

FFFAP Data Bundle

Guidance for submitting data application requests

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How to apply for data that is not publicly available

- The Falls and Fragility Fracture Audit Programme (FFFAP) has <u>publicly available data</u> for healthcare professionals and academic institutions to access for research and analysis purposes. If the data you need are not available, please submit an FFFAP Expression of Interest (EOI) form which can be downloaded <u>here</u>.
- Projects should have been suitably researched at this point and ethical approval status known. Some projects not covered under existing
 FFFAP approvals from the <u>Confidentiality Advisory Group (CAG)</u> may require a standalone CAG approval by the applicant.
- > EOIs will be reviewed by the Scientific and Publications committee and next steps advised.
- > There are several levels of data that are not publicly available, each of which depends on the complexity of information that you require and involves a slightly different application process.
- > This document will provide an explanation of each of the 4 levels of non-publicly available data, enabling you to understand the steps you will need to take to complete your request.
- Please also note that there may be financial costs associated with data requests. These will include costs by RCP for processing and support of your application, costs for processing the extract by our database provider and by HQIP & NHSE (data controllers) who own the FFFAP data. Please check their <u>website</u> for details.



Level One: Request for non-public national data and hospital site data

- If you wish to access a small amount of anonymous and aggregate information that has not yet been published by the project please contact <u>HQIP</u> or <u>FFFAP@rcplondon.ac.uk</u>. These requests may not require the completion of a Data Access Request Form (DARF).
- If your application is for aggregated non-public site level data, you will be required to complete a Data Access Request Form (DARF) and follow the process highlighted in the introductory webpage here: <u>https://www.rcplondon.ac.uk/guidelines-policy/applying-work-fffap-data</u>



Level Two: Request for non-public unlinked anonymised patient level data

- It is important to consider whether or not you need patient identifiable information as these requests are more complex and take longer. E.g. Will age suffice for date of birth? Would death status at a given time point be a feasible alternative to date of death?
- If you require patient level data, you may need to apply for section 251 approval. Section 251 is an agreement with the Health Research Authority which enables organisations to collect data without consent in specific circumstances where there is a public benefit. Find out if you need a section 251 approval <u>here</u>.
- FFFAP datasets are available on the project webpages (<u>NHFD</u>, <u>NAIF</u>, <u>FLS-DB</u>). These will enable you to find the data item you need and what it includes.
- You <u>may</u> be required to complete a Data Access Request Form (DARF) and follow the process highlighted in the introductory webpage here: <u>https://www.rcplondon.ac.uk/guidelines-policy/applying-work-fffap-data</u>



Level Three: Request for unlinked data from FFFAP Database

- You may need to apply for section 251 approval. Section 251 is an agreement with the Health Research Authority which enables
 organisations to collect data without consent in specific circumstances where there is a public benefit. Find out if you need a section
 251 approval <u>here</u>.
- You <u>may</u> be required to complete a Data Access Request Form (DARF) and follow the process highlighted in the introductory webpage here: <u>https://www.rcplondon.ac.uk/guidelines-policy/applying-work-fffap-data</u>

Level Four: Request for linked data to external dataset (ONS, HES, PEDW and other organisations)

- You may need to apply for section 251 approval and/or complete a DARF as detailed above.
- To obtain ONS data you need to be an approved ONS researcher, information about training to become approved can be found here



Data Sharing Agreement

- Once you have completed all the relevant and necessary applications (EOI/DARS/section 251/other), and they have been
 approved by the relevant organisations, you will be sent a Data Sharing Agreement (DSA) which is your agreement for the
 provision of your requested data.
- Data will only be released under a binding DSA, detailing the purposes of analysis, and must be returned or destroyed at the end of the period specified. Exploratory analysis is not permitted.
- Send your completed DSA to the project to process your data request.



Your responsibilities

- > Once the data has been obtained, the applicant's responsibilities include:
- > updating FFFAP on projected publication date of any materials to be published, whether written or oral
- > providing a near-final draft of any materials to be published, whether written or oral, for review and comment
- > acknowledging FFFAP in all work whether written or oral
- > agreeing to be identified in the online database of previous and ongoing projects
- > providing twice yearly written updates of progress to FFFAP.
- > Destroying the data at the end of the specified agreements in line with the conditions included in the DSA.

