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Why do people cooperate with medical research? Findings from three studies☆

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In this paper, we distinguish decisions about cooperation with medical research from decisions about research participation. We offer an empirical and theoretical exploration of why people in three different UK-based medical research projects chose to cooperate. Data analysis of the accounts of 128 participants across the three studies was based on the constant comparative method. Participants' cooperation was engaged by a perception that they would be contributing to the 'public good', but they also wanted to justify their decision as sensible and safe. Critical to their cooperation was their belief that researchers would fulfil their side of the cooperative bargain, by not exposing participants to risks of harm or exploitation. Although participants were generally unaware of the details of the regulatory regime for research, they demonstrated a generalised reliance on regulation as a feature of everyday life that would provide a safe context for cooperation. In their assessment of particular projects, participants made judgements about whether to cooperate based on more specific cues, which acted as signs to assure them that researchers shared their cooperative intentions. These cues included organisational and professional credentials, the role identities and perceived trustworthiness of those involved in recruiting to research, and visible signs of reasonable practice mandated by regulatory systems. Thus participants drew on their understandings of an institutional field that was much broader than that of research alone. We propose that the social organisation of research is fundamental to the judgements people make about cooperation with research. Cooperation may be a more useful way of thinking about how people come to engage in collaboratively oriented actions such as research participation, rather than currently dominant individualistic models. Attention to the institutional context of research is critical to understanding what makes cooperation possible, and has important implications for the design of regulatory regimes for research.

Introduction

Questions about why people engage in cooperative behaviour have been a long-standing interest of the social sciences (Halfpenny, 1999), going back to the work of Durkheim (1984) on pre-contractual solidarity. A very large body of work in economics and psychology has explored cooperation, much of it using game theory. Sociological studies of cooperation have been undertaken under various rubrics, including altruism and reciprocity, and have focused on a diverse range of areas, including the family, charitable giving, blood and organ donation, and helping people escape persecution. In this paper we focus on people's cooperation with medical research. We define medical research broadly as the scientific study of health and illness, though we recognise that the term escapes straightforward and exclusive specification. We propose that the social organisation of research is fundamental to the judgements people make about cooperation with research, and that cooperation may be a more useful way of thinking about how people come to engage in collaboratively oriented actions such as research participation, rather than currently dominant (and individualistic) models such as those concerned with the adequacy of consent.

We begin by making an important distinction between cooperation and decisions about participation. A burgeoning literature on research participation has aimed to understand individuals' reasoning, motives, and beliefs, and other factors that influence the decisions they make about participation. This literature has identified the values and characteristics of individual participants (e.g.

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Fry & Dwyer, 2001), people's perceptions of the benefits of participation, such as the possibility of securing better treatment and specialist attention (Slevin et al., 1995; Wendler, Krohmal, Emanuel, & Grady, 2008), risks, costs and benefits of participation (Lowton, 2005) and aspects of information (Ellis, 2000; Jenkins & Fallowfield, 2000) that are relevant to such decisions. But participation is distinct from cooperation. While participation focuses on an individual's involvement in a matter or event, cooperation necessarily involves joint action or coordination *with other parties*. Drawing on a number of different approaches, we will, for purposes of this paper, define cooperation as purposeful personal contribution to a common effort. Cooperation, crucially, encompasses individuals' beliefs about the cooperative intentions of the other parties involved in the effort (Pruitt & Kimmel, 1977) as well individuals' own motives for cooperation. Thus, for example, it is possible that individuals might be keen to join a research project (for example to gain access to new treatments) but might decline an invitation to do so if they are sceptical of the cooperative intentions of the researchers/research community.

Medical research is an interesting area for scholarly work on cooperation because of two features. First, it has many of the characteristics of a public good or a commons, with the attendant familiar dilemma that it may impose costs or burdens on those who contribute (such as volunteering personal information, contributing biological materials, undergoing additional tests or invasive procedures, or making extra visits to clinics), while allowing many to benefit. The research effort therefore depends on engaging the cooperation of those with the potential to contribute. But its second characteristic is that it appears, on the face of it, rather an unpromising candidate for securing cooperation: it involves risks, including those that derive from the fact that the interests of researchers may not always be identical to those of research participants. Commercial organisations or individual researchers' careers can, for example, profit from the voluntary contributions of participants. A history of scandals has served to heighten awareness of risks of mistreatment and exploitation; physical, psychological, and emotional harms; and assaults on human rights and dignity (Dixon-Woods & Ashcroft, 2008), demonstrating that the research community cannot always be trusted to have cooperative intentions. Taken together, these potential risks and burdens would seem to pose challenges related to *fairness* and *exploitation*, which generally undermine people's tendency to cooperate (Fehr & Schmidt, 2001). Given this, why would individuals choose to cooperate with medical research, and what are the conditions necessary for their cooperation?

These are important questions, not least because a focus on cooperation affords a perspective on how decisions about participation may be socially organised, even when they appear to be highly individual. It directs attention in particular to the institutional and organisational features that help to structure and shape individuals' interests, desires, decisions and actions, and the accounts they give of these (Lawrence & Suddaby, 2006; Powell & Colyvas, 2008). It encourages a recognition of how institutional forces frame the possibilities for choice and action, where institutions are understood, following Ostrom (1990), as the prescriptions that humans use to organise all forms of repetitive and structured interactions, including institutionalised cultural rules as well as formal organisations.

This argument is consistent with recent approaches in the sociological literature on charitable behaviour that stress the socially embedded nature of individuals' philanthropic endeavours (Ostrander, 2007), and see recipient organisations' tactics and practices, efficiency, resources, and logistics as helping to shape the behaviour of donors. Similarly, in his analysis of blood and organ donation, Kieran Healy (2006) argues that 'giving' is structured, promoted, and made logistically possible by the organisations and institutions that have interests in securing such giving. Healy recognises that organisations do not simply manipulate their donors; rather, the discourses and resources available to organisations to secure cooperation are dependent on social and institutional contexts.

These kinds of analyses encourage a recognition of both researchers and research participants as located within an institutional field. For medical research, this includes an extensive regulatory apparatus aimed at ensuring safe and ethical conduct of research, and that participants are not exposed to undue risks of harm. In the UK, the Research Governance Framework (RGF) for Health and Social Care (Department of Health, 2005), governs virtually all research conducted within the National Health Service (NHS). It begins by recognising the possible benefits of research, but emphasises the possible risks and the consequent need for governance, and the public's right to have:

> […] confidence in, and benefit from, quality research in health and social care. The public has a right to expect high scientific, ethical and financial standards, transparent decision-making processes, clear allocation of responsibilities and robust monitoring arrangements. (2005: 2)

The RGF further emphasises the responsibilities and accountability of researchers. It institutes a series of external controls over what researchers are permitted to do, including the requirement that all research involving patients be approved by a Research Ethics Committee and receive research governance approval from the organisations where the research is to be conducted. The regulatory regime for research extends well beyond the RGF, and also includes many other actors, legal instruments, and formal institutions. Taken together, the regime directly or indirectly structures what researchers are allowed to do and say about their own projects, but seeks also to structure the ways in which people respond to research *as an institution*. By constructing an accountability regime and associated rules and structures, cooperation is thus invited on grounds that formal governance procedures allow people to be confident that any risks are controlled and managed and their safety can be assured.

The formalisation and codification of this regulatory regime for research might be seen as a turn towards a 'confidence' based approach, where confidence is seen as secured through use of formal rules, legalistic procedures, contractual forms, and the availability of monitoring and sanctioning procedures, away from a 'trust' based approach, which relies on ethical relations that are not conditioned by an external framework of controls (Checkland, Marshall, & Harrison, 2004; Harrison & Smith, 2004; Smith, 2001; Tonkiss & Passey, 1999). At a policy level, it is no longer seen as sufficient to place trust in researchers' own moral and ethical frameworks to ensure that research will be conducted safely and ethically. Rather, formal regulatory frameworks such as the RGF explicitly self-identify as being directed towards gaining people's *confidence* by providing a rational basis for their engagement, and thus avoiding the lack of accountability and potential for lapses associated with trust-based approaches (Dixon-Woods & Ashcroft, 2008). A vocal critique has pointed to the importance of trust in medicine and medical research, and the risk that rule- and contract-based forms of regulation may do violence to trust, with negative consequences (Checkland et al., 2004; O'Neill, 2004). Despite this, there is surprisingly little empirically informed understanding of the basis of people's cooperation with medical research, and the extent to which these kinds of regulatory interventions are salient to the grounds on which people make their decisions to cooperate. Using taking part in three different biomedical research projects, this paper