UK Medical Education Database: an issue of assumed consent

On discussion with current medical students and recent medical graduates (n=23 and n=21, respectively), few were aware of the large scale UK initiative to collate data on medical students and junior doctors into a single database: the UK Medical Education Database (UKMED). The UKMED Development Group has representatives from the Medical Schools Council, General Medical Council, NHS Health Education England, Academy of Medical Royal Colleges, British Medical Association, UK Foundation Programme Office, Conference of Postgraduate Medical Deans, Northern Ireland Medical and Dental Training Agency, NHS Education for Scotland, Wales Deanery, UK Clinical Aptitude Test (UKCAT) consortium, BioMedical Admissions Test and Graduate Australian Medical Schools Admissions Test. The project created a central database of medical student and graduate information to facilitate research and guide both policy and workforce planning. This database contains linked personal data on demographics and performance in various assessments. There is also discussion of linking and incorporating information from the Universities and Colleges Admissions Service (UCAS) into the database. The data housed is very detailed. Some examples of personal information include an individual's schooling, ethnicity and parental occupation as well as assessment outcomes and test dates (eg UKCAT test date, UKCAT score and successful completion of annual review of competence progression in the Foundation Programme).

Recently, the Care.data initiative, which planned to link and share patient data across England, collapsed. The Care Quality Commission had been commissioned to undertake a review of data security in the NHS. Additionally, Dame Fiona Caldicott, the National Data Guardian for Health and Care, was commissioned to undertake an independent review of data security and consent. The findings from the reviews then led the Parliamentary Under-Secretary of State for Life Sciences (George Freeman), to announce that in light of Dame Caldicott's recommendations, NHS England had taken the decision to close the Care.data programme.² A prominent issue leading to the closure related to gaining consent from individuals to share and link personal data that were previously collected. There were also concerns surrounding how the linked data would be used. Parallels can be drawn here, except the UKMED database is already up and running whereas Care. data never got off the ground.³ It is significant that concerns over data protection and consent were raised at an initial scoping meeting to consider the UKMED proposal in 2012:⁴

It was also recognised that data protection and consent could be a significant issue and that all stakeholders particularly students and trainees would need reassurance that their data were being handled appropriately. It was suggested that doctors could be afforded the opportunity to opt out at any time after having given their consent to for their data to be used, which would drive good practice in terms of data protection and security.

None of the medical students and recent graduates we approached were aware of giving informed consent, allowing data from these various bodies to be linked. Most were aware that their data were collected, but assumed their data were confidential and only being

used for their own personal assessment. When informed about the project, most raised concerns about who will have access to this data and what exactly it will be used for. Several did not want detailed sensitive information shared with (potentially commercial) third parties or being shared, consciously or unconsciously, with potential employers. Most raised the question of why they were not consulted before their data were included into the database:

What an invasion of privacy. Surely that can't be legally allowed?

We definitely did not ever knowingly consent to that.

Care.data and the UKMED initiatives are worthwhile projects in their respective fields and could indeed help us make scientific, educational and policy decisions more evidence based. However, both projects appear to share significant concerns surrounding participant consent.

In order for UKMED to avoid a similar fate to Care.data, which absorbed a significant amount of public funding, we urge those involved to address the issues surrounding consent and confidentiality related to data collation. Perhaps, an upfront opt-out consent model, where individuals can give informed consent or opt out of adding their data to the database, should be implemented.

Conflicts of interest

The authors have no conflicts of interest to declare.

REBECCA BEST*

medical student, Cardiff University School of Medicine, Cardiff, UK

JASON LEO WALSH*

core medical trainee, Centre for Medical Education, Cardiff University School of Medicine, Cardiff, UK and St George's Hospital, Tooting, London, UK

BENJAMIN HOWELL LOLE HARRIS

core medical trainee, Centre for Medical Education, Cardiff University School of Medicine, Cardiff, UK and St Anne's College, University of Oxford, Oxford, UK

DAVID WILSON

professor of medical education and director of admissions, Centre for Medical Education, Cardiff University School of Medicine, Cardiff, UK

*contributed equally

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