

## Introduction

**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 the 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.**

## About you/your child's condition

\* 1. Are you a patient or parent/carer of a child with a rare condition?

Patient

Parent/Carer

Other (please specify)

\* 2. Have you completed this questionnaire before?

Yes

No

If yes, how long ago?

3. Do you or your child attend a hospital in Glasgow?

Yes

No

Hospital attended (please specify)

\* 4. Have you or your child been formally diagnosed or is it suspected that you have a rare condition?

Formally diagnosed

Currently undiagnosed

Suspected to have a specific rare condition

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

\* 5. Which rare condition do you or your child have or is it suspected that you or your child have? Please enter N/A if undiagnosed.

\* 6. At what age did you or your child first develop symptoms?

\* 7. How long did it take to receive a diagnosis from the time you first approached a healthcare professional about your or your child's symptoms? Please enter N/A if undiagnosed.

\* 8. At time of diagnosis, or suspected diagnosis, how much information were you given about the condition?

- Lots of information was given.  No information was given.
- Adequate information was given.  N/A (currently undiagnosed)
- Little information was given.

Comments:

\* 9. Where did/do you find information about this condition?

- Through a healthcare professional  N/A (currently undiagnosed)
- Through the literature/website of a patient support organisation
- Other (please specify)

\* 10. Do you feel you have enough information on this condition?

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

Comments:

## About the support you/your child gets.

### You have completed more than a quarter of the survey already

\* 11. 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

If you haven't, would you like to be given such an opportunity?

\* 12. Do you know of a support group/patient association for your condition or for undiagnosed conditions?

Yes

No

Comments:

\* 13. Are you a member of this or any other patient support group?

Yes

No

Comments:

\* 14. Do you feel well-supported generally?

Yes

No

Comments

\* 15. How much support do you or your child receive in every day life from the following people?

	Lots	Some	Very occasionally	Not at all	Not applicable
Family	<input type="radio"/>				
Hospital-based healthcare professional	<input type="radio"/>				
Your GP	<input type="radio"/>				
Other community-based healthcare professional	<input type="radio"/>				
School staff	<input type="radio"/>				
Friend	<input type="radio"/>				

Other/comments:

About the health services you attend.

**You have nearly completed the survey - 7 questions to go.**

\* 16. With regards to you/your child's care, is there one specialist service which takes the lead?

Yes

No

If yes, which service at which hospital takes the lead?

\* 17. How satisfied are you with the following?

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

Comments:

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

- Yes
- No
- Don't know

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

- Yes
- No
- Don't know

20. If yes, who or what service has provided this support?

21. Are you currently taking part in any research regarding your condition?

- Yes
- No
- Don't Know

22. Would you be interested in taking part in any research regarding your condition?

- Yes
- No

Comments

The next section of this survey is to identify the specific needs of people affected by rare, unusual, and undiagnosed conditions in relation to the COVID 19 pandemic and to propose practical solutions to ensure their needs are taken into account when planning the work of the Office for Rare Conditions, Glasgow.

23. Did you receive a letter or advice to shield yourself or your child?

- Yes
- No

If yes, please tell us from where.

24. Do you feel you have had access to all the information you need?

- Most of the time
- Some of the time
- A little of the time
- Not at all

25. Have you felt well supported generally?

- Yes
- No

26. Have you had experience of online consultations or any other form of telemedicine online or via your phone?

- Yes, and its new to me
- Yes and i have used it before the COVID 19 Pandemic
- No, it was offered but I didn't use
- No, it wasn't offered

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

28. Has the routine healthcare that you or your child receive been disrupted?

	Cancelled	Postponed	No change	N/A	
Hospital Clinic Appointments	<input type="radio"/>				
Therapy Appointments	<input type="radio"/>				
Diagnostic tests	<input type="radio"/>				
Surgery	<input type="radio"/>				
GP appointments	<input type="radio"/>				

29. Are you concerned about any disruptions to routine care?

- Yes
- No

If yes, please tell us your concerns

30. Do you feel you have been given enough information on the COVID-19 vaccine?

- Yes
- No
- Don't Know

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

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

## Office for Rare Conditions Activities

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

Yes

No

34. If your answer is yes, where did you hear about us?

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

Yes

No

Comments:

36. Is there anything else you want to raise?

Thank you!

37. 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.)

Name

Email Address

38. If you're providing your name and email 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

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

40. Date of completion of questionnaire.

Date / Time

Date