Retention-related perspectives of senior trial stakeholders: A qualitative exploration

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Background

Modern data suggest that well over 20% of trial participants terminate trials early, and as measurement bias is expected if the attrition rates exceed 20% optimising patient retention is critical.

Retention is any set of behaviours trial participants need to undergo over the duration of the trial (e.g., clinic visits, daily diaries, etc.).

While emerging initiatives like STEER and PRioRiTy II have begun to address this, research on retention remains limited.

Objective

To address this gap via qualitative exploration of retention-related perspectives of senior stakeholders, purposively sampled within clinical research organisations – by examining what role, if any, retention-related attention plays.

Methods

Clinical stakeholders were purposively sampled from within clinical research organisations.

Eight semi-structured interviews were conducted, lasting ~30 minutes. Interviews were conducted online due to the Covid-19 pandemic.

The interview guide consisted of questions focusing on drivers of retention-related attention, whether these are individual or situational, and perspectives for improving retention.

Findings

Three key findings about current and proposed retention-relation solutions emerged in this study:

1. Self-serving bias
2. Lack of training support for trial staff
3. Streamline the trial for patients

Key findings	Illustrative participant quotes
Participants demonstrated a noticeable self-serving bias, wherein accepted that poor retention in organisations is common, but they rejected that the trials they oversee themselves suffer attrition. Participants also attributed the problem of poor retention, more broadly, to an over-focus on recruitment, such as monetary incentives for trial staff for recruitment optimisation but not for retention	*"So I think it all depends on the patient cohort… We work with Cystic Fibrosis patients, they are very research active and want to be involved in the trial, so patient retention tends not to be a problem for us".* *"Sometimes there are posters and stuff, but that's more of a recruitment than a retention strategy, really".*
Participants perceive the relationships between trial site staff and patients as critical for optimal retention. However, when investigated more closely, participants revealed that specific engagement training is rarely, if ever, offered to site staff.	*"There is no particular training, because as I said, it's a fine line that we walk… You can't coerce people to stay on so there isn't. It's kind of using your own common sense, really".*
Participants re-affirmed the well-established notion that retention can be improved when the trial process is streamlined for patients as best as possible.	*"If anything crops up, they can pick up the phone and there's someone at the end of it – and if they can't sort out the problem for them, we'll find somebody who can. The feedback we get is that they're reassured, and that in itself is very helpful in keeping them on [the trial]".* *"What we do know actually works is making their experience of the trial as easy as possible".*

Objective

Early data suggest trial managers and site staff can often be untrained or unsupported by management in retention-specific strategies, or can display unconscious bias towards their efficacy in optimising retention. This highlights the critical need for a multi-stakeholder, versus a patient-only, approach and buy-in from senior trial stakeholders.

While this study was a useful first step, comprehensive work building upon this should now be undertaken..

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