2.5 DATA AND INFORMATION

Chair: Prof Nancy Krieger, USA

02-5.1 INTERNATIONAL DATA SETS ON HEALTH: DATA COLLECTION AND SHARING FOR POLICY DESIGN

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Introduction A growing number of countries are developing or reforming pension and health policies in response to population ageing and to enhance the welfare of their citizens. The adoption of different policies by different countries has resulted in several natural experiments. These offer unusual opportunities to examine the effects of varying policies influencing health. Realising these opportunities requires harmonised data-collection efforts.
Methods An increasing number of countries have agreed to provide data harmonised with the Health and Retirement Study in the United States. This article discusses these data sets, including their key parameters of health status, research designs, samples, and response rates. It also discusses the opportunities they offer for cross-national studies and their implications for policy evaluation and development.
Results The HRS family of surveys shares a common research design and collects comparable micro-data with a common goal to better understand the multifaceted lives of older individuals and their families and to track and identify changes over time. As the longitudinal data from harmonised HRS surveys accumulate, their scientific value will grow with the research opportunity to examine longitudinal changes in health and its determinants. Armed with knowledge about causal relationships, researchers can also use longitudinal, cross-country data to simulate what might happen under different policy scenarios. As policy reforms continue, researchers can use panel data to identify how the adoption of a policy reform launched in one country might be applied in another country, and the implications of such policies for health outcomes.

02-5.2 PUBLIC RESPONSES TO THE SCOTTISH HEALTH INFORMATICS PROGRAMME: PREFERENCES AND CONCERNS AROUND THE USE OF PERSONAL MEDICAL RECORDS IN RESEARCH

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The Scottish Health Informatics Programme is an ambitious, Scotland-wide research platform for the collation, management, dissemination and analysis of electronic patient records. It is creating a research portal for electronic patient records held by NHS Scotland that will provide rapid, secure access to the type of data required by population health scientists. However, such data linkage and subsequent use raise a range of social and ethical issues. A concurrent programme of public engagement is exploring opinions and concerns in order to develop a transparent, publicly acceptable approach to Scottish Health Informatics Programme's work. The first phase involved a series of 10 focus groups across Scotland with a diversity of participants. These data have been analysed qualitatively and inductively. Key concerns relate to security of databases; what data will be used for and the extent to which patients can control the use of their data. A central theme throughout discussions was trust: participants were less concerned about uses of their data when they trusted the individual/organisation using it. A further important finding was that participants were very troubled about linking health data with non-health data for research purposes. These findings have important implications for the governance of health related data and research. They demonstrate the importance of engaging with public views at every stage of a programme's development if it is to achieve high levels of trust and transparency.

02-5.3 IMPROVING THE COLLECTION OF DATA ON RACE/ETHNICITY IN GENERAL PRACTICE

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Despite increasing pressure to include ethnicity/race in health data, there is considerable debate about whether this information will result in reduced disadvantage or will simply contribute to the reification of ethnic origin as a cause of health problems. We conducted a study to identify promising strategies to improve the identification of Aboriginal and Torres Strait Islander people in general practice.
Methods Methods included a systematic review of the literature on interventions to improve identification, analysis of Primary Health Care Research and Information Service and Medicare general practice data, and a series of key informant interviews, workshops and case studies.
Results Both clinicians and community members recognised the population health imperatives to reduce ethnic disparities in health but they also had difficulty conceptualising how information about a patient's ethnicity could be clinically useful. Clinicians who were able to articulate how ethnic identification was linked to their practice were the most willing to ask patients about their ethnic status. This was supported by health service data which suggested that increasing awareness around health services specifically available to Aboriginal and Torres Strait Islander people in significant increases in identification and completed health assessments (Aged 15–54 years: OR 95% CI 2.38, 1.78 to 3.19 Aged 55 years: OR 95% CI 2.92, 2.46 to 3.47).
Conclusion Improving the willingness of physicians to enquire about ethnicity will require strengthening the link between knowing a patients ethnicity and quality of care. This will require having systems in place that enable information about ethnicity to contribute to improved quality of care in an explicit way.

02-5.4 OVERVIEW AND DEVELOPMENT FOR POLICIES ON SHARING PROSPECTIVE EPIDEMIOLOGICAL DATA

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Introduction With the establishment of prospective bio-bank studies around the world and need for better collaborative use of the resources, there is growing demand for open data sharing both from funders and the research community. However, there is no standard framework for their data sharing policies.
Methods From numerous websites and publications, we identified large (N≥50 000) well-established population-based studies of common non-communicable chronic diseases among adults' involving blood collection. A detailed review of their data-access policies (DAP) was undertaken using a structured form.
Results Fifty (34% US-led, 12% UK-based and 16% Chinese-targeted) studies were identified, of which 24 indicated data sharing. However, only nine studies made their DAP available online. Common components of these DAPs include: policy principles; data information and application procedures; evaluation criteria; timeline and process of data release; accessibility to data; output sharing and accountability. In most studies, the data were released for 1–3 years, after the research proposal was approved and the user agreement was signed. The data were released either without any charge, covered in a grant, or on a fee-for-analysis basis. Joint-authorship papers and open-to-public output are expected. Even when the

studies were conducted in developing countries, most did not provide preferential access to researchers from there.
Conclusion A useful DAP should encompass complex issues ranging from ethical and legal to feasibility and practicability while remaining user-friendly to encourage collaboration. Giving consideration to researchers from countries involved in the study will promote international collaboration which will facilitate local research and enhance epidemiological knowledge.

02-5.5 ESTIMATION OF THE BURDEN OF OCCUPATIONAL CANCER IN GREAT BRITAIN

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Introduction Prioritising control of occupationally-related cancers should be evidence based. We have estimated the current burden of cancer in Great Britain attributable to occupation for IARC group 1 and 2A carcinogens.
Methods We calculated attributable fractions and numbers for mortality/incidence using risk estimates from published literature and national data sources to estimate proportions exposed.
Results Cancer deaths attributable to occupation in 2005 are 5.3% (8023) (men: 8.2% (6366); women 2.3% (1657)). Attributable incidence estimates are 13694 (4.0%) cancer registrations (men: 10074 (5.7%); women 3620 (2.1%)). Occupational attributable fractions are over 2% for mesothelioma, sinonasal, lung, nasopharynx, breast, non-melanoma skin, bladder, oesophagus, soft tissue sarcoma and stomach cancers. Asbestos, shift work, mineral oils, solar radiation, silica, diesel engine exhaust, coal tars and pitches, occupation as a painter or welder, dioxins, environmental tobacco smoke, radon, tetrachloroethylene, arsenic and strong inorganic mists each contribute 100+ registrations. Industries/occupations with over 200 cancer registrations include construction, women's shift work, metal working, personal/household services, mining, land transport, printing/publishing, retail/hotels/restaurants, public administration/defence, farming and several manufacturing sectors.
Conclusions This study is the first detailed cancer burden study using all IARC 1 and 2A carcinogens and quantifying the contribution of individual industry sectors. Our methodology provides a basis for adaptation for use in other countries and global occupational burden estimation and for extension to include social and economic impact evaluation. The results highlight specific carcinogenic agents and the occupational circumstances and industrial areas where exposures to these agents occurs, facilitating prioritisation of risk reduction strategies.

02-5.6 PUBLIC GOOD, PERSONAL PRIVACY: A CITIZENS' DELIBERATION ABOUT USING MEDICAL INFORMATION FOR PHARMACOEPIDEMIOLOGICAL RESEARCH

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Introduction Epidemiologists have long argued for access to personal health data to monitor, investigate, and improve the public health. At the same time, legislation and ethical guidelines have increasingly been framed in terms of protecting the privacy rights of individuals, rather than in terms of the public interest in the results of research. A 2002 Nuffield Trust report on the secondary use of medical data recommended a dialogue with the public about the arguments for use without consent and the appropriate safeguards. In 2006, the UK Academy of Medical Sciences noted that evidence regarding public attitudes towards the use of medical information in research was still largely absent, and the investigations that had been undertaken asked undifferentiated questions which were not adequate to assess attitudes towards different types of research conducted by different groups for different purposes.
Methods We took up the challenge of having a dialogue with the New Zealand public about the balance between the public interest and privacy arguments, using a citizens' jury approach. A 3-day hearing was held to explore public views about the use of medical information for a specific purpose—researching the safety of medicines.
Results The jury unanimously concluded that publicly-funded researchers should be permitted to use medical information about identifiable people, without their consent, for the above purpose—providing existing ethical guidelines and relevant laws are followed.
Conclusions This outcome suggests that an informed public does not place personal privacy above societal benefits in the particular circumstance of medicines' safety research.

2.6 MATERNAL AND CHILD HEALTH RISK FACTORS FOR PREGNANCY OUTCOME

Chair: Prof. Jill Pell, UK

02-6.1 A SECOND CHANCE? PROBABILITY OF A LIVE BIRTH FOLLOWING INITIAL PREGNANCY LOSS: SURVIVAL ANALYSIS OF SCOTTISH NATIONAL DATA

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Objective To ascertain the chance of a second pregnancy resulting in live birth following pregnancy loss.
Methods Scottish data on all women whose first pregnancy occurred between 1981 and 2000 were linked to records of a subsequent pregnancy. The exposed cohorts comprised women with a first ectopic pregnancy, miscarriage, stillbirth or termination. The unexposed cohort comprised women who had an initial live birth. Kaplan–Meier curves of time to second pregnancy outcome and live birth from the date of first pregnancy were constructed. Cox's proportional hazards models were used to calculate the HR with 95% CI of any second pregnancy and live birth. The reference category was women whose first pregnancy ended in a live birth.
Results There were 667 144 women with an initial live birth, 39 530 with a miscarriage, 2969 with an ectopic first pregnancy, 3094 with a stillbirth and 78 493 with termination of their first pregnancy. After adjusting for maternal age at first delivery, socioeconomic status and year of first pregnancy event, the HR (95% CI) of any second pregnancy was 1.35 (1.28 to 1.42), 2.24 (2.21 to 2.27), 2.44 (2.35 to 2.54), 0.66 (0.65 to 0.67) following ectopic, miscarriage, stillbirth and termination respectively. The adjusted hazards of a live birth following ectopic, miscarriage, stillbirth and termination were 0.71 (0.64 to 0.79); 0.92 (0.90 to 0.95), 1.17 (1.06 to 1.29), 0.62 (0.60 to 0.63) respectively.
Conclusion Compared to an initial live birth, pregnancy loss increased the chance of another pregnancy (except in case of termination) but decreased the chance of a live birth (except stillbirth), emphasising the role of voluntary contraception in fertility patterns.

02-6.2 WITHDRAWN