JPND Joint Transnational Expert Working Groups Call "Use of digital technologies in neurodegenerative disease research and clinical practice" (2023)

Guidance Notes

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Key Dates & Times	
Application Open	2 November 2023
Application Closing Date	12 December 2023 @11:00 GMT

Applications must be completed and submitted through the the JPND electronic submission and evaluation system. 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 of the HRB to bring together relevant stakeholder groups to help to address major health challenges in society and have an impact on tomorrow's healthcare.

Neurodegenerative diseases are debilitating conditions that are strongly linked with age. Worldwide, there are estimated to be more than 50 million people living with Alzheimer's disease and related disorders, the most common class of neurodegenerative diseases. This figure is expected to double every 20 years as the population ages. With no causative treatment being available today, neurodegenerative diseases have high personal, societal and economic impact.

Digital technologies have taken a central position in peoples' everyday lives, e.g. by managing daily routines, offering timely information and navigation or allowing boundless communication. They have also made their way into health and social care research and practice, e.g. by offering automated data processing and analysis, algorithms facilitating human efforts or tracking people's health and physical status. Besides the impressive features offered already today, technological advancements are rapid and temporarily erratic, *e.g.*, with regard to the conceivable roll-out of virtual reality and artificial intelligence. Assessing the impact of such cutting-edge technologies on health and social care research and services often generates a high level of uncertainty. In addition, the fast progression makes it complicated to implement them in research and in the care of patients. However, both fields may potentially benefit from making use of cutting-edge digital technologies. This specifically relates to neurodegenerative diseases, where patients require enhanced levels of support and scientists strive to unravel the functioning of the brain, which is the most complex organ in the human body. The use of advanced digital technologies for the diagnosis, disease modelling, treatment and care has the potential to improve life for people with neurodegenerative diseases.

The EU Joint Programme - Neurodegenerative Disease Research (JPND) has been established 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. To identify research priorities, the JPND Research and Innovation Strategy, published in 2019, provides a framework for future investment. This is the fourth Working Group call under this initiative.

2   Aim and Objectives

The aim of the call is to establish a number of ambitious, innovative, multi-disciplinary and multi-national expert Working Groups to assess the current and future impact of digital technologies on research and care in the field of neurodegenerative diseases.

Working Groups are to be research community-led and must demonstrate a clear scientific benefit from working across national borders and, in particular, bringing scientific communities with different areas of expertise together to work collaboratively. The approaches should be integrative (e.g. involve clinicians, engineers, physicists, computer scientists, mathematicians and non-medical personnel as well as, legal, technological and social experts) and include disability, gender, ethic,

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

socioeconomic and cultural aspects, where possible. Experts' discussion is envisaged to identify the appropriate developments specific for the field while involving experts from outside the boundaries of the neurodegenerative disease field.

3 Scope of Call

Working Groups may address the following aspects:

- Identification of the most relevant technologies, their current and potential use as well as their impact on the field in the next decade,

- Outlining the gaps, barriers and hurdles and opportunities in research in order to improve the use of specific digital technologies in the future for the diagnosis and treatment of ND,

- Analyzing the risks and opportunities that go along with an advanced use of specific digital technologies,

- Ethical considerations with a focus on the perspective of patients, relatives and carers (please refer to: https://legalinstruments.oecd.org/en/instruments/OECD-LEGAL-0457).

Working Groups 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)

The call does not support direct research activities and studies.

The Working Groups should discuss innovative and new ideas and meet for one or two small workshops. They must provide outputs of value to JPND and the broader research community by delivering a report at the end of the funding period. A usual arrangement would entail small workshops at the beginning and end of the process, with sub-groups established to achieve more focused work through remote working. A joint workshop of all funded Working Groups is envisaged at the end of the funding period. Participation of all the funded project coordinators as a result of this call in the final workshop will be mandatory.

Working Groups are required to produce a report at the end of the funding period to be published on the JPND website. Reports should contain guidelines or a methodological framework and are expected to act as reference points for the wider research community in planning and delivering future studies. In addition, Working Groups are encouraged to share their thoughts on future developments and relevant research questions to be tackled in the future. Working Groups should also put forward an appropriate plan for wide dissemination of their outcomes, for example, through

publication in a scientific journal. All outputs must include a proper acknowledgement of JPND and the respective funding organisations. For this purpose, a JPND [dissemination strategy](#) has been agreed upon, which can be downloaded from the JPND website.

Patient-related research as envisaged by this call benefits from the active involvement of the persons concerned. Thus, Working Groups need to adequately involve patients, their relatives and carers and the public (see the JPND website for further information). This relates to the planning stage during the application as well as the later work of the panel. Applications must describe how patients, their relatives and carers are involved and from where they are recruited.

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

4 Funding Available, Duration and Start Date

The JPND Working Group call 2023 will provide funding for projects up to a maximum of **€50,000** (overheads will not be covered) per award. The HRB plans to commit up to €50,000, meaning that, quality permitting, a minimum of one award will be funded. Awards will have a duration of up to 12 months.

Each selected Working Group receives financial support from one of the funding organisations participating in this call. The award must be used to compensate for the expenses of the entire group and is typically provided to the coordinator – *i.e.*, in the case of Irish coordinators, HRB will typically fund the Working Group.

Funding may be used to conduct the workshops (*e.g.*, costs related to accommodation and catering or temporary student staff) and to compensate for travel costs of the participants. It may also be used to utilize remote working as well as data exchange and harmonisation and dissemination.

The HRB will cover the following costs for Irish coordinators, who will cover costs for all Working Group activities:

a) Personnel: salary-related costs (for administrative tasks only)

b) Travel costs for members of the network

c) Direct running costs such as venue hire for workshops, or ad hoc/hourly staff costs.

d) Costs for Patient, Carer and Public Involvement (PPI) in research

e) FAIR data management costs

f) Open Access Publication Costs

No funding is provided for direct research activities (*e.g.*, costs for research equipment, salaries of investigators or scientific staff as well as student stipends).

No overheads are payable.

5 Eligibility Criteria

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

These criteria summarise key criteria from the [central JPND call text](#) and provide specific eligibility criteria for Irish coordinators.

5.1 Consortium Composition

A Working Group must be led by a coordinator from an institution being eligible for one of the participating funding organisations[2] – for Irish coordinators, this is the HRB. The coordinator assembles the Working Group, acts as first point of contact and is responsible for the management (such as monitoring, reporting, intellectual property rights issues and sharing of data). Experts may join multiple Working Groups; however, they must not act as the coordinator of more than one Working Group.

Only transnational Working Groups are funded. A minimum of six experts, including the coordinator, from at least five different countries must be involved in a Working Group, which should not exceed 25 participants.

The Working Group may include experts from any country worldwide, including countries who are not financially participating in the call. In order to gain a wider perspective, Working Groups are encouraged to include expertise from partners established in European countries with a less well-established scientific community in health and social care research, where relevant. However, at least half of the participants of the Working Group must be from JPND countries [3]

5.1.1 Lead Applicant based in Ireland

The following will apply to partners seeking HRB funding – i.e., typically coordinators based in Ireland, as outlined in Section 4. The **Lead Applicant** based in Ireland 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 direction of the Irish programme. They have primary fiduciary responsibility and accountability for carrying out the activities within the funding limits awarded and in accordance with the terms and conditions of the HRB. All other partners based in Ireland will be recorded as Co-Applicants and do not need to meet the below eligibility criteria.

The Lead Applicant **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 does not necessarily need to be employed by the Host Institution at the time of the application submission.

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[2] Australia (NHMRC), France (ANR), Germany (BMBF), Italy (IT-MOH), Netherlands (ZonMW) and UK (MRC, UKRI)

[3] Albania, Australia, Austria, Belgium, Bulgaria, Canada, Croatia, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Ireland, Israel, Italy, Luxembourg, Netherlands, Norway, Poland, Portugal, Romania, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, Turkey and United Kingdom

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-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 an award.

Only one application per Lead Applicant to this scheme will be considered, though Lead Applicants can be experts in other Working Groups, as outlined in Section 5.1.

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

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** 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 underlined 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[4].

Host Institution Letters of Support must be provided for **(1) all Lead Applicants in a contract position and (2) Adjunct Professors not directly employed by the HI.** These must be emailed to eujointprogrammes@hrb.ie before the pre-proposal submission deadline. The formal letter on

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

headed notepaper, dated and signed by the Head of School/Research Centre/Hospital must include the following information:

- Case (1): [*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 are fully responsible for at least the duration of the award, and (iii) has the capability and authority to mentor and supervise the research team.

- Case (2): [*Host Institution - insert name*] confirms that [*applicant - insert name*] has the authority and resources allocated to hold and manage a grant under their Adjunct status for at least the duration of the award.

7 Application, Review Process and Assessment Criteria

7.1   Application

There will be a one-stage application procedure for applications. One joint proposal document (in English, on the proposal template (.docx)) shall be prepared by the partners and must be submitted by the Coordinator in electronic format no later than 11:00 GMT on 12 December 2023 via the JPND electronic submission and evaluation 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. Applicants must demonstrate that they meet the eligibility criteria by completing the Lead Applicant eligibility form by the submission deadline.

They must also submit a 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 call procedures document (.docx). All submitted proposals are checked to ensure that they meet the formal conditions as well as the specific eligibility criteria of the participating funding organisations. Proposals that successfully pass these checks are assigned to peer-review. At least three international and independent peer-reviewers evaluate each eligible proposal.

Based on the written evaluations, the funding organisations take final funding decisions. It is their goal to maximise the number of high-quality Working Groups to be supported through this call. The coordinators receive written information about the outcome of the evaluation and the final funding decision in June 2024. The working groups are expected to start their activities as of the second half of 2024.

7.3   Assessment Criteria

Reviewers evaluate proposals according to the following criteria:

- Scientific fit to the topic of the call

- Relevance and likely impact of the activity

- Involved expertise and their appropriate mix, including diversity in gender, geographic and seniority

- Potential outcomes and plans for dissemination, including a focus on open science and open access

8 Timeframe

Date	
02 Nov 2023	Call Opening
12 Dec 2023 @11:00	Call Closing

9 Contacts

For further information on the JPND Joint Transnational Working Group Call 2022 contact:

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

DLR Project Management Agency

Sabrina Voß and Sara Breid

E-mail: jpnd@dlr.de

For country-specific information for Irish Partners, 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[5]. 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.

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[5] 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[6] and open publishing directly through the HRB Open Research platform[7]. 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[8] 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[9], 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.

General Data Protection Regulation

Personal data will be treated as confidential by the funders in accordance with all applicable laws governing the confidentiality and privacy of personal data. Funders shall use these personal data only in accordance with applicable laws and the applicable consents provided by the data subjects. In addition, the funders will take such additional steps and/or enter into such specific agreement(s) as may be required to ensure that they are and remain in compliance with all applicable laws (i.e. GDPR

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

[7] https://hrbopenresearch.org/

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

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

and national laws and regulations) governing the confidentiality and privacy of personal data. The funders will not share personal data with third parties other than parties necessary for the execution of the joint transnational call and parties required by national laws.

The transfer of personal data 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)[10]. 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[11].

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

[11] https://hrcdc.ie/

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[12] and Retention Policies[13].

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

[13] 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/

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

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

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/