



Consent and Data Protection

The information you provide will be treated with the utmost confidentiality. It will be used to help us update our support services and to help us fundraise, with anonymity protected. Your privacy will be protected, and no names will be used to ensure confidentiality and to comply with ethical guidelines. Please note that participation in this study is completely voluntary, and you have the right to withdraw at any time without providing a reason.



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research & support 



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Let's Connect

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Research Study: Me & r(20)

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research & support 

Information and Support services
Making connections, Supporting families

Help us, to help you!

Why participate...

Initial results from our **Living with r(20)** Survey in 2023, tell us that r(20) has a profound impact on the lives of those diagnosed and the families who care for them. Final results are expected to be published later in 2024 (keep an eye on our social media and eNews).

We realise that it is important to take a deeper dive into the differing support needs across family members, find out where you currently seek help, what works, and ask "what's missing?" that would make a meaningful difference to your lives.

By understanding your real-world experiences, we can signpost families to the most useful resources, whilst also highlighting any gaps in provision of information and services and what can be done to address them.

Am I eligible...

The study is open to all individuals and their families who are living with a ring chromosome 20 worldwide. You do not need to have participated in last year's patient survey to take part in this study, and if you did take part in the survey, we would still like to hear from you.

Where possible, our Ring20 Champions may help conduct interviews in other languages including: French, Dutch, Italian, Portuguese, Japanese, Spanish, German.

Will this benefit me...

Ring20 will use the findings from this study to help shape our own information and support services, tailoring them where possible to try to address the gaps left by other providers to better meet your needs.

YOU ASK, WE LISTEN

What will I have to do...

1. Tell us you'd like to take part by sending an email to: funding@ring20researchsupport.co.uk
2. We will arrange for you to be part of a small focus group to discuss the impact of r(20). Group sessions will take place online (via Zoom) and will last for about an hour. One to one sessions are available on request.
3. Prepare by thinking about your support needs:
 - Are you able to get the help you need?
 - Do you face any barriers to accessing support?
 - What would make a difference to you?
 - How does Ring20, the charity, help you?
 - What Ring20 services do you use?
 - What could Ring20 do to improve in future?

Topics you rated in our last survey as 'high impact':

Social Life

Employment Prospects and Work Life

Mental Health

Finance

Emotional Wellbeing

Relationships

Focus groups will be arranged between:

June - August 2024

Please let us know if there are dates when you are unavailable.

What will happen after.....

We aim to publish a research paper on the support needs of all those impacted by r(20) and use this to evidence the unmet needs of our community. By sharing your insights, you will contribute to making change happen.

Any questions...

If you have any questions regarding the research study, please contact us funding@ring20researchsupport.co.uk. We will be more than happy to address any concerns or provide additional information.

All experiences are welcomed...there are no wrong answers!

