

# **SWAT 55: Prioritising key motivators and challenges influencing informal caregivers to participate in randomised trials**

## **Objective of this SWAT**

To determine the key motivators and challenges that influence informal caregivers who are deciding whether to participate in a randomised trial, and to prioritise these to inform future trial design and conduct.

Study area: Recruitment, Retention

Sample type: Carer/Parent, Caregivers as members of the general public

Estimated funding level needed: Medium

## **Background**

In 2016, the Health Research Board-Trials Methodology Research Network (HRB-TMRN), in collaboration with the James Lind Alliance, participated in a priority setting partnership (PSP), to identify and prioritise unanswered questions around trial recruitment (the PRioRiTty study). The PSP culminated in a face-to-face meeting, attended by key stakeholders (members of the public, recruiting clinicians and researchers), where a top-10 list of unanswered questions on trial recruitment was agreed and ranked in order of importance. Ranked highly was a question on key motivators influencing members of the public when they are deciding whether or not to participate in a randomised trial. Informal (unpaid) caregivers represent a discrete group within the general public who are geographically dispersed and who might face specific challenges when deciding to participate in a trial. Presently, there is little evidence on their key motivators or challenges [1] or on optimum methods for identifying these. The host trial for this SWAT will test a mindfulness-based cognitive therapy intervention, and presents an excellent opportunity to embed methodology research to ascertain the key motivators and challenges that influence informal caregivers when they are deciding about participating in trials. The findings from this SWAT will help advance the design and conduct of future trials, including influences on attrition bias, in this population and others that are similar.

## **Interventions and comparators**

Intervention 1: One-to-one interviews with a sub-sample of participants in the host trial to ascertain their key motivators and their experiences of key challenges of participating in the trial. The collated lists from these interviews will be used to develop a survey instrument to facilitate a prioritisation exercise that will rank the key motivators and challenges for informal caregivers in order of importance. The survey will be administered online, nationally, with the assistance of Family Carers Ireland, via their email list manager, and snowball sampling.

Index Type: Method of Recruitment

## **Method for allocating to intervention or comparator**

## **Outcome measures**

Primary: Prioritised list of key motivators 2. Prioritised list of key challenges.

Secondary: Collated list (from interviews) of key motivators 2. Collated list (from interviews) of key challenges.

## **Analysis plans**

Interviews: Thematic analysis will be used to analyse the interview data. This will involve listening to recordings, reading and rereading the transcripts, coding the data, categorising the codes and developing themes. A computer software package (e.g. NVivo) will be used to assist with data management and analysis. Collated lists on i) motivators and ii) challenges will be developed from the themes. Stepwise replication will be used to enhance study rigour (dependability), whereby two researchers will swap a number of transcripts, allowing for independent interpretations of the data, which can be compared and contrasted subsequently.[2] An 'audit trail' will also be maintained to ensure confirmability.

Survey: Quantitative analytical techniques will be used to aggregate individual's ranking of motivators and challenges. Each participant will be asked to rank each list separately from 1-n

(where n is the total number of motivators and challenges in each list), in order of importance to them. Participants' ranking of each motivator / challenge will be summed and, subsequently, organised in descending order from most important to least important, based on a 'least scores' principle (i.e. the motivator that receives the least summed score is deemed to be 'most important', from the perspective of participants). Priority lists of informal carers' motivators and challenges for participating in randomised trials will then be determined.

### **Possible problems in implementing this SWAT**

Collating the original lists of motivators and challenges, for use in the online national survey, is dependent on sufficient interest in being interviewed from the participants in the host trial.

### **References**

1. Gysels MH, Evans C, Higginson IJ. Patient, caregiver, health professional and researcher views and experiences of participating in research at the end of life: a critical interpretive synthesis of the literature. *BMC Medical Research Methodology* 2012, 12:123.
2. Cronin P. Coughlan M. Smith V. *Understanding Nursing and Healthcare Research*. 2015, Sage: London, New York.

### **Publications or presentations of this SWAT design**

#### **Examples of the implementation of this SWAT**

Smith V, Corry M, Devane D, Treweek S, Hunter A, Grylka-Baeschlin S, Hannon K. Prioritising key motivators and challenges influencing informal carers' decisions for participating in randomised trials: An embedded Study Within A before and after Trial (SWAT 55) [version 1; peer review: awaiting peer review] *HRB Open Research* 2020;3:71 [doi: 10.12688/hrbopenres.13125]

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