

Public attitudes towards research participation during an infectious disease pandemic: a qualitative study across four European countries

Nina Gobat, Micaela Gal, Christopher C Butler, Nicholas A Francis, Sibyl Anthierens, Hilde Bastiaens, Maciek Godycki-ćwirko, Anna Kowalczyk, Mariona Pons-Vigués, Enriqueta Pujol-Ribera, Anna Berenguera, Helen Stanton, Angela Watkins, Kerenza Hood, Ronnie Moore, Prasanth Sukumar, Steve A R Webb, Alistair Nichol

Abstract

Background Pandemics of infectious disease are recurrent events that impact global health and security. International, collaborative planning for future pandemics is a priority for public health officials, the research community, and the general public. However, little is known about the public's attitudes to participating in pandemic research and about their views on associated ethical dilemmas. We aimed to determine public perceptions about involvement in clinical research conducted in primary and critical care during a pandemic.

Methods We conducted ten, 2 hour focus groups (6–10 participants each) and 16 one-to-one follow-up interviews involving 80 members of the public in Belgium, Poland, Spain, and the UK between Sept 1 and Dec 31, 2015. Recruitment was through local advertisement. Data were collected by local researchers who followed a scenario-based topic guide, transcribed verbatim and translated into English. We used framework analysis to identify the range and diversity of participants' perspectives.

Findings Public understandings of pandemics were shaped by personal factors (illness during the H1N1 pandemic, experience of life-threatening illness) and social factors (historical references, media, public health information). Motivations to participate in pandemic research were influenced by altruism, therapeutic misconception, trust, and perception of risk. Use of routinely collected data and clinical samples without explicit prior consent was supported in principle, but was less acceptable when a profit motive was perceived. Participants recognised and appreciated the protections provided by ethically robust research procedures. However, they described having become desensitised to the importance and meaning of consent processes because of the frequency with which they authorise terms and conditions in everyday life. Participants proposed different models that might apply in a pandemic context (eg, advanced consent, verbal consent).

Interpretation Public engagement in clinical research on pandemic planning is possible, useful, but as yet underdeveloped in Europe. Effective pandemic preparation for clinical research requires active public engagement to mitigate therapeutic misconception and engender trust. This bottom-up approach to ascertaining public views on pandemic research participation has identified support for minimising disproportionate research protection procedures for publicly funded, low risk studies.

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Contributors

NG developed the idea, study design and study materials, obtained ethics approvals, collected data in Wales, and led the analysis and writing of the abstract. MGa developed the idea, study design and study materials, obtained ethics approvals, collected and double-coded data in Wales, and contributed to analysis. CCB conceived the idea, and contributed to study design, development, and analysis. NAF developed the idea, and contributed to study design, data collection in Wales, and analysis. SA and HB obtained ethics approvals and collected data in Belgium, and contributed to analysis. MGo and AK obtained ethics approvals and collected data in Poland, and contributed to analysis. MP-V, EP-R, and AB obtained ethics approvals and collected data in Spain, and contributed to analysis. HS analysed interview data. AW developed study materials, contributed to data collection in Wales, and coordinated study management. KH, RM, PS, and SARW contributed to study design and development. AN developed the idea, contributed subject matter expertise to study design, and is the principal investigator. All authors contributed to writing the abstract.

Declaration of interests

We declare no competing interests.

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PRIME Centre Wales, Division of Population Medicine, School of Medicine, Cardiff University, Cardiff, UK (N Gobat PhD, M Gal DPhil, N A Francis PhD, H Stanton BSc, A Watkins BA); Nuffield Department of Primary Care Health Sciences, Oxford University, Oxford, UK (Prof C C Butler FMedSci); Primary and Interdisciplinary Care, Faculty of Medicine and Health Sciences, University of Antwerp, Antwerp, Belgium (S Anthierens PhD, Prof H Bastiaens PhD); Centre for Family and Community Medicine, Faculty of Medical Sciences, Medical University of Lodz, Lodz, Poland (Prof M Godycki-ćwirko PhD, A Kowalczyk MPH); Institut Universitari d'Investigació en Atenció Primària Jordi Gol, Barcelona, Spain (M Pons-Vigués PhD, E Pujol-Ribera MD, A Berenguera PhD); Centre for Trials Research, Cardiff University, Cardiff, UK (Prof K Hood PhD); University College Dublin, Dublin, Ireland (R Moore DPhil, P Sukumar MPhil, Prof A Nichol PhD); and University of Western Australia, Perth, WA, Australia (Prof S A R Webb PhD)

Correspondence to:

Dr Nina Gobat, PRIME Centre Wales, Division of Population Medicine, School of Medicine, Cardiff University, Heath Park, Cardiff CF14 4YS, UK
GobatNH@cardiff.ac.uk