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HINTS & KINKS

Why do people participate in health-related studies?

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Introduction

Researchers experience decreasing participation in population-based studies (Sheehan 2001; Singer and Ye 2013). Previous research focused on characteristics of non-responders and effects of non-response on sample composition (Porst and von Briel 1995; Singer 2011; Singer and Ye 2013), but less is known about reasons for actual participation.

There are different theoretical approaches to explain the decision to participate. According to Esser (1986), participation is a social act. The decision is based on cost–benefit calculation (Esser 1986; Roose et al. 2007; Singer 2011). Porst and von Briel (1995) grouped reasons to participate in three categories; (1) altruistic, (2) personal, and (3) survey-related reasons. They interviewed 140 adults via telephone: respondents selected altruistic and survey-related reasons with equal frequency; personal reasons were mentioned less frequently. This was confirmed by other surveys (Singer 2011; Singer and Ye 2013). Loosveldt and Storms (2008) identified five dimensions for survey participation: survey enjoyment, survey value, survey costs, survey reliability and survey privacy. "Collaboration with science" (Costas et al. 2012), "making a contribution to society" as well as "receiving information about my health" (Akmatov et al. 2017) have already been reported as important reasons for participation in vaccination studies. We aimed to investigate (1) why people participate in health-related studies in general and (2) if reasons to participate are associated with characteristics of participants.

Methods

Study sample

We implemented a questionnaire about reasons for participation within a population-based online study, which is described elsewhere (Akmatov et al. 2015). In brief, 1334 inhabitants of Hanover, Lower Saxony, Germany (drawn by proportional stratified random sampling from the population registry; aged 20–69 years) were invited via land mail to participate in an online study on acute infections that would cover a period of three months (June to August 2013). A weekly e-mail was sent to participants with a link to an online questionnaire.

Questionnaire

In the last week of the study, we added questions (Online Resource 1) regarding socio-demographic factors, health status, and 16 items about reasons to participate in a health-

Hannah Bongartz and Nicole Rübsamen contributed equally to this work.

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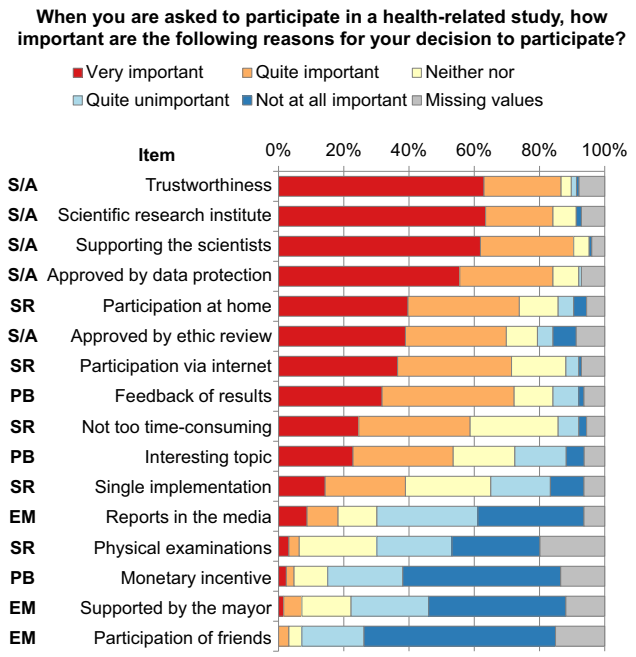

Fig. 1 Reasons to participate in a health-related study, sorted by importance. *EM* external motivation, *PB* personal benefit, *S/A* seriousness of the study and altruism, *SR* study-related reasons

related study (not just the reasons to participate in this specific online study). The reasons included (1) seriousness of the study and altruism (five items), (2) study-related reasons (five items), (3) external motivation (three items), and (4) personal benefit (three items) (Fig. 1). The participants rated the importance on a 5-point Likert scale from "not at all important" to "very important".

Statistical analysis

Differences between groups were tested with the χ^2-test (for categorical variables) and the Mann–Whitney U test (for continuous variables). We assumed that the variables measured on the 5-point Likert scale were of interval type. We used two-step cluster analysis (with log-likelihood as distance measure) to identify groups of participants with similar attitudes towards participation: Pre-clusters were defined by a BIRCH algorithm (Zhang et al. 1996). They were joined to clusters using an agglomerative hierarchical algorithm (SPSS 2001). We considered $p \leq 0.05$ as significant. All analyses were performed in IBM SPSS Statistics, version 20 (IBM Corporation, Armonk, NY, USA).

Results

Of the 1334 invited individuals, 145 (11%) agreed to participate in the online study, of whom 135 (88%) completed the questionnaire about reasons for participation. The median age of participants was 55 years (interquartile range 46–63 years). More than half (59%, $n = 57$) had high educational level (German Abitur or equivalent) and most were married (73%, $n = 69$).

Implementation by a scientific research institution, trustworthiness, contribution to research, and positive vote of the data protection authority were rated as the most important reasons to participate (Fig. 1). In contrast, participation of friends, support through the mayor, monetary incentives, and offer of physical examination were rather unimportant.

Based on the rating of these characteristics, two clusters appeared (Fig. 2). Participants in cluster 1 (39%, $n = 38$) rated most of the offered items higher than those in cluster 2 (61%, $n = 59$). External motivation played no role in cluster 2 and had moderate importance in cluster 1 (Fig. 3). There was no significant association between cluster membership and sex ($p = 0.92$), age ($p = 0.16$), education ($p = 0.43$), marital status ($p = 0.39$) or employment status ($p = 0.41$). Based on the response profiles we propose the terms "enthusiastic/dutiful" and "regular" for participants in cluster 1 and 2, respectively.

Discussion

In our study, trustworthiness of those conducting research appeared as most important for the decision to participate in a health-related study. External motivation was only moderately important in a subgroup, while the remaining participants attached no importance to it. Thus, our results confirm for health-related studies previous findings related to surveys in general (Porst and von Briel 1995; Loosveldt and Storms 2008). Furthermore, in contrast to Akmatov et al. (2017), feedback of results was not rated high in our study.

To increase participation, the researcher should emphasize the aspects which will yield a higher participation, e.g. the possible contribution to society (altruism) (Singer 2011). Thus, researchers should highlight the primary motives for participation: trustworthiness and the usefulness of the study for the research and the common good. A subgroup might additionally respond to external motivation ("dutiful"), but even this group rates the above reasons very high (and might not need external motivation). As was already discussed Couper et al. (2010) and Singer (2011), focussing on the personal costs (e.g. data protection, required time contribution) does not yield higher participation because it does not increase motivation. Nevertheless, in a study with sensible data, e.g. sexual behaviour, the assurance of data protection might be most crucial. Some circumstances limit the generalizability of our results: The sample is small, not representative of the population, and by its very nature restricted to those who

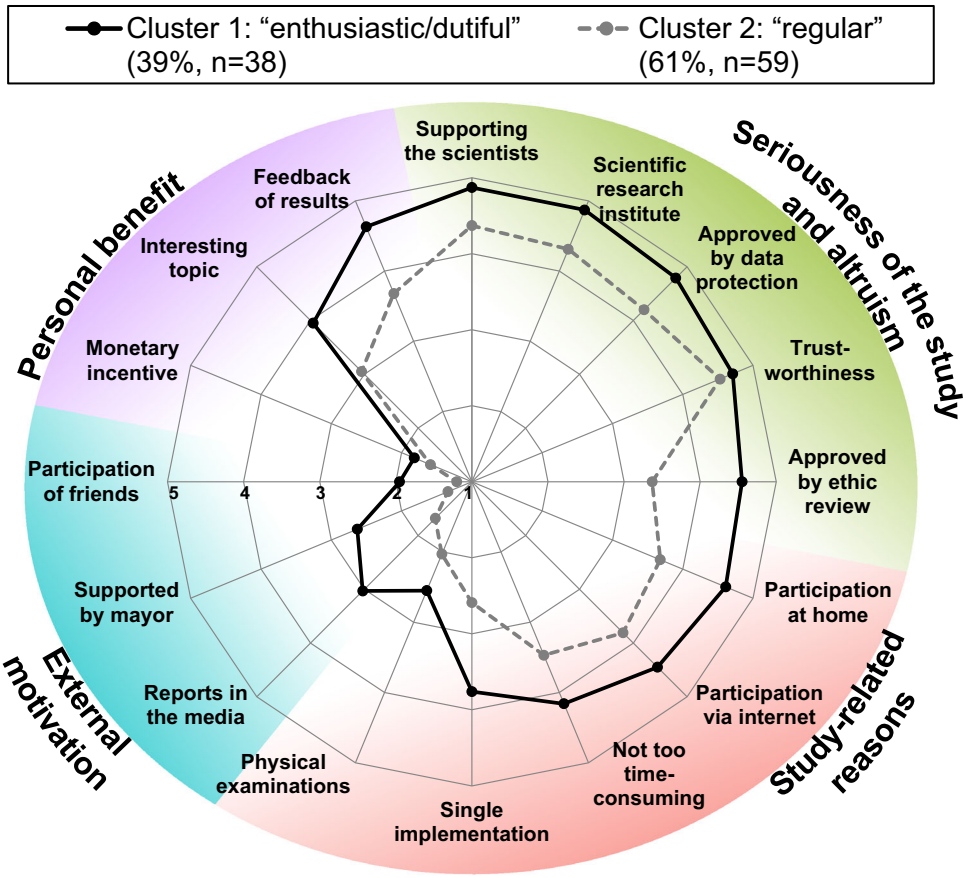

Fig. 2 Importance of reasons for participation [item means in "enthusiastic/dutiful" respondents (cluster 1) and "regular" respondents (cluster 2)]. Means are presented on a scale from 1 (not at all important) to 5 (very important). The two-step cluster analysis revealed two clusters [of note, 38 participants (28% of all 135 respondents) could not be assigned to a cluster because of missing responses for individual items]

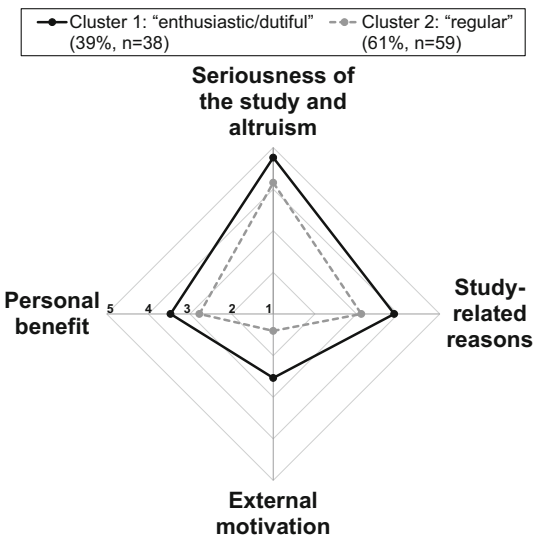

Fig. 3 Importance of constructs explaining participation [means for predefined scales (see Fig. 2) in "enthusiastic/dutiful" respondents (cluster 1) and "regular" respondents (cluster 2)]

agreed to participate in a specific study. Nevertheless, with decreasing participation and no possibility to learn reasons from true non-responders, understanding choice to participate among those who do can be an interesting option to maximise participation.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical standards The study was approved by the Ethics Committee of the State Board of Physicians of the German Federal State of Lower Saxony.

Informed consent All subjects gave written informed consent before entering the study.

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