



[REDACTED]

14 July 2023

Dear [REDACTED],

Freedom of Information request: FOI2023/00245

Thank you for your Freedom of Information request received on the 2 May, and subsequent clarification received on 1 June, in which you requested the following:

Your request:

The MRC has supported ME/CFS research through a cross-board highlight notice since 2003. UKRI provides on its website data about funded research projects from 2004–2017: <https://www.ukri.org/publications/mrc-chronic-fatigue-syndrome-research-projects-2004-to-2017/>

I am kindly requesting that you provide:

- (i) updated data on funded projects in this area covering the period 2004–present (May 2023), preferably by sharing an updated version of the XLSX spreadsheet linked above.*
- (ii) information on unfunded/rejected proposals in this area for the same period (2004–present), to include statistics on the number of rejected proposals each year, and any available information on individual rejected proposals.*

Data/information on funded and unfunded/rejected proposals should include all funding types—i.e., fellowships, grants, and other funding that doesn't fit into either category.

The MRC's ME/CFS highlight notice (<https://www.ukri.org/opportunity/researching-me-cfs-highlight-notice/>) was recently updated to include information on the ME/CFS Priority Setting Partnership (ME/CFS PSP) themes. Therefore, I am also requesting [(iii)] any information and documents pertinent to this update—such as external correspondence with PSP stakeholders and internal documents/correspondence relating to the ME/CFS PSP and MRC's strategy and outlook on ME/CFS funding—since the priority themes were published online in May 2022.

Clarification:

I would like you to proceed with the first part of my request—i.e., parts (i) and (ii)—as this information should be relatively easy and quick to extract and summarize. A suitable spreadsheet already exists for (i) and simply needs updating. For (ii), a spreadsheet, in the manner of (i), of unfunded/rejected proposals will suffice, and the addition documents for (ii) can be limited to proposal/project summaries.

With regards to the second part of my request, a key word search for "highlight notice" will return results that aren't within scope, because there are other MRC highlight notices (such as for motor neuron disease). Therefore, I would like MRC to conduct a keyword search for "ME/CFS highlight notice" and to reevaluate the amount of information returned.

If the information returned still exceeds the statutory limits, I am happy to restrict the scope of this request to meeting minutes and documents where the MRC's strategy on ME/CFS and/or the ME/CFS highlight notice is discussed (from May 2022 to present).

Our response:

I can confirm that UK Research and Innovation (UKRI) hold information relevant to your request. Please see the information below and attached.

(i) updated data on funded projects in this area covering the period 2004–present (May 2023)

Please see the attached spreadsheet “*MRC-291121-CFSMEResearchProjectsFrom2004To201617k - 2017 to 2023*”.

(ii) information on unfunded/rejected proposals in this area for the same period (2004–present), to include statistics on the number of rejected proposals each year, and any available information on individual rejected proposals

Please see attached document “*FOI2023 00245 MECFS Applications Summary 2002-03 to May 2023*”.

To note, the information contained in this document is based on the date the application was assessed at the relevant board/panel meeting and in some instances a successful project may have started in the following financial year. We have therefore included data of applications that were assessed in 2002/03, as the projects of both successful applications were not started until 2003/04.

In addition, as indicated in the spreadsheet of funded projects, one project is an extension of another and is not considered a separate award. The extension did not go through the same application process and subsequently, is not recorded as a successful, or unsuccessful, application in this summary document.

(iii) any information and documents pertinent to this update—such as external correspondence with PSP stakeholders and internal documents/correspondence relating to the ME/CFS PSP and MRC's strategy and outlook on ME/CFS funding—since the priority themes were published online in May 2022

Please find attached document “*FOI2023 00245 Email Correspondence_Redacted*” which contains email correspondence related to the ME/CFS highlight notice update. There are also three attachments relevant to these documents, which we have included:

- “*PSMB March 2023 - ME-CFS update*” – attachment of email dated 2 March 2023 on page 2
- “*Funding Opportunity - ME CFS Highlight notice update Jan 2023*” – linked in email dated 2 February 2023 on page 11
- “*ME CFS Strategy page update 2023*” – linked in email dated 2 February 2023 on page 11

We have redacted any information that is not relevant to the update of the highlight notice, as it is out of scope of your request. We are also exempting the names and contact information of individuals under section 40(2) of the FOIA. Disclosing this information would contravene the first Data Protection Principle as defined under Section 86 of the Data Protection Act 2018 and Article 5 of UK General Data Protection Regulation (UK GDPR).

Section 40(2) is an absolute exemption and does not require a public interest test.

Also attached is “*FOI2023 00245 Highlight Notice References Extracted_Redacted*”, which contains extracts of various meeting minutes where the ME/CFS highlight notice update was discussed. This document lists the meeting at which the topic was discussed, the date when it occurred and relevant extract from the minutes. In all cases the remainder of the meeting minutes was deemed out of scope of your request, as they held no relevance to the update of the highlight notice.

If you have any queries regarding our response or you are unhappy with the outcome of your request and wish to seek an internal review of the decision, please contact within the next 40 working days:

Head of Information Governance
Email: foi@ukri.org

Please quote the reference number above in any future communications.

If you are still not content with the outcome of the internal review, you may apply to refer the matter to the Information Commissioner for a decision. Generally, the ICO cannot make a decision unless you have exhausted the review procedure provided by UKRI. The Information Commissioner can be contacted at: www.ico.org.uk.

If you wish to raise a complaint regarding the service you have received or the conduct of any UKRI staff in relation to your request, please see UKRI's complaints policy: <https://www.ukri.org/about-us/policies-and-standards/complaints-policy/>

Yours sincerely,


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