Frequently asked questions (FAQ): further information about the Data Access and Release Policy

Who is the audience for this policy?

The policy is targeted at people working for institutions and universities undertaking medical research where that research will benefit the health of the wider Australian community. It is not aimed at the individual health consumer who is interested in finding out about a particular health condition or to access their health records.

I am doing research about a personal health condition. How can I get access to information I am after?

The Department of Health website contains a comprehensive range of <u>health information</u> <u>relevant for consumers</u>, and the Department of Human Services provides facilities to help consumers manage their personal health care information online.

Will the Data Access and Release policy make it easy for researchers to access my personal health records for research purposes?

No. The release of health data must comply with relevant health and privacy legislation to ensure confidentiality and privacy of information. There is a range of legislation and government policy protecting the privacy of individuals and the confidentiality and use of their health data. Examples include the Privacy Act 1988, the Australian Privacy Principles, the Health Insurance Act 1973, the National Health Act 1953 and the NHMRC National Statement on Ethical Conduct in Human Research. These provide the cornerstone of considerations when research requests for data are received.

How do I request access to health data?

Most research requests are for Medical Benefits Scheme (MBS) and Pharmaceutical Benefits Schedule (PBS) data. Where the data requested is not already available publically, researchers can submit a request for MBS and/or PBS data by sending an email to statistics@humanservices.gov.au.

Enquiries about access to other Commonwealth health data can be made via email to data.release@health.gov.au.

Is ethics approval required before the department will release data?

Any research involving humans, or requiring access to personal information, will require approval from a Human Research Ethics Committee. More information about whether ethics approval is required and how an ethics submission for approval can be made is available from the <u>Department of Health Human Research Ethics Committee website</u>.