

Medical Genomics Research Bank Information Handling Statement

In collaboration with the NSW Ministry of Health, the Garvan Institute of Medical Research (**Garvan**) has established and operates the Medical Genomics Reference Bank (**MGRB**). MGRB is a reference bank of blood samples (from which Garvan will derive genomic data) and health data associated with those samples, from which identifying information has been removed. MGRB is established as a resource to support health and disease specific genomic research by building a dataset of whole genome sequences for a cohort of healthy individuals.

Information handled in the operation of the MGRB

The MGRB includes samples and associated information collected by Monash University and the Sax Institute and provided to Garvan (with identifying information removed) from participants in the:

- **ASPREE Study (ASPIrin in Reducing Events in the Elderly Study - Monash University):** blood samples and associated participant information including year of birth, gender, height, weight, waist circumference, systolic blood pressure, fasting blood glucose levels and self-reported history of macular degeneration; and
- **45 and Up Study (Sax Institute):** blood samples and associated participant information including year of birth bands, sex, height bands, weight bands, BMI categories, records of treatment for high blood pressure, records for treatment for high blood cholesterol and family histories.

Garvan has entered into agreements with Monash University and the Sax Institute for the provision of these blood samples and associated information in the MGRB. Under these agreements, Monash University and the Sax Institute are required to handle personal information (ie information that identifies the study participants) in compliance with all applicable laws including the Australian Privacy Principles set out in the *Privacy Act 1988* (Cth). The organisations do not disclose to Garvan information that would enable the identification of individuals. All identifying information (personal information) will be removed from the samples and information provided to Garvan. Therefore, the risk of you being identified from the samples or information included in the MGRB is very low.

What happens if over time the MGRB does involve Garvan handling your personal information?

The processes and systems put in place by Garvan to facilitate whole genome sequencing of samples provided by Monash University and the Sax Institute are designed to ensure that information handled remains de-identified. However, if at any time the operation of the MGRB would involve Garvan handling personal information, Garvan will handle the information in accordance with its [Privacy Policy](#) and in compliance with Australian privacy laws.

Any questions about the MGRB may be directed to sgc@garvan.org.au.