



Australian Research Data Commons



# **HeSANDA INITIATIVE STAKEHOLDER CONSULTATION PROJECT: Executive Summary**

**August 2021**

## Executive Summary

This summary outlines the key themes emerging from a targeted consultation process facilitated by the [Australian Clinical Trials Alliance](#) (ACTA) on behalf of the [Australian Research Data Commons](#) (ARDC) to inform the planning and design of the [Health Studies Australian National Data Asset \(HeSANDA\) initiative](#). Feedback was sought from clinical trialists and consumers across Australia with experience and insights in a range of health and research areas. Consultations gathered insights from 116 people through four virtual workshops and an online survey during May and June 2021.

Consultations were designed to gain insights into a series of questions with a view to ratifying and adding detail to feedback provided through the initial consultations undertaken to inform the initiative. A summary of insights is provided below.

### OVERALL FINDINGS

Overall findings from the consultation process included:

- support from participating consumers and trialists for the goal of facilitating secondary use of data from clinical trials for research purposes, with a strong emphasis placed on the need for secondary sharing and use of data to be facilitated in an appropriate, effective and efficient way
- reinforcement by clinical trialists of the need for the design and implementation of HeSANDA to consider data governance and ethics; to include simple and standardised processes and to ensure that commercial and academic intellectual property is protected
- reinforcement by consumers of the importance of informed consent for sharing data from clinical trials and the need to protect individual identification through shared data to protect against misuse or misrepresentation.

### FEEDBACK ON THE HESANDA PRINCIPLES

Feedback gathered through the ACTA consultation process broadly aligns with and supports the principles previously proposed to underpin the development of HeSANDA.

Feedback suggests three additional principles that are focused on:

- the importance of evaluation to understand whether HeSANDA is meeting its goals and to make refinements as required ('Purpose' principle)
- the importance of ensuring appropriate use and interpretation of data in a way that protects academic and commercial intellectual property and guards against misuse or misrepresentation of data ('Data governance' principle)
- reinforcement of a commitment to the inclusion of consumers/people with lived experience within all aspects of planning, design and implementation ('Stakeholder coordination' principle).

In addition, feedback provided further nuance and considerations for implementing the existing principles under the four theme areas of: Purpose; Data content and quality; Data governance; and Stakeholder coordination. While some of the issues identified (e.g. issues under the 'Data content and quality' theme) may be beyond the scope of HeSANDA itself, HeSANDA could act as a catalyst for sector-wide action to address these issues.

To access a full copy of the report, please contact Fiona Nemeh ([fiona.nemeh@clinicaltrialsalliance.org.au](mailto:fiona.nemeh@clinicaltrialsalliance.org.au))

For questions about the HeSANDA initiative, please contact the ARDC (<https://ardc.edu.au/collaborations/strategic-activities/national-data-assets/health-studies-national-data-asset-program/>)