

Is health research undertaken where it is needed most? Geographical inequalities in recruitment to research in England 2013-2018

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Abstract

Background

Research is fundamental to high quality care, but concerns have been raised about whether health research is conducted in the populations most affected by high disease prevalence. We explored whether patient recruitment in primary care is aligned with disease prevalence in England.

Methods

To assess disease prevalence, we used data from the Quality and Outcomes Framework on all chronic conditions, mental health and diabetes. To assess patient recruitment, we used data from the National Institute of Health Research Clinical Research Network. We presented geographical variation in the rate of patient recruitment. We calculated the share of patients that would need to be redistributed to align recruitment with prevalence. We explored whether there was any systematic association between recruitment rate and disease prevalence and whether this association varied between condition, and over time.

Findings

There was significant geographical variation in recruitment rate. We found evidence that recruitment was not aligned with prevalence, with disproportionate recruitment in areas of lower prevalence in total chronic conditions and mental health. The extent of the misalignment varied depending on the data used, and the conditions examined. There was no obvious trend in alignment over time.

Interpretation

The existence of substantial geographical variation which is not related to prevalence suggests that the drivers are research capability rather than the suitability of the population for research. Research activity data can support the development of indicators to assess the fit between research and need, and allow assessment of the impact of interventions among funders, research organisations and patients to encourage closer alignment.

Patient and Public Involvement (PPI)

Public interest in the reuse of routinely collected electronic health data for research purposes has never been higher. This proposal presents a valuable opportunity to build on existing efforts to develop meaningful and productive PPIE collaborations in observational studies that make use of secondary data. In the latter stages of the study, jointly with PPIE partners, we will plan and deliver appropriate dissemination activities targeted at a wider public audience, which will include seminars, blogs and workshops. We will consider whether these can be aligned with the plans of complementary e-health and primary care projects to maximise impact and resources.