



Participant Information Leaflet



Survey title:

The Irish Research Nurse Network (IRNN) National Clinical Research Nurse/Midwife Workforce Survey

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You are being invited to take part in a survey conducted by the Irish Research Nurses Network (IRNN). Before you decide whether you wish to take part, you should read the information provided below carefully making sure that you clearly understand the potential risks and benefits of taking part. This process is known as 'Informed Consent'. You are not obliged to participate in this survey.

Why is this survey being done?

The IRNN is undertaking a national survey to measure and describe the Clinical Research Nurse and Midwife (CRN) workforce in Ireland. The aim of this survey is to discover:

- How many research nurses/midwives are currently working in Ireland
- Where they are located
- The terms of employment
- The roles and responsibilities.

Currently the number of CRNs working in Ireland is unknown but is estimated to be in the region of 200. While many CRNs are based in hospitals or established clinical research centres/facilities they are usually employed through universities. CRNs may also be employed by commercial organisations or medical research charity groups.

CRN job titles, roles and responsibilities and terms of employment may vary between organisations and even from one post to another. A consequence of the lack of standardisation is an absence of job security. Furthermore, there is little professional support and no clear or defined career pathway for CRNs. Given these factors, nurses may be less inclined to consider the CRN role as a long-term career prospect.

This survey is being conducted by the Irish Research Nurses Network (IRNN). The IRNN is a voluntary group that provides resources and professional support to CRNs. However, there is a lack of basic data about the research nurse resource in Ireland. In 2018 the IRNN was awarded a grant from the Health Research Board (HRB) which is supporting the conduct of this survey.

Why am I being asked to take part?

You are being asked to take part in this survey because you are a nurse or midwife on the active register with Bord Altranais agus Cnáimhseachais na hÉireann and you are currently employed in a clinical research role and/or setting.

How will the survey be carried out?

This will be a national survey of CRNs based in a variety of settings (e.g. universities, hospitals, industry, and primary care). Recruitment will commence in January 2019 and the report of the findings will be completed in June 2019.

A sample size has not been determined for this survey, as the aim is to reach as many eligible participants as possible and to measure the entire population of CRNs in Ireland.

Should you decide to participate you may use the link to the IRNN website at the end of this information leaflet which will direct you to the survey. Hard copies of the survey are also

available for participants wishing to complete by hand. Completion of the survey will be deemed as consent to participate.

On completion of the survey participants will be given the option to consent to providing personal identifiable data, (name, contact details) that will be retained on the IRNN 'Contact' database for future contact. This information will not be entered into the 'Survey' database and will not be linked to the survey information provided by participants. Consent to provide this additional data is voluntary and you are not obliged to do so.

What will happen to me if I agree to take part?

If you agree to participate you will be asked to complete the survey once, either electronically on line or using a hard copy. Completion of the survey should take no longer than 10 minutes and does not involve any interaction with the investigator. There will be no follow-up in relation to the survey.

If you give consent for your personal details to be collected for the CRN database, you will be asked to enter this information on an additional form. This information will be entered onto a separate CRN database which will be maintained by the IRNN. In accordance with IRNN policies this database will be maintained on a secure server with restricted access and will not be shared with third parties. However, you may receive communications from or through the IRNN committee relating to topics of interest to CRNs or invitations to participate in future research. Further information in relation to data protection can be found below.

What are the benefits and risks of taking part in this survey?

There are no individual benefits anticipated in the short term, however for nurses that were previously unaware of the IRNN, this survey provides an opportunity to network and avail of the resources and support of this group. It is hoped that this survey will increase recognition of the contribution made by CRNs to the research infrastructure in Ireland and lead to increased investment from funders which may support opportunities for professional development.

No risks have been identified in relation to participation in this survey.

Is the survey confidential?

All data received will be treated with full respect for confidentiality and individual data will not be discussed with any third parties. Completed survey forms will be stored securely and destroyed as soon as data has been entered into the 'Survey' database and the researchers are satisfied that there are no transcription errors. Once the data is entered in the 'Survey' database it is anonymous and cannot be linked to the participant. Data entered into the 'Survey' database may be viewed by statisticians providing support in analysing and interpreting the data. As re-identification will not be possible you will not be able to request that your information is withdrawn once it is entered in the 'Survey' database.

A secondary objective of the survey is to create a national CRN Database. This will be retained securely on the IRNN website and will be accessible to authorised member of the IRNN

committee and website support personnel only. It will be used to track CRN employment trends and to advocate for issues of concern to CRNs such as security of tenure, clarity about employment grades and opportunities for professional development and career progression. On completion of this survey the CRN Database will be maintained as a live dataset – CRNs can be added or have their data removed on request. The control of this data will be transferred to the currently elected IRNN executive committee, who will be identified on the IRNN website.

Data Protection

1. The purpose or reason for processing your personal data.

Personally identifiable data (e.g. name, email address or other contact details) will be used to initiate contact with CRNs. This information has or will be provided by CRNs through promotion of the survey and utilisation of existing networking channels. A survey announcement and ‘Consent for Contact’ form has been developed for this purpose. These consent for contact lists will be used for initial survey contact only and not saved for inclusion in the proposed CRN database. The purpose of this process is to maximise the success of the survey, which has the primary aim of establishing contact with all CRNs in Ireland. The core survey dataset will not include personally identifiable data, but respondents will have the option of providing contact details for inclusion in a separate CRN Database in SurveyMonkey® that will be maintained by IRNN on completion of the survey.

2. The legal basis under which we are processing your data.

The legal basis for processing your data within the context of this survey is consent. Consent for inclusion in the survey is implied by your completion and submission of the survey form. Your provision of contact details for initial contact by the researchers and the CRN Database requires explicit consent. In question 16 of the survey you have the opportunity to consent to providing identifiable information for future contact if you wish to do so.

3. Who are the recipients of the data

The PI and Project Manager will have access to data provided by each participant in the survey. Survey responses will be exported to a survey database for analysis and interpretation. The survey database may be viewed by statisticians where necessary. Contact information for the CRN database will be collected separately via SurveyMonkey®. This information will be accessed by the PI and Project Manager.

4. How long will the data be stored for?

Hard copies of the survey will be checked for completeness prior to manually entering into the survey database. A further quality check will be made, after which scanned copies will be made and the hard copies destroyed. SurveyMonkey® responses will be exported to the survey database. The scanned copies and SurveyMonkey® responses will be destroyed once all data accuracy has been verified. This is expected to be no later than July 2019. The survey database will be deleted when the researchers are satisfied that all data analysis has been performed and no further interrogation of the data is necessary – not later than December 2019.

SurveyMonkey® will also be used to design a CRN database that is separate to the survey responses. Participants will enter their contact details on the CRN database for the duration of the survey after which the data will be exported to an excel file, encrypted, password protected and saved in the project folder. Following verification for accuracy the raw data in SurveyMonkey® will be deleted. This is expected to be no later than July 2019. The exported data will be kept for up to 5 years following the end of the survey, with the proviso that explicit consent has been obtained and that participants may request to have their details removed at any time.

5. Risks and/or implications that might arise as a result of the processing of your data

Hard copies of the survey will be scanned and then destroyed following input into the database. Electronic data will be located on a password protected project specific folder and stored on the organisation 'v' drive. No sensitive data is being collected for this survey, but identifiable information may be collected for the CRN database if participants consent. A password protected laptop will be used by the Project Manager for study purposes, however all data will be saved to the RCSI server.

6. Withdrawal of consent.

There is no obligation to take part in the survey or provide contact details for the CRN database. However, if you do decide to complete the survey, the responses are anonymous and cannot be linked to participants, therefore any request for information to be withdrawn once it is submitted will not be possible. Participants wishing to withdraw their identifiable data must submit a request in writing to the Project Manager. This can be done at any time during or after the survey. The request should include the participant's full name, email and telephone number to ensure that details for the correct participant is removed from the database. The Project Manager will confirm in writing when the participant's details have been removed.

7. Additional data protection rights relevant to this survey

- If you have any concerns about how your personal data has been accessed or processed, you have the right to submit a complaint to the Data Protection Commission.
- You have a right to request access to your data and receive a copy of it.
- You have a right to restrict or object to processing of personally identifiable data related to aims and objectives of this survey – participation is entirely voluntary, and the option to provide contact details for the CRN Database is not a condition of being included in the survey.
- You have a right to have any inaccurate information about you corrected or deleted, except where data has been irrevocably de-identified

Consent to Future Uses

The data collected in the survey will be used for this project only and will not be retained for future use. On completion of the survey the CRN Database will be maintained by authorised members of the IRNN committee and may be used for future research into the role of the CRN or aspects of clinical research. Should this be the case you will be contacted via the IRNN with

information about the proposed project and invited to express interest. The IRNN will not share your contact details directly with other researchers.

Where can I get further information?

If you have any further questions about the survey, or you need any further information now or at any time in the future, please contact:

Name: Carole Schilling

Address: RCSI Clinical Research centre, Smurfit Building, Beaumont Hospital

caroleschilling@rcsi.ie 01 8093703

To complete the survey please follow the link below:

<https://www.surveymonkey.com/r/irnncountmein>