

November 2021

Working with HDR UK – a briefing for AMRC charity members

As users of data to create insights for policy work, and as funders of research that generate data, there are many ways that AMRC members could work with HDR UK. Here we have set out some current opportunities, but we welcome discussions to understand your ambitions for health data and how we could work collaboratively to delivery them.

1. Support wider discovery and access to datasets relevant to your disease area

The [Health Innovation Gateway](#) is a portal enabling researchers and innovators in academia, industry and the NHS to search for and request access to a wide range of datasets. Getting data funded by your charity onto the Gateway can increase its findability and wider use by other researchers, supporting open science and increasing impact and utility of research you've funded.

- Identify datasets in your portfolio that have wide potential for reuse and connect the data owners with HDR UK to explore making the dataset findable on the Gateway. This can be done at any stage of the research lifecycle, including making it a condition of funding.
- Work with HDR UK to create a [Collection of resources](#) that are relevant to your disease area. We can work together to promote its use to a wide community of researchers.
- Join us for one of our Gateway Open door sessions to learn more – they are held every month [Gateway Open Door and Q&A: November - HDR UK](#).

Please contact gateway@hdruk.ac.uk to continue the discussion. The Gateway functionality is growing all the time to support federated data discovery across multiple platforms, a standardised data access request process, and a suite of other data science tools.

2. Explore what a Health Data Research Hub could do for your field

A [Data Research Hub](#) takes a national leadership role in curating and improving the quality and access of data in disease and topic areas.

- There are nine Hubs delivered in partnership with HDR UK, and we are working on a range of other Hubs in development. HDR UK has developed a suite of materials and resources to support the creation of new Hubs and can support the efficient design and set up of a data Hub. We welcome partnership with charities in exploring and designing Hubs in areas of unmet need.

Please get in touch with James.pickett@hdruk.ac.uk to explore building a Hub proposition in your disease area, working together to shape the purpose, case studies and potential sources of funding.

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3. Promote capacity building and training in your community

As the UK's national institute for health data science, we are committed to ensuring that health data scientists have the education and training they need for a flourishing future. We offer a cadre of opportunities from introductory to expert and can work to tailor activities for your community's needs.

- Promote [HDR UK Futures](#) to your community as a way to increase data science skills. HDR UK Futures is an expanding library of bitesize videos, tools and resources.
- Host a data intern as part of our [Black Internship Programme](#).
- Connect us with data science expertise in your community to develop new training materials.

Please get in touch with sarah.cadman@hdruk.ac.uk or learn@hdruk.ac.uk to discuss any specific training needs or challenges faced by your community.

4. Join the UK Health Research Alliance to shape health data ecosystem

Charities wishing to play an active role in shaping the health data research ecosystem could join the [Alliance](#), convened by HDR UK. Through different workstreams, the Alliance develops and co-ordinates the adoption of tools, techniques, conventions, technologies, and designs that enable the use of health data in a trustworthy and ethical way for research and innovation. All Alliance members agree to work together through an [agreed set of principles](#).

Please contact paola.quattroni@hdruk.ac.uk for more information about joining the Alliance.

5. Public and patient involvement and engagement

HDR UK works with and learns from the needs and experiences of members of the public and people using the health and care system. Patient and Public Involvement and Engagement (PPIE) is vital to our work.

- Please get in touch with HDR UK as you embed PPIE in data-specific work. Whilst the principles of involvement and engagement are relatively the same, we've gathered a lot of learnings about approaches and supporting our public contributors to get involved that are specific to data-specific work compared to other areas
- Share any case studies you have of PPIE with HDR UK– we are working on sharing best practice and different examples across the data community
- Please consider promoting our patient and public network, [HDR UK Voices](#) to your groups and panels as an opportunity to help shape and influence the growing and field of health data research
- Please ask your PPIE leads to get in touch with the team at involvement@hdruk.ac.uk so that we can keep them updated as HDR UK start to run regular shared learning events around PPIE in data science.

6. Something else?

Please don't hesitate to get in touch with any of the contacts listed above to explore something different. Subscribe to HDR UK mailing list to get regular updates on [activities and events](#).