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.
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)

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)

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)
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
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.