

# INDEPENDENT NEUROLOGY INQUIRY

## **Guide to the Neurology Questionnaire**

This guide provide an explanation of the Inquiry and its work, and provides guidance as to how you can share relevant information.

The work of the Inquiry is independent from all other organisations including government departments, regulators and healthcare providers. The Inquiry encourages you to assist it by engaging with its work.

The Inquiry invites written contributions to be submitted by **7 December 2018** and details as to how you can respond are set out in the following pages.

If you require this guide in a different format such as large print, braille, or a language other than English please contact **0300 200 7829**. If you require help or support in completing the questionnaire please see the section in this guide under the heading “Help and Support”.

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## Background

The Independent Neurology Inquiry (“The Inquiry”) wishes to receive information from the public to assist with its work. We are particularly keen to hear from patients and their family members regarding concerns or complaints that they may have had in relation to Neurology Services. The Inquiry is interested in Neurology Services provided both by both the NHS and the private sector. Whether or not you acted on any concerns should not prevent you completing the questionnaire.

We also welcome comment from anyone else who may have had concerns regarding Neurology Services, for example, those working in or alongside the health service.

The following content is intended to help you understand the work of the Inquiry and to provide you with information relating to the questionnaire, so that you can make an informed decision as to whether and how you wish to respond. We are also keen that you provide information, which is of use to this Inquiry in fulfilling its remit. For this reason, on the following pages, you will find an explanation of what type of information we are seeking.

## What this Inquiry is investigating

The Inquiry is investigating whether appropriate action was taken in light of the information that was known, or ought to have been known, by those with responsibility for decision making or oversight. At the end of the Inquiry’s work it is hoped that recommendations and learning points can be identified.

The Inquiry is independent of all other organisations and is of an inquisitorial nature.

The Inquiry Panel is chaired by Mr Brett Lockhart QC, who is a senior barrister, and Professor Hugo Mascie-Taylor who is a qualified medical doctor with significant expertise in clinical governance.

## The work of the Inquiry

The work of the Inquiry is to review the events which led to the Belfast Trust initiating a recall of neurology patients in May 2018 and to consider issues such as:

- whether the Trust's investigations were sufficient;
- whether the steps taken were appropriate;
- whether relevant organisations were adequately performing their function; and
- whether alternative steps could, or ought to, have been taken at an earlier stage.

The Inquiry's investigations will consider the corporate decision making, including the clinical governance procedures and arrangements within the healthcare system and the escalation and reporting of concerns relating to patient care and safety.

It is likely that these investigations will result in the Inquiry reviewing the role and input of various organisations including the other Health and Social Care Trusts, the Health and Social Care Board, the Public Health Agency, the Department of Health, the Regulation Quality and Improvement Authority ("RQIA") and the independent care providers.

## What the Inquiry is not doing

To avoid any misunderstanding the Inquiry wishes to make clear what it is **not** doing:

- We are not making decisions on the clinical practice or employment status of Dr Michael Watt, Consultant Neurologist;
- We are not responsible for the recall process;
- We are not involved in any compensation scheme for anyone who may be dissatisfied with the Neurology Services they have received.
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## Other related reviews

It is also important to explain that there are a number of other reviews and investigations currently ongoing and relating to either Neurology Services or arising out of the same circumstances, which led to the Inquiry being commissioned.

Whilst some of the reviews and investigations may overlap with the work of the Inquiry, and some of their outcomes may be of interest to the work of this Inquiry at a later stage, the work of the Inquiry is distinct from, and independent of, the other reviews.

An overview of the purpose of the other reviews and investigations is set out below together with details of the organisation responsible for each of the review/investigation. In the event that the Inquiry receives information which is relevant to one of the matters listed below it may be necessary to forward the information you provide on to the relevant organisation.

### Public Health Agency and the Regional Health and Social Care Board:

- The recall of Dr Watt's neurology patients - This process is being carried out by the Belfast Trust and is being overseen by the Public Health Agency and the Regional Health and Social Care Board. Any patients with concerns or issues in respect of the recall process should contact Belfast Health & Social Care Trust.

Belfast Health and Social Care Trust  
Trust Headquarters, A Floor  
Belfast City Hospital  
Lisburn Road  
Belfast. BT9 7AB  
Email: [info@belfasttrust.hscni.net](mailto:info@belfasttrust.hscni.net)  
Tel: 028 9504 0100  
Web: <http://www.belfasttrust.hscni.net/>

### Belfast Health and Social Care Trust:

- Investigation into the clinical practice of Dr Watt during the course of his employment – The Belfast Trust is carrying out an investigation within the terms of the framework document “Maintaining High Professional Standards” and any information you wish to provide in respect of this investigation should be addressed to the Belfast Health and Social Care Trust.

Belfast Health and Social Care Trust  
Trust Headquarters, A Floor  
Belfast City Hospital  
Lisburn Road  
Belfast. BT9 7AB  
Email: [info@belfasttrust.hscni.net](mailto:info@belfasttrust.hscni.net)  
Tel: 028 9504 0100  
Web: <http://www.belfasttrust.hscni.net/>

### General Medical Council (GMC):

- An investigation into the professional conduct of Dr Watt – This investigation is being conducted by the General Medical Council.  
3 Hardman Street  
Manchester.  
M3 3AW

### Regulation and Quality Improvement Authority (RQIA):

- A review of the governance of outpatient services in the Belfast Trust with a particular focus on neurology service - This review is being conducted by the RQIA and any concerns or issues should be addressed to the RQIA.

The Regulation and Quality Improvement Authority,  
9<sup>th</sup> Floor Riverside Tower  
5 Lanyon Place  
Belfast. BT1 3BT  
Email: [info@rqia.org.uk](mailto:info@rqia.org.uk)  
Tel: 028 9536 1111  
Web: <https://rqia.org.uk/>

- An expert review of the records of all patients or former patients of Dr Watt who have died over the past ten years - This review is also being conducted by the RQIA and any concerns or issues should be addressed to the RQIA.
- A review of the corporate and clinical governance of health services delivered in the independent sector in Northern Ireland - This review is also being conducted by the RQIA and any concerns or issues should be addressed to the RQIA.

## Department of Health:

- Regional Review of Neurology Services – The Department of Health announced on the 31 July 2018 that work will commence on the review of neurology services covering all neurology specialities. This Departmental review is unrelated to the Inquiry. Any queries in relation to this Departmental review should be addressed to the Department of Health –

Department of Health

Information Office

C5.20, Castle Buildings

Stormont

Belfast. BT4 3SQ

Tel: 028 9052 0500

Email: [webmaster@health-ni.gov.uk](mailto:webmaster@health-ni.gov.uk)

Web: <https://www.health-ni.gov.uk/contact>

## Information of relevance from the public

The Inquiry is specifically interested in concerns or complaints raised relating to patient care and safety within Neurology Services and it is in this area that we wish to receive input from the public.

The questionnaire is specifically designed to enable you to provide the Inquiry with details of any such concerns or complaints. The questions posed have been carefully worded to help ensure that the information sought falls within the remit of the Inquiry.

It is clear to the Inquiry that the more information it obtains about concerns or complaints relating to Neurology Services (including in respect of individual Consultant Neurologists), the better placed it will be to fulfil its remit. We are therefore anxious that anyone who had concerns, even if they were not communicated, engages with the work of the Inquiry by completing the questionnaire.

## Your input

Your input can make a difference to the work of the Inquiry. You do not have to complete all the questions, but we would encourage you to complete all those that are relevant to you. Section 1 asks you for your personal details and information about where and when you (or your relative) was receiving neurology care.

If you are providing information in relation to a deceased relative you should discuss the position with other relatives and agree in advance that there are no objections to information being shared with the Inquiry. There is a box or boxes to tick to confirm that you have the necessary agreements/permissions.

## Completing Section 2

This section of the questionnaire allows you to provide information relating to any concerns you raised in the past relating to Neurology Services. You should complete this section if you raised concerns regardless of whether you did this formally or informally. Please provide as much information as necessary and attach any additional sheets if required.



Where you have documentation relating to the information you have provided (for example if you sent a complaint letter or kept notes of discussions or telephone calls), please attach a copy of that documentation (and not originals) to your questionnaire. Please note that we do **not** require sight of your medical notes and records as part of this public engagement so please do not send these documents to us.

### Completing Section 3

This section of the questionnaire allows you to provide information if you had concerns about Neurology Services but for some reason did not raise the concerns. If you fall into this category the Inquiry is particularly keen to understand why the concerns were not raised. The Inquiry is interested to understand what led to those concerns not being shared with others. The Inquiry will not judge you for not raising these at the time. Please provide as much information as necessary and attach any additional sheets as required.

### Completing Section 4

This section of the questionnaire allows you as an organisation to provide information in respect of concerns.

### Where should completed questionnaires be sent?

Completed questionnaires can be returned by post addressed as follows:

**The Independent Neurology Inquiry**  
**106 University Street**  
**Belfast. BT7 1EU**

Alternatively, completed questionnaires can be emailed to:

[info@neurologyinquiry.org.uk](mailto:info@neurologyinquiry.org.uk)

## Personal Details

Please be assured that we will handle your personal information in keeping with the relevant law including the Data Protection Act 2018 and General Data Protection Regulations 2018.

The Inquiry may wish to invite specific individuals to address them in person. By providing your personal information you will enable the Inquiry to do so. Please do not let the possibility of being invited to attend the Inquiry in person prevent you from completing a questionnaire. We will not take steps to compel anyone who completes a questionnaire to attend the Inquiry in person against their wishes. Similarly, the completion of a questionnaire does not automatically result in any entitlement to attend the Inquiry in person, as any such invite will be at the discretion of the Inquiry Panel.

## Choosing not to provide your personal details

If you so wish, you can complete the questionnaire anonymously. Please note however that completing the questionnaire anonymously will limit your input to the Inquiry in a number of ways: -

1. if you complete the questionnaire anonymously it will not be possible to invite you to attend before the Inquiry in person;
2. anonymised questionnaires are likely to be of less evidential value to the Inquiry; and
3. if the Inquiry considers the information provided by you is relevant to a review/investigation being carried out by another organisation then we may share this information with the relevant organisation and without your personal details we will be unable to notify you of this.

The Inquiry is committed to openness in its proceedings where possible and for that purpose it has established its own website ([www.neurologyinquiry.org.uk](http://www.neurologyinquiry.org.uk)).

**Please note** that in some very limited circumstances it may still be necessary for the Inquiry to share the information you have provided with another organisation. Where

this is the case, we will contact you further to discuss this and take all reasonable steps to protect your privacy and personal data.

## Documents you may wish to read

The following documents are available on the Inquiry website:

- Frequently Asked Questions (FAQs)  
<https://neurologyinquiry.org.uk/patients-and-family-members>
- Privacy Notice, which provides details on how we handle data  
<https://neurologyinquiry.org.uk/privacy-notice>
- Terms of Reference, for background purposes only  
<https://neurologyinquiry.org.uk/sites/ini/files/terms-of-reference-for-the-independent-neurology-inquiry.pdf>

## Help and Support

We recognise that completing this questionnaire may be difficult, and in some circumstances traumatic. Help and support is available from a number of organisations. These are detailed on the next page.

# CHARITY CONTACT DETAILS

## NINCA - NI NEUROLOGICAL CHARITIES ALLIANCE

THE NORTHERN IRELAND  
NEUROLOGICAL CHARITIES  
ALLIANCE (NINCA) WAS  
ESTABLISHED IN 2006 TO  
REPRESENT AND PROVIDE A  
VOICE ON BEHALF OF PEOPLE  
LIVING WITH A NEUROLOGICAL  
CONDITION IN NORTHERN  
IRELAND.

OUR MISSION:

TO BE THE UNITED VOICE ON  
BEHALF OF PEOPLE LIVING  
WITH NEUROLOGICAL  
CONDITIONS IN NORTHERN  
IRELAND

CONTACT US:  
INFO@NINCA.ORG  
WWW.NINCA.ORG.UK

**niNCA**   
Neurological Charities Alliance

## BRAINWAVES NI (SUPPORTING THOSE AFFECTED BY A BRAIN TUMOUR)

OFFICE: 02893 353995  
EMAIL: K.FERGUSON@BRAINWAVES-NO.ORG

## CHILD BRAIN INJURY TRUST

TEL: 02890 817 145  
EMAIL: INFO@CBITUK.ORG

## THE DYSTONIA SOCIETY

OFFICE: 020 7793 3651  
HELPLINE: 020 7793 3650  
HELPLINE EMAIL: SUPPORT@DYSTONIA.ORG.UK

## EPILEPSY ACTION NORTHERN IRELAND

HELPLINE: 0808 800 5050 - FREE FROM ALL UK  
LANDLINES AND MOBILES.  
HELPLINE EMAIL: HELPLINE@EPILEPSY.ORG.UK  
UK TEXT MESSAGES: 0753 741 0044

## HEADWAY THE BRAIN INJURY ASSOCIATION

NURSE LED CONFIDENTIAL HELPLINE: 0808 800 2244  
HELPLINE EMAIL: HELPLINE@HEADWAY.ORG.UK  
CONTACT: 078 2690 9110  
CONTACT EMAIL: JOHNY.TURNBULL@HEADWAY.ORG.UK

## MND ASSOCIATION

MNDA BRANCH CONTACT SIOBHAN ROONEY  
TEL: 07434839842  
EMAIL: MNDANI@HOTMAIL.CO.UK  
OR MNDA: TEL 0808 802 6262  
EMAIL: MNDCONNECT@MNDASSOCIATION.ORG

## MS SOCIETY NORTHERN IRELAND

COUNSELLING SERVICE: 02890 802 802  
HELPLINE: 0808 800 8000 - FREE FROM ALL UK  
LANDLINES AND MOBILES.  
HELPLINE EMAIL: HELPLINE@MSSOCIETY.ORG.UK

## PARKINSON'S UK NORTHERN IRELAND

HELPLINE: 0808 800 0303  
EMAIL: HELLO@PARKINSONS.ORG.UK  
PARKINSON'S LOCAL ADVISORS COVERING EACH OF THE  
HEALTH TRUSTS CAN BE CONTACTED VIA OUR SERVICE  
MANAGER PATRICIA JORDAN ON 0344 225 3682

## SYRINGOMYELIA ARNOLD CHIARI ASSOCIATION (SACA)

HELPLINE TEL: 07826 004008  
EMAIL: SACA.INFO@YAHOO.CO.UK