

FAQs

Is my data included in this technical platform and how did it get there?

If your GP clinic is part of a program called *Data for Decisions*, then it is likely that your data is part of this research data. *Data for Decisions* is developed and managed by the University of Melbourne's Department of General Practice.

Many Australian GPs also participate in a *MedicineInsight* program. *MedicineInsight* data from Victorian GPs can also be part of our research data.

If you have been admitted to or visited an emergency department or outpatients' clinic at one of the Victorian Comprehensive Cancer Centre Alliance's member hospitals, your health information may also be part of the data. If you have been treated in a major Melbourne hospital for a type of cancer that is listed as one of our research areas (see list below), then your health information will be included in this collection of data.

I can't recall giving permission to anybody to collect and link my data – how was this done?

In Australia, permission is implied for the collection of your data during health care and treatment by GPs and hospitals. This is to ensure the best health care for individuals. The use of your data for medical research can be approved by an ethics committee without the active consent of individuals, as long as privacy is protected. BioGrid Australia is structured to ensure that an individual's identifying and clinical information are kept separate. *This means researchers can never know the identity of the individuals whose information is stored in the databases.* Researchers can conduct research while individual privacy is fully protected.

How do I find out if my GP is sharing my information?

Over 120 Victorian GPs partner with *Data for Decisions*. Some practices remain anonymous, and some want to be named. A list of the practices that are named is available from [Data for Decisions and the Patron program \(unimelb.edu.au\)](https://www.unimelb.edu.au/data-for-decisions). GPs may also have a poster promoting their involvement in their waiting or consulting rooms.

Can I withdraw consent and ask for my data to be removed?

If your GP or other primary healthcare provider is participating in *Data for Decisions* or the *MedicineInsight* program, and you do not want your de-identified medical records to be used for this research program, let your healthcare professional or the practice manager know, and then they can withdraw you from the program. Withdrawing will NOT affect the direct care that you receive from your doctor.

If you wish to have your hospital information removed, you can complete a [patient opt out form](#) and withdraw at any time.

Who owns my data given that it is actually mine and how does that work?

You own your healthcare data and can ask for a copy of your patient records at any time from your GP or other healthcare provider. The systems to de-identify your data before it is used for research purposes are robust and meet the obligations under the Privacy Act as the risk of re-identification is extremely low and very tightly managed.

What research has been done using this data?

The data is being used, or has been used for the following projects:

- Understanding how different diagnosis timeframes for lung and colorectal cancer patients impact on health outcomes and survival (PhD projects)
- Investigating different uses and the costs of primary and acute services by colorectal cancer patients to understand differences in their survival.
- Mapping the way people diagnosed with sarcoma; head and neck cancer; pancreatic cancer; and young onset colorectal cancer are diagnosed and the different pathways they take to access treatment.
- Using machine learning techniques to identify and predict a person's risk of upper gastrointestinal cancers.
- Use of primary care services in the last six months of life for cancer patients.
- Weight loss as an early indicator of cancer, in collaboration with University of Oxford.
- Management of chronic diseases in colorectal cancer survivors
- Patterns of pathology test requests and abnormalities prior to a diagnosis of colorectal or lung cancer in collaboration with University College London.
- Analysis of skin checks and skin cancer diagnoses to inform a health-economic model of skin cancer screening in collaboration with University of Sydney.
- Early breast cancer to examine predictors of clinical outcomes.



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