

Territory Kidney Care Project Data Participation Agreement

Between

Menzies School of Health Research

And

Northern Territory Department of Health

And

[Health Service]

Date

Parties

Menzies School of Health Research

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(Menzies)

Northern Territory Department of Health

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(Department of Health)

(The Health Service)

Recitals

- A. Territory Kidney Care (**TKC or the System**) is an integrated clinical decision support system for the early identification and management of chronic kidney disease. TKC is a project of Menzies School of Health Research, supported by Department of Health.
- B. Department of Health employs the Business System Owner responsible for the data in the TKC Database and transfer of Department of Health data to TKC.
- C. The Health Service is non-government health service provider that holds and owns the Health Service Data. The Health Service wishes to participate in the TKC and has agreed to transfer Health Service Data to the TKC Database.
- D. The parties now enter into this agreement (**Agreement**) to document the terms on which the Shared Data will be transferred to the TKC Database and may be used by the parties.

The parties agree, in consideration of, among other things, the mutual promises contained in this document as follows:

1. Term

- 1.1 This Agreement commences on the date it is signed and ends on the date of completion of Phase 4 of the implementation and evaluation of TKC.
- 1.2 Upon the completion of Phase 4, this Agreement may be modified by mutual consent between the parties, to reflect the end of Menzies School of Health Research role as project implementer and evaluator.

2. Termination

The participating Health Service may terminate the Agreement at any time by notifying the other parties in writing.

3. Ownership of Shared Data

- 3.1 All Health Service Data transferred to the TKC Database shall remain the property of the Health Service and shall be returned to the Health Service or destroyed with the Health Service's written consent upon termination of this Agreement.
- 3.2 All Department of Health Data transferred to the TKC Database shall remain the property of Department of Health and shall be returned to Department of Health or destroyed with Department of Health's written consent upon termination of this Agreement.

4. Management of Shared Data

- 4.1 All Shared Data will be held in the TKC Database and managed by Department of Health.
- 4.2 The TKC Business System Owner is responsible to ensure that:
 - (a) The TKC System, including the Database, is operated in accordance with *Australian Standard A/NZS ISO/IEC 17799:2001 Information Technology – Code of Practice for Information Security Management*; **(The Standards)**, and
 - (b) all Shared Data is held, used, stored and processed in accordance with:
 - (i) Privacy Law;
 - (ii) The Standards; and
 - (iii) Any requirements specified by The Health Service relating to management or disclosure of the Shared Data.

5. Access and Use of Shared Data

- 5.1 The parties to this Agreement grant each other a right to access and use Shared Data solely for the Agreed Use Cases.

- 5.2 Further to clause 5.1, the parties to this Agreement grant the following users the right to access and use Shared Data, for the limited additional purposes outlined in the below table.

| User | Data Level Access | Right of access and use limited to the following purpose |
|---|---|--|
| Department of Health TKC System Administrator | Full TKC Database access granted | To manage the technical operations of the TKC Database, including troubleshooting on a daily basis and identifying immediate and longer-term threats to system functions and sustainability. |
| Department of Health Clinical Support Unit | Full TKC Database access granted | To prepare TKC Outputs |
| TKC Project Team | Limited period access (from the date of this Agreement to 31 December 2024, unless otherwise agreed in writing) for the development, implementation and evaluation phase of the project. Once the system is fully transitioned to Department of Health – the TKC Project Team will not have access to TKC Database information. | To manage and implement TKC, including testing and system quality, audit during build and test phase and to deliver TKC Database Evaluation Report during the project. |

- 5.3 Any access to Shared Data will be in accordance with the Department of Health Data Security and Privacy Protocols, Privacy Law and the Standards.
- 5.4 Shared Data cannot be accessed by or disclosed to third parties other than as set out in this Agreement and the Department of Health Data Security and Privacy Protocols.

6. Transmission of Shared Data

- 6.1 Shared Data must be transmitted between the Health Service or the Department of Health and the TKC Database via a secure, encrypted and automated data extract delivery mechanism.
- 6.2 All Shared Data will undergo transformation in accordance with TKC Business Rules and Data Dictionary to comply with TKC Database requirements.

7. Department of Health Obligations

- 7.1 Department of Health agrees to:
- (a) ensure that its Personnel:
 - (i) use the data solely for the purpose of performing the TKC Services under this Agreement, and not for any other purpose; and

- (ii) keep the data solely within the control of Department of Health and its personnel, unless the Health Service otherwise approves, in writing.
- (b) host the TKC Database within NT Government-approved facilities;
- (c) comply with all applicable Privacy Law and Standards;
- (d) be the Data Custodian of the Shared Data;
- (e) ensure Shared Data is only used for the purposes outlined in this Participation Agreement; and
- (f) participate with Menzies School of Health Research in the evaluation of TKC.

8. Health Service Obligations

8.1 Each Health Service agrees to:

- (a) have a written policy in place that outlines that the Health Service will inform patients at the point of service that:
 - (i) attendance and participation in the Health Service may result in their Data being shared with the TKC Database; and
 - (ii) if their Data is shared with the TKC Database, that Data will be used to improve the quality, coverage and scope of health services and protect public health;
- (b) provide Health Service patients with an opportunity to 'opt-out' of the TKC Database and take reasonable steps to ensure the information of patients who elect to opt out is not shared with the TKC Database;
- (c) ensure that information received via TKC Outputs is:
 - (i) accessed only by individuals with a legitimate need to access that information, based on their role within the Health Service; and
 - (ii) is used only for the TKC Agreed Use Cases.
- (d) ensure the Data entered into its clinical system is:
 - (i) relevant, accurate, timely, coherent and able to be interpreted.
- (e) Develop a Health Service Implementation Plan; and
- (f) participate with Menzies School of Health Research in the evaluation of TKC.

9. Menzies School of Health Research Obligations

9.1 Menzies School of Health Research agrees to:

- (a) ensure that its personnel:
 - (i) use the data solely for the purpose of performing the TKC Agreed Use Cases under this Agreement, and not for any other purpose; and
 - (ii) keep the data solely within the control of Menzies School of Health Research and its personnel, unless the Health Service otherwise approves, in writing;

- (b) comply with the Privacy Law and the Standards;
- (c) oversee the TKC Project Team;
- (d) collaborate with stakeholders on the design and build of the TKC Database, and TKC's governance structures and implementation;
- (e) evaluate the impact of the System to:
 - (i) improve the care and management of people with kidney disease,
 - (ii) smooth the patient journey between primary and tertiary care;
 - (iii) better understand demand to assist with forward planning and advocacy for resourcing; and
 - (iv) provide a cost/benefit to individuals and health services.
- (f) work with Department of Health to determine mechanisms needed to provide ongoing support to the System and to transition the system to Department of Health seamlessly.

10. Reporting

- 10.1 The Clinical Support Unit will provide reports to the Health Service as outlined in their Health Service Implementation Plan.
- 10.2 Reports will be delivered to the Health Service securely from the Clinical Support Unit in accordance with clause 6.

11. Confidentiality

- 11.1 Each party and its personnel must keep confidential, and not use or disclose, other than as permitted by this Agreement, and any confidential information of any other party.
- 11.2 All parties shall comply with all Commonwealth and Territory laws and regulations governing the confidentiality of the information that is the subject of this Agreement.

12. Definitions

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| Agreed Use Cases | <p>means:</p> <p>(a) Treatment: for the provision, coordination or management of health care and related services;</p> <p>(b) Health care operations: to analyse Shared Data to develop a better understanding of the patient population and evaluate the impact of clinical interventions;</p> <p>(c) Evaluation: to evaluate the extent to which the TKC Database is achieving the TKC Objectives.</p> |
| Business System Owner | <p>the individual who, on behalf of Department of Health:</p> <ul style="list-style-type: none"> • Is responsible for the function and security of the TKC data • Endorses the outcome of user-acceptance testing. • Represent Department of Health service in business strategy discussions related to TKC. • Reviews and approves (if acceptable) identified Department of Health service risks and mitigations. • Owns the Department of Health TKC service roadmap. |
| Clinical Support Unit | The Department of Health Nephrologists, Nurses and Informatics Nurse who are named by Department of Health as members of the Clinical Support Unit for the purposes of this Agreement. |
| Confidential Information | <p>of a person, means all information (regardless of the form of disclosure or the medium used to store it):</p> <p>(a) treated by that person as confidential; or</p> <p>(b) which the person to whom it is disclosed ought to reasonably know is confidential.</p> |
| Data | Personal information or other data relating to an individual person. |
| Data Custodian | The entity with responsibility for holding, maintaining, reviewing and securing the Shared Data. |
| Data Dictionary | The set of information describing contents, format and structure of a database and relationship between its elements |
| Department of Health Data | All data owned and operated by Department of Health, regardless of whether it has been transferred by Department of Health to the TKC. |
| Department of Health Data Security and Privacy Protocols | Standards and Guidelines used by Department of Health (See Standards for list) |
| Health Service Data | All data owned and operated by the Health Service, regardless of whether it has been transferred by the Health Service to the TKC. |
| Health Service Implementation Plan | The document developed and specific to each health service |
| Personnel | The officers, employees, contractors (including subcontractors) and agents of a person or any of its related bodies corporate (as defined in the |

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| | <i>Corporations Act 2001 (Cth))</i> and any other person that forms part of any of their supply chains. |
| Phase 4 | The Evaluation Phase of the System, which will be complete when written findings have been delivered by Menzies to the parties. |
| Privacy Law | Information Act 2002 (NT), including the Information Privacy Principles, and the Privacy Act 1988 (Cth). |
| Shared Data | Data shared by TKC Participants and stored in the TKC Database. |
| Standards | <ul style="list-style-type: none"> (a) NT Public Sector Organisation Records and Information Management Standard; (b) Standard of Cultural Security outlined in the National Aboriginal and Torres Strait Islander Health Data Principles 2006; (c) Department of Health Privacy Policy; (d) Department of Health Data Guidelines; (e) Department of Health Data Release Guidelines; (f) NTG – Digital Security Policy; (g) NTG ICT Access Standard; (h) NTG Data Governance Protocols |
| TKC Business Rules | Describes the operations, definitions and constraints applied to TKC. |
| TKC Database | The Shared Data hosted by the Department of Health. |
| TKC Objectives | To support primary health clinicians to improve the identification and management of people with kidney disease, delay the progression to dialysis and support forward planning. |
| TKC Outputs | <ul style="list-style-type: none"> (a) TKC Level 1 reports: provide individual patient advice from the CSU Nephrologist, directly to a clinician or the clinic manager. They contain identified patient information; (b) TKC Level 2 reports: provide lists of patients who are at high risk of progressing to chronic kidney disease (CKD). These patients are not individually case managed by TKC Clinical Services Unit. Reports are designed to support health service patient management and may be used to improve operational aspects of care, for example a prioritisation of workload. Reports contain identified patient information and are provided by the Clinical Services Unit clinicians to Health Service in accordance with their established protocols (e.g. may be provided to the chronic disease coordinator, clinic manager). They can be customised to each health service, although it is intended that a suite of standardised reports will be developed to be delivered at pre-determined intervals; and (c) TKC Level 3 reports: intended for use by the Health Service to support their own service planning projections, advocacy and annual reporting. They can be customised although it is intended |

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| | that a suite of standardised reports will be developed to be delivered at pre-determined intervals. The development of each Health Service Implementation Plan will identify to what level aggregated reports may be developed and shared among participant Health Services given that by joining TKC, each health service becomes a provider and recipient of data in TKC. |
| TKC Participants | The parties to this Agreement and any third parties that participate in and share Data with the TKC Database and enter into a Data Participation Agreement on substantially the same terms as this Agreement. |
| TKC Project Team | The team of personnel tasked with the design, build and test of TKC overseen by Menzies and includes Department of Health clinicians, private contractors and Menzies staff. |
| TKC Steering Committee | The committee (10-14 members) responsible to provide strategic direction during the implementation and evaluation phases of TKC that meets annually in person and monthly by teleconference. |
| TKC System Administrator | The Department of Health Informatics Officer responsible for <ul style="list-style-type: none"> • day to day system management and monitoring • providing access to eligible clinicians and monitoring usage, • ensuring notifications of outages are timely, • managing data access protocols and requests. |
| User | A user permitted to use and access the TKC Database in accordance with clause 6.2 of this Agreement. |

13. Miscellaneous

13.1 Governing law and jurisdiction

- (a) This Agreement is governed by the law in force in the Northern Territory of Australia.
- (b) Each party irrevocably submits to the non-exclusive jurisdiction of courts exercising jurisdiction in the Northern Territory of Australia and the courts having appeal from them.

13.2 Relationship of the parties

- (a) The parties are not to be taken to be in a partnership, joint venture, employment or fiduciary relationship.
- (b) Nothing in this Agreement gives a party authority to bind any other party in any way.

13.3 Executed as agreement

Executed for and on behalf of Menzies
School of Health Research in Darwin,
Northern Territory on the _____ day of __,
_____ by its representative in the presence
of:

Signature of witness

Signature of representative

Full name of witness (print)

Full name of representative (print)

Address of witness (print)

Address of representative (print)

Executed for and on behalf of _____ in

on the _____ day of __, _____ by its
representative in the presence of:

Signature of witness

Signature of representative

Full name of witness (print)

Full name of representative (print)

Address of witness (print)

Address of representative (print)

Executed by
(print name of delegate)

for and on behalf of the **NORTHERN TERRITORY
OF AUSTRALIA (ABN 84 085 734 992)** care of its
agency the Department of Health pursuant to a
delegation under the *Contracts Act 1978* (NT)

on the day of
_____ in the presence of:

.....
Signature of Delegate

.....
Signature of Witness

.....
Name of Witness