

The RD-WIFI Questionnaire

SOURCES OF INFORMATION ABOUT YOUR CHILD'S CONDITION

1. Who is the person in your family MOST likely to seek information about your child's condition?

- € Myself
- € Spouse or partner
- € Other (please specify)

2. Where do you get information about your child's condition?

Please choose all that apply.

- € Internet or websites
- € Health care provider
- € Early intervention service
- € Books or literature
- € Family and friends
- € Word of mouth
- € Media e.g. television and newspapers
- € Other (please specify)

3. Do you use the Internet to get information about your child's condition?

- € Yes (Please go to Q4)
- € No (Many thanks for the information that you have provided above. You do not need to proceed any further. Please return this questionnaire to Dr. Honor Nicholl using the addressed envelope).

**INFORMATION ABOUT YOUR USE OF THE INTERNET TO FIND INFORMATION
ABOUT YOUR CHILD'S CONDITION**

4. How comfortable are you using the Internet?

- € Very comfortable
- € Somewhat comfortable
- € Comfortable
- € Somewhat uncomfortable
- € Very uncomfortable

5. From where do you most often access the Internet?

- € Home
- € Work
- € Public library
- € Don't know
- € Other (please specify)

6. What time of the day do you MOST OFTEN use the Internet?

- € Midnight to 6am
- € 7am to midday
- € 1pm to 6pm
- € 7pm to midnight
- € No pattern

7. How often do you use the Internet to find information about your child's condition?

- € Every day
- € Once a week
- € Several times a week
- € Once a month
- € Several times a month
- € Every few months
- € Don't know

8. When you go online to look for information about your child's condition, how often are you able to find the information you are looking for?

- € Always
- € Most of the time
- € Sometimes
- € Hardly ever
- € Never
- € Don't know

9. How many websites do you usually visit or browse when looking for information about your child's condition?

- € 1
- € 2 to 3
- € 4 to 5
- € 6 to 9
- € 10 to 20
- € More than 20
- € Don't know

10. Which of the following factors do you take into account when choosing a website?

Please choose all that apply.

- € Trustworthiness e.g. author, qualifications, IP address
- € Up-to-date
- € Relevant and accurate
- € Nice layout
- € Easy to understand
- € Recommended to me by a medical/healthcare professional
- € Has other website links within it
- € Other (please specify)

11. What device do you use MOST OFTEN to access the Internet?

- € PC or Mac
- € Smartphone
- € Tablet (iPad or similar)
- € Other (please specify)

12. Which of the following applies to you?

Please choose all that apply.

- € I have an email address
- € I have a Facebook account
- € I have a Twitter account
- € I have a Skype account
- € I have a LinkedIn account
- € I have an MSN/Messenger account
- € I write or contribute to a blog
- € I use health-related apps for my smartphone/tablet (please specify)

13. Are you registered in a forum or social network group dedicated to your child's condition?

€ Yes (Please go to Q14)

€ No (Please go to Q15)

14. Do you share information about your child's condition with these communities?

€ Yes

€ No

15. How do you find websites about your child's condition?

Please choose all that apply.

€ By visiting search engines such as Google, Yahoo, Bing, Ask Jeeves, Aol, Baidu etc.

€ By visiting Orphanet

€ By visiting a website that specialises in rare conditions (please specify)

€ Other (please specify)

16. Do you visit websites recommended by:

Please choose all that apply.

€ A doctor or healthcare professional

€ A friend or family member

€ Parents of children with rare conditions

€ Not applicable

€ Other (please specify)

17. The website(s) I **MOST FREQUENTLY** visit is(are):

18. When your child was **FIRST** diagnosed or when you **FIRST** had a concern that something was wrong, what topics of information did you look for on the Internet?
Please choose all that apply.

- € my child's diagnosis
- € my child's condition or symptoms
- € the care of my child's condition
- € the management of my child's condition
- € child development
- € managing family dynamics
- € medical / healthcare professionals
- € where to get a second opinion
- € early intervention options
- € educational options
- € treatments
- € alternative treatments / therapies
- € preventing complications
- € nutrition
- € physical activities
- € vaccinations
- € hospitals, hospices, medical centres
- € genetics
- € future pregnancies
- € support groups
- € organisations and/or societies
- € upcoming events or workshops
- € state services
- € financial assistance
- € research and innovation
- € accessing medicines or alternative treatments / therapies online
- € other topics (please specify)

19. I **CURRENTLY** use the Internet to look for information about:

Please choose all that apply.

- € my child's diagnosis
- € my child's condition or symptoms
- € the care of my child's condition
- € the management of my child's condition
- € child development
- € managing family dynamics
- € medical / healthcare professionals
- € where to get a second opinion
- € early intervention options
- € educational options
- € treatments
- € alternative treatments / therapies
- € preventing complications
- € nutrition
- € physical activities
- € vaccinations
- € hospitals, hospices, medical centres
- € genetics
- € future pregnancies
- € support groups
- € organisations and/or societies
- € upcoming events or workshops
- € state services
- € financial assistance
- € research and innovation
- € accessing medicines or alternative treatments / therapies online
- € other topics (please specify)

20. Would you say that the information you find on the Internet influences the decisions you make about your child's condition?

- € Major influence (Please go to Q21)
- € Minor influence (Please go to Q21)
- € Some influence (Please go to Q21)
- € No influence at all (Please go to Q22)
- € Don't know (Please go to Q22)

21. The information I found on the Internet:

Please choose all that apply.

- Was not useful
- Was useful for diagnosing my child's condition
- Improved my understanding of my child's condition
- Improved my ability to manage and care for my child's condition
- Enabled me to explain my child's condition
- Increased my anxiety
- Decreased my anxiety
- Made me change my medical / healthcare professional
- Made me change my child's food habits
- Made me change my child's physical activity
- Was useful for accessing medicines or alternative treatments / therapies online
- Not sure
- Other (please specify)

22. Have you told your doctor or healthcare professional about the information you found on the Internet regarding your child's condition?

- Yes *(Please go to Q23)*
- No *(Please go to Q25)*
- Don't know *(Please go to Q25)*

23. How did you tell your doctor or healthcare professional about the information you found on the Internet?

Please choose all that apply.

- I spoke to him/her directly
- I used email
- I used Facebook
- I used other social networks
- I used telemedicine services
- Other (please specify)

24. When you told your doctor or healthcare professional about the information you found on the Internet, how interested were they?

- Very interested
- Somewhat interested
- Not too interested
- Not at all interested
- Don't know

25. How important is it that a website for parents of children with rare conditions is accessible to anyone with a disability?

- € Very important
- € Important
- € Moderately important
- € Of little importance
- € Unimportant
- € Don't know

26. Should a website for parents of children with rare conditions be available in the Irish language?

- € Yes
- € No
- € Don't know

INFORMATION ABOUT YOUR CHILD OR CHILDREN

27. How many of your children have a rare condition?

- € 1
- € 2
- € 3
- € 4+

CHILD 1

28. Child's age

- € Under 12 months
- € 1 to 3
- € 4 to 7
- € 8 to 12
- € 13 to 19
- € 20 to 29
- € 30 to 39
- € 40 to 49
- € 50+

29. Child's sex

- € Male
- € Female

30. Does your child have a diagnosis?

- € Yes (Please go to Q31)
- € No (Please go to Q32)

31. Child's age when diagnosed

- € Under 12 months
- € 1 to 3
- € 4 to 7
- € 8 to 12
- € 13 to 19
- € 20 to 29
- € 30 to 39
- € 40 to 49
- € 50+

32. Does your child's condition include a disability?

- € Yes (Please go to Q33)
- € No (Please go to Q34)

33. If you answered Yes to question 32, please specify the type or types of disability:

- € Physical
- € Intellectual
- € Physical and intellectual
- € Other (please specify)

34. Does your child use equipment for:

Please choose all that apply.

- € Moving
- € Eating
- € Breathing
- € Hearing
- € Speech
- € None
- € Other (please specify)

**If you have additional children with a rare condition
please complete the following pages for each child.**

Otherwise please go to page 14.

CHILD 2

35. Child's age

- € Under 12 months
- € 1 to 3
- € 4 to 7
- € 8 to 12
- € 13 to 19
- € 20 to 29
- € 30 to 39
- € 40 to 49
- € 50+

36. Child's sex

- € Male
- € Female

37. Does your child have a diagnosis?

- € Yes *(Please go to Q38)*
- € No *(Please go to Q39)*

38. Child's age when diagnosed

- € Under 12 months
- € 1 to 3
- € 4 to 7
- € 8 to 12
- € 13 to 19
- € 20 to 29
- € 30 to 39
- € 40 to 49
- € 50+

39. Does your child's condition include a disability?

- € Yes *(Please go to Q40)*
- € No *(Please go to Q41)*

40. If you answered Yes to question 39, please specify the type or types of disability:

- € Physical
- € Intellectual
- € Physical and intellectual
- € Other (please specify)

41. Does your child use equipment for:

Please choose all that apply.

- Moving
- Eating
- Breathing
- Hearing
- Speech
- None
- Other (please specify)

CHILD 3

42. Child's age

- Under 12 months
- 1 to 3
- 4 to 7
- 8 to 12
- 13 to 19
- 20 to 29
- 30 to 39
- 40 to 49
- 50+

43. Child's sex

- Male
- Female

44. Does your child have a diagnosis?

- Yes *(Please go to Q45)*
- No *(Please go to Q46)*

45. Child's age when diagnosed

- Under 12 months
- 1 to 3
- 4 to 7
- 8 to 12
- 13 to 19
- 20 to 29
- 30 to 39
- 40 to 49
- 50+

46. Does your child's condition include a disability?

- € Yes (Please go to Q47)
- € No (Please go to Q48)

47. If you answered Yes to question 46, please specify the type or types of disability:

- € Physical
- € Intellectual
- € Physical and intellectual
- € Other (please specify)

48. Does your child use equipment for:

Please choose all that apply.

- € Moving
- € Eating
- € Breathing
- € Hearing
- € Speech
- € None
- € Other (please specify)

CHILD 4

49. Child's age

- € Under 12 months
- € 1 to 3
- € 4 to 7
- € 8 to 12
- € 13 to 19
- € 20 to 29
- € 30 to 39
- € 40 to 49
- € 50+

50. Child's sex

- € Male
- € Female

51. Does your child have a diagnosis?

€ Yes (Please go to Q52)

€ No (Please go to Q53)

52. Child's age when diagnosed

€ Under 12 months

€ 1 to 3

€ 4 to 7

€ 8 to 12

€ 13 to 19

€ 20 to 29

€ 30 to 39

€ 40 to 49

€ 50+

53. Does your child's condition include a disability?

€ Yes (Please go to Q54)

€ No (Please go to Q55)

54. If you answered Yes to question 53, please specify the type or types of disability:

€ Physical

€ Intellectual

€ Physical and intellectual

€ Other (please specify)

55. Does your child use equipment for:

Please choose all that apply.

€ Moving

€ Eating

€ Breathing

€ Hearing

€ Speech

€ None

€ Other (please specify)

INFORMATION ABOUT YOURSELF

56. Are you the child or children's:

- Father
- Mother
- Legal guardian
- None of the above

57. Are you?

- Male
- Female

58. What is your age?

- Under 18
- 18 to 34
- 35 to 49
- 50 to 64
- 65 to 79
- 80 or older

59. Do you live in?

- the Republic of Ireland
- Northern Ireland
- the United Kingdom
- Europe
- Other (please specify)

60. What location BEST describes where you live?

- City
- Town
- Village
- Rural

61. What is your HIGHEST level of education?

- Primary school
- Secondary school
- Vocational training
- Undergraduate degree

€ Postgraduate degree

62. Are you:

€ Employed full-time (Please go to Q64)

€ Employed part-time (Please go to Q63)

€ Self-employed (Please go to Q63)

€ Your child/children's main carer (Please go to Q63)

€ A homemaker (Please go to Q63)

€ A student (Please go to Q63)

€ Unemployed (Please go to Q63)

€ Other (please specify) (Please go to Q63)

63. If not employed full-time, did you leave your full-time job to care for your child/children?

€ Yes

€ No

€ Not applicable

64. How comfortable are you SPEAKING English?

€ Very comfortable

€ Somewhat comfortable

€ Comfortable

€ Somewhat uncomfortable

€ Very uncomfortable

65. How comfortable are you READING English?

€ Very comfortable

€ Somewhat comfortable

€ Comfortable

€ Somewhat uncomfortable

€ Very uncomfortable

66. Finally, if you were creating a website for parents of children with rare conditions, what is the **ONE** thing you would like to see on that website?

Thank you for your time, input to and support of this study.

References: Porter & Edirippulige (2007), Roberts (2010) and Tozzi *et al.* (2013).