

# SHOAMP SERUM MANAGEMENT COMMITTEE ACTIVITY REPORT 2023

## Background

The Study of Health Outcomes in Aircraft Maintenance Personnel (SHOAMP) Serum Management Committee (SMC) reports to the Repatriation Commission and the Military Rehabilitation and Compensation Commission (the Commissions) about its operational activities, including the continued storage of serum samples and associated matters, any research proposals received by the SMC and any requests from individual study participants.

## **Summary of 2023 Activities**

The following activities were undertaken by the SHOAMP SMC in 2023 and are discussed in more detail below:

- Committee meeting;
- Committee-membership updates;
- Completion of the Work Order with The University of Newcastle Research Associates (TUNRA);
- Contracted the Australian Institute of Family Studies (AIFS) to provide storage and support services for the data-linkage key;
- Transferred the data-linkage key from TUNRA to AIFS; and
- Published a communique targeting former study participants, advising the serum samples held in long-term storage had moved facilities and reminding them of the option to opt-out of storage.

## **Committee Meetings**

The SMC met once in 2023 on 9 November, via online video conference.

## **Committee Members**

Personnel changed in 2023 due to staff movements. The members as at 31 December 2023 were:

Chair	
Mr Kahlil FEGAN (DSC, AM)	Repatriation Commissioner
Members	
Mr John CLARKSON	Victorian President, Air Force Association
Ms Nadine CLODE	Assistant Secretary, Community Policy & Research Branch, DVA
Dr Anna COLWELL	Deputy Chief Health Officer, DVA
Mr Geoff CURL	Veteran advocate, SHOAMP Deseal—Reseal Support Group
Dr Victoria ROSS	Senior Medical Advisor, Military Population Health, Joint Health Command, Department of Defence
Observers	
Dr Ray CARR	Assistant Director, Defence and Veteran Insight Unit, Australian Institute of Health and Welfare
Ms Susan LIST-ARMITAGE	Sample Processing Manager, QIMR Berghofer Medical Research Institute
Ms Melissa SUARES	Project Lead, Data Management and Linkage, Australian Institute of Family Studies

#### **Transfer of De-Identified Data**

The de-identified study data was transferred from the University of Newcastle to the Australian Institute of Health and Welfare (AIHW) on 8 November 2022.

#### Human Research Ethics Committee Approval

Approval was received from AIHW Ethics Committee in December 2021 for AIHW to store 12 deidentified datasets received from the University of Newcastle. Additional approval was received from the Committee in February 2023 for additional steps undertaken by AIHW to strengthen the safeguards for ongoing storage of the data.

#### **Transfer of Data-Linkage Key**

AIFS was appointed as the data-linkage key storage-and-support provider on behalf of the Air Force Association. AIFS completed a Privacy Impact Assessment and a Data-Access Protocol which was endorsed by the SMC. The data-linkage key was transferred from the University of Newcastle to AIFS in June 2023.

#### Human Research Ethics Committee Approval

Approval from the Defence and DVA Human Research Ethics Committee (DDVA HREC) was received in May 2023 for the Data-Access Protocol and transfer of the data-linkage key from the University of Newcastle to AIFS.

## **Communique to Study Participants**

A communique targeting study participants was released in December 2023. The communique:

- advised participants that serum samples held in long-term storage at QML Pathology were moved to bio-banking facilities at QIMR Berghofer Medical Research Institute in Brisbane; and
- provided access to a web form providing participants the option to request access to their individual study data and/or withdraw consent for their sample to be used for further research if they wish.

The communique was released over various communication channels, including:

- DVA website
- DVA social media
- Print/online articles including:
  - o DVA's VetAffairs, eNews, and Advocacy News
  - o Department of Defence Newspapers (Army, Navy, Air Force) and ForceNet
  - Air Force Association WINGS magazine and online notice-to-members facility.

### Human Research Ethics Committee Approval

Approval was received from DDVA HREC in July and October 2023 for the wording and key messages contained in the communique.

#### Access and withdrawal requests

As a result of the communique, in late 2023 six requests were received from study participants, requesting a record of their individual study data. The data-transfer process and procedures, including the requirements for management of participant requests for access to their data, are outlined in the Data-Access Protocol (as outlined above). Supported by the Data-Access Protocol, AIFS, AIHW (both accredited data integrators), and DVA commenced the required steps to progress these requests, ensuring the data-transfer process is secure and robust and includes necessary protections to participants' information and privacy. This work will be completed in 2024. During 2023, AIFS did not action any requests from:

- participants to withdraw their data or serum sample, or
- researchers to use the de-identified SHOAMP study data, or access the serum samples for research purposes.

DVA continues to monitor for requests from study participants and researchers, in conjunction with AIFS and AIHW.