EU Joint Programme – Neurodegenerative Disease Research (JPND) Joint Transnational Call (2023)

"Large scale analysis of OMICS data for drug-target finding in neurodegenerative diseases"

Guidance Notes

Guidance Notes

Key Dates & Times	
Application Open	4 January 2023
Application Closing Date	7 March 2023 @11:00

Applications must be completed and submitted through the JPND electronic submission system, and this system will close automatically at the stated deadline and timeline listed above.

This document provides additional guidance to researchers based in Ireland applying to this call as part of a transnational consortium. A summary of the call is presented herein along with eligibility criteria for Irish applicants requesting HRB funding.

This document must be read in conjunction with the call documents provided on the main JPND call webpage, and the HRB FAQ for this call on the HRB call website.

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1 Introduction

The Health Research Board (HRB) Strategy (2021-2025)[1] sets out a lead role for the HRB to invest in research that delivers value for health, the health system, society, and the economy, as well as to foster and enhance European and international coordination, collaboration and engagement. In the field of Neurodegenerative diseases, the HRB works closely with European partners within the EU Joint Programme for Neurodegenerative Disease Research (JPND) to better coordinate research efforts across countries and disciplines to more rapidly find causes, develop cures and identify better ways to care for people with neurodegenerative diseases.

Neurodegenerative diseases are debilitating and largely untreatable conditions that are strongly linked with age. Worldwide, there are estimated to be 50 million people with Alzheimer's disease and related disorders, the most common group of neurodegenerative diseases. This figure is expected to double every 20 years as the population ages. The total direct and informal care costs of Alzheimer's, Parkinson's and related disorders are expected to surpass €350 billion per year across the European Union. Existing treatments for neurodegenerative diseases are limited in effect and mainly address the symptoms rather than the cause or the progressive course.

Despite several remarkable achievements and advances in technology during the past years, the pathophysiology of neurodegenerative diseases remains elusive and not fully understood. It is becoming more evident from recent studies that diseases are complex and multifactorial which is a hurdle to discover novel therapies. Access to current data and biomaterials from animals and cellular models and patients and targeted acquisition of new data opens the opportunity to explore changes at epigenetic, transcriptomic, proteomic, metabolomic, and lipidomic levels in a more comprehensive way. The data obtained from multi-omics studies analysed with the methods of systems biology can further elucidate the connection between the contributing factors and disease pathophysiology. Additionally, the identified cellular changes from the multi-omics studies may be translated to animal and cellular models and to the human situation to study the disease mechanisms. This will permit novel strategies for validation of clinical therapeutic approaches.

For this reason, the EU Joint Programme - Neurodegenerative Disease Research (JPND) launches this joint transnational call with the aim to improve the understanding of the complex and multifactorial pathogenesis of neurodegenerative diseases through multi-OMICS and Big Data approaches designed to find new drug targets and target biomarkers for the development of tailored and personalised treatment approaches.

2 Aim and Objectives

The aim of the call is to establish a number of ambitious, innovative, multi-disciplinary and multi-national collaborative research projects that seek to improve the understanding of the complex and multifactorial pathogenesis of neurodegenerative diseases by applying multi-OMICs and Big data approaches in order to generate useful information for the diagnosis, treatment, prognosis, and drug discovery of neurodegenerative diseases.

[1] https://www.hrb.ie/strategy-2025/

3 Scope of Call

Proposals must focus on one or several of the following neurodegenerative diseases: Alzheimer's disease and other dementias, Parkinson's disease and PD-related disorders, Prion diseases, Motor neuron diseases, Huntington's disease, Spinocerebellar ataxia (SCA), Spinal muscular atrophy (SMA).

Proposals submitted under this call may include, but are not limited to, the following types of research:

- Using the potential from existing animal and cellular models and cohorts, including available data and biomaterial, for conducting large-scale OMICS approaches to unravel the interplay and interactions of molecules from multiple molecular levels driving disease pathogenesis.
- Better understanding the complex and multi-factorial mechanisms of disease onset and progression as well as the corresponding influencing factors.
- Translating the findings from Big Data analysis and multi-OMICS approaches to existing animal and cellular models, thereby enhancing the potential of these models.
- Identification of new drug targets or novel starting points for pharmacological interventions and prevention.
- Sharpening the current understanding of disease definition, thus leading to enhanced sub-classification and better patient stratification.
- Identification of novel and validation of already established biomarkers.

The research approaches should be integrative, combining relevant scientific approaches (e.g. clinical, epidemiological, molecular, experimental) and involve state-of-the art methodology and techniques. Proposals must be hypothesis-driven and should have a strong emphasis on reliable methodology. They should be based on mechanistic approaches rather than pure correlational research.

The potential of existing cohorts and data sets should be exploited. Projects should ideally aim at using state-of-the-art techniques based on existing biomaterials and complementing existing data sets. In preparation of the proposal it is encouraged to use European Research Infrastructure Networks such as EBRAINS (Brain research technologies), BBMRI (Biobanking and Biomolecular Resources Research Infrastructure), EATRIS (European infrastructure for translational medicine) or ECRIN (European Clinical Research Infrastructure Network) as valuable resources and platforms for knowledge exchange. Different platforms can be found via the European Strategy Forum for Research Infrastructures in Europe - ESFRI.

Proposals should have novel, ambitious aims and ideas combined with well-structured work plans and clearly defined objectives deliverable within three years.

Proposals should consider the diversity and differentiation of the target group in terms of factors like ethnic background, gender, age, socioeconomic situation, level of education, migration and cultural background, and sexual orientation, where it is relevant for the implementation of the project. For assessing the well-being of people suffering from neurodegenerative diseases, quality of life measures should be used.

Most patient-related research would be impossible without the active involvement of patients. Thus, JPND has determined that Patient and Public Involvement (PPI) should be an integrated part of the implementation of its Research and Innovation Strategy. Proposals to be funded under this call will therefore need to adequately involve patients, carers and the public. Consortia are expected to make every effort to include approaches that involve these groups, where appropriate, at each stage of the research process including the preparation of the application (see the JPND website and Appendices below for further information). In the application, it must be described in which step of the research process patients, their relatives or carers will be involved, from where they will be recruited and which roles they would play. This section will be evaluated by JPNDs PPI network. Appropriate justification must be given if such an approach is not taken.

To optimise benefit, data, tools and resources being generated within the research projects should be made widely available to the public domain, considering national and international legal and ethical requirements. Access must be provided to other bona fide research groups. Consortia are strongly advised to define arrangements to deal with this issue across countries, while preserving integrity of study participants as early as at the submission of the preproposal.

To have an impact at European and partner country levels, it is expected that all proposals will link activities across laboratories and clinics within JPND member countries. Proposals are encouraged to utilise expertise from areas outside of neurodegeneration research, which can bring innovation to the proposed research approach. The benefits of the multidisciplinary collaboration should be stated.

Irish Partner(s) are not eligible for HRB funding for:

- Proposals seeking to evaluate a pilot or feasibility study[2]
- Proposals seeking to evaluate a definitive intervention[3]
- Proposals involving basic biomedical research
- Research intended to create human embryos solely for the purposes of research or for the purposes of stem cell procurement, including by means of somatic cell nuclear transfer.

Where an application is outside the scope of the scheme, the application will be deemed ineligible and will not be accepted for review.

[2] **Feasibility studies:** For the purposes of this scheme, we adopt the concept of feasibility as described by Eldridge et al (2016). Eldridge describes 'feasibility' as an overarching concept, within which we distinguish between three distinct types of studies (1) randomised pilot studies (2) non-randomised pilot studies and (3) feasibility studies that are not pilot studies. This call is open to all types of stand-alone feasibility studies conducted in preparation for a future definitive trial of an intervention.

[3] **Definitive interventions: Intervention studies** of any appropriate design, including randomised controlled trials and non-randomised trials, are designed to assess the efficacy, effectiveness, cost and broad impact of a therapy or intervention. Interventions can be on individual human participants (patients or healthy volunteers), or alternatively could involve an intervention on an element of the health system, e.g. testing an intervention on healthcare setting, healthcare pathway, with the aim being to improve how healthcare is delivered. **Definitive interventions** should have potential for immediate use for decision makers in everyday clinical practice or policy, must have supporting feasibility information, and must have a basis in evidence that has been synthesised systematically.

4 Funding Available, Duration and Start Date

The HRB plans to commit in the region of up to **€370,000** (inclusive of overheads) to the JPND JTC2023 awards. Additional funding of up to €130,000 will be made available for coordination activities (excludes equipment and consumables), bringing the total maximum funding to **€500,000 for applicants who take on the role of coordinator**. Quality permitting a minimum of one award will be funded. Awards will have a duration of 36 months.

The award will offer research related costs for:

a) Personnel
   i. Salary-related costs in line with the IUA most recent scale for funded personnel
   ii. Stipends and fees (EU rate only)
b) Small equipment costs (not expected to exceed €10k)
c) Direct running costs (including travel, or mobility costs)
d) FAIR data management costs: Data stewardship costs (e.g. service/fees from data steward, access to secondary data, costs of making data FAIR, etc). Please refer to Appendix I for additional guidance on FAIR data management costings.
e) Dissemination and knowledge exchange activities (including dissemination-related travel)
f) Overheads contribution

Projects are expected to start in Quarter 1 2024.

5 Eligibility Criteria

Please also refer to Section 3 for excluded approaches and topics.

This call is not open for Host Institutions from Northern Ireland.

5.1 Consortium Composition

Consortia may consist of partners who receive funding for research by funding organisations participating in this joint call ("regular partners")[4] as well as non-funded external collaborators. Each partner must verify their eligibility to request funding from one of the funding organisation(s) of their respective country participating in the call – applicants based in Ireland should refer to section 5.1.1 below.

Collaborations with companies from outside the traditional medical sector (e.g. computing, artificial intelligence) are welcome.

[4] Austria, Belgium, Canada, Czech Republic, France, Germany*, Hungary*, Ireland, Israel, Italy, Luxembourg, Netherlands, Poland, Slovakia, Spain, Sweden, Switzerland, Turkey*. At time of publication, confirmation is pending for countries marked with an asterisk.

Each proposal must involve:

- A minimum of three and a maximum of six partners, including the coordinator, from at least three different countries participating in this call.[4] If the proposal involves at least one partner from an EU-13 country (Czech Republic, Hungary, Poland and Slovakia) or Turkey, the maximum number of partners is extended to seven.
- For reasons of transnational balance, no more than two partners from the same country are allowed to join a proposal.

5.1.1 Lead Applicants based in Ireland

The following will apply to partners seeking HRB funding – i.e., Lead Applicants based in Ireland.[5] The **Lead Applicant** will serve as the primary point of contact for the HRB during the review process and on the award, if successful. The Lead Applicant will be responsible for the scientific and technical direction of the Irish research programme. They have primary fiduciary responsibility and accountability for carrying out the research within the funding limits awarded and in accordance with the terms and conditions of the HRB.

The Lead Applicant based in Ireland **must**:

Hold a post (permanent or a contract that covers the duration of the award) in a HRB recognised Host Institution in the Republic of Ireland (the "Host Institution") as an independent investigator. For clinicians, an adjunct position in a HRB recognised Host Institution is acceptable.

OR

Be an individual who will be recognised by the Host Institution upon receipt of an award as an independent investigator who will have a dedicated office and research space for the duration of award, for which they will be fully responsible. The Lead Applicant based in Ireland does not necessarily need to be employed by the Host Institution at the time of the application submission.

They **must** show evidence of achievement as an independent researcher in their chosen research field by:

a) Demonstrating a record of research output, with at least three publications of original research in peer reviewed journals. Where appropriate, they should also provide evidence of other outputs (e.g., published book chapters, reports to government, research data and datasets, research materials, databases, audio/video products, national and/or international reports, patents, models and protocols, software production, evidence of influence on health policy and practice, outreach and/or knowledge exchange activities, media coverage or other relevant activities) and/or any other relevant outputs that have resulted in a significant impact in their field.

b) Demonstrating record of independence by showing that they have secured at least one peer-reviewed research grant for a research project/s, as either the Lead Applicant or a Co-

[5] In view of the overwhelming evidence that both active and passive smoking of tobacco are injurious to health, the HRB is unwilling to fund applications from individuals applying for, holding, or employed under a research grant from the tobacco industry.

Applicant. Funding received for travel to seminars/conferences and/or small personal bursaries will not be considered in this regard.

c) Show evidence that they possess the capability and authority to manage and supervise the research team.

Where an applicant fails to meet the eligibility criteria, the application will be deemed ineligible and will not be accepted for review. The Joint Call Secretariat will contact the consortium in the event that this situation arises.

5.1.2 Collaborators

External collaborators (e.g., research groups from countries not participating in this call or research groups that are from countries participating in this call but do not apply for funding) may participate in proposals. External collaborators must secure their own funding. They must state in the proposal if these funds are already secured or how they plan to obtain funding in advance of the project start date.

6 Host Institution

A HRB Host Institution is a research performing organisation that is approved by the HRB for the purpose of receiving and administering HRB grant funding and is responsible for compliance with all general and specific terms and conditions of awards. HRB Host Institution status is a requirement to submit an application under all HRB award schemes. The **Host Institution for the award** is normally that of the **Lead Applicant** based in Ireland but it may be another organisation/institution designated by the research team, where it is clearly justified. In order to be eligible to apply for funding, an Institution must be an approved HRB Host Institution no later than two calendar months before the closing date of a call. A list of currently approved HRB Host Institutions and information on the application process for research performing organisations to be approved as HRB Host Institutions can be found on the HRB website[6].

Host Institution Letters of Support must be provided for **(1) all Lead Applicants in a contract position and (2) Co-Applicants in a contract position who are seeking their own salary.** The formal letter on headed notepaper, dated and signed by the Head of School/Research Centre/Hospital must include the following information; [*Host Institution - insert name*] which is the host institution of [*applicant - insert name*] confirms that [*applicant - insert name*]: (i) holds an employment contract which extends until [*insert date*] or will be recognized by the host institution upon receipt of the HRB [scheme] award as a contract researcher; (ii) has an independent office and research space/facilities for which they is fully responsible for at least the duration of the award, and (iii) has the capability and authority to mentor and supervise the research team. Electronic signatures are acceptable for letters that are uploaded on the HRB GEMS system.

[6] http://www.hrb.ie/funding/funding-schemes/before-you-apply/all-grant-policies/hrb-policy-on-approval-of-host-institutions/

7 Application, Review Process and Assessment Criteria

7.1 Application

There will be a two-stage application procedure for joined applications. One joint proposal document (in English) shall be prepared by the partners and must be submitted by the Coordinator in electronic format no later than 11:00 GMT on 7 March 2023 via the JPND electronic submission system. **No other means of submission will be accepted.**

For further details, please refer to the respective submission forms available through the JPND website. If you need additional information, please contact the Joint Call Secretariat (JCS). Please refer also to HRB Grant Policies.

Lead Applicants based in Ireland will be required to provide additional information to the HRB at the time of submission of full proposals. This will include justification for their requested budget, and clarification on deliverables assigned to the partner from Ireland. A template requesting the information required from applicants from Ireland will be provided by the HRB.

7.2 Review Process

Detailed information on the evaluation and decision-making process can be obtained from the accompanying call procedures document.

At each stage:

- The Joint Call Secretariat (JCS; responsible for the central management of the call) will check proposals at both pre- and full proposal stage to ensure that they meet the call's formal conditions. In parallel, the Call Steering Committee (CSC; comprising all participating funding organisations) will perform eligibility assessments according to their specific criteria.
- Proposals passing the formal and specific eligibility check will be evaluated by the Peer Review Panel. Based on these recommendations, the CSC will make a final decision.
- The JCS will inform each coordinator about the outcome of the evaluation, providing the recommendation, written evaluations (anonymous), the final decision of the CSC and any further relevant information at each stage.

7.3 Assessment Criteria

The Peer Review Panel will carry out the evaluation of pre-proposals and full proposals. The following evaluation criteria will be applied:

- Relevance to the aim of the call.
- Scientific quality including level of innovation, originality and feasibility.
- Transnational added value from working together as a research consortium, including planned scientific interaction, knowledge exchange and training.
- International competitiveness of participating research groups, including the demonstrated scientific expertise, and their appropriate combination.
- Deliverable outcomes in the short, medium and long-term, including risk assessment and management.

8 Timeframe

Date	
4 January 2023	Call Opening
7 March 2023 @11:00	Call Closing

9 Contacts

For further information on the JPND JTC2023 for Large scale analysis of OMICS data for drug-target finding in neurodegenerative diseases contact:

For general information, please contact the Joint Call Secretariat (JCS):

DLR-PT, Health Division, Germany
Sabrina Voß and Sara Breid
E-mail: jpnd@dlr.de

For country-specific information for Irish Partners, please contact the HRB, Ireland:

Dr Siobhán Hackett
Email: eujointprogrammes@hrb.ie

Appendix I: HRB Funding Policies and Procedures

Public, Patient and Carer Involvement (PPI) in Research

The HRB promotes the active involvement of members of the public, patients and carers in the research that we fund[7]. Public and patient involvement in research means that the public and patients are involved in planning and doing research from start to finish and help tell the public about the results of research. PPI, as defined here, is distinct from and additional to activities which raise awareness, share knowledge, and create a dialogue with the public, and it is also distinct from recruitment of patients/members of the public/carers as participants in research.

PPI represents an active partnership between members of the public, patients and carers and researchers in the research process. This can include, for example, involvement in the selection of research topics, assisting in the design, advising throughout or at specific decision points of the research project or in carrying out the research.

PPI contributors should be actively involved and part of decision making. Involving members of the public in research can improve quality and relevance of research. It can:

- Provide a different perspective - even if you are an expert in your field, your knowledge and experience will be different to the experience of someone who is using the service or living with a health condition.
- Help to ensure that the research uses outcomes that are important to the public.
- Identify a wider set of research topics than if health or social care professionals had worked alone.
- Make the language and content of information such as questionnaires and information leaflets clear and accessible.
- Help to ensure that the methods proposed for the study are acceptable and sensitive to the situations of potential research participants.
- Help you increase participation in your research by making it more acceptable to potential participants.

In addition to improving relevance and quality of research, it ensures that research is influenced by broader principles of citizenship, accountability, and transparency. PPI is an ethos as well as a practice. It should be context-specific and should aim to ensure that all voices are heard. Where members of the public, patients or carers are involved, they must be compensated for their time and contributions.

In the application, you are asked to describe any public involvement in your research throughout the various stages of identifying and prioritising the research question, the research design, conduct, analysis, and dissemination. We recognise that the nature and extent of active public involvement is likely to vary depending on the context of each study or award. PPI contributors should be named as Co-applicants where justified by their level of involvement.

[7] https://www.hrb.ie/funding/funding-schemes/public-and-patient-involvement-in-research/

For guidance and support on PPI in your research please consult with the PPI Ignite Network Ireland or your Host Institution. The PPI Ignite Network Ireland has offices located in the following seven Host Institutions: DCU, NUIG, RCSI, TCD, UCC, UCD, UL.

FAIR Data Management and Stewardship

Data management/stewardship plans (DMP) are nowadays widely accepted as part of good research practice. The HRB support open research[8] and open publishing directly through the HRB Open Research platform[9]. The HRB is driving the making of research data **FAIR** (**F**indable, **A**ccessible, **I**nteroperable and **R**e-usable) in order to benefit science by increasing the re-use of data and by promoting transparency and accountability.

FAIR data principles[10] provide a guideline for those wishing to enhance the re-usability of their data holdings: these principles put specific emphasis on enhancing the ability of machines to automatically find and use the data, in addition to supporting its re-use by individuals. For researchers, the move to FAIR and open data, where applicable, means researchers should consider data management issues and find suitable data repositories at the research planning stage. Applicants will have to provide information about their plans for data management and data sharing at application stage.

In line with the HRB's policy on management and sharing of research data[11], all successful applicants are required to submit a completed data management plan (DMP) to the HRB on or before three months after the award start date, and a final updated version of the DMP with the last annual report.

The DMP will need to be submitted alongside a certification of completion from the designated representative(s) within the Host Institution.

Applicants will have to provide an outline of their plans for data management and data sharing in the application inclusive of the costs associated to the plan.

The timing for completion and submission of the DMPs must be also included among the objectives and deliverables of the programme.

Additional guidance to on FAIR Data Management Costs

People	Staff time per hour for data collection, data anonymisation, etc
	Staff time per hour for data management/stewardship support, training, etc
Storage and computation	Cloud storage, domain hosting charge

[8] http://www.hrb.ie/funding/policies-and-principles/open-research/

[9] https://hrbopenresearch.org/

[10] https://www.nature.com/articles/sdata201618

[11] https://www.hrb.ie/fileadmin/user_upload/HRB_Policy_on_sharing_of_research_data.pdf

Data access	Secondary data access, costs for preparing data for sharing (e.g. anonymisation)
Deposition and reuse	Costs for depositing research data and metadata in an open access data repository
	Defining semantic models, making data linkable, choosing the licence, defining metadata for dataset, deploying/publishing
Others	Please provide explanations.
Notes	*The HRB is currently not covering the cost of long-term preservation of data*
	This list is not exhaustive and aims to provide examples only of eligible costs

General Data Protection Regulation

Personal data will be treated as confidential by the Participants (participating transnational funding bodies) in accordance only with applicable law governing the confidentiality and privacy of personal data in the country of the Participant. Participants will use these personal data only in accordance with their applicable law and the applicable consents provided by the data subjects, and the Participants intend to take such additional steps and/or to enter into such specific instrument(s) as may be required to ensure consistency with applicable law (i.e. the EU General Data Protection Regulation only for Participants based in the European Union as well as national laws and regulations) governing the confidentiality and privacy of personal data. In any case, all the Participants will provide a level of data protection at least equivalent to the EU General Data Protection Regulation. The Participants will not share personal data with third parties other than those necessary for the execution of the joint transnational call and those required by national laws.

The transfer of personal data in the scope of the execution of the Participants' Memorandum of Understanding to a party or a third party situated in a country that does not present adequate safeguards under the GDPR shall ensure that such transfer is possible and that it complies with the GDPR on the basis of an adequacy decision or on the basis of standard data protection clauses adopted by the commission in accordance with the examination procedure or pursuant to Article 49 of the GDPR.

Use of personal data by HRB

By participating in this call, you agree to the use of the information you provide (regarding all applicant team members) for HRB to consider your application, contact you about your application, and if you are successful, to manage your grant throughout its lifetime in accordance with HRB general T&C for research awards.

This will include contacting you with regard to monitoring of progress through written reporting and other means e.g., interim review. We will publish some basic information on successful awards including PI, Host Institution, amount awarded and lay summary on our website and may highlight individual awards or researchers in more detail (with specific consent). We will also use the information you have provided to generate general statistics around our current funding portfolio, and to evaluate our funding mechanisms and investment. After your grant has ended, we will

continue to keep your information on file (in accordance with HRB policies) to allow us to evaluate the outcomes, outputs and impacts of HRB investment in your research.

Please note that we will also use information associated with *unsuccessful* applications for a number of the purposes outlined above such as generating general statistics around our current funding portfolio, and to evaluate our funding mechanisms and investment e.g., demographics of applicants, research areas of applicants. Similarly, we will use the information provided about people employed on awards to help evaluate our career support and capacity building initiatives.

The Health Research Regulations

Following the implementation of GDPR, a regulation for health research known as the Health Research Regulations 2018 (S.I. 314) has been implemented, with further amendments made in 2019 (S.I. 188) and 2021 (S.I. 18)[12]. These regulations outline the mandatory suitable and specific measures for the processing of personal data for the purposes of health research. They further set out that explicit consent is a mandatory safeguard that must be obtained from individuals when using their personal data for health research. Where it is not feasible to obtain explicit consent, an application for a consent declaration can be made to the Health Research Consent Declaration Committee[13].

Research on Research

The HRB is developing its approach to research on research (RoR) with the aim of enhancing the evidence base for HRB research funding practices. We may also collaborate with researchers on request regarding specific RoR questions. Should your application become of interest to such a study, the HRB will seek your consent for the use of your information.

Privacy Policy and Retention Policy

To understand why we collect the information we collect and what we do with that information, please see our Privacy[14] and Retention Policies[15].

[12] http://www.irishstatutebook.ie/eli/2021/si/18/made/en/pdf

[13] https://hrcdc.ie/

[14] https://www.hrb.ie/about/legal/privacy-policy/

[15] https://www.hrb.ie/fileadmin/user_upload/HRB_Document_retention_policy..docx

Appendix II: Resources/Useful Links

REPORTING

COMET (Core Outcome Measures in Effectiveness Trials) Initiative: development and application of agreed standardised sets of outcomes, known as 'core outcome sets'

http://www.comet-initiative.org/

EQUATOR Network Library for health research reporting: an international initiative that seeks to improve reliability and value of health research literature by promoting transparent and accurate reporting of research studies

https://www.equator-network.org/library/

Registry of Research Data Repositories

http://www.re3data.org/

Zenodo Data Repository (OpenAIR)

https://zenodo.org/about

https://zenodo.org/

EVIDENCE SYNTHESIS

Evidence Synthesis Ireland: aims to build evidence synthesis knowledge, awareness and capacity among the public, health care institutions and policymakers, clinicians, and researchers on the Island of Ireland.

https://evidencesynthesisireland.ie/

The Cochrane Library: online collection of databases in medicine and other healthcare specialties which summarise and interpret the results of medical research.

www.thecochranelibrary.com

The Campbell Collaboration: promotes positive social and economic change through the production and use of systematic reviews and other evidence synthesis for evidence-based policy and practice.

https://www.campbellcollaboration.org/

The Campbell Collaboration UK & Ireland: hub at Queens University Belfast.

https://www.qub.ac.uk/research-centres/CampbellUKIreland/

EQUATOR Network Library for health research reporting: an international initiative that seeks to improve reliability and value of health research literature by promoting transparent and accurate reporting of research studies.

http://www.equator-network.org/resource-centre/library-of-health-research-reporting/

BIOBANKING

Council of Europe Recommendation of the Committee of Ministers to member States on research on biological materials of human origin (2016)

https://search.coe.int/cm/Pages/result_details.aspx?ObjectId=090000168064e8ff

BBMRI-ERIC is a European research infrastructure for biobanking

https://www.bbmri-eric.eu/

OECD Guidelines on Human Biobanks and Genetic Research Databases

http://www.oecd.org/science/biotech/44054609.pdf

ISBER Best Practices for Repositories

https://www.isber.org/page/BPR

Molecular Medicine Ireland Biobanking Guidelines

http://www.molecularmedicineireland.ie/resources/biobanking-guidelines/

NCI Best Practices for Biospecimen Resources (2016 version)

https://biospecimens.cancer.gov/bestpractices/2016-NCIBestPractices.pdf

PUBLIC, PATIENT AND CARER INVOLVEMENT IN RESEARCH & RESEARCH PRIORITIES

The National PPI Ignite Network https://ppinetwork.ie/

NIHR PPI resources

https://www.nihr.ac.uk/documents/ppi-patient-and-public-involvement-resources-for-applicants-to-nihr-research-programmes/23437

Patient-Centred Outcomes Research Institute (PCORI)

http://www.pcori.org

Public Involvement Impact Assessment Framework: Provides tools for successful involvement of members of the public in research projects and for assessment of impacts.

http://piiaf.org.uk/

NIHR Payment guidance for researchers and professionals

https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392

European Patient Forum Value + Handbook: For Project Co-ordinators, Leaders and Promoters on Meaningful Patient Involvement.

http://www.eu-patient.eu/globalassets/projects/valueplus/doc_epf_handbook.pdf

The James Lind Alliance Priority Setting Partnerships: Research priorities in disease areas set jointly by patients, clinicians, and researchers.

http://www.jla.nihr.ac.uk/

Campus Engage: Supporting Irish HEIs to embed civic engagement in their work. Includes resources, how-to-guides, and case studies for engaged research.

http://www.campusengage.ie/what-we-do/publications/

UK Standards for Public Involvement: The six UK Standards for Public Involvement provide clear, concise statements of effective public involvement against which improvement can be assessed.

https://sites.google.com/nihr.ac.uk/pi-standards/home

USE OF ANIMALS IN RESEARCH

Experimental Design Assistant (EDA) (online tool for design of animal experiments)

https://www.nc3rs.org.uk/experimental-design-assistant-eda

ARRIVE (Animal Research: Reporting of In Vivo Experiments) guidelines

https://www.nc3rs.org.uk/arrive-guidelines

SYRCLE (Systematic review of animal studies, register 2014-2017)

https://www.radboudumc.nl/en/research/departments/health-evidence/systematic-review-center-for-laboratory-animal-experimentation

PROSPERO (Register for systematic reviews including animal studies 2018)

https://www.crd.york.ac.uk/PROSPERO/

GENDER AND/OR SEX ISSUES IN RESEARCH

Examples of case studies in Health & Medicine where gender/sex in research matters

http://genderedinnovations.stanford.edu/case-studies-medicine.html

Gender Toolkit in EU-funded research for examples and guidance

http://www.yellowwindow.be/genderinresearch/downloads/YW2009_GenderToolKit_Module1.pdf

Sex/Gender Influences in Health and Disease

https://orwh.od.nih.gov/sex-gender/sexgender-influences-health-and-disease

Methods and Techniques for Integrating Sex into Research

https://orwh.od.nih.gov/sex-gender/methods-techniques-integrating-sex-research

NIH Policy on Sex as a Biological Variable

https://orwh.od.nih.gov/sex-gender/nih-policy-sex-biological-variable

DATA MANAGEMENT AND SHARNG AND FAIR PRINCIPLES

Digital Curation Centre: How to develop a data management and sharing plan and examples DMPs.

http://www.dcc.ac.uk/resources/data-management-plans/guidance-examples

FAIR data principles FORCE 11

https://www.force11.org/fairprinciples

UK Concordat on Open Research Data (July 2016)

https://www.ukri.org/wp-content/uploads/2020/10/UKRI-020920-ConcordatonOpenResearchData.pdf

Guidelines on FAIR data management plans in Horizon 2020

http://ec.europa.eu/research/participants/data/ref/h2020/grants_manual/hi/oa_pilot/h2020-hi-oa-data-mgt_en.pdf

FAIR at the Dutch centre for Life sciences

https://www.dtls.nl/fair-data/

Registry of Research Data Repositories

http://www.re3data.org/

RESEARCH DATA MANAGEMENT PLANS

Data Stewardship Wizard created by ELIXIR CZ and NL

https://dmp.fairdata.solutions/

DMPonline of the Digital Curation Centre (DCC), UK

https://dmponline.dcc.ac.uk/

DMPTool of University of California Curation Center of the California Digital Library (CDL), USA

https://dmptool.org/

RDMO Research Data Management Organiser of the German Research Foundation, Germany

https://rdmorganiser.github.io/en/

Guidelines on FAIR data management plans in Horizon 2020

http://ec.europa.eu/research/participants/data/ref/h2020/grants_manual/hi/oa_pilot/h2020-hi-oa-data-mgt_en.pdf

KNOWLEDGE TRANSLATION RESOURCES

Health Service Executive Research & Development Main Page

https://hseresearch.ie/research-dissemination-and-translation/

Health Service Executive Research & Development: Knowledge Translation, Dissemination, and Impact A Practical Guide for Researchers

https://hseresearch.ie/wp-content/uploads/2021/04/Tools-and-templates-.pdf

Integrated Knowledge Translation (iKT) NUI Galway

https://www.nuigalway.ie/hbcrg/ikt/

The Canadian Institutes of Health Research: Guide to Knowledge Translation Planning

https://cihr-irsc.gc.ca/e/45321.html

Training Institute for Dissemination and Implementation Research in Health: Open Access Course

https://cancercontrol.cancer.gov/is/training-education/TIDIRC-open-access

IMPLEMENTATION SCIENCE RESOURCES

Centre for Effective Services

https://www.effectiveservices.org/resources/implementation

UCC Implementation Science Training Institute

https://www.ucc.ie/en/cpd/options/medhealth/cpd1778uccimplementationsciencetraininginstitute/

European Implementation Collaborative

https://implementation.eu/resources/

CO-CREATION RESOURCES

ACCOMPLISSH Guide to impact planning

https://www.accomplissh.eu/publications-and-deliverables

Working together to co-create knowledge: A unique co-creation tool – Carnegie UK Trust

https://www.carnegieuktrust.org.uk/publications/working-together-to-co-create-knowledge-a-unique-co-creation-tool/

INFORMATION ON PERSISTENT IDENTIFIERS

DOI: List of current DOI registration agencies provided by the International DOI Foundation

http://www.doi.org/registration_agencies.html

Handle: Assigning, managing and resolving persistent identifiers for digital objects and other Internet resources provided by the Corporation for National Research Initiatives (CNRI)

http://www.handle.net/

PURL: Persistent Identifiers developed by the Online Computer Library Center (OCLC). Since 2016 hosted by the Internet Archive

https://archive.org/services/purl/

URN: List of all registered namespaces provided by the Internet Assigned Numbers Authority (IANA)

https://www.iana.org/assignments/urn-namespaces/urn-namespaces.xml

DATA REPOSITORIES

Registry of Research Data Repositories

http://www.re3data.org/

Data centers accredited by the German Data forum according to uniform and transparent standards (Germany)

https://www.ratswd.de/forschungsdaten/fdz

Zenodo Data Repository (OpenAIR)

https://zenodo.org/

FAIR/OTHER USEFUL LINKS

Main FAIR Principles

https://www.go-fair.org/fair-principles/

UK Concordat on Open Research Data (July 2016)

http://www.rcuk.ac.uk/documents/documents/concordatopenresearchdata-pdf/

Tool that helps to select and apply a license to a resource, provided by Creative Commons

https://creativecommons.org/choose/