



The University of Dublin, Trinity College

Faculty of Health Sciences

**School of Nursing & Midwifery**

24 D'Olier Street, Dublin 2.

Tel: + 353 1 8963702 Fax: + 353 1 8963001 <http://www.nursing-midwifery.tcd.ie/>

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May 13<sup>th</sup> 2014

Dear Sir/Madam,

My name is Honor Nicholl and I am a registered children's nurse and Assistant Professor in the School of Nursing and Midwifery in Trinity College, Dublin. Along with some of my colleagues, I am currently undertaking a research study entitled RD-WIFI. The study aim is to identify appropriate web based information sources for use by parents of children with rare diseases in Ireland. This research study has been granted ethical approval from the Faculty of Health Sciences, Trinity College, Dublin and has been kindly funded by The Saoirse Foundation.

I am contacting you as a parent of a child/young person diagnosed with a rare disorder. Your experiences of the need for information for parents who are caring a child with a rare disease are relevant to this research study.

Enclosed is information about the study that I would like you to consider. We would like your input to this work by contributing to a focus group interview which will be held in Dublin on May 27<sup>th</sup> 2014. With your permission the meeting will be recorded and a copy of the transcript of the summary of the focus group outcome will be available to you if you wish to receive this. You will also need to sign a consent form on the day of the focus group. A payment of €25 will be given to you to assist in travel expenses and light refreshments will also be available.

If you need any further information, or if anything in the documents is unclear, please contact me telephone 01-8963702 or by email at [nichollh@tcd.ie](mailto:nichollh@tcd.ie) and I will be happy to discuss the study further with you.

Next steps:

1. Please read the enclosed information sheet and consent form.
2. Decide if you wish to take part in the study or not.
3. **Contact me to let me know you will be attending at nichollh@tcd.ie**

Please feel free to contact me with any queries. I would be really grateful for your co-operation and look forward to further contact with you in relation to this work.

Yours sincerely,

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Dr. Honor Nicholl



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## FOCUS GROUP PARTICIPANT INFORMATION SHEET

### 1. Title of study:

Rare disease web information for families in Ireland.

**2. Introduction:** Parents of children who require complex care have needs for information, yet international literature identifies that these needs are not met, nor are the parents' needs for information always appreciated by health care professionals.

The aim of this study is to identify appropriate information sources for use by parents of children with rare diseases in Ireland. It will focus on the identification of content to meet the needs of parents who seek health information on the web and when accessing a web based information resources for information, support and advice.

### Objectives

The objectives of the study are to:

1. identify parents web based information needs
2. make recommendations for the information collected to help provide data that can be used to devise a web information resource for parents who are involved in the care of children with rare diseases.

If you decide to participate in this study you will be invited to attend a focus group interview with 15 other parents. This will take approximately 60-90 minutes and will take place in a central location. Before you can be involved you will need to sign the consent form **and let Dr Honor Nicholl know you are attending at nichollh@tcd.ie or 01 8963702.**

### 3. Procedures:

You have been invited to participate because, as a parent of a child with a rare disease. Your experiences of the need for information for the child you care for are relevant. Other parents of children diagnosed with rare diseases have also been invited.

### 4. Benefits:

While there may be no direct benefit to you from this study, it is anticipated that the findings will improve the information available to parents.

### 5. Risks:

It is not anticipated that there will be any adverse outcome for you. You can choose to partake in the study and sign the consent form. There will be no impact if you choose not to contribute.

**6. Exclusion from participation:** *You cannot participate in this study if any of the following are true:*



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You are a parent of a child with a rare disease who, having been invited, has not agreed to participate in the study.

**7. Confidentiality:**

Your identity will remain confidential. Your name will not be published and will not be disclosed to anyone outside the study group. All information cited in the report or any future publications arising from this study will not identify you. All information/data will be held in secure locked cabinet accessible only by the researcher and all computerised data will be stored on a password protected computer only accessible by the research team. I agree that anonymised data from the study may be stored and used in future related studies without further consent being sought from me.

**8. Compensation:**

This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.

**9. Voluntary Participation:** If you decide to volunteer to participate in this study, you may withdraw at any time. If you decide not to participate, or if you withdraw, you will not be penalised and will not give up any benefits that you had before entering the study.

**10. Stopping the study:** You understand that the investigators may withdraw your participation in the study at any time without your consent.

**11. Permission:** This research study has received ethical approval from the Faculty of Health Sciences, Trinity College, Dublin.

**12. Further information:** You can get more information or answers to your questions about the study, your participation in the study, and your rights, from Dr. Honor Nicholl who can be telephoned at 01- 8963702. If the study team learns of important new information that might affect your desire to remain in the study, you will be informed at once.

I realise that this may be a busy time for you and I really appreciate you taking the time to read this information leaflet.

Yours sincerely,

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Dr. Honor Nicholl