



STANDARD OPERATING PROCEDURE FOR CAPTURING AND PROCESSING WITHDRAWAL REQUESTS FROM THE NRS DIABETES REGISTER

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1. PURPOSE

This document defines the procedures for capturing, transmitting and processing withdrawal requests from the NHS Research Scotland (NRS) Diabetes Register (register).

2. SCOPE

This document applies to:

- Any member of a research team who receives a withdrawal request (see [4.2 Table 1](#));
- NRS Diabetes network staff who receive a withdrawal request directly or, indirectly, from NHS health care service personnel (see [4.2](#) and [Table 1](#));
- NRS Diabetes management office staff who have been delegated access rights that enable patients to be withdrawn from the register (see [4.3](#) and [4.4](#)).

3. RESPONSIBILITIES

Responsibility for capturing the required information and notifying the NRS Diabetes management office lies with the recipient. For withdrawal requests received out with the NRS Diabetes management office, recipients comprise of NRS Diabetes network staff and research team members who have used the register.

The register manager is responsible for processing withdrawals and for delegating this as a shared role to other NRS Diabetes management office staff member(s) (user) to allow patients to be withdrawn. Delegation of these roles are recorded on the register delegation of duties log.

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4. PROCEDURES

4.1 Access pre-requisites to withdraw patients from the register

- 4.1.1 The register manager will confirm the user to be delegated a withdrawal role. Prior to recorded delegation and access, users must have an NHSmail account and a SCI-Diabetes account. As per SCI-Diabetes Access and Login guidelines, each healthboard may operate different procedures for managing SCI-Diabetes user accounts. Those seeking access to SCI-Diabetes should contact their regions' Diabetes Managed Clinical Network (MCN). A list of MCN contacts can be found at [MyDiabetesMyWay](#) and an example of an access process at [NHS Tayside data access procedure](#).
- 4.1.2 Once access to SCI-Diabetes has been confirmed, the register manager will process the access rights required for users to withdraw patients from the register. Delegation of this role will be recorded on the register delegation of duties.

4.2 For Recipients of a Withdrawal Request: capturing, recording and transmitting requests

4.2.1 When research team members contact patients on the register with an invitation to participate in a study it is important that all patients who decline are also asked whether they wish to remain on the register. For patients who wish to withdraw from the register, the procedures outlined below apply.

4.2.2 Patients wishing to withdraw from the register may notify NRS Diabetes network staff, a research team member or an NHS Scotland healthcare service. The process for recording and transmitting a request to withdraw will depend on how the request has been received. Approaches to request withdrawal include:

- Verbally with NRS Diabetes network staff, members of a research team, an NHS healthcare service provider;
- in writing, by email or letter, to the register clinical inbox, NRS Diabetes management office, NRS Diabetes network staff, a member of a research team or an NHS healthcare service.

4.2.2.1 The procedure required for each type of withdrawal approach is defined in ['Table 1: Actions required upon receipt of a withdrawal request by type of approach and recipient'](#)

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**Table 1: Actions required upon receipt of a withdrawal request by type of approach and recipient**

Withdrawal Approach	Recipient of Withdrawal Request	Recipient Action 1: Recording the request/notifying NRS Diabetes office*	Recipient Action 2: Notifying/ transmitting the request to NRS Diabetes office*
Telephone	NRS Diabetes office*	Record directly on to the Withdrawal Form .	The Withdrawal Form should be passed immediately to the register manager or to a staff member with delegated access to process withdrawals.
	NRS Diabetes network staff member <i>or</i> Research team member	Record directly on to the Withdrawal Form <i>or</i> as a minimum, record the patient's name, postcode and date of birth. Please, ensure this information remains secure and, once transcribed, safely disposed of in confidential waste.	Notify the NRS Diabetes office* as soon as possible by telephone (01382 383 595) or by email to tay-uhb.sdrn@nhs.net and provide the minimum information required to process the withdrawal. If the patient's minimum information has been noted separately, transcribe the information captured on to the Withdrawal Form (alternatively, the Withdrawal Form can be completed by the NRS Diabetes office*) Send the Withdrawal Form either via NHSmail (as a scanned copy) to tay-uhb.sdrn@nhs.net or by post in a sealed envelope using NHS internal mail to the NRS Diabetes office*.
Face-to-face	NRS Diabetes network staff member <i>or</i> Research team member		

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Table 1 (continued): Actions required upon receipt of a withdrawal request by type of approach and recipient

Withdrawal Approach	Recipient of Withdrawal Request	Recipient Action 1: Recording the request/notifying NRS Diabetes office*	Recipient Action 2: Notifying/ transmitting the request to NRS Diabetes office* for processing
Email	Register clinical inbox	(for processing see 4.3.2.3) Email, and any subsequent email(s) in exchange, are processed and archived as withdrawal records.	
	NRS Diabetes network staff member <i>or</i> Research team member	Forward the email as soon as possible to the register clinical inbox at tay-uhb.sdrn@nhs.net	
Letter	NRS Diabetes office	(for processing see 4.3.2.4) Letters are processed and archived as the withdrawal record.	Letters requesting withdrawal should be passed immediately to the register manager or to a staff member with delegated access to process withdrawals.
	NRS Diabetes network staff member <i>or</i> Research team member	Upon receipt of the letter, notify the NRS Diabetes office* as soon as possible by telephone (01382 383 595) or email to tay-uhb.sdrn@nhs.net . If available, confirm the patient's name, postcode and date of birth.	Post the letter in a sealed envelope using NHS internal mail to the NRS Diabetes office.
Any approach to NHS health care service personnel	Notification is likely to come directly to the NRS Diabetes office or to a local NRS Diabetes network staff member.	Refer to the type of approach made above (telephone/face-to-face/email/letter) and follow the corresponding steps.	

*NRS Diabetes management office. Telephone 01382 383 595. Address: NRS Diabetes, Diabetes Support Unit (Level 8), Ninewells Hospital & Medical School, Dundee, DD1 9SY.

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4.3 For NRS Diabetes staff delegated to withdraw patients: receipt of withdrawal requests

4.3.1 Notification to process a withdrawal will be indicated by receipt of:

- the minimum information (name, postcode and date of birth);
- a Withdrawal Form (electronic copy or paper);
- an Email or;
- a Letter.

The process required for each of these notifications is outlined below:

4.3.2.1 **The minimum information** required to withdraw a patient (name, postcode and date of birth) must be obtained by the recipient of the request.

- This information may be received verbally or in writing in advance of a completed Withdrawal Form from the initial recipient of the withdrawal request (the Withdrawal Form can also be completed on behalf of the recipient and noted as additional information on the form).
- The withdrawal should be processed based on the minimum information (see 4.4). Any record of this information should be securely disposed of in confidential waste once it has been transcribed.
- The designated section at the end of the Withdrawal Form should be completed before filing the form in the register archive (see 4.5).
- If requested, confirmation of the withdrawal should be provided to the recipient.

4.3.2.2 **Withdrawal Form:**

- The Withdrawal Form may be a paper copy or an electronic copy. Electronic copies should be printed.
- The withdrawal should be processed if the required minimum information has been provided.
- Missing information or additional information if necessary should be requested.
- Following withdrawal of the patient from the register (see 4.4), the designated section at the end of the Withdrawal Form should be completed before filing the form in the register archive (see 4.5).
- If requested, confirmation of the withdrawal should be provided.

4.3.2.3 **An email requesting withdrawal:**

- Emails may be received directly from the patient or forwarded from the initial recipient to the register clinical inbox at tay-uhb.sdm@nhs.net. Any email received in another shared, or personal inbox, should be forwarded to the clinical inbox (tay-uhb.sdm@nhs.net).
- Emails should contain the required minimum information (name, postcode and date of birth) with any missing information requested as necessary.

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- If the minimum information is complete, emails should be moved to folder 3.1 (in the clinical inbox) to indicate that the withdrawal is ready for processing. Withdrawals should be completed as soon as possible from receipt of the required information.
- If requested, confirmation of the withdrawal should be provided.
- Completed withdrawal email(s) should be moved to folder 3.2 to indicate to indicate completion of the process.

4.3.2.4 A letter requesting withdrawal:

- The withdrawal should be processed immediately if the letter contains the required minimum information (name, postcode and date of birth). Patients should be contacted if the further information is required.
- When the withdrawal is complete, confirmation should be provided to the patient by letter reply.
- The following details should be added to the letter:
 - Date withdrawal completed
 - Initials of user (as they appear on the delegation log)
 - Any additional information including:
 - any reason for the withdrawal not being completed (for example, if the patient is not registered or has already been withdrawn) and;
 - (only if the patient has made this request) confirmation that the patient's additional information has been erased/destroyed.
- The letter should be filed in the register archive (see [4.5](#)).

4.4 For NRS Diabetes staff delegated to withdraw patients: Processing Withdrawals on SCI-Diabetes

4.4.1 Login to SCI-Diabetes and navigate the following pathway:

- Main Menu
 - NRS Diabetes
 - [click on] Find and Select a Patient

4.4.2 *Find and Select a Patient*: Referring to the patient's details provided as part of the withdrawal request, populate one or more of the following fields under '*Find and Select a Patient*' before clicking on the 'Search' button:

Field name	Guidance
• CHI	If provided, populate the CHI field alone.
• Surname	This field accepts a minimum of two letters.
• Date Born is	Click on the data entry field to activate the calendar dialogue box. A date must be selected from this format and cannot be entered manually. Dates can be

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removed by cursor selection and keyboard backspace or Delete keys.

- Postcode This field accepts a minimum of two characters.

4.4.3 A list will be presented with one or more results depending on the details entered in the previous search fields. The list format consists of the column headers presented in table 2.

Table 2. Identifying the patient in SCI-Diabetes search results and confirming registration status

Column headers in the SCI-Diabetes result list:	Patient ID/ CHI	Practice Name	4.4.4 Fields to identify the patient			4.4.5 Fields to check registration status		
			Name (surname, forename)	Born	Address	Last Updated By	Last Updated	Registered With
			<p>4.4.6 If the 'Patient Consented' status is 'Yes'</p> <p>Click on the patient's name in this cell.</p>					<p>'No' or 'Withdrawn' = the patient has already been withdrawn</p> <p>'NRS Diabetes' (or) 'SDRN' = the patient is registered</p> <p>None = not registered</p>

4.4.4 Referring to the patient's details provided for the withdrawal, the patient's full name, date of birth and postcode should be matched to results (see [Table 2, 4.4.4](#)).

4.4.5 Once the patient has been identified in the list presented in SCI-Diabetes, check the final column entitled 'Registered With' (see [Table 2, 4.4.5](#)). If the cell is populated with:

- 'No' or 'Withdrawn', the patient has already been withdrawn from the register. If the cell is not populated or contains 'None', the patient is not registered. For either of these results, no further action is required to process the withdrawal. This outcome should be recorded on the Withdrawal Form, email or letter.
- 'NRS Diabetes' or 'SDRN', the patient is currently registered and should be withdrawn.

4.4.6 If the 'Registered With' cell is populated with 'NRS Diabetes' or 'SDRN', move the cursor to, and click on, the patient's name in the third column (see [Table 2, 4.4.6](#)).

4.4.7 *Manage Patient Consent*: following selection of the patient's name, a page entitled '*Manage Patient Consent*' will be accessed. If the patient has asked for their information to be erased (see Withdrawal Form/email) delete any telephone numbers and email addresses in the section entitled 'Contact Information'.

4.4.8 Patient Preferences: Under the section 'Recording Consent', select 'NRS Diabetes Consent' and select 'Withdraw' or 'No' (whichever is presented).

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4.4.9 **Save:** click on the 'Save' icon on the main menu at the top of the page. By clicking on 'Save' SCI-Diabetes changes the patient's consent to the register as 'No' or 'Withdrawn' and completes the withdrawal process. Both the user's name and the date upon which the patient was withdrawn is recorded in SCI-Diabetes.

4.5 Archiving of Withdrawal Request Records

All completed withdrawal records (Withdrawal Forms or Letters) should be filed and securely stored at the NRS Diabetes management office according to the date of processing (or receipt if processed over 1 month from receipt) recorded on the form.

5. ABBREVIATIONS & DEFINITIONS

Clinical inbox

NRS Diabetes Register's NHSmail clinical inbox: tay-uhb.sdrn@nhs.net ('diabetesresearchregister' in Open mailbox search field)

HCP Health Care Professional

NRS Diabetes (management) office

Location of the NRS Diabetes Management Team. NRS Diabetes, Diabetes Support Unit (Level 8), Ninewells Hospital & Medical School, Dundee, DD1 9SY.

MCN Diabetes Managed Clinical Network

NRS NHS Research Scotland

NRS Diabetes network staff

The NRS Diabetes Management Team comprising of the NRS Diabetes Manager, NRS Diabetes Research Register Manager and others working within the NRS Diabetes Management Team; NRS Diabetes Research Nurses, Clinicians, Investigators and Support Staff who are funded or part funded by NRS Diabetes and/or serve on the NRS Diabetes Executive Group and research nurses, clinicians and investigators conducting diabetes-related research who are part of the NRS Diabetes circulation list irrespective of their funding source.

Register NRS Diabetes Register

Research team member / members of a research team:

Individuals conducting diabetes-related research projects that have made use of the register.

User(s) NRS Diabetes network staff member(s) with delegated access to process withdrawals.

6. ASSOCIATED DOCUMENTS & REFERENCES

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NRS Diabetes Register Withdrawal Form: available on the NRS Diabetes Website <https://www.nhsresearchscotland.org.uk/research-areas/diabetes> or on request from the NRS Diabetes Management office.

MyDiabetesMyWay:

<http://www.mydiabetesmyway.scot.nhs.uk/LocalServices.aspx>


NHS Tayside data access procedure:

http://www.diabetes-healthnet.ac.uk/Documents/Uploaded/MCN_-_SCI-Diabetes_-_Access_Flow_Chart_1301.pdf

7. DOCUMENT HISTORY

Version Number	Reviewed By (Job Title)	Effective Date	Reason for Change
1.0			New
2.0	Register Manager	23 March 2020	Minor updates to filing process and new pathway for navigating updated SCI-Diabetes screens.

8. APPROVALS

Sign	Date
APPROVED BY: John Kerr <i>Signature</i> 	23 March 2020

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