### FFFAP Data Bundle

·FFAP improvement

Guidance for submitting data application requests



Falls and Fragility Fracture Audit Programme (FFFAP)

#### How to apply for our data

- > The Falls and Fragility Fracture Audit Programme (FFFAP) has a wealth of <u>publicly available data.</u>
- > 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 these levels and the steps required to complete your request.
- > If the data you need are not available, please submit an <u>Expression of Interest (EOI) form</u>. Projects should have been suitably researched at this point and ethical approval status known. Some projects may require a standalone <u>Confidentiality Advisory Group</u> approval by the applicant.
- > EOIs will be reviewed by the FFFAP Scientific and Publications committee within 4 weeks, feedback provided and next steps advised.
- > It is important to note that there may be financial costs associated with data requests. These will include costs by RCP for processing and support of your application, for processing the extract by our database provider and by HQIP & NHSE (data controllers) who own the FFFAP data. Please check their website for details.

#### Your responsibilities as a data applicant

- > Once the data has been obtained, your 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.

#### Level One: Request for non-public national or 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 complete the EOI form and contact <a href="fffap@rcp.ac.uk">FFFAP@rcp.ac.uk</a>.
- Please note mortality data for NHFD is obtained through NHS England linked data and therefore a level four request.
- If your application is for aggregated non-public site level data, you will be required to first complete and send the EOI form then complete a Data Access Request Form (DARF) and follow the process highlighted in the introductory webpage here: <a href="https://www.rcplondon.ac.uk/guidelines-policy/applying-work-fffap-data">https://www.rcplondon.ac.uk/guidelines-policy/applying-work-fffap-data</a>

#### Level Two: Non-public unlinked anonymised patient level data

- If you require patient level data, <u>you will</u> need to apply for <u>section 251 support</u> for your application. 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.
- 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 will also be required to complete an EOI and Data Access Request Form (DARF) and follow the process highlighted in the introductory webpage here: <a href="https://www.rcplondon.ac.uk/guidelines-policy/applying-work-fffap-data">https://www.rcplondon.ac.uk/guidelines-policy/applying-work-fffap-data</a>

## Level Three: Request for unlinked, identifiable, patient-level data from FFFAP Database

- > Before applying for this level of data, it is important to consider whether or not you need patient identifiable information as these requests are more complex and take longer. For example, instead of asking for DOB would knowing the age suffice for date of birth; or would death status at a given time point be a feasible alternative to knowing date of death.
- > If you require patient level data, you <u>will need</u> to apply for <u>section 251 support</u> for your application. 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.
- > You will also be required to complete an EOI and Data Access Request Form (DARF) and follow the process highlighted in the introductory webpage here: <a href="https://www.rcplondon.ac.uk/guidelines-policy/applying-work-fffap-data">https://www.rcplondon.ac.uk/guidelines-policy/applying-work-fffap-data</a>

# Level Four: Request for identifiable, patient-level data or linked data to external dataset (eg Civil Registration data, HES, PEDW and other organisations)

- > For this level of data, you <u>will need</u> to apply for <u>section 251 support</u> for your application. 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.
- > You will also be required to complete an EOI and Data Access Request Form (DARF) and follow the process highlighted in the introductory webpage here: <a href="https://www.rcplondon.ac.uk/guidelines-policy/applying-work-fffap-data">https://www.rcplondon.ac.uk/guidelines-policy/applying-work-fffap-data</a>
- > To obtain Civil Registration data you need to be an approved researcher, information about training to become approved can be found <a href="here">here</a>

#### Data sharing agreement

- Once you all the relevant and necessary have been completed and 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 the data must be returned or destroyed at the end of the period specified. Exploratory analysis is not permitted.
- Send your completed DSA back to us at <a href="mailto:fffap@rcp.ac.uk">fffap@rcp.ac.uk</a> to process your data request.