Record Linkage in Australian epidemiological research: health benefits, privacy safeguards and future potential

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Abstract: Epidemiologists are increasingly concerned with the health effects of interventions and of exposure to noninfectious agents, but there may be long periods between exposure and outcome. Collecting information from respondents is a costly and often inefficient way of obtaining the longitudinal data necessary to study these effects. Linking existing data can be an effective and efficient alternative. However, it is often not practicable to obtain informed consent from the individuals whose records are to be linked. This raises important issues relating to protection of privacy. This paper examines the health benefits and privacy issues of epidemiological and health services research involving record linkage in Australia. The future potential for studies based on record linkage is discussed in the context of recent national and international developments in data protection. In the interests of public health and the rational use of health resources a balance must be struck between protecting individual privacy and conducting such health research for the common good. (Aust J Public Health 1995; 19: 250-6)