**ADDENDUM TO EPIC-NORFOLK**

**DATA REQUEST**

Request Date: \_\_ / \_\_ / \_\_

Name: ………………………………………………………………………................................................

Original Data Release ID: EN..………………………………………………...........................................

Supervisor Name (if applicable):.…………………………………… Signed: ……………………………..

**I agree to the terms of data release and use specified on this form (see reverse):**

Signature of researcher making data request:

Signed: ………...……………………………………………….. Date:…………………………………

This new data request falls within the scope of the original

Data request and the data will be used for the same purpose. Yes No

\* If “No” please fill in a new data request form as this is classified as a new data request

**Reason for extension**:

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**Additional variables required** (write below or attach a list including the variable name and [data dictionary ID](https://www.epic-norfolk.org.uk/cgi-bin/dictionary?FMT=topterms)):

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Expected number (if known) n= …………..

**Discoverability of the resource**

Please indicate below how you became aware of the EPIC-Norfolk resource:

Scientific publication / data access statement [ ]

Conference presentation [ ]

EPIC-Norfolk website [ ]

Via collaborators [ ]

Other [ ], please specify:

**TERMS OF DATA RELEASE AND USE**

Your signature on this form guarantees that you will maintain the data securely and that you will limit access to the data to those described above for analyses within the stated purpose. You will not make any copies of this data or transfer to third parties. No other use of this information is permitted without first seeking further approval from the EPIC-Norfolk Management Committee (or their delegates). Any released information is confidential and should not be disclosed to any other parties under any circumstances without additional approval. Please quote the Unique Identifier for your release in all subsequent correspondence.

Where data is accessed on SRCP, **you guarantee that your assigned individual user account is kept confidential and not shared with anyone else under any circumstances**, including collaborators listed on this request. Each individual must only use their own user account.

The EPIC-Norfolk study follows participants through medical record linkage with NHS England. Data processing prior to release aggregates the data by groups of ICD codes and converts dates to tenth of year. This data is then available for requests only if the numbers in the groups are large enough. The aggregated data will be disseminated with small numbers suppressed in line with the HES analysis guide.

**CONDITIONS FOR THE USE OF DATA**

Datasets provided for one project should not be used for another unrelated project. Permission must be sought to continue using data in the event of any change to your institution circumstances (e.g. leaving your institution or changing institutions).

**ACKNOWLEDGEMENTS**

All publications must be published in line with the [UKRI Open Access Policy](https://www.ukri.org/publications/ukri-open-access-policy/). Please provide the EPIC-Norfolk team with a copy of any papers published on EPIC-Norfolk data and any press releases related to publications.

Please use the following when acknowledging the EPIC-Norfolk study:

“The EPIC-Norfolk study (DOI 10.22025/2019.10.105.00004) has received funding from the Medical Research Council (MR/N003284/1 MC-UU\_12015/1 and MC\_UU\_00006/1) and Cancer Research UK (C864/A14136). The genetics work in the EPIC-Norfolk study was funded by the Medical Research Council (MC\_PC\_13048). We are grateful to all the participants who have been part of the project and to the many members of the study teams at the University of Cambridge who have enabled this research.”

**DERIVED DATA**

Any new derived data points generated from the approved project data must be shared with the EPIC-Norfolk study team so they can be incorporated into the study database where appropriate, and added to the EPIC-Norfolk data dictionary.

**DESCRIPTION OF YOUR REQUEST ON THE EPIC-NORFOLK WEBSITE**

To reduce inadvertent duplication, information about approved data requests will be made public on the EPIC-Norfolk website. Published information will comprise the title of the proposed analysis, your name and research institution.

**HELP AND INFORMATION ABOUT THE STUDY AND THER DATA COLLECTED**

The website contains a great deal of background information about the study [www.epic-norfolk.org.uk](http://www.epic-norfolk.org.uk). A web based [data dictionary](https://www.epic-norfolk.org.uk/cgi-bin/dictionary?FMT=topterms) describing all EPIC-Norfolk variables is available to help collaborators make a selection. The EPIC-Norfolk team can help collaborators who are unfamiliar with the study, email [epic-norfolk@mrc-epid.cam.ac.uk](mailto:epic-norfolk@mrc-epid.cam.ac.uk)

**CONFIRMATION**

I confirm that I have read and understood the information outlined in this data request form [ ]