



<sup>1</sup> University of Edinburgh, Edinburgh, UK

<sup>2</sup> School of Medicine, University of St Andrews, St Andrews, UK

<sup>3</sup> SHARE Scottish Health Research Register, Ninewells Hospital and Medical School, University of Dundee, Dundee, UK

brian.mckinstry@ed.ac.uk

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## PRESUMED CONSENT AND SHARING MEDICAL DATA

### Presumed consent and sharing medical data: Scottish register allows researchers to approach patients

Brian McKinstry,<sup>1</sup> Frank Sullivan,<sup>2</sup> Shobna Vasishta<sup>3</sup>

Salisbury wonders whether presumed consent is enough for sharing medical data and concludes that data sharing needs a clear plan.<sup>1</sup>

In Scotland we have asked people to join SHARE, the Scottish Health Research Register.<sup>2</sup> They give consent for their NHS data to be used to identify them for research projects and are contacted by the SHARE team with details of research that may be appropriate for them. With their further consent their contact details are given to research teams. In addition, they can give permission for their unused blood from routine investigations to be used anonymously for genetic research.

Almost 300 000 people in Scotland have signed up. Most are told about it by trained recruiters while they are attending hospital or GP appointments, and around 90% of those approached say yes. Very few (around 50 per year) subsequently withdraw, usually for reasons of frailty or serious illness.

Competing interests: BMcK and FS are directors of SHARE, the Scottish Health Research Register. SV is national project manager of SHARE.

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<sup>2</sup> McKinstry B, Sullivan FM, Vasishta S, et al. Cohort profile: the Scottish Research register SHARE. A register of people interested in research participation linked to NHS data sets. *BMJ Open* 2017;7:e013351. doi: 10.1136/bmjopen-2016-013351 pmid: 28148535