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LETTERS

CARE.DATA

The Scottish Health and Ethnicity Linkage Study shows the value of national datasets and that data can be securely linked

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NHS England's Care Data programme poses challenges that need careful appraisal.¹ Linkage of census, hospital, and primary care data in the Scottish Health and Ethnicity Linkage study (SHELS) has provided insights,² particularly as census linkage comprises an extra important step.

We studied ethnic variations in disease risk and outcomes across Scotland. Because individual consent from patients was impractical, approval bodies and primary care teams had to judge whether the purposes justified linkage and whether appropriate privacy safeguards were in place. Ethnic variations were shown by linkage of hospital admission/mortality records to the 2001 Scottish census.³⁻⁵ Data on risk factors, drugs, and comorbidity, available only from primary care, were needed to understand these variations. Ten (of 17) invited general practices supported assessment of the feasibility and value of primary care data linkage within SHELS. We gained approval from ethics and privacy advisory committees to link primary care data to our pre-existing datasets. Approval was predicated on holding data on a standalone PC in a locked room in a safe setting and scrutiny of outputs by a data disclosure committee. We extracted primary care data with one personal identifier—an encrypted community health index number—creating a pseudo-anonymised database of more than 100 000 patients; about half were subsequently linked to our pre-existing database. We faced challenges in recruiting general practices, maintaining communications, and preparing data for analysis and

interpretation, especially because the same information is recorded differently across different records.

SHELS has shown the value of national datasets and that data can be securely linked. When primary care datasets holding high quality data are linked, we can anticipate advances in public health and healthcare planning, as well as opportunities for research. Utilisation of data will help enhance data quality and is an important part of the process in reaching this goal.

Competing interests: None declared.

Full response at: www.bmj.com/content/348/bmj.g1702/rr/688541.

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