

Researcher Toolkit

Supporting high quality applications in ME/CFS research



Background

- Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a poorly understood, complex and debilitating medical condition.
- Rates of research funding in ME/CFS in the UK are low. More high-quality research proposals in this area are needed.
- In 2022, the [top 10+ ME/CFS research priorities](#) were identified by people with ME/CFS, their carers and clinicians
- This slide set contains links to resources to support researchers in developing high quality research applications to submit to research funders.
- This resource was developed by the government funders of research in ME/CFS, academic researchers and persons or representatives of persons/groups with lived experience of ME/CFS through the [UKCRC Research Working Group](#).
- This document focusses on the UK government research funding. Information on [charitable funding for ME/CFS research](#) is available via the charity websites.

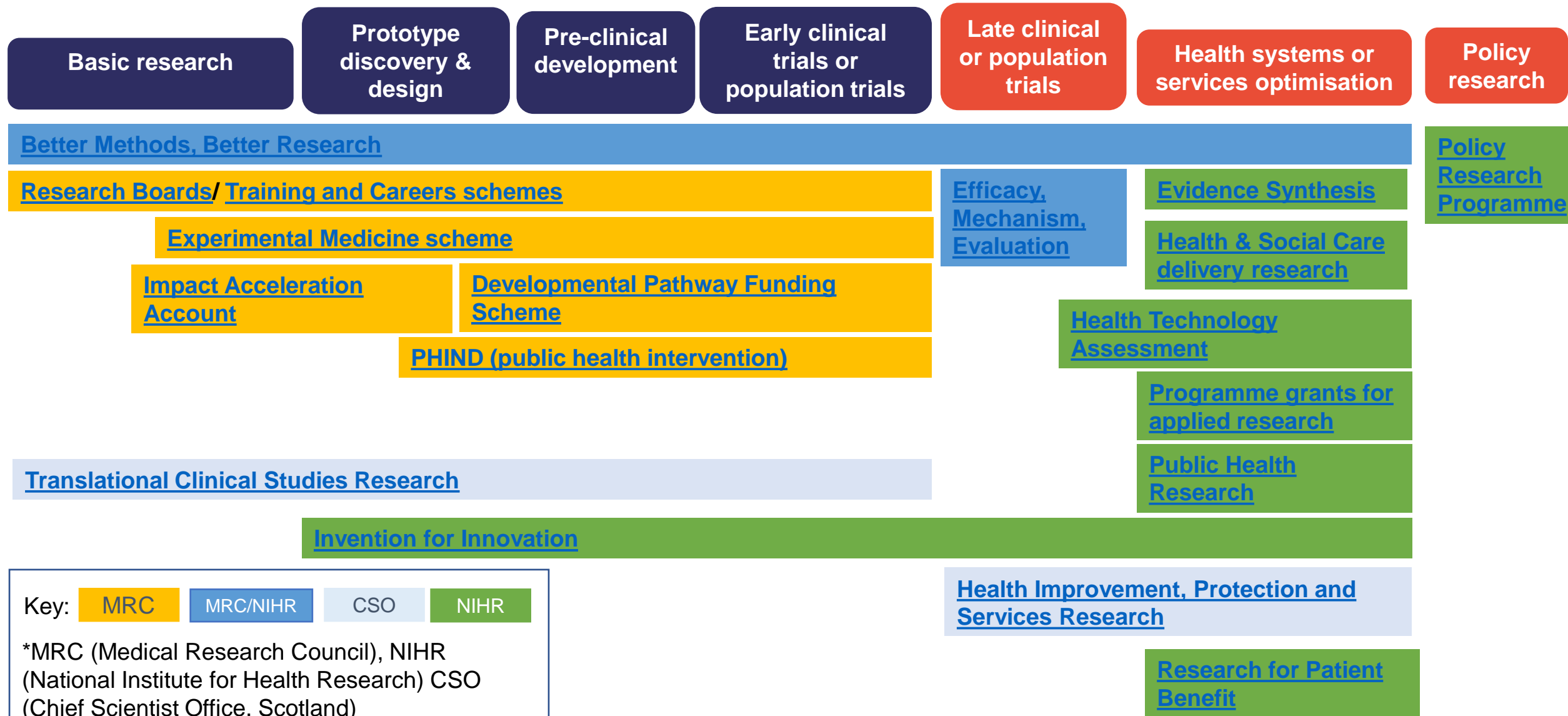
Funding opportunities for ME/CFS research

- This [spreadsheet](#) contains a list of funding opportunities* for which ME/CFS research is eligible across a variety of career stages
 - Applicants are encouraged to contact the funder at any point in the application process for advice and support. Contact information for each funding stream can be found on the relevant funding opportunity webpage.
- Slide 4 of this Toolkit shows an overview of funding opportunities by research type across 3 UK Government funders
- In addition, the following two opportunities are of relevance to ME/CFS research:
 - The NIHR are looking to receive applications for research studies addressing JLA PSPs' research priorities, which includes the [top 10+ ME/CFS research priorities](#). Please see here for more information [22/161 NIHR James Lind Alliance Priority Setting Partnerships rolling call \(EME Programme\) | NIHR](#) and the [NIHR NICE rolling call \(HSDR Programme\)](#).
 - To help encourage high-quality research applications in ME/CFS research, applications submitted under the [MRC ME/CFS highlight notice](#) will receive prioritisation for funding against other applications attaining the same median ranking score
- A broader map of health and innovation funding can be found here: <https://iuk.ktn-uk.org/programme/health-funding-map/>

**Only standing schemes are included, not one-off or strategic calls for funding*

Funding opportunities for ME/CFS research

Overview of research funding available by Research Type across three UK Government funding bodies*



Embedding public, patient and carer involvement (PPI) in research

- Research benefits from including people from outside the research community in a process of shared learning. This may be described in a variety of ways: co-production, collaboration or participant and public involvement.
- Public involvement in research can:
 - Improve the quality of research
 - Make research more relevant
 - Help define what is acceptable to participants
 - Improve the process of informed consent
 - Improve the experience of participating in research
 - Improve the communication of finding to participants and the wider public
- In developing your proposal, suitable resources for public and patient involvement and engagement activities should be requested.

Resources: Embedding public, patient and carer involvement & engagement in research

Public and Patient Involvement and Engagement (PPIE) resources

UK Standards for Public Involvement

[UK-Standards-for-Public-Involvement_Nov19.pdf](#)

PPI resources for applicants (NIHR)

Including standards, guidance for researchers, payment and recognition, co-production and evaluation

[PPI \(Patient and Public Involvement\) resources for applicants to NIHR research programmes | NIHR](#)

Public engagement (UKRI)

Guidance on engaging the public with your research.

[Public engagement – UKRI](#)

Stakeholder engagement – Patients and the public (UKRI)

Including advice on what to consider and what resources will be required.

[Patients and the public – UKRI](#)

Principles for meaningful involvement of patients and the public in health and social care research from the Health Research Authority

[Public Involvement - Health Research Authority \(hra.nhs.uk\)](#)

Briefing notes for researchers (NIHR)

Guidance is for researchers new to public involvement in research and just starting to consider how best to involve members of the public in their work

[Briefing notes for researchers - public involvement in NHS, health and social care research | NIHR](#)

National Co-ordinating Centre for Public Engagement

Supporting universities to increase the quality and impact of their public engagement activity. Guidance and best practice recommendations on how to plan, fund, deliver and evaluate public engagement activities.

[NCCPE \(publicengagement.ac.uk\)](#)

Resources: Embedding public, patient and carer involvement & engagement in research

Specific considerations for ME/CFS research

Involving people with ME and other energy limiting conditions

[Involving People with ME and Other Energy Limiting Conditions - A guide by the World ME Alliance](#)

How to enhance your ME research by involving People with ME as advisors and participants

[How to enhance your ME research by involving People with ME as advisors and participants](#)

Language use in relation to ME/CFS - a personal perspective

[Language used in relation to ME/CFS - A personal perspective plus implications for researchers](#)

Involving the Severely and Very Severely Affected ME/CFS patient voice in research

[Ensuring the Voice of the Very Severely Affected Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Patient Is Heard in Research - A Research Model \(mdpi.com\)](#)

Key principles of Co-production in the DecodeME study

Details on how people with lived experience were involved in the co-production of an ME/CFS research project

[DecodeME: community recruitment for a large genetics study of myalgic encephalomyelitis / chronic fatigue syndrome - PMC \(nih.gov\)](#)

Resources: Embedding public, patient and carer involvement & engagement in research

Getting involved in research

Clinical trials

How to find and get involved with clinical trials

[Clinical trials - NHS \(www.nhs.uk\)](http://www.nhs.uk)

[Taking Part in a Clinical Trial | MRC Clinical Trials Unit at UCL](#)

Taking part in Medical Research (MRC)

Including how to give permission for your health information to be used, taking part in population based studies and tissue and brain donation.

[Taking part in medical research – UKRI](#)

I want to help with research (NIHR)

Including how to suggest a research question, giving opinion on potential research, becoming a research champion and joining a committee

[I want to help with research | NIHR](#)

DecodeME

Learn about the world's largest ME/CFS study

[Home page – DecodeME](#)

Be Part of Research (NIHR)

Find out about health and social care research taking place in England, Northern Ireland, Scotland and Wales.

[Be Part of Research \(nihr.ac.uk\)](http://nihr.ac.uk)

SHARE

SHARE is an NHS Research Scotland initiative. It has been created to establish a register of people, aged 11 and over, interested in participating in health research.

[SHARE | RegisterforSHARE](#)

Resources: Developing high quality proposals

Grant writing

How to prepare a strong application for funding (NIHR)

Advice on how to plan and develop your research application, and the support available to you

[Make a strong application | NIHR](#)

12 top tips for writing a grant application (MRC)

[12 top tips for writing a grant application – UKRI](#)

MRC New Investigator Research Grants

Guidance on writing applications for Early Career Researchers

[New investigator research grant \(NIRG\) – UKRI](#)

Working with industry

NIHR Support for Industry

Information on support the life sciences industry to translate innovations into the health and care system and on to market.

[Industry | NIHR](#)

MRC Industry Collaboration Framework

Supports applicants submitting collaborative research projects between academic and industry researchers,

[MRC Industry Collaboration Framework \(ICF\) – UKRI](#)

Resources: Developing high quality proposals

Research design and regulatory support

MRC Regulatory Support Centre

Provides support and guidance for those conducting research with human participants, their tissues or data.

[MRC Regulatory Support Centre – UKRI](#)

UKRI's Good Research Resource Hub

Policies, standards and guidance to support researchers, innovators and organisations.

[Good research resource hub – UKRI](#)

MRC Health Data Access Toolkit

Helps researchers navigate the processes required to access routinely collected NHS Health Data

[Health Data Access Tool Kit \(hda-toolkit.org\)](#)

MRC and LifeArc Medicines Repurposing Toolkit

Outlines steps in the repurposing pathway and signposts useful information, including sources of funding, and contacts.

[Repurposing medicines - Home](#)

NIHR Research Design Service

Support to health, social care and public health researchers across England on all aspects of developing and writing a funding application, including research design, research methods, identifying funding sources and involving patients and the public

[Research Design Service | NIHR](#)

NC3R's Experimental Design Assistant

A free online tool designed to guide researchers through the design of their experiments, helping to ensure that they use the minimum number of animals consistent with their scientific objectives, methods to reduce subjective bias, and appropriate statistical analysis.

[The Experimental Design Assistant - EDA | NC3Rs](#)

Resources: Developing high quality proposals

Clinical Trials

NIHR Clinical Trials guide

[Clinical Trials Guide | NIHR](#)

Identifying the appropriate funding source for your clinical study or trial

MRC and NIHR work in collaboration to provide a spectrum of funding opportunities for clinical studies and trials. This information is designed to help applicants identify the most appropriate funding scheme for their proposed clinical study

[MRC-200123-MRCNIHRProgrammeComparisonTable.pdf \(ukri.org\)](#)

NIHR Clinical Trials Toolkit

The NIHR provides a clinical trials toolkit that gives practical advice to those planning or running clinical trials in the UK.

<https://www.ct-toolkit.ac.uk/>

Clinical trials guidance pack

Produced by the UK Trails Methodology Research Partnership, the guidance pack contains publications, guidance documents, resources and recommendations for trialists.

[Network Hubs :: Guidance pack \(mrc.ac.uk\)](#)

Resources: Developing high quality proposals

Research resources

UK ME/CFS Biobank

An open resource for clinical and biomedical research into ME/CFS, and in particular for research into biomarkers of the disease. It empowers research into the diagnosis, prognosis, and stratification (sub-grouping) of ME/CFS, enabling a wide range of research studies in an extremely cost-effective manner.

[The UK ME/CFS Biobank – CureMe \(Ishtm.ac.uk\)](https://www.ishtm.ac.uk/research/uk-me-cfs-biobank)

DecodeME

The world's largest ME/CFS study which aims to find genetic causes of why people become ill with ME/CFS

[Home page - DecodeME](https://www.decode-me.com/)

Experimental medicine initiative to explore new therapies (EMINENT)

a unique collaborative network able to access GSK's clinic ready portfolio to enable experimental medicine studies aimed at enhancing understanding of disease mechanisms and accelerating development of novel therapeutics for patients in under-served disease areas.

[Experimental Medicine Initiative to Explore New Therapies \(EMINENT\) | EMINENT CONSORTIUM - UCL – University College London](https://www.eminent-consortium.com/)

The Nucleic Acid Therapy Accelerator (NATA)

Provides dedicated research capability, infrastructure and support to enable advances in the development of nucleic acid therapeutics.

[NATA - Nucleic Acid Therapy Accelerator \(natahub.org\)](https://www.natahub.org/)

Resources: Developing high quality proposals

Research resources

The MRC-AstraZeneca Centre for Lead Discovery

to support academic researchers in discovering potential starting points for small molecule medicinal drugs. Academic researchers could benefit from unprecedented access to over two million molecules in AstraZeneca's compound library, as well as its state-of-the-art, high-throughput screening facilities and industry expertise.

[Develop new approaches to small molecule medicine – UKRI](#)

MRC Cohort Directory

The cohort directory is a collection of UK population cohorts. The aim of the directory is to signpost users to individual cohorts to maximise the use and translation of findings of these valuable UK assets.

[Cohort directory – UKRI](#)

UK Health Data Research Innovation Gateway

The UK Health Data Research Innovation Gateway as a search-engine or 'portal' to help you find health datasets that exist in the UK, but also associated health data resources such as tools, research projects and publications.

[HDRUK Innovation Gateway | Homepage \(healthdatagateway.org\)](#)

UK Health Data Research Alliance

an independent alliance of leading healthcare and research organisations united to establish best practice for the ethical use of UK health data for research at scale

[UK Health Data Research Alliance \(the 'Alliance'\) | UKHDRA](#)

Resources: Developing high quality proposals

Useful information

UKRI Gateway to Research

Searchable UKRI funded research projects

[GtR \(ukri.org\)](https://ukri.org)

MRC peer review process

An overview of the MRC peer review process, how reviewers are selected and how to conduct a peer review.

[Peer reviews – MRC – UKRI](#)

UKRI funding finder

All UKRI funding opportunities

[Opportunities – UKRI](#)

Suggest a research topic (NIHR)

[Suggest a research topic | NIHR](#)

NIHR Funding and Awards

Search for and analyse information on NIHR supported activity in health and care research, including expenditure and research findings

[Search - NIHR Funding and Awards](#)

Resources: Educational material

Engaging the public, patients and carers in research

NICE Guideline for ME/CFS (2021)

[Overview | Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management | Guidance | NICE](#)

Explaining Post-exertional malaise (PEM)

[\(1\) Post Exertional Malaise \(PEM\) - YouTube](#)

NICE research recommendations for ME/CFS (2021)

[Recommendations for research | Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management | Guidance | NICE](#)

Report by the All-Party Parliamentary Group on Myalgic Encephalomyelitis (2022)

[Rethinking-ME-a-report-by-the-APPG-on-ME-2022.pdf \(appgme.co.uk\)](#)

Defining future ME/CFS research (full report from the ME/CFS Priority Setting Partnership) (2022)

[The full report - ME/CFS Priority Setting Partnership \(psp-me.co.uk\)](#)

[Final Report design appendices \(psp-me.co.uk\)](#)