

Short report

Promoting research participation: Why not advertise altruism?

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Abstract

Participation rates have a major impact on the quality, cost and timeliness of health research. There is growing evidence that participation rates may be falling and that new research governance structures and procedures may be increasing the likelihood of recruitment bias. It may be possible to encourage public reflection about research participation and enhance recruitment by providing information about the potential benefits of research to others as well as to research participants and by stimulating debate and influencing social expectations about involvement. Publicly funded and charitable bodies use various forms of advertising to encourage altruistic behaviour and generate social expectations about donating money, blood and organs for the benefit of others. Consideration should be given to the use of similar persuasive communications to promote wider participation in health research generally.

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Introduction

There is growing evidence that participation rates in both observational and experimental studies are highly variable across social groups and contexts, and that in some instances participation rates may be falling over time. Comparative international data do suggest significant variation in the ability to recruit promised numbers to clinical trials, with Switzerland, the Czech Republic, France and the USA all achieving over 100%, the UK meeting less than 80%, and Italy only marginally more than 40% (Smith, 2000). Response rates to government-funded national surveys have dropped steadily over the past three decades (Harris-Kojetin

& Tucker, 1999), and the shift from “opt-out” to “opt-in” recruitment processes in a number of countries seems set to reduce participation in health-related research (Junghans, Feder, Hemmingway, Timmis, & Jones, 2005; Trevena, Irwig, & Barratt, 2006). Low participation rates are problematic because they slow study progress, increase research costs and undermine the validity of findings (McColl et al., 2001).

Although research into behaviour in the health arena has generally concentrated on cognitive factors (Conner & Norman, 1998) there has been an increasing acknowledgement and emphasis on the reciprocal relationship between personal characteristics and structural and environmental influences (Bandura, 1997; Bradley & Caldwell, 1995). However, despite these developments the majority of interventions and strategies to promote behaviour change have continued to stress

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cognitions as more open to change than other structural variables. Efforts to promote particular behaviours have therefore focussed on addressing perceived practical and cost barriers, perceptions of the benefits of the behaviour, one's own ability to carry it out and of other people's views about what they should do (Ajzen, 1991; Bandura, 1977). In this paper we consider the desirability and feasibility of promoting research participation via project recruitment communications and broader advertising campaigns that emphasise the benefits for others of an individual's participation in health-related research and cultivate the view that research participation is socially desirable.

Motivations to participate: research benefits and social endorsement

Much health-related research depends on individuals' willingness to contribute without remuneration, typically by giving at least time and personal data. Participation in clinical trials may sometimes offer positive personal benefits in terms of access to drugs otherwise unavailable and possible improved clinical outcome (Braunholtz, Edwards, & Lilford, 2001; Sackett, 2005; Titmuss, 1970). For other studies, particularly healthy volunteers or observational studies more generally, the benefits are likely to be intangible feelings of enhanced self worth — of knowing that “one has done a good deed” so long as it is not experienced as overwhelming (Kiecolt-Glaser, Preacher, MacCallum, Malarkey, & Glaser, 2003; Schwartz, Meisenhelder, Ma, & Reed, 2003). However, the potential for most participants to benefit directly is often very limited and many people are justifiably sceptical about it (Harris Interactive, 2006). In some research contexts and cultures research participants may be offered financial rewards. However, there are ongoing debates as to whether this constitutes “undue influence” or whether it is acceptable and simply conveys respect and acknowledgement for the time and contribution that research subjects make (Grady, 2001). Even if such inducements are deemed acceptable it continues to be the case that they are unlikely to be appropriate in all contexts and their size and form would be important. However, appropriate guidance on such issues is lacking (Fry, Hall, Ritter, & Jenkinson, 2006).

The potential to help others may also be an important motivator towards research participation (Fry & Dwyer, 2001; Haddow & Cunningham-Burley, 2004). People may be more willing to participate if they believe that the potential benefits of their participation are *large* (e.g. life versus death), *highly likely* to materialise, *quickly attained*, likely to *accrue to someone important*

to them, and/or dependent on their specific (*not easily substitutable*) contribution.

Little is known about the nature or strength of perceived social norms in relation to research participation, but the emphasis on individual choice in much current policy in many countries suggests that people might be increasingly unlikely to think that others *expect* them to participate unless they have a particular reason not to. For example, a recent Danish study found that few people regarded declining participation in a clinical trial as a moral problem. Participants were significantly more likely than non-participants (24% versus 12%) to report non-participation as a moral issue (Madsen et al., 2002).

Promoting the benefits and social desirability of research participation

There is scope to improve research participation by increasing the extent to which people are well informed about all the potential benefits of participation and convinced that other people would generally endorse their participation. This might be achieved by developing the content of project recruitment communications and/or by running media-advertising campaigns that promote participation in health research more generally.

Project specific recruitment information

The information that researchers give to potential participants is subject to regulation in most countries. Legislation and guidance generally reflect the principles that individuals should be able to make informed choices about research participation and be free from coercion. It emphasises the importance of providing accurate and honest information in contexts that do not put undue pressure on people to participate (COREC, 2005). Attention has tended to focus on disclosure of the potential benefits and harms of research participation to participants. Less attention has been paid to the potential importance and acceptability of messages that

1. highlight the potential benefits of an individual's participation for others (and perhaps their future selves) or in general;
2. highlight the potential negative consequences for others or in general of an individual's non-participation (or of low overall participation rates);
3. suggest that participation is socially valued.

Refusal to participate may not stem from an objection to research participation in principle but rather from

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