Involving parents of children treated for cancer in Sweden as public contributors to inform the design and conduct of an evaluation of an internet-administered self-help for parents of children treated for cancer: a protocol

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Introduction

- Public contribution in research can facilitate the design and conduct of meaningful research.
- The evidence base concerning the acceptability, feasibility, and impact of public contribution in research is limited.

Context

- We developed EJDeR, an internet-administered, guided, low intensity cognitive behavior therapy based self-help intervention for parents of children treated for cancer.
- The acceptability and feasibility of EJDeR was examined in the single-arm feasibility trial ENGAGE, indicating study procedures and EJDeR are acceptable and feasible.
- Next, we will examine the efficacy and cost-effectiveness of EJDeR plus treatment as usual (TAU) vs TAU for symptoms of depression and/or Generalized Anxiety Disorder in a superiority randomized controlled trial with an internal pilot phase (the CHANGE trial).

Aims

- Involve parents of children treated for cancer in the managing and undertaking, analysis and interpretation, and dissemination phases of the CHANGE trial.
- Examine the acceptability, feasibility, and perceived impact of Parent Advisory Board (PAB) contribution to the CHANGE trial from the perspective of the PAB members and public contribution coordinators (PCCs).

Design

- A mixed-method evaluation of public contribution activities embedded into the CHANGE trial.

Method

Setting:
- Online workshops and bi-monthly steering meetings where PAB members will contribute to the: managing and undertaking, analysis and interpretation, and dissemination phases of the CHANGE trial (see Figure 1).

PAB members:
- 6-8 parents of children treated for cancer.

Public contribution coordinators:
- Arrange and facilitate PAB workshops/meetings.
- Liaise with the research team.
- Support and maintain contact with PAB members.

Data collection:
- Discussions noted in impact log during and after each workshop/meeting.
- Semi-structured interviews with the PAB and PCCs, conducted six months after the PAB has been formed and at the end of the CHANGE trial.

Data analysis:
- Impact logs will be read, with impacts extracted and summarized and the total percentage of ideas and suggestions implemented for each category calculated and reported, in accordance with the GRIPP2 checklist.
- Interviews will be analyzed using manifest content analysis and reported in accordance with the SRQR checklist.

Conclusion

- We expect that adding public contribution to the CHANGE trial will enhance the relevance and quality of the research.
- We hope that adding public contribution to the CHANGE trial will provide other researchers with guidance on how to embed public contribution in clinical research.
- We hope to add to the growing evidence base concerning the value and impact of public contribution in research.

Figure 1. Preliminary PAB workshop and bi-monthly trial steering meeting topics to inform the managing and undertaking, analysis and interpretation, and dissemination phases of the CHANGE trial.

References

3. Williams J, Pawson D, Sharpe A, Richmond C, et al. Structured interviews with the PAB and PCCs, conducted six months after the PAB has been formed and at the end of the CHANGE trial.
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