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CENTRE FOR INTERNATIONAL RESEARCH ON CARE, LABOUR & EQUALITIES

Patient, participant and person: What's in a name?

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E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL | UK Research and Innovation

Innovation in Person-Centred Approaches Conference, Oxford - May 2019

"We need to recruit more patients into the study."

Activity

- Working in small groups, label individuals from the following stories as patients, participants or people.

- Be ready to share your decision and why you chose a particular label.

Story 1

A 24-year old female joins an experimental research study as a ‘healthy’ participant in a control arm.

Story 2

A 37-year old male manages his diabetes at home through regular blood-glucose testing and an insulin pump.

Story 3

A 54-year old female lives in her own home with her husband and two teenagers. She is admitted to hospital after experiencing severe headaches. Imaging reveals a tumour in her brain. There her consultant offers her the opportunity to take part in a randomised controlled trial for a new experimental treatment.

What's the point?

Views And Reviews

We need person centred research for person centred care

BMJ 2019 ; 364 doi: https://doi.org/10.1136/bmj.l405 (Published 30 January 2019)
Cite this as: *BMJ* 2019;364:l405

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After the initial phone call from the research nurse, I later received the participant information sheet in the post. I was dismayed that the information "sheet" was actually 45 pages long and written in language that was at times too detailed, yet also written in inappropriate scientific jargon. The methods of the study did not dispel my despair. The study required participants to visit the clinic every week for the first month to have a research nurse administer the treatment until they were confident and competent enough to self-administer. Each of these weekly visits could take *up to five hours*. If the participant still experienced a bleeding episode between doses of the new treatment (i.e. breakthrough bleeding), then they needed to visit their haemophilia centre *within 48 hours*.

I declined the invitation to participate in the trial—not because I doubted the efficacy or safety of the new treatment, indeed it appeared it could greatly improve my quality of life—but because of the methodological design of the trial described above which appeared to place the burden of participation on patients rather than clinical research staff. I understand that such oversight is necessary to monitor patients for adverse events, ensure that breakthrough bleeds are managed appropriately, and protect the haemophilia centre and hospital from litigation. I live in the city relatively close to my centre, however, I would have trouble getting there every week for an appointment. Do they expect participants with full-time employment to take annual leave to participate and attend follow-up appointments? What about people with mobility problems or who must travel for work or live in rural areas? How will they attend the mandatory clinic if they are away from home and their haemophilia centre? These questions raise a further question: how did the trial advisory group involve people with haemophilia or their carers in the design of the study? Answers to these questions may reveal how trials actively, even if unconsciously, imagine patients as participants in their studies. It may also highlight trialists' narrow understanding and appreciation of patients' obligations, values and activities outside of the clinic.

All people, regardless of disability or state of health, live with other responsibilities and relationships that require their attention and obligate their time. Despite the prominence as the defining characteristic for the trial's inclusion criteria, a person's illness is only one aspect of their identity—one that may not be as important as other ones, such as their gender, ethnicity, sexuality, religious affiliation, or occupation. We should no longer accept tokenist or "tick-box" approaches to patient and public involvement (PPI). Let patients determine what meaningful involvement means to them commensurate with their skills and other responsibilities in an ongoing, living exchange. Major funding organisations (e.g. United Kingdom Research and Innovation, National Institute for Health Research, and Wellcome Trust), the Department of Health and Social Care and the Health Research Authority may have roles to play to incentivise, promote, or regulate better PPI arrangements in health, medical, and social care research.

Take Away Messages

- We need to not only think about person-centred care but also *person-centred research*.
- The argument for scientific validity is no longer an adequate pretence to disadvantage people from participating in studies.
- We must develop techniques for robust and rigorous research that also considers the lived experiences of participants as people with full lives, not only patients in the clinic.

"We need to recruit more patients into the study."

Business? Care Provider? Let's collaborate!

Ongoing project: *Accelerating implementation and uptake of new technologies to support ageing in place*

Funding: Economic and Social Research Council Innovation Fellowship (~£310,000)

Dates: January 2018 – December2020

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