

# Survey for Patients, Families and Carers (January 2023)

The purpose of this survey is to understand what it is like to live with a rare condition, what kind of support works well or not so well, and what services and support you feel might be helpful. We are keen to identify gaps in the provision of services and areas of good practice.

Your responses will help direct priorities in the future work of the Office for Rare Conditions, Glasgow. When completing this survey you can choose to remain anonymous. The information you and others provide will be shared with patients, families/carers, health care professionals and patient support organisations.

If you would like to receive feedback on the information gathered please supply your name and contact details at the end of this survey.

**Thank you for your participation in this survey!**

## About you/your child's condition

1. Are you a

- ☐ Patient      ☐ Parent/Carer

2. Have you completed this questionnaire before?

- ☐ Yes- how long ago? \_\_\_\_\_
- ☐ No

3. Do you or your child attend, or have you previously attended, a hospital in the West of Scotland?

- ☐ Yes
- ☐ No- Thank you for your interest in this survey, please do not complete any further as the survey is currently open only to those who attend or have attended a hospital in the West of Scotland.

4. Please provide the details (hospital and approximate date attended) of your attendance below and continue to complete the survey

5. Have you/your child been formally diagnosed or is it suspected that you/your child have a rare condition?

- ☐ Formally diagnosed
- ☐ Suspected to have a rare condition
- ☐ Currently undiagnosed

*If currently undiagnosed, how long has it been since you first reported your/your child's symptoms to a healthcare professional?*

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6. What rare condition do you/your child have or are suspected to have?

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**7. At what age were there concerns for a rare condition/did symptoms first develop?**

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**8. At what age were you/your child formally diagnosed?**

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**9. How long did it take to get a diagnosis from initial concerns/symptoms?**

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**10. At the time of diagnosis, or suspected diagnosis, how much information were you given about the condition?**

- ☐ Lots of information was given
- ☐ Adequate information was given
- ☐ Little information was given
- ☐ No information was given

**11. Where do you find information about this condition?**

- ☐ Through a healthcare professional
- ☐ Through the literature/website of a patient support organisation
- ☐ Other (please specify) \_\_\_\_\_

**12. Do you feel you have enough information on this condition?**

- ☐ Yes, I feel I know a lot about this condition
- ☐ Yes, I have some information about this condition and am satisfied with what I know
- ☐ No, I have access to some information but would like to know more about this condition
- ☐ No, I don't know anything about the condition

**13. If you do not have access to information about your/your child's condition, what kind of information would you like?**

- ☐ Medical information
- ☐ Future expectations
- ☐ Signposting to resources
- ☐ Signposting to finance information
- ☐ Signposting to patient support

## About the support you/your child gets

14. Have you had the opportunity to meet another person/family with this condition (or someone who is in a similar situation, e.g. undiagnosed)

☐ Yes ☐ No

15. If you haven't would you like to have the opportunity to meet someone?

☐ Yes ☐ No

16. Do you know of a support group/patient association for your conditions or for undiagnosed conditions?

☐ Yes ☐ No

17. Are you a member of this or any other patient support group?

☐ Yes ☐ No

18. Do you feel well supported generally?

☐ Yes ☐ No

19. How much support do you/your child receive in everyday life from the following people?

	Lots	Some	Very Occasionally	Not at all	N/A
Family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital-based Healthcare Professional	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your family doctor/ GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other community based HCP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
School Staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support Groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## About the health services you attend

20. With regards to you/your child's care, is there one specialist service that takes the lead?

☐ Yes (please specify) \_\_\_\_\_

☐ No

21. How satisfied are you with the following?

	Very Satisfied	Satisfied	Not Satisfied or dissatisfied	Dissatisfied	Very Dissatisfied
Having a consistent team of health professionals taking overall responsibility for you/your child's health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The overall support that you get from health professionals for you/your child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How much health professionals know about you/your child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Knowing which healthcare professional to contact for guidance/support with you/your child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

22. Do you think your child has a life limiting condition?

☐ Yes

☐ No

☐ Don't know

23. If yes, have you received any special support for that?

☐ Yes

☐ No

☐ Don't know

Please specify the kind of support you have received.

## Research

24. Are you/your child currently taking part in any research regarding your condition?

- ☐ Yes
- ☐ No
- ☐ Don't know

25. Are you aware of any research regarding you/your child's condition that is currently taking place?

- ☐ Yes, but I don't want to take part in it
- ☐ Yes, but I am unable to take part in it
- ☐ No, I don't know of any research taking place

26. Please tell us why you are unable to take part in the research

27. Would you be interested in taking part in research regarding you/your child's condition?

- ☐ Yes
- ☐ No

28. Do you know where/how to find information about research related to you/your child's condition?

- ☐ Yes
- ☐ No



29. Have you had any experience of online or telephone consultations?

☐ Yes

☐ No

30. Please tell us how you feel about using online and telephone consultations to keep in touch with healthcare professionals.

	Very Satisfied	Satisfied	Not Satisfied or dissatisfied	Dissatisfied	Very Dissatisfied
Video Consultations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Telephone Consultations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

31. Please tell us about any positive experiences you have had in relation to care received (please give as much detail as you can).

32. Please tell us about any negative experiences you have had in relation to care received (please give as much detail as possible).

## Office for Rare Conditions Activities

33. Are you aware of the Office for Rare Conditions?

- ☐ Yes- how did you hear about us? \_\_\_\_\_
- ☐ No

34. Would you be interested in attending family days organised by the Office for Rare Conditions?

- ☐ Yes
- ☐ No

35. Is there anything else you would like to raise?

36. Thank you very much for taking the time to complete this survey.

*If you would like to receive feedback on the information gathered, please supply your name and email address. (By providing these details, your response will no longer be anonymous)*

First name:

Last name:

Email:

37. If you're providing your name and e-mail address, would you like to receive the Office for Rare Conditions newsletter to keep up to date with the latest news and events?

- ☐ Yes
- ☐ No

38. Your feedback on this questionnaire is appreciated. Can you think of how it can be improved?

Date of completion of questionnaire: \_\_\_\_\_