Trinity St James's
Cancer Institute

RESEARCH DEVELOPMENT SUPPORTS

Trinity St James's
Cancer Institute

ECI
COMPREHENSIVE
Cancer Centre

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Figure 1. *Trinity College Dublin.*

1.0 TRINITY ST JAMES'S CANCER INSTITUTE (TSJCI)

The Trinity St James's Cancer Institute, the first of its kind in Ireland, builds on the long tradition of outstanding comprehensive cancer care delivered at Ireland's largest academic health campus at St James's Hospital in central Dublin, with the research and educational excellence of Trinity College Dublin, Ireland's leading university. Trinity St James's Cancer Institute is the first Irish cancer institute to be accredited by the Organisation of European Cancer Institutes (OECI) as a Comprehensive Cancer Centre. The OECI mission is to foster high quality comprehensive cancer care, research, and education, with the aim of improving patient outcomes throughout Europe.

Our mission is to integrate innovative and ground-breaking cancer science with compassionate, multidisciplinary, patient-focused clinical care through translation of key research findings into incremental advances in the prevention, diagnosis and treatment of cancer. We will achieve these goals utilizing the extensive resources located on the St James's campus, allied with the research and educational expertise of Trinity College Dublin and in partnership with the wider cancer care community.

The ambition of the Trinity St James's Cancer Institute is to develop a comprehensive cancer centre with national services in areas such as genomics and immunology, to become a leading international institution for translational cancer research, and through its structure and national and international collaborative network to represent a standard bearer for Ireland internationally.

We will continue to work across academia, and will align the efforts of government, industry, philanthropy, and patient groups. Ultimately, the Trinity St James's Cancer Institute will provide national leadership to decrease cancer mortality and continuously improve the cancer patient's experience and outcome.

The management of the TSJCI is coordinated by two Directors, Prof John Kennedy, Medical Director and Prof Maeve Lowery, Academic Director, supported by strategic Pillar Leads and the Programme Office.

Pillar	Lead
Clinical	Prof John Reynolds
Cancer Clinical Trials	Prof Maeve Lowery
Education	Prof Jacintha O'Sullivan
Research	Prof Lorraine O'Driscoll
Nursing	Ms Sharon Slattery

2.0 RESEARCH AT TSJCI

2.1 Who We Are

Directed by Professor Lorraine O'Driscoll, TSJCI's research is focussed on improving outcomes for people with cancer through innovative and ground-breaking fundamental, translational, and clinical research. Synergising the research of clinician and non-clinical researchers, and also informed by our patients' representative group, this will be achieved via 4 interconnected Research Themes (Figure 2) leading to improvments in health and quality of life for people in Ireland and beyond [1]

Theme 1: Cancer Prevention and Early Diagnosis
Theme 2: Molecular and Precision Oncology
Theme 3: Cancer Immunology
Theme 4: Cancer Survivorship and Supportive Care

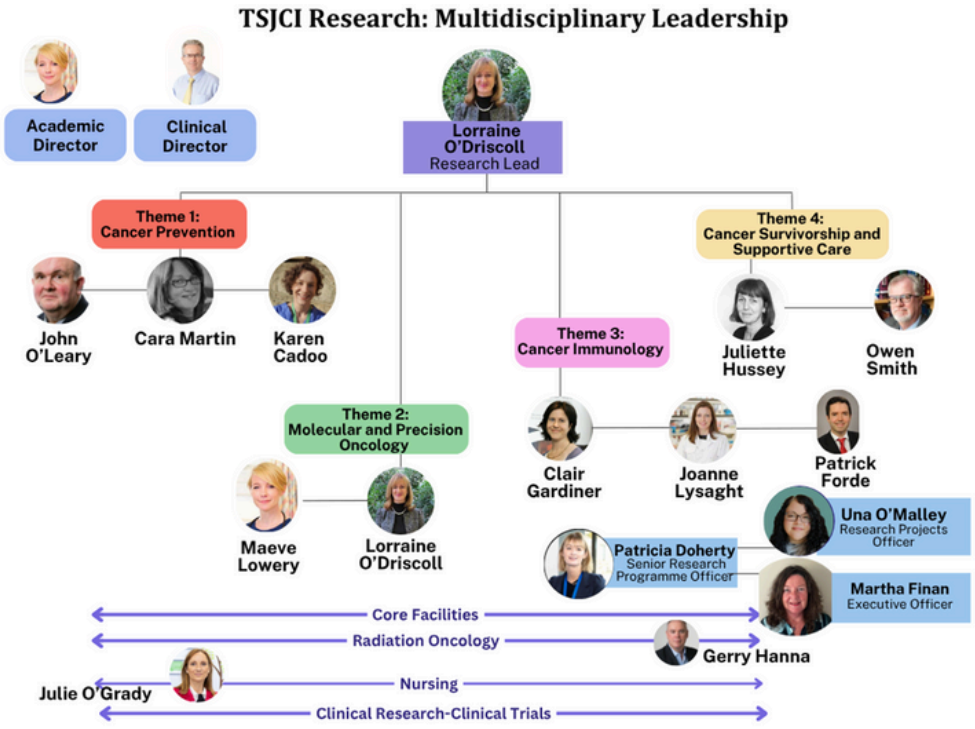


Figure 2. *Trinity St James's Cancer Institute research thematic structure*

[1] For further information on research at TSJCI, please contact: Prof. Lorraine O'Driscoll, TSJCI Research Lead lodrisc@tcd.ie and/or Dr Patricia Doherty, Senior Research Programme Officer Patricia.Doherty@tcd.ie

2.2 What supports are available for researchers?

The TSJCI research unit provides a range of supports for researchers. See Figure 3 below which outlines several opportunities for linking in with these supports. Please contact patricia.doherty@tcd.ie for further information.

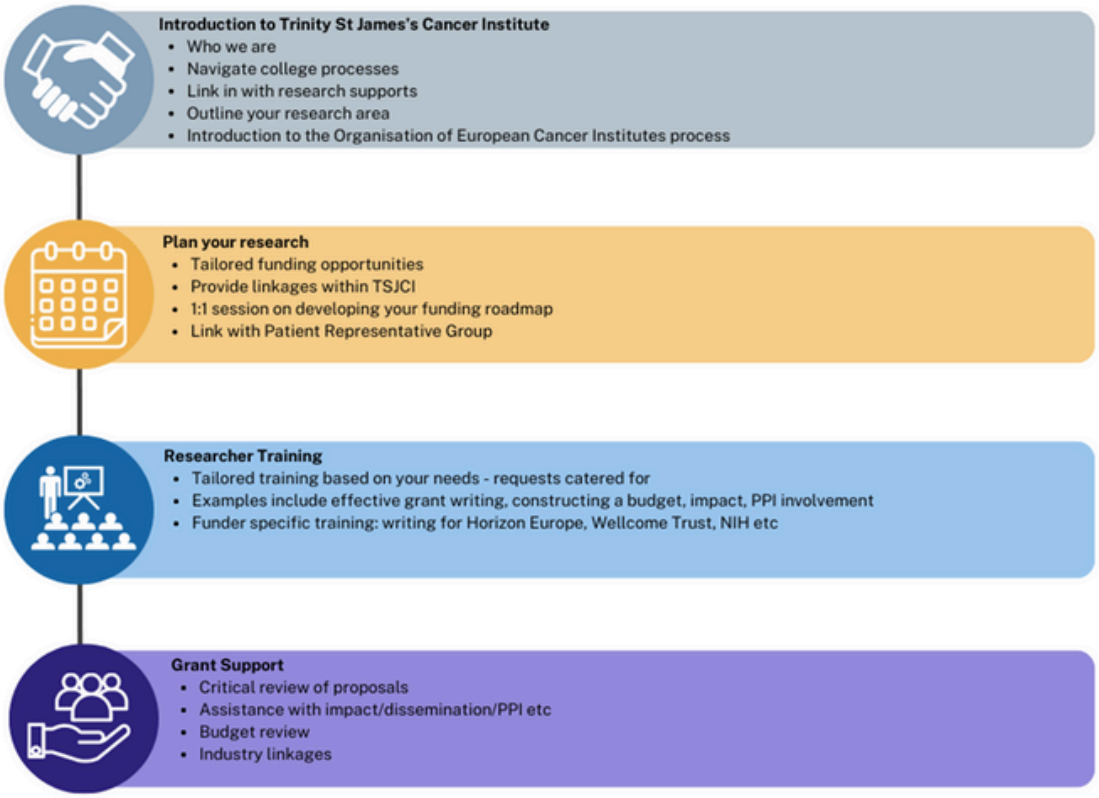


Figure 3. *Research supports for Trinity St James's Cancer Institute. See also https://www.stjames.ie/cancer/research/researchsupport/*

2.2.1 Are you a clinician in St James's Hospital?

a. How to get a TCD staff nomination – click here
b. How to get TCD Network and Email Access – click here
c. If you want to apply to the Health Research Board for funding but don't have a PhD, you may need to complete a PhD equivalency form (currently under review by HRB). PhD equivalence must be granted by the HRB before the call submission date and will not be considered after application submission so please be aware of this requirement. Please check contact information in relevant call.

2.2.2 Planning a research study using clinical samples?

If you plan to conduct research in St James's Hospital you will need to submit an application to the Research and Innovation Office (R&I) Office. The R&I Office approves research proposals and provides research support to staff.

The R&I application form must be filled out on the St James's Hospital internal intranet. If you do not have access to the online form, you can request a word document version by emailing research@stjames.ie

What does the review process include?
A submission to the R&I Office can be made in parallel with an Ethics Committee. An R&I reference number is needed when applying to the SJH/TUH Joint Research Ethics Committee (JREC). You will receive this number once you submit an R&I application form. The R&I application will be reviewed by the R&I Office team, the Data Protection Officer and the Legal Insurance Office.

Please note: While the R&I application and JREC application can be submitted at the same time, they are separate application forms and separate approval processes. Any documents requested from R&I must be emailed to research@stjames.ie.

How to apply?
You can apply to the R&I office by completing an online application form.This form must be submitted using an SJH-networked computer. Please see here for guidance. If you do not have access to the SJH network, a word document application form can be requested by emailing research@stjames.ie. The word format will have to be submitted online on your behalf by an SJH employee.

2.2.3 Research Ethics Applications[2]

Research involving humans and animals will require ethical review, however, other types of research may often have ethical considerations that should be addressed.

All research should be undertaken with cognisance of the Trinity College Guidelines for Good Research Practice. As of January 2023, ethics applications are online via the Research Ethics Application Management System (REAMS). Please see: https://www.tcd.ie/research/support/ethics-approval.php for information on the process.

2.2.4 Data Protection in Health Research

Researchers must assess and manage the data protection risks of their research projects. Please see here for Data Protection in Research guidance from Trinity College Dublin. All researchers using personal data for their research, must be aware of and comply with EU and national data protection law: the EU General Data Protection Regulation 2016 ('GDPR') and Data Protection Acts 1988-2018.

Researchers carrying out health research must also comply with the Health Research Regulations 2018 including the 2021 Amendments to the Regulations. See TCD information page here.

We encourage all researchers to complete the College Data Protection Training Module and all Researchers should familiarise themselves with the College Data Protection Policy and the accompanying Handbook.

[2] https://www.tcd.ie/healthsciences/research/ethics.php

Trinity College Dublin has developed templates to assist researchers with compliance with the GDPR and national implementing law, when using personal or pseudonymised data for research purposes.

- Data Protection Impact Assessment
- Participant Information Leaflet - Health Research
- Consent Form - Health Research (Please note that the Consent Form is provided as guidance from an ethical perspective).

Useful Contacts:
TCD Data Protection Office: dataprotection@tcd.ie
SJH Data Protection Office: data protection@stjames.ie

2.2.5 How to get Research Funding Alerts?

a. Research Focus- Every Wednesday
For TCD staff and students. Subscribe for funding opportunities, events and notices at https://www.tcd.ie/research_innovation/research/support-services/research-focus.php

b. Research Professional
Online database of research funders where you can create customised searches (use TCD affiliation to login) and e-mail alerts at https://www.researchprofessional.com/sso/login?service=https://www.researchprofessional.com/0/

2.2.6 Trinity Research Integrity/Scientific Misconduct

Trinity College, Dublin is committed to ensuring the highest standards of integrity in all aspects of research. In circumstances where the research integrity of a member of college staff is called in to question, following a full investigation into the matter, the Senior Dean is responsible for chairing the Research Ethics Committee which determines what actions should be taken as a result of the inquiry.[3]
Procedure for dealing with research misconduct can be found here.

[3] https://www.tcd.ie/healthsciences/research/ethics.php

2.2.7 Planning a Grant Application?

If you wish to submit a research funding proposal to an external funding body (national, international or charity source) or wish to find out about funding opportunities you may be eligible to apply for, please contact Dr Patricia Doherty, Senior Research Programme Officer: patricia.doherty@tcd.ie. Varying levels of support are available to you (Figure 4).

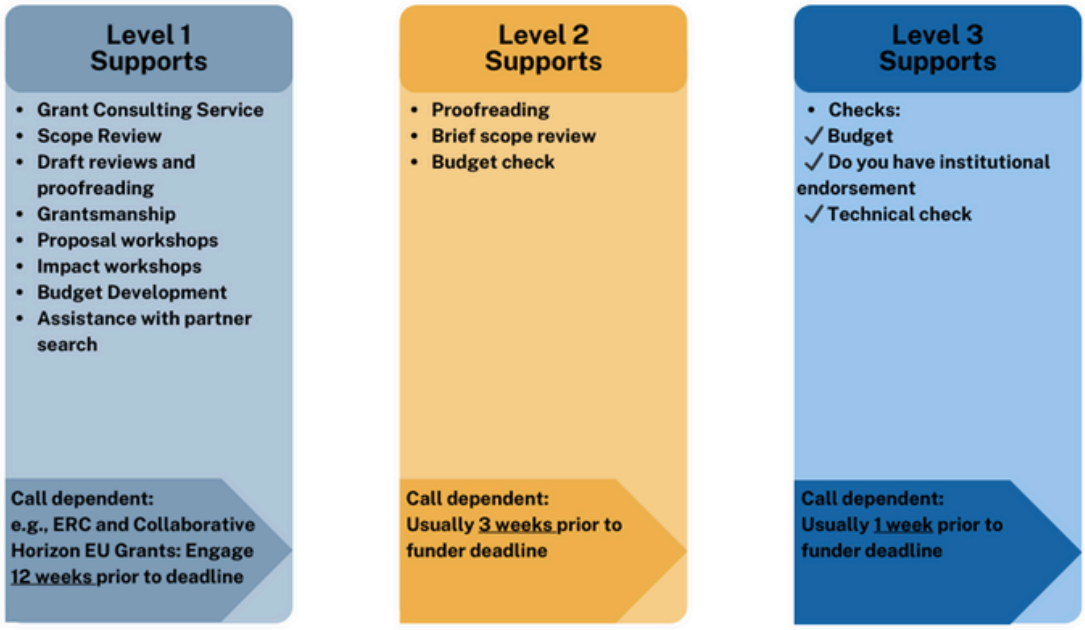


Figure 4. *Levels of research development support offered to TSJCI researchers*

2.2.8 School of Medicine Research Process

If you are a researcher in the School of Medicine[4] all applications for research funding and acceptances of research awards must be endorsed by the Head of School. To gain Head of School endorsement, all School of Medicine staff members should follow the guidelines on the next page.

[4] Please see https://www.tcd.ie/medicine/research/funding/grant/index.php for School of Medicine procedures

Research Applications

A minimum of 3 days prior to your submission of a research funding application please email the School Research Office (research.medicine@tcd.ie) providing:

1. A copy of the final application
2. A copy of the budget
3. A link to the funding call to which you are applying
4. Notice of the deadline for submission
5. The endorsement of your Academic Head of Department should also be provided via email

Letters of Support for Research Applications

Some funders require letters of support from TCD for the applicant.

It is commonplace for templates of these letters to be provided by the College Research Office, these letters should be completed and provided via email to research.medicine@tcd.ie for the Head of School to sign. Trinity letterhead should be used when the Dean of Research is to co-sign these letters. School of Medicine letterhead should be only used when the Head of School is to sign.

All queries relating to such letters should be sent at the earliest time to research.medicine@tcd.ie

2.2.8.1 Research Impact

Researchers are now faced with increasingly novel (and sometimes complex) requirements to showcase their personal impact using a diverse set of impacts, indicators, and metrics. Research proposals, career progression applications and awards are often based on impact (Ref: Research Impact Framework, Lima, and Bowman).[5] Please see here for Researcher Impact Framework.

For School of Medicine Researchers, Bridget Gavin can over a Research Impact Profiling Session using online tools. Contact gavinb1@tcd.ie to avail of this session. See also **Appendix 1** for a sample research profile inventory.

[5] http://www.tara.tcd.ie/bitstream/handle/2262/98474/LimaG_BowmanS_ResearcherImpactFramework_Oct2022.pdf?sequence=9&isAllowed=y

2.2.9 Industry Partnerships and Knowledge Exchange

The Technology Transfer Team[6] within Trinity Innovation supports and enables the research community to translate innovative research excellence into outputs for maximum societal and economic impact. Commercialisation, intellectual property protection and knowledge transfer is an integral component of the technology transfer journey and is supported by the Team in a variety of ways. The Technology Transfer Team is responsible for the implementation of Trinity's policies with respect to knowledge transfer and licensing, intellectual property protection and campus company formation. The following are some of the many areas that they can advise on:

- IP identification and patent protection strategy and management
- Non-patentable IP and/or non-commercial distribution of research outputs such as open source
- Commercialisation, licensing strategy, and industry engagement with respects to IP transfer
- Campus Company Formation, Spin in Engagements, Venture Capital, and seed investment
- Guidance on IP considerations for research projects (Both State and Industry funded)
- Advice on the development of research projects with commerical potential
- IP confidentiality/non-disclosure of IP to third parties for early engagement with third parties

See also supports for:
a. Consultancy work: https://www.tcd.ie/innovation/consult/
b. Industry collaborations: https://www.tcd.ie/innovation/industry/corp-partnerships/
c. Campus company/spin outs: https://www.tcd.ie/innovation/industry/campus-companies/

[6] https://www.tcd.ie/innovation/transfer-supports.php

2.2.10 Data Management

A Data Management Plan (DMP) is required for most funding bodies.Funders expect researchers to make their research available with as few restrictions as possible.

What is a DMP?
It is a document outlining how research data will be handled during a research project, and even after the project is completed, describing what data will be collected, processed or generated and following what methodology and standards, whether and how this data will be shared and/or made open, and how it will be curated and preserved. The Digital Curation Centre (DCC) has produced a useful guide How to Develop a Data Management Plan that will help with writing both the short outline at proposal stage and the longer DMP. Their Checklist for a Data Management Plan is also very helpful in breaking down the elements required for a DMP.

A number of examples of data management plans are available from the DCC website, including examples from different disciplines (and different funders). See also **Appendix 2** for more information.

Examples of what to cost for your data management:
Cost of TCD data steward time for DMP (Estimated 2 days)
Hard drives (Dell Seagate 4T USB hard drive)
Laptop encryption
Network storage

2.2.11 Public Patient Involvement

Public and Patient Involvement (PPI) is the term for public involvement and coproduction frequently used within the disciplines of health and social care research. PPI is a research practice that involves public(s) and patients in decision-making, prioritising, planning, conducting and communicating research with the overall goal of improving research relevance and impact. It is defined as research carried out with or by patients and those who have experience of a condition, rather than for, to, or about them. It is the concept of involving people, who are not researchers, in the research and seeking their input to shape and guide it. It is about moving their role from one of participant to one of partnership.

TSJCI Research have compiled a guidance document. Please see **Appendix 3** for information.
In addition, TSJCI have a Patient Representative Group. To meet with the PRG, please get in touch with Grainne Smith, TSJCI PPP Lead (GrSmith@stjames.ie) and complete the research summary form in **Appendix 4**.

3.0 POST AWARD SUPPORTS

If you have been awarded funding for research at Trinity College Dublin, there are lots of supports in place to get your project up and running, and to manage the research process through to realising the impact of your ideas. Supports are delivered across many units in College.
See here for key pointers for managing your research award (local access page).

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

APPENDIX I

Profile Inventory Worksheet for Health Researchers

Use this worksheet to explore your online scholarly profiles. The goal of this exercise it to support you in understanding how you are capturing and showcasing your scholarly impact and achievements and highlights the visibility of your research to the public and stakeholders.

1. You've been googled!

When someone searches for my name online

- ☐ They can **easily** find professional information about me
- ☐ There is at least one webpage with my professional profile in the **top results**
- ☐ Most search results are **professionally relevant**

2. ORCID

- ☐ I **have an** ORCID iD that distinguishes me from every other researcher
- ☐ My ORCID biography is **connected** to Trinity College Dublin and is up to date
- ☐ My **publications** list is updated on my ORCID profile
- ☐ I have other professional **profiles** connected to my ORCID page, such as TCD Research Profile
- ☐ My ORCID **keywords** are relevant to my research and career ambitions

3. TRINITY'S RESEARCH SUPPORT SYSTEM (RSS)

- ☐ My RSS Profile is **fully up to date** with extensive information in Biography sections including Teaching, Research Interests, Service to Discipline, Qualifications, Memberships, Awards, Education, Conferences, Collaborations, Keywords, Tags, Projects, Publications, References
- ☐ My RSS Profile is **connected** to my ORCID profile
- ☐ My RSS Profile is **consistent** with my CV and publications list
- ☐ Where relevant, my publications have **permanent identifiers** (e.g. DOIs or URLs)
- ☐ When relevant, I have uploaded my publications to TARA, Trinity's **Open Access** Repository

4. GOOGLE SCHOLAR PROFILE

- ☐ I have a **verified** Google Scholar **Profile**
- ☐ My **publications** list is updated on my Google Scholar profile
- ☐ My Google Scholar **keywords** are relevant to my research and career ambitions and consistent with other profiles
- ☐ **I can use** the information on Google Scholar such as co-authorship and citation data to showcase my research profile in future applications

5. SCOPUS PROFILE AND BIBLIOMETRICS

- ☐ I have a **verified** Scopus **ID and I only appear once**
- ☐ My Trinity College Dublin **affiliation** is up to date
- ☐ Scopus is relevant to me as the **databases** in Scopus capture where I am usually publishing
- ☐ My **publications** list on Scopus is comprehensive, if relevant
- ☐ **I can use** the information on Scopus such as co-authorship and citation data to showcase my research profile in future applications

6. ALTMETRIC.COM

- ☐ I have **access** to an account with Altmetric through Trinity's Library
- ☐ I have a saved list of my publications' **permanent identifiers** on Altmetric.com
- ☐ I know which of my publications are gaining more **traction** and who is engaging with it
- ☐ I know how to identify potential **collaborators and publication venues** using Altmetric.com

7. SOCIAL MEDIA AND OTHER PROFESSIONAL PROFILES

- ☐ I have **considered** multiple social media and professional platforms
- ☐ I have adopted accounts in platforms that make sense for my **research area**
- ☐ Existing and new academic and professional connections **find and contact me**
- ☐ I have reviewed my **privacy settings** in the last year
- ☐ My relevant professional profiles are **associated with Trinity College Dublin**
- ☐ I am **engaging** with stakeholders that could benefit my work and benefit from it

8. WEBSITES

- ☐ I have **considered** having my own personal website
- ☐ I have **updated** my profile in every research groups websites I am part of
- ☐ I have reviewed my **privacy settings** in the last year
- ☐ My relevant professional profiles are **associated with Trinity College Dublin**
- ☐ I am **engaging** with stakeholders that could benefit my work and benefit from it

9. COLLABORATION

☐ I have considered fostering international mobilities and networks (possibly via COST Actions, Eurolife, Horizon Europe, the School of Medicine TRAM scheme or another)

☐ I have considered joining a transdisciplinary research activity via collaboration with a different school, research centre or Discipline

☐ I have set up tracking processes to record all my external collaborative partners across all sectors including academia, clinical partners, Public Patient representatives, community groups, industry, Government, NGOs etc.

Further references:

HRB Monitoring and Evaluation Strategy for Funded Research 2022- 2025

https://libguides.tcd.ie/researchprofile.

https://www.sfi.ie/funding/award-management/research-impact/

https://esrc.ukri.org/research/impact-toolkit/

https://www.ukri.org/about-us/research-england/research-excellence/ref-impact/

Researcher Impact Framework: Building Audience-Focused Evidence-Based Impact Narratives

Engaged Research Framework: How-To Guide

Engaged Research Planning for Impact Framework: How-To Guide

Engaged Research Principles & Good Practices

For further information or to enquire about a one hour research impact check, contact: research.medicine@tcd.ie

APPENDIX II

Template for Data Management Plan[1]

Title of project:

1. Description of the data

1.1 Types of data

What types of data will the project generate/collect? Types of research data to be managed in the following terms: quantitative, qualitative; generated from surveys, clinical measurements, interviews, medical records, electronic health records, administrative records, genotypic data, images, tissue samples etc.

The table below outlines a sample of data outputs – *tailor this to your own project outputs*.

Output #	Type of data	Output	Format	Access plan
1	Microarray	Genotypic data on xx	Affymetrix, file format etc. Size of file	Open access via xxx
2	Set of x digital images	Photo exhibition	JPEG, 1MB each	Open access via xxx

It can be useful to capture your data in community-accepted data formats – this makes your data interoperable. Non-proprietary formats are preferable.

2. Data management, curation and preservation

2.1 Data Collection

Documentation and handling methods/protocols. What standards will be applied to data collection, processing and annotation?

2.1 Managing, storing and curating data.

Describe how data will be stored, backed-up, managed and curated in the short to medium term. Specify any community agreed or other formal data standards used. Refer to any BIMS system that may be in place for biobank management if applicable. SOPs used etc.
Any existing standards relating to your specific discipline? If there are none, do you plan to create new standards?

2.2 Metadata documentation

Plans for documenting, annotating and describing data so that research data are usable by others than your own team. This may include documenting the methods used to generate the data, analytical and procedural information, capturing instrument metadata alongside data, documenting provenance of data and their coding, detailed descriptions for variables, records, etc.

2.3 Data preservation strategy and standards

How will you ensure that key datasets are preserved to ensure their long term value? Where will data be stored and for how long? Approximate end volume/size? Associated costs[2] and how they might be covered.

Where to deposit your data?
Trinity's open access repository is TARA http://www.tara.tcd.ie/.

[1] Modified from CRUK DMP

[2] Data management costs should be included running costs of project budget where possible. UK Data Service have developed a costing tool for data management in the social sciences https://www.ukdataservice.ac.uk/manage-data/plan/costing, which may assist in our costings.

Other data repositories can be found at Re3data, www.re3data.org.

3. Data security and confidentiality of potentially disclosive personal information

Complete this section only if your research data include **personal data relating to human participants in research**. Information provided will be in line with your ethical review.

Main risks to data security

If not using formal standards, summarise the main risks to the confidentiality and security of information related to human participants, and how these risks will be managed. Cover the main processes or facilities for storage and processing of personal data, data access, with controls put in place and any auditing of user compliance with consent and security conditions.

How your data will be managed in accordance with GDPR and Health Research Regulations.

4. Data sharing and access

4.1 Mechanisms for sharing

Data generated across all research areas has the potential for re-use and should be shared regardless of whether they have been used in a publication. How will this data be exploited and/or shared/made accessible for verification and re-use? If data cannot be made available, explain why.

Describe how the data will be shared, any embargo periods, mechanisms of dissemination, software/other tools to enable re-use, all access plans (any restrictions to specific groups?). Where data will be stored. Any reasons data cannot be shared?

How will data be disseminated to promote continued use?

4.2 Discovery by potential users of the research data

Indicate how potential new users can find out about your data and identify whether they could be suitable for their research purposes, e.g. through summary information (metadata) being readily available on the study website, or in other databases or catalogues.

Indicate whether your policy or approach to data sharing is (or will be) published on your study website (or by other means).

Mention period of exclusivity for study team to use data – there is an understanding that a limited, defined period of exclusive use of data for primary research is reasonable according to the nature and value of the data, and that this restriction on sharing should be based on simple, clear principles.

4.4 Restrictions or delays to sharing, with planned actions to limit such restrictions

Possible reasons for restrictions:

- IP protection/commercialisation
- Proprietary data (due to collaboration agreements, material transfer agreements)
- Confidentiality/ethical or consent issues that may arise with use of data involving human subjects.

4.5 Governance of access

Identify who makes or will make the decision on whether to supply research data to a potential new user, and indicate how independent oversight of data access and sharing works (or will work). Include details of the person to contact for potential new users to request data (unless plans involve submission of data to a third party repository). Will new users/external users are (will be) bound by data sharing agreements

5. Responsibilities

Specify who, alongside the PI, is responsible for ensuring the study-wide data management, as well as for specific roles such as metadata creation, data security and quality assurance of data.

6. Relevant institutional, departmental or study policies on data sharing and data security	
Policy	**URL or Reference**
TCD Policy for Good Research Practice	Good_Research_Practice_June2021.pdf (tcd.ie)
7. Author of this Data Management Plan (Name) and, if different to that of the Principal Investigator, their **telephone & email contact details**	

Making Data FAIR (see 1. Below)

Findable, Accessible, Interoperable and Reusable

Box 2 | The FAIR Guiding Principles

To be Findable:
F1. (meta)data are assigned a globally unique and persistent identifier
F2. data are described with rich metadata (defined by R1 below)
F3. metadata clearly and explicitly include the identifier of the data it describes
F4. (meta)data are registered or indexed in a searchable resource

To be Accessible:
A1. (meta)data are retrievable by their identifier using a standardized communications protocol
A1.1 the protocol is open, free, and universally implementable
A1.2 the protocol allows for an authentication and authorization procedure, where necessary
A2. metadata are accessible, even when the data are no longer available

To be Interoperable:
I1. (meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation.
I2. (meta)data use vocabularies that follow FAIR principles
I3. (meta)data include qualified references to other (meta)data

To be Reusable:
R1. meta(data) are richly described with a plurality of accurate and relevant attributes
R1.1. (meta)data are released with a clear and accessible data usage license
R1.2. (meta)data are associated with detailed provenance
R1.3. (meta)data meet domain-relevant community standards

Useful Resources:

1.FAIR GUIDING PRINCIPLES for scientific data management and data stewardship: Findability, Accessibility, Interoperability, and Reusability: http://www.nature.com/articles/sdata201618
2. Costing Data Management https://www.ukdataservice.ac.uk/manage-data/plan/costing
3. Data sharing guidelines (CRUK) http://www.cancerresearchuk.org/funding-for-researchers/applying-for-funding/policies-that-affect-your-grant/submission-of-a-data-sharing-and-preservation-strategy/data-sharing-guidelines
4. Developing a data management plan (Wellcome Trust) https://wellcome.ac.uk/funding/managing-grant/developing-data-management-and-sharing-plan
5. Guidelines for Data management in Horizon Europe (from Enspire Science) Data Management Plan in Horizon Europe - Enspire Science Ltd.
6. https://www.tcd.ie/library/riss/research-data.php

APPENDIX III
General guidance on including PPI in your research proposal

Introduction

Public and Patient Involvement (PPI) is the term for public involvement and co-production frequently used within the disciplines of health and social care research. PPI is a research practice that involves public(s) and patients in decision-making, prioritising, planning, conducting and communicating research with the overall goal of improving research relevance and impact.

It is defined as ***research carried out with or by patients and those who have experience of a condition, rather than for, to, or about them***.

It is the concept of involving people, who are not researchers, in the research and seeking their input to shape and guide it. It is about moving their role from one of participant to one of partnership.

In an effort to clarify what is meant by involvement, Irish Universities Association's **Campus Engage** differentiates between three different ways in which people can become a part of the research process:

- **Participation**: Being recruited as study participants is defined as participation in research;

- **Engagement**: Efforts aimed at raising awareness among the public around research, such as newspaper articles, or outreach activities such as open days in research facilities can be described as engagement. Engagement activities are required for both participation and involvement;

- **Involvement**: Refers to co-created and co-produced research with a focus on collaboration

(Ref: https://www.tcd.ie/tcaid/assets/pdf/MakingAStart_PPIToolkit.pdf
MAKING A START: A toolkit for research charities to begin a PPI relationship)

What PPI is:

• PPI describes a whole variety of ways that researchers engage with people for whom their research holds relevance.
• PPI plays an important role in ensuring that patients are informed about research that is relevant to them. This is likely to result in increased patient support for research and the improved likelihood of patient involvement in the case of clinical research.
• PPI is an important step in ensuring that the real-life experiences of patients are considered in decision-making processes around research.
• PPI is key to ensuring that patients and their families have the express the questions and needs that matter most to them, which is likely to improve the relevance of research.

• PPI helps to ensure that studies involving patients are designed to be sensitive to the needs of the study participants.

What PPI is NOT:

• PPI is not an attempt to make amateur scientists out of lay people. It is well recognised that, in general, it is not appropriate to ask lay people to assess the validity or methodology of an avenue of research.
• The use of PPI is not intended to focus research on short-term health goals. Patients, in particular, often have great understanding of the need for research at all stages of the spectrum, from basic to applied.
• The adoption of PPI into funding and policy processes is not meant to imply that researchers have no empathy or understanding of the needs of patients.
• The use of PPI is not intended to confuse or provide false hope to people who are vulnerable.

(Ref: Irish Health Research Forum, https://859556ce-4d33-4b82-be63-d48940ba7029.filesusr.com/ugd/75eae6_5ee17a6102544c3c8119362d36bb751b.pdf)

Why do PPI?

Involving patients and the public in research is seen as a marker of good research practice because it leads to research that is relevant, better designed, with clearer outcomes, and a faster uptake of new evidence.

It is important to realise that Patients/Public can be involved in research in a number of different ways;

1. As co-applicants on a research project.
2. Involvement in identifying research priorities (at a national, institutional or charity level).
3. As members of a project advisory or steering group.
4. Assisting with the developing of patient information leaflets or other research materials.
5. Carrying out the research.
6. Dissemination and implementation of the research outcomes

The spectrum of ways in which a patient or members of the public might be involved in research:

Ref: Public and Patient Involvement (PPI) in Research: Irish Health Research Forum https://859556ce-4d33-4b82-be63-d48940ba7029.filesusr.com/ugd/75eae6_5ee17a6102544c3c8119362d36bb751b.pdf

How to start

Planning PPI Templates:

Activity	Role for PPI?	PPI approach?
Agree the research question – what is the most important thing to address right now, with the resources and time we have available?		
What data will you need to answer this question?		
Where will you find that data (if already collected)? *And/or* Who will provide the data (these are study participants)?		
Will you need ethical approval to collect data? If yes, list the steps involved:		
How will you collect data (this is study methodology and protocol)?		
How will you analyse the data?		
How will you report on and share the results?		
What is the next step when you have shared the results?		

Ref: PPI Ignite @ NUI Galway

Here are a few questions to help you to work out what roles PPI contributors will play.

Stage	What role will PPI contributors play*?	What PPI activities are needed to help them play a role?	How does this benefit the research, its impact or the team?
Identifying & Prioritising stage			
Design stage			
Undertaking & Management stage			
Analysing & Interpreting stage			
Dissemination stage			
Implementation & Impact stage			

Ref: PPI Ignite at Trinity College Dublin (https://www.tcd.ie/tcaid/ignite/)

Research Planning Canvas

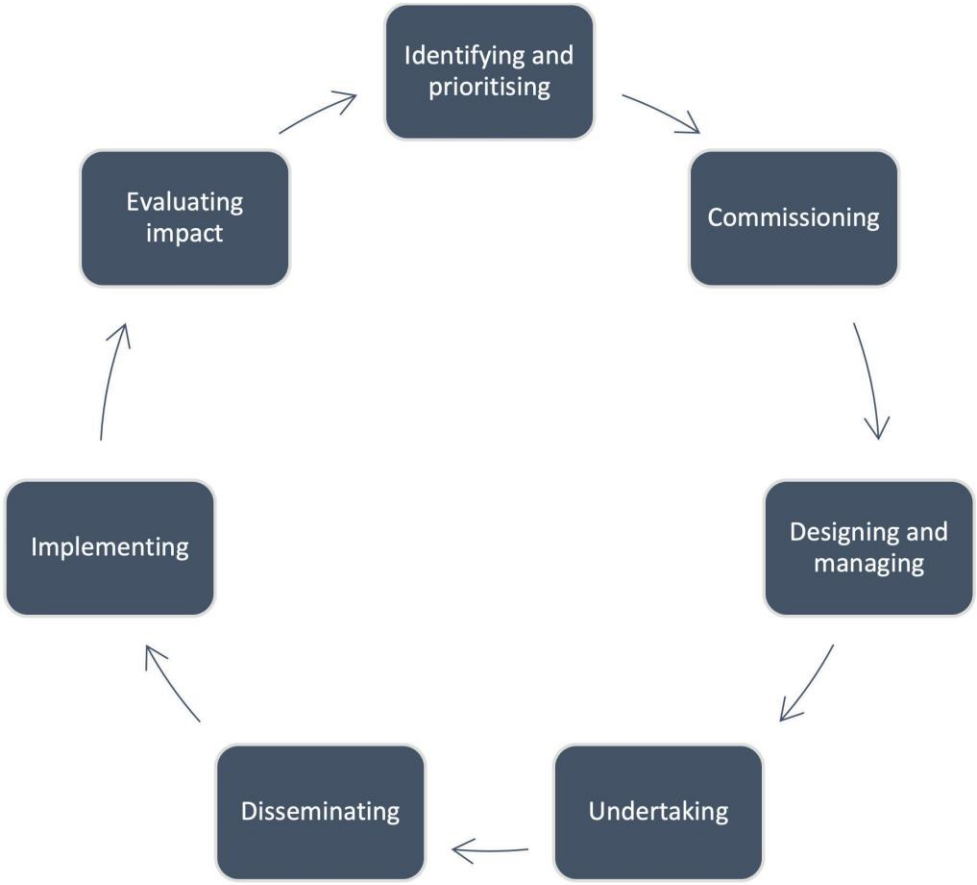
To make a strategic, considered plan for the involvement of patients and public(s) throughout all stages of research, the PPI planning canvas is a useful resource.

Ref:https://www.ucd.ie/research/portal/outcomesandimpacts/publicengagementandengagedresearch/).

PPI Researcher Planning Canvas

<table>
<tr><th>CHALLENGE</th><th>RESPONSE</th><th>VALUE</th></tr>
<tr><td>Barriers
Institutional policies, procedures or situations that my hinder PPI</td><td rowspan="3">→</td><td>What additional benefit will PPI bring to your research</td></tr>
<tr><td>Worries
Personal hurdles that cause anxiety or unease about PPI</td><td rowspan="2">IMPACT
What effect on impact will inclusion of PPI bring? (Cultural, economic, health, political, social, knowledge etc.)</td></tr>
<tr><td>Concerns
Perceived impediments to research value or practice</td></tr>
<tr><td colspan="2">Time
Related timeframes to prepare for PPI</td><td>Funding
Your funding roadmap to enable preparation for PPI</td></tr>
</table>

PPI participants can make contributions at every stage of the Research Process.



Source: INVOLVE (2012) Briefing notes for researchers.

How do I cost it?

The following proposed PPI budget template is a TCD PPI Ignite tool reminder of the types of costs that often occur for PPI activities.

Budget Item	Per er item cost	Total Cost
PERSONNEL		
PPI specific team member[1]	€ per day	
PPI Office support time	€ per day + prep time	
External facilitator	€ per day + prep time	
NGO facilitator	€ per day + prep time	
ACTIVITY COSTS (including induction and training)		
Room hire for activities	€ per event	
Tea / Coffee	€ per PPI contributor +other attendees	
Lunch	€ per PPI contributor +other attendees	
Train, Bus, Taxi per event	€ to and from	
Mileage (if permissible)	€ per km	
Overnights (if required)	€ bed-night + breakfast	
Stationery, materials	€ per event	
Data Costs (for online contributors)	€ per hour	
Fees for Conference or Event attendance	€ per Contributor per event	
CONTRIBUTOR ACKNOWLEDGEMENT		
PPI Contributor payment (if permissible)	€ per day per contributor	
PPI honorarium	€ per contributor	
ACCESSIBLITY COSTS		
Sign Language Interpreter	€ per event	
Assistive technology hire	€ per Contributor per event	
Braille material	€ per Contributor per event	
Audio material	€ per Contributor per event	
RECRUITMENT COSTS		
Advertisements	€ per run of ad	

Ref: PPI Ignite at Trinity College Dublin
(https://www.tcd.ie/tcaid/assets/pdf/ignite/TrinityPPIBudget.pdf)

[1] Please see Trinity Centre for Ageing and Intellectual Disability - Trinity College Dublin (tcd.ie) on challenges of costing a contributors time and how it can be managed.

Additional resources

1. HRB PPI Guide: https://www.hrb.ie/funding/funding-schemes/public-patient-and-carer-involvement-in-research/.

2. Campus Engage: https://www.campusengage.ie/wp-content/uploads/2021/04/WEB-IUA-Campus-Engage-Online-Engagement-Publication.pdf.

3. TCD PPI Ignite Toolkit: https://www.tcd.ie/tcaid/assets/pdf/MakingAStart_PPIToolkit.pdf.

4. HSE PPI Patient and Public Involvement in Research (PPI) - HSE | Research & Development (hseresearch.ie)

5. University of Oxford 'A researcher's guide to patient and public involvement' A Researcher's Guide to Patient and Public Involvement (nihr.ac.uk)

6. INVOLVE www.invo.org.uk

7. Patient-Centred Outcomes Research Institute (PCORI) www.pcori.org

APPENDIX IV
Research Proposal Summary Overview for TSJCI Patient Representative Group

Research Applicant Name:	
Proposed Research Title:	

What is/are the objective(s) of your proposed study?
What is the aim of your proposed study?
What are the possible benefits envisaged for the patient, from the research?
What are the cost benefits envisaged?

What are the sources of funding?
Where are the outputs of this study going, is this on a National or International scale?
What support do you require from the Patient Representative Group to realise your research project?
Signed by applicant: **Date:**

For office use only

Date of Presentation to PRG:	
Patient Representative Reviewers:	