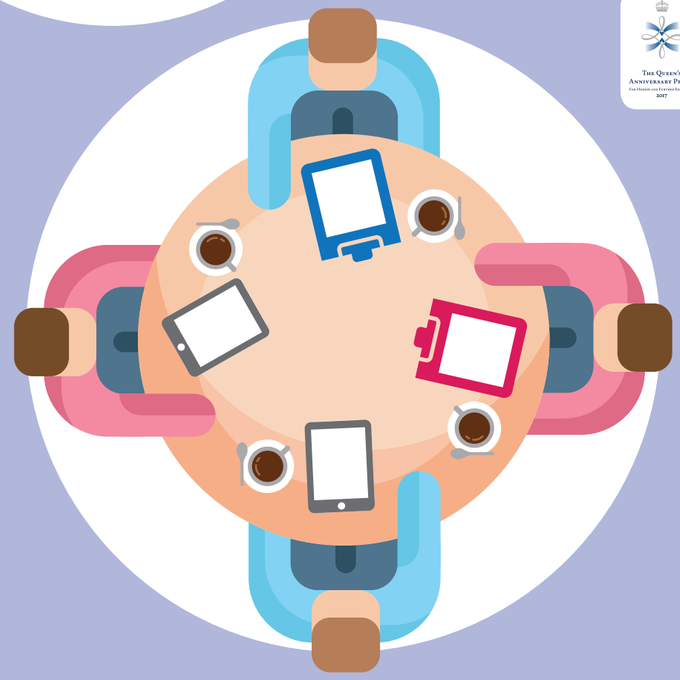
The Queen's Anniversary Prizes for Higher and Further Education 2017



PRioRiTy II

In association with: James Lind Alliance Priority Setting Partnerships

What are the most important questions for research into trial retention?

Priority Setting Partnership

Our Work

We worked together with who we believe to be the key stakeholder groups: patients and members of the public involved in trials, frontline staff invested in trial retention, investigators, and trial methodologists, to find the top 10 research priorities about improving retention to randomised controlled trials. By working together, we have been able to find out what is the most important area for future research as decided by people who experience trials in their daily lives. Whether this was personal or professional, everyone's opinion was given equal attention and weighting in the decision-making, so that together we can shape future research.

Clinical trials are an essential part of improving our healthcare, yet it's common for people who take part in them to stop taking part before it's finished. Around 50% of trials in the UK fail to reach their recruitment target, and have a loss to follow-up rate of over 11%. Without people staying for the duration of a trial, we can lose the ability to say with confidence that what we've found out is accurate and can help people in the future.

At present, to fix this a lot of trials are being designed with many more people than they need to account for the amount of people who might decide to no longer take part. But the average cost of a clinical trial in the UK is around £8,500 per participant. This adds to the cost of a trial, and takes away resources which could otherwise be used elsewhere to provide better care for patients.

With this in mind, it's not surprising that the UK clinical trial community believes improving retention to trials to be a top priority for researchers. To do that, we worked with the James Lind Alliance to create the PRioRiTy II project, which tried to figure out what questions we should be asking, and what is important to people who either help run or take part within clinical trials.

PROCESS OVERVIEW:

1

24 PERSON STEERING GROUP FORMED

The steering group were vital, contributing towards all stages of the project and helping to guide the prioritisation process

4 MEMBERS OF THE PUBLIC

16 SPECIALISTS

2 MEMBERS OF THE JAMES LIND ALLIANCE

2 RESEARCHERS

2

INITIAL SURVEY QUESTIONS

Six open-ended questions asking for any comments, thoughts or questions people had about retention in randomised trials was made available online or by post for four weeks to any members of the key stakeholder groups.

456 people from across UK and Ireland responded

3

ANALYSING THE DATA

Responses were analysed by coding and sorting into thematic groups to create a list of unanswered questions.

4

INTERIM STAGE

A second survey asked people to choose their top 10 of the identified unanswered questions they felt were important and needed to be answered.

21 questions Top 10

5

FINAL CONSENSUS MEETING

We held a face-to-face consensus meeting alongside:

30 KEY STAKEHOLDERS

12 PATIENTS AND MEMBERS OF THE PUBLIC

9 CLINICIANS

9 RESEARCHERS AND OTHER STAFF

3 MEMBERS OF THE JAMES LIND ALLIANCE

10 MEMBERS OF THE STEERING GROUP

for the prioritising and ranking of the identified questions.