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Introducing the PRIDAL model for linking routine health and identifiable patient reported data in HTA

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Background: The rise in availability, quality and use of routine health data has resulted in well-developed methods for anonymised linkage of data from multiple sources. However methods for combining identifiable data (e.g. patient-reported questionnaires) with routine anonymised data are not yet tried-and-tested. Linking these data presents opportunities to improve the feasibility and effectiveness of observational and experimental studies, but emerging data linkage processes must address the appropriate balance between data security and usability.

Objectives: To present an efficient privacy-protecting model for linking routine and identifiable patient-reported research data.

Methods: The Process for Routine and Identifiable Data Linkage (PRIDaL) was devised to efficiently link routine hospital data and patient-reported quality of life and quality of care questionnaire data as part of the PRISMATIC trial (2) – a mixed methods cluster randomised trial of the efficacy of an emergency admission risk tool in primary care. PRIDAL was conceived by a group of specialists in e-trials, health informatics, information governance and process mapping who reviewed data sources, flows, owners, and security to develop a practical and intuitive process model.

Results: We will present the PRIDAL process model for the first time and use PRISMATIC findings from data matching of 2,400 questionnaire responses to patients in an overall study dataset of over 200,000. (Data matching will complete in April 2015). We will demonstrate that the model achieves high matching rate, and consider the lessons learnt in its application.

Conclusions: The linking of routine health and patient self-reported data presents valuable research opportunities, but clear, replicable models, are needed to support ethical and practical data linkage. We present the PRIDAL model as a potential solution.

Biography

Helen Snooks is the Professor of Health Services Research in the Swansea University Medical School, UK. She is the Interim Director of the Swansea Trials Unit (STU) and leads the Patient and Population Health and Informatics (PPHI) research stream at Swansea University. Helen's main research interests and expertise lie in the fields of Emergency Pre-hospital and Unscheduled Care, Clinical Audit and Effectiveness, and research support. The focus of her work is to plan, design and carry out evaluations of health technologies and new models of service delivery. Helen has a Bsc (Hons) Economics, Sociology, Statistics from University of Surrey with a PhD in Health Services Research 'Post Traumatic Stress Disorder in seriously injured accident victims' at the University of Sheffield in 2000.

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