OpenDeID Corpus data usage terms & conditions (Version 1.0 November 2021)

I AGREE that I will access and use the OpenDeID Corpus data (hereinafter called "the OpenDeID corpus") made available to me by the Translational Cancer Research Network[1] and Secure Research Environment for Digital Health Consortium[2] at UNSW Australia (hereafter "UNSW"), in accordance with the following conditions:

1. Access and use of the OpenDeID Corpus is restricted to non-commercial research and educational purposes only.
2. Apply to relevant IRB or Ethics committee to use the data for non-commercial research and educational purposes.
3. The data will be used only by recipient for the purpose described in IRB or ethics application.
4. The privacy and confidentiality of the research participants must be respected and always protected. Therefore:
    a. I will not do any act or engage in any practice that may result in the disclosure of the identity of any research participant.
    b. I will notify UNSW immediately in writing if the identity of any research participant is discovered.
    c. I will not present or publish in any medium OpenDeID corpus:
        (i)   where an individual research participant can or may be identified.
        (ii)   concerning groups of less than five research participants, unless prior written permission has been granted by UNSW Sydney.
    d. I will not link or attempt to link the OpenDeID corpus with personally identified or potentially identifiable data from a secondary data source.
    e. I will take all reasonable measures to prevent unauthorised use or disclosure of the OpenDeID corpus, including keeping my username and password secure. Account access, login or password details will not be shared with others. If I suspect or learn that the security of my username and/or password has been compromised in any way, I will immediately change my password and inform UNSW in writing of the event.
5. I will only reproduce or publicly disseminate de-identified, aggregate-level statistical reports obtained from analysis of the OpenDeID corpus if the following requirements are satisfied:
    a. I have gained approval from at least one of the OpenDeID Study Chief Investigators regarding any proposed reproduction or public dissemination.
    b. I have appropriately cited the source of the OpenDeID corpus. The preferred citations are:
        • Jonnagaddala, J., Chen, A., Batongbacal, S., & Nekkantti, C. (2021). The OpenDeID corpus for patient de-identification. *Scientific reports*, *11*(1), 1-8.
        • Chen, A., Jonnagaddala, J., Nekkantti, C., & Liaw, S. T. (2019). Generation of surrogates for de-identification of electronic health records. In *MEDINFO 2019: Health and Wellbeing e-Networks for All* (pp. 70-73). IOS Press.
        • Alla, N. L. V., Chen, A., Batongbacal, S., Nekkantti, C., Dai, H. J., & Jonnagaddala, J. (2021). Cohort selection for construction of a clinical natural language processing corpus. *Computer Methods and Programs in Biomedicine Update*, *1*, 100024.
    c. I have included a statement that UNSW researchers bear no responsibility for the further analysis or interpretation of the OpenDeID corpus.
6. I must not disclose, reproduce, or distribute the OpenDeID corpus to a third party either in whole or in part (whether incorporated with other data or information), except as provided in section 3 or with the written prior approval of UNSW.
7. I accept that the access and use of the OpenDeID corpus is solely at my own risk and I agree to indemnify UNSW from and against any liability that UNSW may have to any party, including research participants, to the extent that the liability arises from or in connection with any act or omission of my own conduct.
8. UNSW provides no warranty and accepts no responsibility for the accuracy and completeness of the OpenDeID corpus.

9. I acknowledge and accept that all rights, title, and interest in the OpenDeID corpus, including intellectual property rights, remains the property of UNSW.
10. I acknowledge that any breach of these conditions may result in UNSW immediately terminating my access and use of the OpenDeID corpus.

I confirm that I have read and agree to comply with sections 1-10 of the OpenDeID corpus Terms and Conditions listed above when accessing and using the OpenDeID corpus.

Chief investigator
Title & Full Name:
Qualifications:
Institution/School:
Work email address
Preferred contact number (including area code):

Signature:
Date:

Co-Investigator
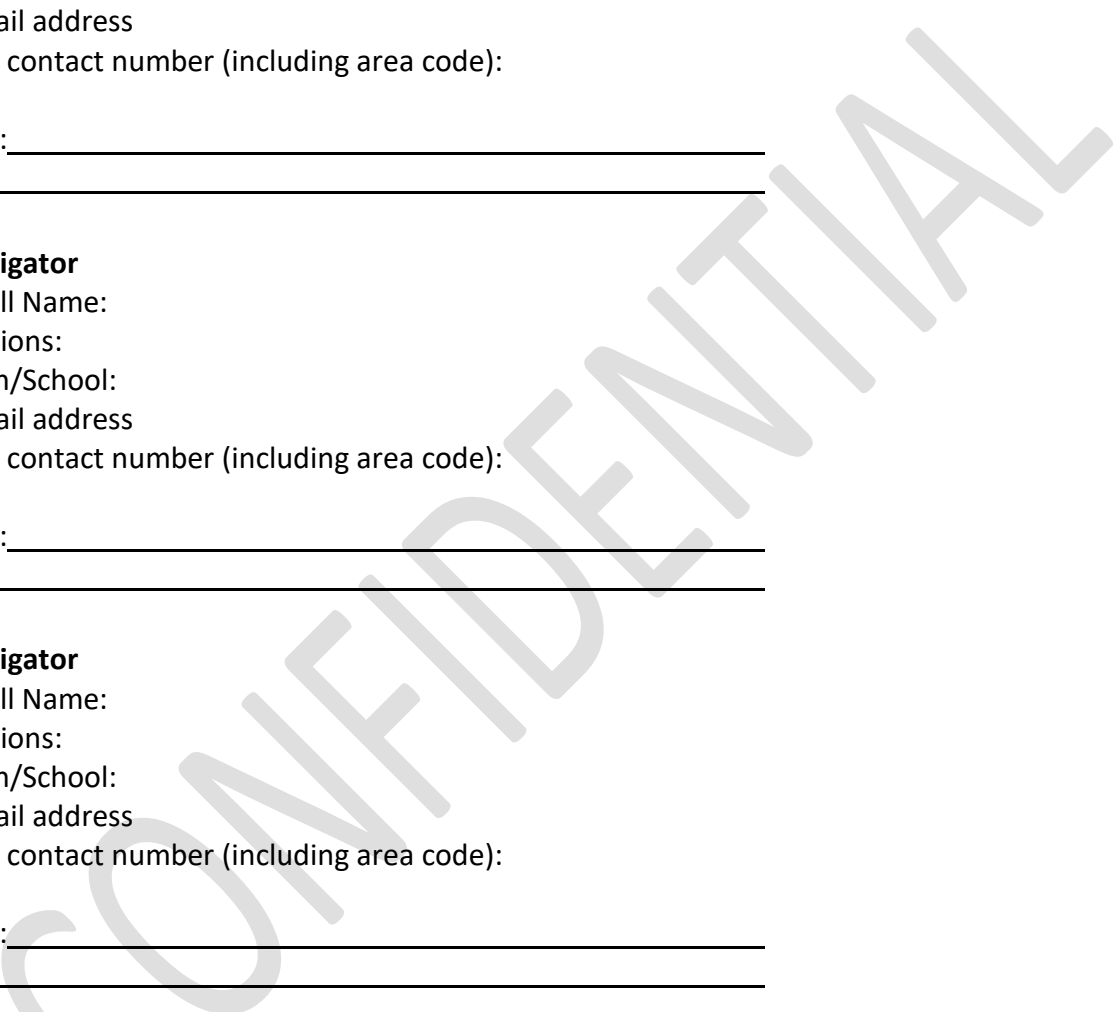Title & Full Name:
Qualifications:
Institution/School:
Work email address
Preferred contact number (including area code):

Signature:
Date:

Co-Investigator
Title & Full Name:
Qualifications:
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Preferred contact number (including area code):

Signature:
Date:

Student Investigator
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Work email address
Preferred contact number (including area code):

Signature:
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Student Investigator

Title & Full Name:

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Institution/School:

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Student Investigator

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Qualifications:

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Work email address

Preferred contact number (including area code):

Signature: _____

Date: _____

Student Investigator

Title & Full Name:

Qualifications:

Institution/School:

Work email address

Preferred contact number (including area code):

Signature: _____

Date: _____

Student Investigator

Title & Full Name:

Qualifications:

Institution/School:

Work email address

Preferred contact number (including area code):

Signature: _____

Date: _____

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1   http://www.tcrn.unsw.edu.au/translational-bioinformatics

2   https://www.sredhconsortium.org/