|  |  |
| --- | --- |
|  | Questions are followed by answer fields. Use the ‘Tab’ key to navigate through. Replace Y/N or Yes/No fields with your answer. |
| Northern Territory Cancer Registry (NTCR) |
| Purpose of this formThis form is required when you are requesting access to **unit record** data (where each row contains details about a single person or cancer) from the Northern Territory Cancer Registry (NTCR). Under the [NT Cancer (Registration) Act](https://legislation.nt.gov.au/Legislation/CANCER-REGISTRATION-ACT-2009)[[1]](#footnote-1), the NTCR Registrar can release aggregate data without the approval of the NT Chief Health Officer (CHO). The data release and subsequent use are also governed by the [NT Information Act](https://infocomm.nt.gov.au/about-us/the-information-act)[[2]](#footnote-2), [Information Privacy Principles](https://infocomm.nt.gov.au/privacy/information-privacy-principles)[[3]](#footnote-3), [NT Public Service Code of Conduct](https://ocpe.nt.gov.au/working-in-the-public-sector/code-of-conduct)[[4]](#footnote-4) and [Department of Health Privacy Policy](https://digitallibrary.health.nt.gov.au/prodjspui/handle/10137/726)[[5]](#footnote-5).The NTCR Registrar will first assess the research project against the [Five Safes framework](https://www.aihw.gov.au/about-our-data/data-governance/the-five-safes-framework)[[6]](#footnote-6) then recommend to the CHO whether a data release should be approved. The NT Cancer Registrar will also consider: * The format in which the data are requested **as well as** the format in which the data will be reported
* Whether all the requested variables are available for release
* Whether it will be necessary to group variables due to small numbers
* Whether the data request is beyond the current resource capacity of the NTCR
* Whether a Human Research Ethics Committee (HREC) application has been approved, and whether it explicitly states which identifiable or re-identifiable variables (e.g. names, HRN, address/locality, date of birth, date of death) are requested
* Anticipated reporting outcomes and composition of the HREC granting approval, as outlined in the table below.
 |
| **Reporting outcomes** | **Specific HREC requirement** |
| NT data will be reported separately | Must have [NT Health and Menzies School of Health Research (NT HREC)](https://www.menzies.edu.au/page/Research/Ethics_approval/)[[7]](#footnote-7) approval |
| NT data will not be reported separately | May be the Researcher’s home institution HREC or [NT HREC](https://www.menzies.edu.au/page/Research/Ethics_approval/)[[8]](#footnote-8) |
| Data will be reported by Indigenous status | Must be [NT HREC](https://www.menzies.edu.au/page/Research/Ethics_approval/) or a HREC with appropriate Indigenous representation and capacity to assess ethical issues relating to such research |
| Once the approval is granted, the data will be forwarded to you by secure electronic file transfer. Please **complete** this form and email to NTCancerRegistry.DoH@nt.gov.au with any HREC documentation. |
| Section 1: Safe people |
| About the person making the request |
| Name |  | Position |  |
| Organisation |  |
| Address |  |
| Suburb |  | State |  | Post code |  |
| Phone |  | Email |  |
| Section 2: Safe projects and safe settings |
| Briefly describe the project and scope of the data request - only complete applicable parts |
| Project name |  |
| **Data request scope** (inclusion and exclusion criteria, such as cancer type, data period, age coverage) |
|  |
| **Will NTCR data be linked to any other data which you have access to?** If so, please provide details |
|  |
| Section 3: Safe data and safe outputs |
| Data items required – browse the [NTCR Data Item List](https://health.nt.gov.au/__data/assets/excel_doc/0008/714059/NTCR-data-item-list.xlsx)[[9]](#footnote-9) for available data fields |
|  |
| Section 4: Conditions of data release |
| The following conditions of data release apply:1. The data will only be used for the purpose specified in this data request form.
2. The data will be deleted at the end of the analysis period, in line with your institutional data retention policy.
3. The privacy of individual records included in the data file must be respected. No attempt will be made to re-identify any record.
4. The NTCR will be notified of any completed &/or published reports within 30 days.
5. An acknowledgement of NTCR will be included in any resulting publications including internal reports and student theses.

I am aware of, and agree to abide by the conditions of the data release as listed above: |
| Name |  |
| Signature |  | Date |  |
| Privacy statementThe Northern Territory Government values and is committed to protecting your privacy. We handle your personal information in accordance with the information privacy principles in the [*Information Act 2002*](https://legislation.nt.gov.au/en/Legislation/INFORMATION-ACT-2002)*[[10]](#footnote-10)*. We will only use personal information contained in the forms to provide you with a department service or program. We don't share information about you with other government agencies or other organisations without your permission unless:* it's necessary to provide you with a service that you have requested
* it's required or authorised by law
* it will prevent or lessen a serious and imminent threat to somebody's health.
 |
| End of form |

1. https://legislation.nt.gov.au/Legislation/CANCER-REGISTRATION-ACT-2009 [↑](#footnote-ref-1)
2. https://infocomm.nt.gov.au/about-us/the-information-act [↑](#footnote-ref-2)
3. https://infocomm.nt.gov.au/privacy/information-privacy-principles [↑](#footnote-ref-3)
4. <https://ocpe.nt.gov.au/working-in-the-public-sector/code-of-conduct> [↑](#footnote-ref-4)
5. https://digitallibrary.health.nt.gov.au/prodjspui/handle/10137/726 [↑](#footnote-ref-5)
6. https://www.aihw.gov.au/about-our-data/data-governance/the-five-safes-framework [↑](#footnote-ref-6)
7. https://www.menzies.edu.au/page/Research/Ethics\_approval/ [↑](#footnote-ref-7)
8. <https://www.menzies.edu.au/page/Research/Ethics_approval/> [↑](#footnote-ref-8)
9. https://health.nt.gov.au/\_\_data/assets/excel\_doc/0008/714059/NTCR-data-item-list.xlsx [↑](#footnote-ref-9)
10. https://legislation.nt.gov.au/en/Legislation/INFORMATION-ACT-2002 [↑](#footnote-ref-10)