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Whose Benefit is it Anyway? Public Expectations of Public Benefits from Health Informatics Research

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Introduction

Public benefits serve as a key justification for secondary uses of data in health research. Yet, while it is known that assurances of public benefits are vital for ongoing public support, there is a lack of clarity regarding what constitutes a public benefit.

Conclusion/Implications

Perceived public benefits are crucial for maintaining public support for health informatics research. Our workshops found that there is value in keeping "public benefits" as a broad, loosely defined term. Nevertheless, across each of the workshops the discussions suggested that research should benefit society as widely and fully as possible.

Objectives and Approach

Our research aimed to understand public expectations regarding "public benefits" from health informatics research.

In May and June 2017 three full-day deliberative workshops were held with members of the public across Scotland (between 20 and 25 participants per workshop). Participants were selected through quota sampling to represent key demographic characteristics. Workshops were structured around brief introductory presentations, videos in which data scientists presented the ways in which their research was anticipated to lead to public benefits, small group discussions, plenary discussions and activities.

Results

Workshop participants generally conceptualised "the public" as being "everyone" and had an inclusive view of this often taking an international or global perspective. This led to preferences for research to benefit the widest possible public, however participants also discussed the potential for benefits to be focussed at vulnerable or disadvantaged groups. There were wide-ranging views on what would constitute a "benefit" and participants generally acknowledged the value in keeping this loosely defined. A key theme to emerge was that, while some research might benefit particular individuals or groups more than others, the benefits should be societal benefits. In discussing the various data science projects presented, it was considered important that research had mechanisms in place in order to realise the benefits it was aiming for.