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One in 30 people in the UK take part in cohort studies

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On March 21st 2014, the UK Medical Research Council (MRC) published its Strategic Review of the Largest UK Population Cohort Studies[1], funded by the MRC and other major funders. The MRC has a 50-year history of support for population cohort studies, including the 1946 Birth Cohort,[2] the world's longest continuously running birth cohort, UK Biobank,[3] which tracks half a million participants, and the Million Women Study,[4] the largest longitudinal study of women's health. Almost £30 million is spent per year on the 34 largest UK population cohort studies, half of which have been followed for more than 20 years. The vast majority of participants are aged 45 years or above (92%) and female (62% after exclusion of the Million Women Study), with men aged 20-40 years less well represented. Given that science is dependent on the support and engagement of the public, it is noteworthy that 2·2 million people in the UK are currently taking part in these large population cohort studies[1].

Population cohort studies are a major long-term commitment for participants, study teams, and funders, but their strength is in their ability to identify multiple risk factors over time. This is particularly relevant in assessment of exposures that cannot be randomised, notably health behaviours such as smoking and social circumstances, or in identifying the effect of one risk factor on multiple outcomes. For example, long-term follow-up in the European Prospective Investigation of Cancer (EPIC) Norfolk study showed that exercise, a healthy diet, and not smoking increased life expectancy by 14 years.[5] The Million Women Study has measured the effects of hormone replacement therapy on fracture incidence, cancers, and other conditions.[4]

The UK population cohort portfolio has wide coverage: from before conception to old age, both sexes, and all major ethnic groups. Cohorts are traditionally more inclusive than randomised trials which are often highly selective. Findings from cohort studies may, therefore, be more generalisable to the population as a whole. In addition, some cohorts,

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such as the Avon Longitudinal Study of Parents and Children (ALSPAC),[6] include data from several generations that enable investigators to study familial clustering of risk and disease and the underlying mechanisms.

The Strategic Review highlights how new technologies have been readily adopted by cohort studies. 68% of UK cohort studies have undertaken genotyping, and half have epigenetic or metabolomic data.[1] The inclusion of genotyping in large cohorts with longitudinal phenotypic information enables more robust studies of gene–environment interactions, such as the Lothian cohort which showed that genetic factors account for only a quarter of change in intelligence with age.[7] Another strength of many cohorts is the collection of serial measurements and samples that enables measurement of changes in exposure and their effect on health outcomes over time. Some findings that have emerged from UK population cohorts are now widely accepted. The 1946 Birth Cohort provided some of the clearest evidence for the long-term effects of adverse early life circumstances on adult health.[8] The Whitehall Study was one of the first to suggest that low sense of control and variety at work contribute to occupational gradients in health.[9] A retrospective cohort study of people born in Hertfordshire was the first to link birth and early childhood weight with adult mortality and show the importance of early environment on lifelong health.[10]

Cross-cohort collaborations are an effective way to increase statistical power. The HALCyon collaboration[11] merged data from nine cohorts to undertake studies of ageing that would not have been feasible using any single cohort. Similarly, the Cohort and Longitudinal Studies Enhancement Resources (CLOSER) initiative,[12] funded by the MRC and Economic and Social Research Council, brings together nine cohorts with the aim of combining variables across these studies.

Some cohorts may not be representative of the general population in terms of demographics and lifestyle, but the results may nonetheless be generalisable. The generic weaknesses of prospective cohort studies are that they are time consuming to maintain, costly, and may experience systematic loss to follow-up. New strategies are helping to address some of these inherent problems; many cohorts obtain consent to link participants to routine health records, which reduces loss to follow-up and recall bias and is less expensive than active follow-up, and some use remote data capture through the internet. Remote data capture techniques may impact adversely on recruitment, retention, selection bias and the ability to collect samples. Therefore the Review recommends that the merits of adopting these less costly approaches should be considered on a case by case basis and adopted where appropriate. UK Biobank collected extensive data at baseline clinics but follow-up information is collected via record linkage and online questionnaires. The Review recommends that, where possible, broad and enduring consent should be obtained from the participants of all cohorts to obtain additional information via linkage to routine data.

Trustworthy research use of personal data using robust governance processes in secure environments with safeguards that protect confidentiality is fundamental to understanding the causes of disease and improving public health. In addition to spotlighting individual cohorts, the Strategic Review contains a series of recommendations for the MRC and others[1]. Although awareness of cohorts and sharing of data and samples are already policy

for the MRC and other funders, more could be done to enable well-governed use of these resources. Therefore, the Review recommends that cohorts be included in online directories and appropriate meta-data provided. Also, they should use standardised and validated approaches, where possible, to facilitate cross-cohort comparisons. The findings from the cohorts are of great value in informing policy and practice in the UK, as well as further afield, and the Strategic Review highlights the need for closer working with policy makers. It is envisaged that the Strategic Review will encourage more extensive use of UK cohort studies in the future; they are an invaluable national resource that few other countries can match.

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