

The Inform study

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Description

Project Summary

Personal medical records maintained in general practice contain data of enormous value not alone for individual patient care but also in multidisciplinary health service development and delivery and in healthcare research.

Nationally and internationally, concerns over inappropriate use of personal information have resulted in access to these data being affected by increasingly restrictive laws and ethical guidelines.

These developments have considerable implications for the planning and conduct of health service development, delivery and research. It has been argued that in some circumstances respect for individual privacy may prove detrimental to the validity and effectiveness of research and development and therefore the greater social good, constituting a new ethical dilemma.

Yet major stakeholders in these debates, the patients themselves, have rarely been consulted. While much is assumed about patients views relating to personal medical data, UK Medical Research Council guidelines acknowledge that there is little research evidence on how people view the use of this confidential information [1].

This study will employ a combination of qualitative and quantitative methods to explore and evaluate public views about access to their personal medical information for health service development, delivery and research in primary care. It will identify preferences relating to consent, the level of knowledge of the contents of medical records and factors which affect public attitudes to the use of these data.

The study will add to national and international understanding of patient perspectives in this area. It will generate evidence which will inform debate around issues such as data protection and data sharing and will be of value to researchers, service providers, ethics committees and data controllers in the

planning, approval and conduct of protocols for increased appropriate data sharing in primary care practice and research projects.

Objectives

Aims & Objectives

To explore attitudes amongst the Irish public from a range of age and socio-economic groups towards the use of general practice medical record data for research and health service delivery

Qualitative phase

Exploration of public knowledge of the content of general practice medical records.

Exploration of public attitudes relating to the use of general practice medical records in research and service delivery

Exploration of contexts, factors and strategies which affect these attitudes.

Quantitative phase

Evaluation of the prevalence of attitudes to and awareness of data use in research and service delivery as identified in the qualitative phase amongst a representative sample of the Irish public.

Evaluation of hypotheses developed in the qualitative phase regarding contexts, factors and strategies which influence attitudes to data use.

Status Current

Publisher National University of Ireland, Galway, Association of Occupational Therapists of Ireland

Alternative Title A combined methods study to evaluate public attitudes and consent preferences regarding use of personal information contained in general practice medical records for research and service development.

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Description	<p>Nationally and internationally, concerns over inappropriate use of personal information have resulted in access to these data being affected by increasingly restrictive laws and ethical guidelines. These developments have considerable implications for the planning and conduct of health service development, delivery and research. It has been argued that in some circumstances respect for individual privacy may prove detrimental to the validity and effectiveness of research and development and therefore the greater social good, constituting a new ethical dilemma. Yet major stakeholders in these debates, the patients themselves, have rarely been consulted. While much is assumed about patients views relating to personal medical data, UK Medical Research Council guidelines acknowledge that there is little research evidence on how people view the use of this confidential information[1]. This study will employ a combination of qualitative and quantitative methods to explore and evaluate public views about access to their personal medical information for health service development, delivery and research in primary care. It will identify preferences relating to consent, the level of knowledge of the contents of medical records and factors which affect public attitudes to the use of these data. The study will add to national and international understanding of patient perspectives in this area. It will generate evidence which will inform debate around issues such as data protection and data sharing and will be of value to researchers, service providers, ethics committees and data controllers in the planning, approval and conduct of protocols for increased appropriate data sharing in primary care practice and research projects.</p>
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