

Pain research data hub

Opportunity status:	Open
Funders:	Medical Research Council (MRC), Economic and Social Research Council (ESRC), Biotechnology and Biological Sciences Research Council (BBSRC)
Co-funders:	Versus Arthritis, Eli Lilly and Company UK
Funding type:	Grant
Total fund:	£2,000,000
Maximum award:	£2,000,000
Publication date:	7 December 2020
Opening date:	7 December 2020
Closing date:	25 February 2021 16:00 UK time

Last updated: 8 December 2020

Start application

Apply for funding to set up a pain research data hub.

The hub will be part of the UKRI and Versus Arthritis Strategic Priority Fund (SPF) Advanced Pain Discovery Platform. It will underpin original research by providing innovative new data assets for pain research in areas of need. It will not support original research directly.

You must be a UK research organisation eligible for Medical Research Council funding. This includes:

- higher education institutions
- approved independent research organisations
- approved NHS bodies
- research council institutes.

Your proposal must show:

- appropriate scientific and clinical leadership
- a track record of using health data for public benefit
- the ability to process health data for research and innovation
- a commitment to patient and public involvement.

Funding is available for the development of one hub over three years. We'll cover 67% of the full economic costs.

We expect the hub to develop into an ongoing national resource for pain research.

Close all

Who can apply

This funding opportunity is open to applicants from eligible UK-based organisations in accordance with standard UKRI/Versus Arthritis practice.

See our general guidance for applicants for more details on institutional and individual eligibility.

Applications must demonstrate:

- appropriate scientific and clinical leadership
- a track record of the use of health data for public benefit
- the ability to process health data for research and innovation
- that the hub will deliver a national service that will be financially sustainable in the long-term.

Recognising the value of regional data sets and leadership it is expected that proposals involve multi-institutional collaboration. However, proposals must be submitted by a single lead organisation.

Institutions may be partners to more than one application but should only act as the lead institution for one.

At least one member of the partnership must have a demonstrable track record in acting as a data custodian with the ability to make data accessible for research, development and innovation taking place across academia, industry and the NHS.

We strongly encourage collaboration across sectors, including NHS organisations, academia, industry and other partners. Collaborations with industrial partners should be managed via an MRC industry collaboration agreement.

You can also include international co-investigators if they provide expertise that is not available in the UK. We expect a demonstrable commitment to patient involvement in the development and implementation of the Data Hub.

The Pain Research Data Hub is expected to start before 01 June 2021.

What we're looking for

Specification of the pain research data hub

This call for funding is to support the establishment of a pain research data hub over three years. It is anticipated that the hub will continue to grow in scale and ambition beyond the three years, evolving into a sustainable coordinated and integrated national resource for pain research.

It is expected that the data hub will:

- act as a centre of excellence for curation of pain research data at scale and provide UK wide expert research data services. This includes working in close partnership with the APDP consortia and other APDP investments to bring their data into the hub for curation, linkage and wider community access
- create consistent policies and governance frameworks for data access and sharing across the APDP programme and maximise interoperability across the APDP investments
- improve the discoverability, quality, breadth, depth and utilisation of datasets and provide a repeatable curation approach or open source tooling that can be used to enable UK-scale research and interoperability across key data sets
- develop and maintain an appropriate infrastructure that enables data sharing, linkage and analysis
- create world-leading data sets and make these discoverable and accessible to researchers and other users to help improve our understanding of the underlying mechanisms, and the associated biological, social and economic factors, that contribute to pain
- the hub will be expected to define key research focus areas and needs that will drive its strategic approach to data selection. For greater insight into the opportunities and ambitions of the APDP, our community survey will be published on our webpages shortly
- provide services to meet the needs of researchers, NHS, industry, charities, innovators and ultimately people with pain and the public
- be national in outreach, engaging key data custodians and users across the APDP's consortia, related research projects and more broadly, and facilitate pain research data science across sites and regions
- be clearly driven by strong exemplar cases that demonstrate the potential to improve treatment approaches and enable novel insights into pain mechanisms not currently possible without data at this scale
- improve secure access to data at a broader policy level through membership of the UK Health Data Research Alliance (the 'Alliance') and use of the UK Health Data Research Innovation Gateway (the 'Gateway')
- harness opportunities to work across the HDR UK Hub network and link to/complement relevant existing investments, nationally and internationally
- embed patient and public involvement in development, governance and operation of the hub to ensure it is driven by the needs of people with lived experience of pain
- have strong leadership, deep domain expertise and governance, including plans for including people with pain and members of the public in decision-making and

governance and how the hub will ensure that research outcomes from its work are linked to patient benefits

- contribute to efforts for harmonisation of procedures for prospective measurement of pain in studies (including cohorts and longitudinal studies) and measurement of outcomes
- be designed with capacity to evolve and respond to changing needs and opportunities, bring in additional funding and grow in ambition. Incorporate plans for sustainability of the investment, including through grants, industry investment and service provision
- meet delivery milestones and to sign up to the Digital Innovation Hub Programme Principles for Participation – this includes the FAIR data principles (Findable, Accessible, Interoperable and Reusable).

The purpose of the hub is not to perform original research itself, but to underpin research activities supported through other routes. The funding available to applicants will create 'data as infrastructure' through the creation of new data and services that improves access to and quality of data and increases the UK's future research and innovation capability.

Timeline for hub delivery

Milestone one: hub established (within three months of becoming a hub)

- make datasets available in accordance with the principles for participation and discoverable through the Gateway
- provide a description of the number of datasets, and their scale and quality
- demonstrate the hub physical environment is operational
- set out a plan for public and patient involvement in the hub's work, specifically including issues around access to, use of and security of patient data.

Milestone two: service delivery (within 18 months of becoming a hub)

- evidence that the quality of the datasets has been improved (curated) and that the curated data is discoverable through the Gateway
- provide publishable enhanced service case studies (e.g. from industry, academia and NHS) that demonstrate impact (and expected impact) and value to researchers and innovators from a range of sectors, and to people with pain and populations
- focusing on building towards a sustainable business model for the hub; Provide evidence that public involvement is at the centre of the hub's governance processes, that the hub is implementing its plan for meaningful public and patient involvement and demonstrate its effects on the hub's activities.

Milestone three: impact, sustainability and scalability (within two and a half years of becoming a hub)

 evidence enhanced service delivery through additional publishable case studies that demonstrate further impact and value to researchers, innovators, people with pain and populations

- evidence a sustainable business case to support the future service offering of the hub
- provide evidence that the hub's plan for meaningful public and patient involvement continues to be delivered effectively, and involves and engages people with pain and the public.

Additional funding conditions

The funded Hub will be expected to adopt Principles of Participation and subscribe to HDR UK values and policies, including EDI and attribution policies. The funded Hub will be expected to align with branding and communications guidelines that will be set out in the award offer letter.

Funding available

A joint UKRI/Versus Arthritis investment of £2 million over three years is available to support the establishment of the pain research data hub. **Please note given this investment is a partnership between UKRI and Versus Arthritis, awards will be made at 67% FEC.**

Organisations are encouraged to use and build on existing infrastructure and assets (for example, Safe Havens) where appropriate. The funding will not support building work or other significant capital expenditure.

While the hub will be able to apply to MRC for renewed funding for a further three years (where milestones have been achieved), this will be through a competitive process and a clear plan for the hub becoming self-sustaining after this period should be evidenced.

Funding requests may include:

- investigators' salaries the Principal Investigator, Co-Investigators and Researcher Co-Investigators can request funds to cover their salary costs for the time spent on setting up and managing the Hub
- other costs consumables, sub-contractors and other costs directly related to the project, including costs related to linking up with other APDP activities
- costs supporting PPI
- travel and subsistence travel and subsistence enabling members to meet to exchange ideas and expertise. This may include visits by or to experts overseas. Industrial collaborators should meet their own travel costs
- administrative support funding for administrative support can be requested to help in the coordination of the pain research data hub. Reasonable costs for monitoring and dissemination of the hub's output can also be included. Costs to cover any 'Admin Support' can be requested under either 'Other Staff' or 'Other Directly Allocated Costs, depending on the costs being claimed as either Directly Incurred or Directly Allocated
- other staff funding only for staff who will be dedicated to the establishment of the hub, or whose time working on the project can be fully supported by an auditable record for its duration
- funding for pool staff or for staff whose time will be shared with other projects/activities and will not be supported by an auditable record should be

requested under the Other Directly Allocated Costs heading

 the hub should also budget for contribution to HDR UK central costs (for the Gateway, Alliance and Hub coordination) which is estimated at £100k p.a.

For a full account of grant costs please see the <u>MRC Guidance for Applicants</u>. Please note that this hub investment will not support direct research activities into pain.

When developing costings, applicants should take careful note to differentiate the hub's activities from existing funding for related work by the members of the application.

Collaborations are encouraged where these add value to the hub, for example in terms of access to expertise, data, technologies or funding.

We strongly encourage collaborations with an industrial partner(s). You and your potential collaborator(s) are advised to refer to the guidance on <u>MRC Industry</u> <u>Collaboration Agreements (MICAs)</u>. MICAs are the mechanism by which academic-industrial collaborations can apply to the MRC.

How to apply

Please email the Intention to Submit form found below to <u>spfpain@mrc.ukri.org</u> by **16:00, 29 January 2021.** This is mandatory. Proposals will not be accepted from applicants who have failed to provide an intention to submit.

Please include the names of the Principal Investigators, Co-investigators, and any collaborating organisations confirmed at this stage. This is to help us manage conflicts at the panel assessment stage and will not involve any expert assessment.

The full proposal should be submitted via Je-S by **16:00**, **25 February 2021**. The proposal should consist of a completed Je-S form and the following attachments:

Case for support (max 12 sides A4)

The case for support forms the main body of your proposal and should contain the following sections:

- an overview of the hub including its vision, goals, key partnerships and interfaces and expected outputs
- the datasets to be included within the hub. This should describe the datasets that will be brought together under the APDP initiative and linked to the HDR UK Alliance over the course of the award and include the data custodians, modes and sizes of datasets (number of records, populations covered), the current quality of the data (coverage, completeness, validity, timeliness and accuracy) and the environment in which they are currently stored (process and governance for access).

- please describe why these datasets are particularly valuable for research and innovation and which datasets will be immediately ready to become part of the Alliance and discoverable through the Gateway, including the associated metadata to support discoverability
- describe the technical infrastructure, including demonstrating that the level of security and Safe Haven capability that you host/have access is appropriate for the data and services that the hub will be providing
- the curation approach that you will be using the improve the quality of the datasets and what improvements these will enable. Please describe what new research and innovation uses will be created by this improvement in quality, supported by evidence for the demand
- the expert services that will be provided in the hub and the distinct value that the hub will provide to academic users, industry, and other users
- the unmet demand for the curated data and services that the hub will provide should be clearly described, including how the hub will be driven by continuous assessment of user needs
- positioning in the wider landscape: how the proposed hub will add value to, and build on, existing investments and activities. Describe how the services provided by the hub will be uniquely valuable, address a currently unmet need and provide additional capability over and above the existing components of the national data and pain research landscape
- delivery feasibility and risk management. This section should describe how the delivery milestones laid out in the above section will be met. This answer should be supported by an overall project plan (Gantt Chart – separate attachment) and a discussion of the risks with mitigating actions. Describe the project management process that will provide assurance that the delivery milestones and goals will be achieved
- capabilities and partnership. This section should describe the leadership team and key roles, including a named hub Director and a named Chief Data Officer. Each will be expected to have a track record of working with and across organisations and sectors to deliver common goals and objectives, and of building deep collaborative partnerships.
- demonstrate the leadership team's expertise and track record in governance, management systems and achieving outcomes at pace in clinical digital research and innovation. We recognise the diversity of skills necessary for a successful team and encourage proposals to recognise the contribution of technical professionals.
- this section should also describe how clinical leadership will be a part of leadership and governance to ensure decisions on data and services are benefiting people with pain, the NHS and public. How the hub will harness the partnership capabilities to deliver outcomes that could not be achieved by a single organisation
- governance and management. Describe how the Lead Organisation will govern and manage the partnership and how the partnership will deliver to meet user timescale expectations. Describe the systems, processes and organisational behaviours in place to provide assurance that data will be secure and that all access will be appropriate, proportionate and subject to robust governance in line with National Data Guardian and Information Commissioner's Office recommendations;

- the partnership's track record in engaging and involving members of the public, including those with lived experience of chronic pain, in health data research and the underpinning data services. The partnership's plan for public and patient involvement and engagement, detailing how people with pain will be involved in governance of the hub, including developing systems for and decisions about access to, use and security of patient data;
- The outreach plans of the hub to facilitate impact and drive improvement of the hub through user feedback
- How the hub will work in partnership with other hubs in the HDR UK network and other components of the national data infrastructure to deliver a national offer in line with the HDR UK's Principles for Participation
- the physical environment the partnership will provide as a hub base to support collaboration and innovations across a range of users (e.g. data scientists, clinicians) from industry, NHS and academia
- your plan for sustainability of the hub (through, for example, a robust portfolio of grant funding, service charges, commercial funding) while continuing to adhere to the Principles for Participation and a commitment to open access of methodologies, code and findings.

Justification of Resources

Maximum two sides of A4

Gantt chart

 Maximum one side of A4 – including a project plan and risk register with mitigating actions

Data management plan

 this is a mandatory attachment – however, given that its anticipated content should be contained within the Case for Support, please upload a blank attachment

CVs and list of publications

 CVs (max 2 sides A4) and list of publications (max 1 side A4) for the Principal Investigator and each Co-Investigator

Letters of support from Project Partners and Collaborators

MICA form and Heads of Terms (if applicable)

 these attachments apply to applications with an industrial project partner. Please read the MRC guidance to understand if this applies to your proposal

All proposals must be completed and submitted through the Je-S system by **16:00**, **25 February 2021**.

All applications need to be submitted through the lead Research Organisation (RO) which in turn must be Je-S registered. All applicants should consult the team responsible for proposal submissions at their RO to confirm how much time they will need to process the application and complete the submission process.

Please leave enough time to ensure that all Co-I's are fully registered on the system, this process from start to finish can take up to a month. Any public or patient collaborators should be included as project partners.

Should applicants require assistance with any Je-S related matter, please contact the Je-S Helpdesk:

Email: JeSHelp@rcuk.ac.uk

Phone: +44 (0) 1793 44 4164

The Je-S Helpdesk is staffed Monday to Friday 08:30 – 17:00 (excluding bank holidays and other holidays).

If you have a query about the scientific aspects of your proposal, please contact spfpain@mrc.ukri.org

Creating your Je-S application

Please note that the call will be available to select on Je-S from **01 December 2020**.

All investigators (Principal Investigator and Co-Investigators) are required to have a verified Je-S account type. New Je-S users should select <u>Create Account –</u> <u>Terms and Conditions</u> to commence the create account process and gain access to the Je-S system.

Please follow the steps below.

- 1. login to Je-S, select 'Documents' from your account 'Home' page and then select 'Add New Document'
- 2. select MRC as the Council
- 3. select Standard Proposal as the document type
- 4. select: SPF Advanced Pain Discovery Platform Call for establishment of a Pain Research Data Hub
- 5. select Create Document.

How we will assess your application

All eligible proposals that are in scope of the call will be reviewed and assessed by a specially convened independent, multidisciplinary expert panel against the criteria below.

The panel will include representatives from a range of fields, including patient representation, and will be a joint panel with the current call for a Mental Health Data Hub. Shortlisted applicants will receive feedback and be invited to attend a virtual interview with the panel in April 2021.

Interview dates will be updated on this webpage when confirmed. Decisions will be confirmed shortly after.

Applicants invited to interview will be required to give a presentation (using Microsoft PowerPoint and no more than 20 minutes). Up to five people representing the application can attend the interview, ensuring appropriate coverage across multiple partners.

After the interview there will be 20 minutes of questions, which will be based on the application, the panel feedback from the shortlisting stage and the presentation. The criteria by which hub applications will be assessed are summarised below.

Scope and vision

- clarity of vision, including clearly specified goals and expected outputs that align with the scope of the call and will accelerate the use of health data for research and innovation
- evidence of plans to work in close partnership with the APDP consortia and other APDP investments to bring their data into the hub for curation, linkage and wider community access, including plans for consistent policies and governance frameworks for data access and sharing to maximise interoperability across the APDP investments
- clearly positioned in the wider landscape and providing additional unique capability
- evidence that the proposed hub, the data it plans to gather and the resources it will provide are guided by the needs of users and stakeholders, including people with pain and the public
- evidence that the proposed hub will gather data that aim to improve our understanding of the mechanisms of pain and allow improved access to wellphenotyped human populations.

Feasibility and quality

- importance of the unmet needs to be addressed and how these will be continually assessed to shape the hubs strategy
- appropriateness and feasibility of the proposed approach
- evidence that plans for curating data will improve the quality of existing data for research and innovation
- evidence of access to the distinct data to be made discoverable through the HDR UK Gateway to complement existing national datasets and investments.

Impact and engagement

- coherent plans for making hub data and services nationally available to users for research and innovation taking place across academia, industry, the NHS and charities
- evidence that the applicants provide an existing physical environment of crosssector collaboration, with strong relationships with multiple key stakeholder groups and academic consortium members to support research and innovation
- quality of the plans for meaningful patient and public involvement throughout the award, including plans to allow access to data
- potential for economic and societal impact that would otherwise not be possible without the establishment of a Research Data Hub.

Leadership, management and governance

- convincing and coherent leadership, management and governance plans.
 Evidence of the team's scientific and clinical leadership, an effective integration of expertise and skills and a track record of the use of health data for research, innovation and public benefit.
- quality and feasibility of plans to involve key stakeholders, people with pain and members of the public in the governance of the hub.
 Demonstration that the context for hub delivery, including the environment, will be suitable.
- quality of the approach to management, including identification and evaluation of risks with appropriate mitigations in place.
- appropriate identification and management of ethical issues.
- clear evidence of hub sustainability planning
- justification of resources requested and value for money.
- clear confirmation that the hub will become a member of the UK Health Data Research Alliance, adhere to the <u>Principles for Participation</u>, and adhere to all of the existing terms of access for the data.

Contact details

If you have a query about the scientific aspects of your proposal, please contact spfpain@mrc.ukri.org

For queries regarding the direction of the APDP, please contact Prof. David Walsh, APDP Director, at <u>david.walsh@mrc.ukri.org</u>

Additional info

Background

Chronic pain is a major unmet global public health challenge and can have a devastating effect on the lives of those it affects and those around them. It is estimated that up to 20% of the UK population suffer chronic pain. As a result, this also represents a major challenge for the UK economy.

To help address this challenge, a multidisciplinary approach is needed to generate a better understanding of the underlying mechanisms, as well as associated biological, social and economic factors that contribute to pain. As a result, the hope is to develop improved treatments that will ultimately improve the lives of people living with pain conditions and their families.

The <u>Advanced Pain Discovery Platform</u> (APDP) is a 5 year, £24 million initiative funded through the Government's Strategic Priorities Fund and delivered in partnership through MRC, ESRC, BBSRC, Versus Arthritis and Eli Lilly. The APDP aims to deliver a consortium-based platform of national scale, generating discovery

and early translational science that will break through the complexity of pain and reveal new treatment approaches to address a wide spectrum of pain conditions.

As a part of the UKRI/Versus Arthritis SPF Advanced Pain Discovery Platform (APDP) initiative we are launching a call for proposals to establish a pain research data hub that will be embedded within the broader infrastructure and network of Health Data Research UK.

The aim of the data hub as a platform is two-fold. Firstly, it will work to bring together, curate and improve existing data sets that are valuable to the chronic pain research community.

Secondly, the data hub will be central to all data and results generated from across the APDP investments, including the large consortia and research programmes. This will provide a key national resource for the pain research community to tackle the long-term research challenges in understanding the complexity and unpredictability of pain and reveal new and improved treatments across diverse chronic and debilitating pain conditions.

The pain research data hub will work in partnership with each of the APDP investments to facilitate working across different types of data (molecular, cellular, phenotypic, administrative, health, social data etc) and will support industry partnerships, thereby helping to drive translation to health improvements.

Health Data Research UK (HDR UK) was established in 2017 and is the national institute for health data science. It aims to unite the UK's health data to enable discoveries that improve people's lives. This call is for funding to establish the pain research data hub within HDR UK, providing complementarity activities to the existing portfolio of Health Data Research Hubs.

Embedding the data hub within the established infrastructure of HDR UK provides a number of benefits, not least the access to a range of relevant expertise and the opportunity to participate in the development of standardised processes to improve safe access to health data and data linkages.

The hub will adopt the HDR UK brand, offering a trustworthy approach for the public that is recognised by industry and at a national level in policy development. Partnership with other hubs in the network will also be facilitated, providing opportunities to share best practice and deliver collaborative projects.

About HDR UK – UK Health Data Research Alliance & Innovation Gateway

The UK Health Data Research Alliance was established in February 2019. The purpose of the Alliance is to bring together and facilitate partnership working across NHS organisations and other health data custodians, leading to an ethical, consistent approach to data provision and public engagement.

The Alliance coordinates the identification and adoption of standardised tools, techniques, conventions and technologies for the use of healthcare data for research and innovation in a trustworthy way. The members agree, with public participation, best practice and standards for governance and privacy. The Alliance

is working closely with NHSX, NHS Digital and NHS bodies in the devolved nations to support the alignment of policy for health data research.

The Data custodian organisations that contribute to the Pain Research Data Hub will be required to become members of the Alliance, adhering to Alliance principles of participation. In this way, membership of the Alliance will continue to grow, and the new data assets produced by the hub will be discoverable and accessible through the common <u>UK Health Data Research Innovation Gateway</u> (the 'Gateway').

The UK Health Data Research Innovation Gateway provides a common access point for industry, academia and NHS for discovering, accessing, linking and analysing data for research and innovation. This includes national aggregated data (from existing Alliance members) and new curated data provided by hubs and other members of the Alliance.

The Gateway supports interoperability, common standards and secure data provision across the hubs. The Gateway contains no personal identifiable information (PII). All PII is retained by the Data custodians to ensure General Data Protection Regulation compliance.

The Gateway is underpinned by a consistent governance framework. It links with Safe Havens (also known as Trusted Research Environments) which provide secure access to de-identified data for further analysis of sensitive data within the NHS. It provides opportunities for research and innovation, in a safe and ethical manner, that protects privacy and creates a range of possibilities for linking this data with others to develop even greater insight.

The Pain Research Data Hub will be funded as a part of the UKRI/Versus Arthritis Advanced Pain Discovery Platform, however it is expected to align with the overall vision of Health Data Research UK and to become part of its wider network. This involves aligning with the **Principles of Participation** and contributing to the Alliance and the Gateway. This approach builds on the Digital Innovation Hub scheme funded by MRC through the Industrial Strategy Challenge Fund.

The newly-established Pain Research Data Hub will be expected to work collaboratively with the other Health Data Research Hubs in a single UK-wide network and with other components of the relevant national health data landscape.

Supporting documents

Intention to Submit form

Timeline

O 7 December 2020 Competition opens

- O 29 January 2021 16:00 Mandatory intention to submit deadline
- O 25 February 2021 16:00 Full proposal deadline
- O Mid-March 2021 Shortlisting panel
- O Mid-March 2021 Invitations to interview
- O Late March 2021 Interview panel
- O 1 June 2021 Latest hub start date

Related content

MRC Advanced Pain Discovery Platform (APDP)

Related opportunities

Mental health data research hub

NOTE This is the first phase of our new website – let us know if you have **<u>feedback</u>** or would like to <u>**help us test new developments**</u>.

© 2020 Copyright UKRI Cookie policy Privacy notice Terms of use