UK CF Registry

Data Request Form

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| **UK CF Registry data request form** |
| All requests for data or information from the UK CF Registry must be submitted on this form to registry@cysticfibrosis.org.uk . Before starting a request please make sure you have read the UK CF Registry Data Sharing Policy, available at [Cystic Fibrosis Trust UK CF Registry](https://www.cysticfibrosis.org.uk/sites/default/files/2023-08/UK%20CF%20Registry%20Data%20Sharing%20Policy_July%202023_V2.0.pdf) |

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|  | **I/We have read the UK CF Registry Data Sharing Policy** |

# Lead Applicant

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| **Full name** | **Job title** | **Institution**  | **Email address** |
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| **Date of Request** |
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# Research team

*Provide details of everyone in the research team requesting data. Add more rows to the table if required.*

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| **Full name** | **Job title** | **Institution**  | **Email address** |
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| **Title of project / research question** |
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| **Plain English summary** (100 words max)*If your request is granted this and the title of your project will be published on* https://www.cysticfibrosis.org.uk/the-work-we-do/uk-cf-registry/apply-for-data-from-the-uk-cf-registry |
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| **Description and rationale of project**  |
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| *Part 1 – Introduction & background (including short rationale)* |

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| *Part 2 – Methods (for individual patient level data request please provide a summary of your methods. If requesting aggregate data please describe how you intend to use the data)*  |

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| **Intended dissemination of project results** *Including anticipated publications, presentations or reports* |
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| **Name and qualifications of person performing the statistical analysis**  |
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| **Please name any funding bodies that are supporting this work. This should include names of pharmaceutical companies where relevant** |
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|  | **Check this box if no funding has been received to support this work** |

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| **Exact details of data required** |
| Year(s) required: |  |
| Variables required: *(Demographic Pro forma /**Annual review Pro forma)* |  |
| Expected Completion Date: |  |

# *Please note it may take up to 8 weeks to extract, prepare and provide data following approval of a request*

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| If your data request is approved, we would be grateful if you could send the registry copies of any papers or abstracts where this data has been used |

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| *[[1]](#footnote-1)Checklist Pre-Review* | *Date* | *Initials* |
| *Research team includes CF Professional?* |  |  |
| *Is there sufficient methodology?* |  |  |
| *Does request meet all GDPR guidelines for data transfer?* |  |  |
| *Are all variables requested available in registry?* |  |  |

1. FOR OFFICE USE ONLY [↑](#footnote-ref-1)