

# INDEPENDENT NEUROLOGY INQUIRY

## Privacy Notice

Data Controller Name: The Independent Neurology Inquiry  
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### Why are you processing my personal information and what is the lawful basis for processing?

The Independent Neurology Inquiry is a non-statutory inquiry of an inquisitorial nature established by the Department of Health for the purposes of completing a report on the matters set out in the Inquiry's Terms of Reference.

The Inquiry will collect personal information about patients, their families and individual organisational stakeholders in support of its terms of reference. Data will therefore be processed to allow the Inquiry to investigate the circumstances which led to the recall of patients in May 2018 (for the period from November 2016 until May 2018), to evaluate the corporate governance (with particular reference to clinical governance) procedures and arrangements within the Belfast Trust and associated organisations, namely the Health & Social Care Board, the Public Health agency, the Department of Health, the Regulation Quality and Improvement Authority and independent care providers. This specifically includes the communication and escalation of the reporting of issues related to potential concerns about patient care and safety, within and between the Belfast Trust, the HSC Board and Public Health Agency, the Department and any other areas which directly bear on patient care and safety and the general public, including an assessment of the role of the Board of the Belfast Trust.

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Data will also be processed by the Inquiry to facilitate the review of the handling of relevant complaints or concerns, by the relevant organisations, identified or received prior to November 2016, and participation in the processes to maintain standards of professional practice, including appraisals. The Panel are asked to determine whether there were any related concerns or circumstances which should have alerted the Belfast Trust to instigate an earlier and more thorough investigation over and above the extant arrangements for raising concerns and the existing complaints procedure.

Data will be processed to facilitate the Inquiry identifying any learning points and to make recommendations to the Department. In particular the Inquiry will consider the application of any learning arising from the Inquiry to the framework for clinical social care governance, the current balance between problem sensing and assurance seeking in the extant system and its underpinning processes.

The processing of personal information is necessary for the performance of the task detailed above which is carried out in the public interest, under the instruction and authority of the Department of Health (DoH), in line with the Article 6(e) of the General Data Protection Regulation (GDPR). Where we are required to process any sensitive, 'special category' data which includes sensitive personal data, we do so in line with Article 9(g) of GDPR. All processing of personal data by the Inquiry will be done in line with GDPR/DPA and only for what is necessary for the purposes of the Inquiry, in line with substantial public interest, to help ensure the management of the Northern Ireland health and social care system and high standards of quality and safety of healthcare.

## What categories of personal data are you processing?

Evidence to be obtained by the Inquiry is likely to include the following categories: -

- personal health and family information about neurology patients supplied by patients, clinicians and other relevant persons;
- details held in patients records including physical and mental health details;
- written submissions by patients, clinicians and other relevant persons;
- oral evidence by patients, clinicians and other relevant persons;

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- correspondence involving and between clinicians, management, patients and patient's representatives;
- governance documentation including policies, minutes, agendas and action plans;
- employer human resource and performance management documents to include assessment of clinicians professional competence;
- complaints documentation;
- investigations and reports;
- risk management documentation;
- correspondence between and within public bodies and other relevant organisations, and
- Whistleblowing information.

All of said information may include personal data such as names, addresses, telephone numbers or other personal identifiers. Some of the information such as risk management documents, complaints documentation or written submissions by patients is likely to include special category data, including health data.

## Where do you get my personal data from?

The Inquiry will be inviting written submissions directly and these may be received from patients, from family members, clinicians, senior management and others who have an interest in Neurology services. The Inquiry will also obtain evidence directly from public bodies, which may contain personal data.

Those invited to give evidence before the Inquiry Panel, to include patients, clinicians and other persons. These sessions will be recorded and a transcript produced by an independent body on behalf of the Inquiry. Non-disclosure confidentiality agreements and a Memorandum of Understanding are in place in relation to transcription services to ensure the protection of personal data.

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## Do you share my personal data with anyone else?

The Inquiry may share relevant information with participants (such as those called to give evidence or required to provide written responses to questions posed by the Inquiry) as necessary: such participants may include clinicians, the Health & Social Care Board and Trusts, the Department of Health, and the Public Health Agency. Personal information shared will be kept to a minimum and where possible the Inquiry will redact personal information from the information shared.

The Inquiry may decide to place some information that it collects onto the Inquiry website and this may contain personal information. In such cases the Inquiry will seek the consent of individuals to use this information however, where consent is refused, a decision may be taken not to publish the information. Alternatively, where the Inquiry decides to publish personal data contained within documents made available to the Inquiry it will be redacted to protect the individual(s) involved. Should the Inquiry decide to publish the information it collects then it will develop an Anonymity and Redaction Protocol.

Where the Inquiry receives information that is outside its terms of reference but considers that it would be better examined by one of the other parallel investigations into the same matter, it may pass that information on to other public bodies and consent will be obtained where appropriate. The bodies carrying out parallel investigations include the General Medical Council (GMC), the Belfast Health & Social Care Trust and the Regulation and Quality Improvement Authority (RQIA). Any sharing of information will be carried out in accordance with the requirements of GDPR and DPA 2018.

For the purpose of producing a transcript of the Inquiry's oral sessions, data will be shared with the transcription service provider. Non-disclosure confidentiality agreements and Memorandum of Understandings are in place which ensures the Inquiry's compliance with its responsibilities under GDPR and DPA 2108 and sets out the relationship between the Inquiry as Data Controller and the transcription service provider as the Data Processor.

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## Do you transfer my personal data to other countries?

The data will normally be used within the United Kingdom. One of the transcription service providers is based in the Republic of Ireland.

## How long do you keep my personal data?

An end date for the Inquiry isn't clear at present but, as the Inquiry collects more information it will develop and agree a Retention and Disposal Schedule, in consultation with the Public Records Office of Northern Ireland (PRONI). Once the Inquiry has issued its final report the Chairman will make arrangements for the preparation and transfer of the Inquiry Record to PRONI. The Inquiry website will also be captured by PRONI and this will form part of the open record of the Inquiry.

Certain financial and governance records will transfer to the Department of Health to be retained for financial accounting purposes. These records will be retained and eventually destroyed in line with the Department's approved retention and disposal schedule Good Management Good Records (GMGR). All other material not required to be transferred to the Department or PRONI will be securely destroyed.

## (If you use automated decision making or profiling) How do you use my personal data to make decisions about me?

Not applicable.

## What rights do I have?

- You have the right to obtain confirmation that your data is being [processed, and access to your personal data\(external link opens in a new window / tab\)](#)
- You are entitled to have personal data [rectified if it is inaccurate or incomplete \(external link opens in a new window / tab\)](#)

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- You have a right to have personal data [erased and to prevent processing\(external link opens in a new window / tab\)](#), in specific circumstances
- You have the right to [‘block’ or suppress processing of personal data\(external link opens in a new window / tab\)](#), in specific circumstances
- You have the right to [data portability\(external link opens in a new window / tab\)](#), in specific circumstances
- You have the right to [object to the processing\(external link opens in a new window / tab\)](#), in specific circumstances
- You have rights in relation to [automated decision making and profiling\(external link opens in a new window / tab\)](#)

## How do I complain if I am not happy?

**If you are unhappy with how any aspect of this privacy notice, or how your personal information is being processed, please contact Geraldine Quinn, the Data Protection Officer using the details provided above.**

**If you are still not happy, you have the right to lodge a complaint with the Information Commissioner’s Office (ICO): -**

### **Information Commissioner’s Office**

Wycliffe House

Water Lane

Wilmslow

Cheshire. SK9 5AF

Tel: 0303 123 1113

Email: [casework@ico.org.uk](mailto:casework@ico.org.uk)

<https://ico.org.uk/global/contact-us/>

**22 January 2019**