

# CONFIDENTIALITY & DATA PROTECTION

## 1. INTRODUCTION

- 1.1 This Participant Information and Consent Form provides guidance and information to the participants involved in this research study regarding the processing of the research participants' personal data. NUI Galway are committed to protecting and respecting your privacy. This Participant Information and Consent Form together sets out the basis on which any personal data we collect from you or that you provide to us will be processed by us an independent data controller. Please read this Participant Information and Consent Form carefully to understand our treatment and use of your personal data.
- 1.2 The processing of your personal data will be in compliance with the Data Protection Acts 1988 to 2018 (as amended) and the General Data Protection Regulation (the “**Data Protection Legislation**”).
- 1.3 Please note that agreeing to participate in a research program with NUI GALWAY you acknowledge that you have read, understood and agree to this Participant Information and Consent Form.

## 2. IDENTITY OF THE CONTROLLER OF PERSONAL INFORMATION

For the purposes of the Data Protection Legislation, **NUI Galway** are independent data controller in the following circumstances. However, the main guardian of the data is also National University of Ireland Galway University Road, Galway, Ireland H91 TK33.

## 3. CONTACT DETAILS OF THE DATA PROTECTION OFFICER\*

3.1

The data protection officer for NUI Galway  
Name: Sarah Dever  
Address: NUI Galway, Room A129, The Quadrangle, NUI Galway, University Road,  
Galway  
Email: dataprotection@nuigalway.ie

## 4. PROCESSING OF YOUR PERSONAL DATA

**NUI Galway** will process your personal data for the following purposes on the basis of your consent:

Personal data	Purpose of processing <sup>1</sup>
Identification (DOB, racial and ethnic origin (please note this and subsequent information will be pseudo anonymised/coded for data processing).	(a) used for purpose of carrying out research
Laboratory test results	Clinical care, safety measures, research

<sup>1</sup> Please list the Personal Data that will be processed and the purpose of processing such Personal Data.

	outcomes
Clinical and or medication history (not identifiable)	(a) Relevant for understanding study outcomes Captured as research outcomes
Diagnostic tools/machines	Captured as research outcomes

#### 4.1 Where does NUI Galway obtain my personal data from?

Most of the personal data we process is obtained from you directly, but we also obtain personal data about you from your lab test results.

## 5. SHARING OF PERSONAL DATA

Your personal data may be shared with our collaborators listed:

### Research Study Leaders:

Prof. Breda Smyth, Director of Public Health, HSE West, Merlin Park, Galway. [breda.smyth@hse.ie](mailto:breda.smyth@hse.ie) and National University of Ireland Galway [smythb@nuigalway.ie](mailto:smythb@nuigalway.ie)

Prof. Charles Spillane, Genetics & Biotechnology Lab, Ryan Institute, National University of Ireland Galway, University Road, Galway. [charles.spillane@nuigalway.ie](mailto:charles.spillane@nuigalway.ie)

Prof. Kingston Mills, Trinity Biomedical Science Institute, Trinity College Dublin, College Green, Dublin 2. [kingston.mills@tcd.ie](mailto:kingston.mills@tcd.ie)

Prof. Orla Sheils, Faculty of Health Sciences, Trinity College Dublin, College Green, Dublin 2. [osheils@tcd.ie](mailto:osheils@tcd.ie)

Prof. Mary Horgan, Royal College of Physicians of Ireland & University College Cork, College Road, Cork. [m.horgan@ucc.ie](mailto:m.horgan@ucc.ie)

Dr. John MacSharry, School of Medicine & School of Microbiology, University College Cork, College Road, Cork. [j.macsharry@ucc.ie](mailto:j.macsharry@ucc.ie)

Prof. Patrick Mallon, School of Medicine, University College Dublin, Belfield, Dublin 4. [paddy.mallon@ucd.ie](mailto:paddy.mallon@ucd.ie)

Prof. Grace Mulcahy, School of Veterinary Medicine, University College Dublin, Belfield, Dublin 4. [grace.mulcahy@ucd.ie](mailto:grace.mulcahy@ucd.ie)

\*NOTE: These parties will either be acting as Processors of your information as part of this research study e.g. CROs, non-hospital employees supporting research process or Controllers in their own right.

#### 5.1 Service Providers

We use third party service providers who provide services including financial services, occupational health and IT services. In providing the services, your personal data will, where applicable, be processed by the service provider on our behalf.

We will check any third party that we use to ensure that they can provide sufficient guarantees regarding the confidentiality and security of your personal data. We will have written contracts with them which provide assurances regarding the protections that they will give to your personal data and their compliance with our data security standards and international transfer restrictions.

## 5.2 Disclosures to Third Parties

In certain circumstances, we share and/or are obliged to share your personal data with third parties outside National University of Ireland, Galway for the purposes described above and in accordance with Data Protection Legislation.

These third parties include but are not limited to:

- the Health Products Regulatory Authority;
- the Health Service Executive;
- the Joint Commission International;
- external professional advisors; and
- others, where it is permitted by law, or where we have your consent.

## 6. TRANSFERS OUTSIDE THE EUROPEAN ECONOMIC AREA<sup>2</sup>

Your personal information may be transferred, stored and processed in one or more countries outside the European Economic Area (“EEA”), for example, when one of our service providers use employees or equipment based outside the EEA. For transfers of your personal data to third parties outside of the EEA, we take additional steps in line with Data Protection Legislation. We have put in place adequate safeguards with respect to the protection of your privacy, fundamental rights and freedoms, and the exercise of your rights, e.g. we establish an adequate level of data protection through EU Standard Contractual Clauses based on the EU commission’s model clauses.

If you would like to see a copy of any relevant provisions, please contact your data protection officer (see “Contact Us” section below).

## 7. HOW IS MY PERSONAL DATA SECURED

7.1 NUI Galway operate and use appropriate technical and physical security measures to protect your personal data.

7.2 We have in particular taken appropriate security measures to protect your personal data from accidental or unlawful destruction, loss, alteration, unauthorised disclosure of, or access, in connection with this research study. Access is only granted on a need-to-know basis to those people whose roles require them to process your personal data. In addition, our service providers are also selected carefully and required to use appropriate protective measures.

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<sup>2</sup> Position on data transfers to be confirmed.

## 8. STORAGE OF PERSONAL DATA

We will keep your personal data for 15 years after the study ends. This may mean that some information is held for longer than other information.

## 9. YOUR RIGHTS

9.1 You may have various rights under Data Protection Legislation. However, in certain circumstances, these rights may be restricted<sup>3</sup>. In particular, your rights may be restricted where this is necessary: (i) for the prevention, detection, investigation and prosecution of criminal offences; (ii) in contemplation of or for the establishment, exercise or defence of a legal claim or legal proceedings (whether before a court, tribunal, statutory body or an administrative or out-of-court procedure); and/or (iii) for the performance of a task carried out in the public interest or in the exercise of official authority vested in National University of Ireland, Galway.

These rights may include (as relevant):

- (i) **The right of access** enables you to check what type of personal data we hold about you and what we do with that personal data and to receive a copy of this personal data;
- (ii) **The right to object** to processing of your personal data where that processing is carried out on the basis of our legitimate interests. We will stop using your personal data unless we can demonstrate an overriding legitimate ground for the continued processing of this personal data;
- (iii) **The right to rectification** enables you to correct any inaccurate or incomplete personal data that we hold about you;
- (iv) **The right to erasure** enables you to request that we erase personal data held about you in certain circumstances;
- (v) **The right to restrict processing** of your personal data by us in certain cases, including if you believe that the personal data held about you is inaccurate or our use of the personal data is unlawful; and
- (vi) **The right to data portability** enables you to receive your personal data in a structured, commonly used and machine readable format and to have that personal data transmitted to another data controller

## 10. YOUR RIGHT TO LODGE A COMPLAINT WITH A SUPERVISORY AUTHORITY

10.1 Without prejudice to any other administrative or judicial remedy you might have, you may have the right under data protection legislation in your country (where applicable) to lodge a complaint with the relevant data protection supervisory authority in your country (i.e. the Office of the Data Protection Commissioner in Ireland) if you consider that we have infringed applicable data protection legislation when processing your personal data. This means the

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<sup>3</sup> Article 23 of the General Data Protection Regulation, which is transposed into Irish law by section 59 of the Data Protection Act 2018, sets out the circumstances in which your rights may be restricted.

country where you are habitually resident, where you work or where the alleged infringement took place.

## **11. CHANGES TO THIS INFORMATION**

11.1 We may decide to make changes to this Participant Information and Consent Form. If a change is made, we will notify you in person of such changes. An updated Participant Information and Consent Form will be provided to you in advance of any change actually taking effect.

## **12. CONTACT US**

12.1 For further information or if you have any questions or queries about this Participant Information Leaflet, please contact:

**Sarah Dever**  
Data Protection Officer,  
NUI Galway, Room A129,  
The Quadrangle,  
NUI Galway,  
University Road,  
Galway

**By email:**

[dataprotection@nuigalway.ie](mailto:dataprotection@nuigalway.ie)