Building a National Transfusion Dataset (NTD) for Australia

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Introduction:

The National Transfusion Dataset (NTD) project is developing an integrated national database to capture and analyse blood utilisation and clinical outcomes of transfused patients across Australia.

The NTD builds on the existing Australian and New Zealand Massive Transfusion Registry (ANZ-MTR, which has a unique focus on massive transfusion, MT), and the pilot Transfusion Database (TD) project. It will document and analyse clinical use of blood in both the pre-hospital and hospital settings, for all patients who have received a transfusion of any blood product. It will provide new data on transfusion practice including blood utilisation, clinical management and outcomes.

Aims:

- Expand transfusion data coverage: by articulating pre-hospital and hospital transfusion datasets and linking these with transfusion and outcomes data from relevant clinical registries and haemovigilance datasets.
- Strengthen data quality and improve access to transfusion data for stakeholders and researchers.
- Improve Australian transfusion research infrastructure, capacity and efficiency.
- Create new research opportunities (e.g. provide data for health economics analyses).
- Use the data to inform national policy and practice, improve blood utilisation, and optimise patient management and outcomes.

Approach:

The ANZ-MTR is being reconfigured to capture data from pre-hospital services and participating hospitals for ALL blood products transfused to patients ≥18 years. Data items include: demographics, clinical coding (diagnosis, hospital admission), laboratory, transfusion data, and patient outcomes (mortality, clinical response, quality of life).

Where possible, specific patient cohort data (e.g. ICU admission for blood diseases) will be linked with national clinical datasets including: ANZICS Adult Patient Database (ANZICS APD), Aplastic Anaemia and other Bone Marrow Failure Syndromes Registry (AAR), Lymphoma and Related Diseases Registry (LaRDR), Myeloma and Related Diseases Registry (MRDR). Monash University, in collaboration with specialist clinicians and researchers, will carry out data management (aligning with FAIR principles) involving harmonisation, integration, linkage and analysis. (Figure 1)

Results:

Ethics approval has been obtained for incorporation of the TD into the ANZ-MTR to form the NTD. Governance approval and data extractions are underway.

A preliminary linkage has been carried out with the AAR, which demonstrated feasibility, and provided details on admissions, admission length, ICD diagnosis codes and transfusion details including platelet administration.

Expansion of the NTD with CogStack, a natural language processing platform, will incorporate unstructured data from patient electronic medical notes (such as administration, and adverse event reports) into the NTD, and link with haemovigilance data.

Conclusion:

The NTD is underway, and will deliver a more complete picture of transfusion practice – ultimately from donor to product to patient. Once fully established this dataset will be an invaluable resource for researchers, clinicians, government, industry and others to inform patient care, resource management, and clinical guideline development as well as generate hypothesis-driven research.

Future Plans:

Next steps for the NTD:

- Facilitate data integration and linkages of additional health services, clinical datasets and incorporation of Lifeblood data.
- EMR/CogStack validation study with hospital and STIR (Serious Transfusion Incident Reporting) system data.
- Develop national models and health economic analyses of blood supply and demand
- Conduct Australia's first registry-based transfusion clinical trial.

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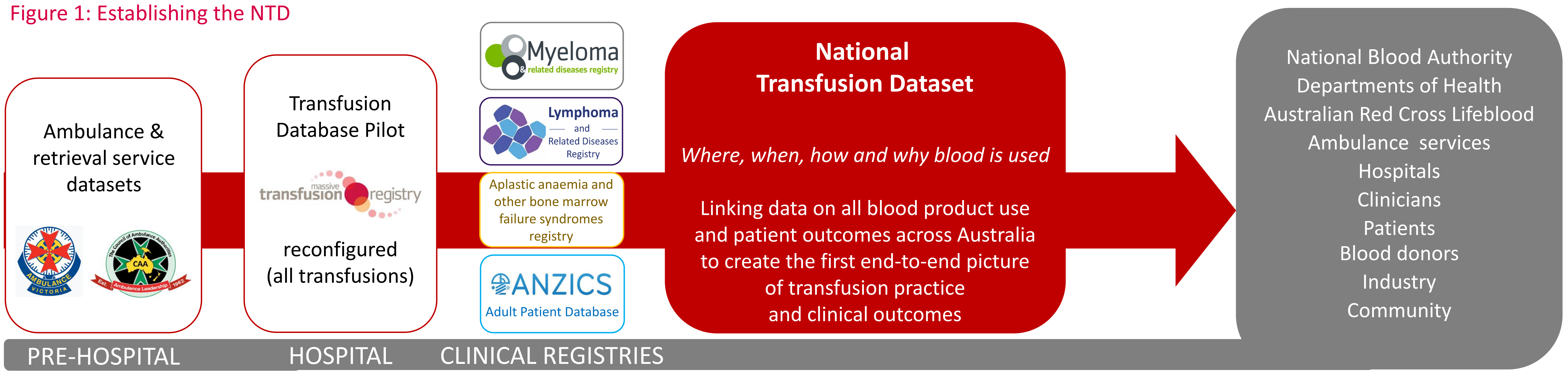
Figure 1: Establishing the NTD



Ambulance & retrieval service datasets

Transfusion Database Pilot

massive transfusion registry

reconfigured (all transfusions)

Myeloma & related diseases registry

Lymphoma and Related Diseases Registry

Aplastic anaemia and other bone marrow failure syndromes registry

ANZICS Adult Patient Database

National Transfusion Dataset

Where, when, how and why blood is used

Linking data on all blood product use and patient outcomes across Australia to create the first end-to-end picture of transfusion practice and clinical outcomes

National Blood Authority
Departments of Health
Australian Red Cross Lifeblood
Ambulance services
Hospitals
Clinicians
Patients
Blood donors
Industry
Community

PRE-HOSPITAL HOSPITAL CLINICAL REGISTRIES

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