

Information leaflet for rare disease support groups

Project title

Evaluating the impact of COVID-19 on rare disease support groups.

About this project

We are keen to understand how groups that are supporting people with rare diseases have been affected by the COVID-19 pandemic. Through this project we hope to identify strategies that are working well for these groups as well as common issues to explore where the development of further resources would be most effective during this COVID-19 pandemic.

This short survey is for individual or collaborative groups (including charities, voluntary, and community groups) to help evaluate the impact of COVID-19 on groups who are supporting people with rare diseases during the pandemic. The role of the charity / volunteer sector is recognised as being critically important in our society, particularly in helping minimise challenges at this difficult time.

We appreciate and welcome your input to this evaluation. If you wish to provide further details and / or have any questions about this survey, please contact raredisease@qub.ac.uk using 'COVID-19 Survey groups' in the subject line

What is the purpose of the study?

We are hoping to evaluate the impact of COVID-19 on groups who are supporting people with rare diseases during the 2020 pandemic.

Invitation to take part in the study

You have been invited to take part in this project because you are part of a collaborative group working in the area of rare diseases.

This leaflet provides important information you will need to think about when deciding whether to take part in this project. The information contained in this leaflet may be made available in other formats – please just ask. If you want more detailed information about something, you can ask any at any time. Some important contact details are listed below:

Amy Jayne McKnight	a.j.mcknight@qub.ac.uk	Rare disease research lead
Julie McMullan	Julie.mcmullan@qub.ac.uk	Postdoctoral research fellow
Ashleen Crowe	acrowe737@qub.ac.uk	PhD student

Do I have to take part?

You can take as much time as you need to think about participating in this project. Only you can choose if you want to take part. If you don't want to participate you don't have to say why.

You may wish to withdraw from this project and this is entirely your choice. You can withdraw at any time from the survey by exiting the browser however any data cannot be withdrawn due to its anonymous nature.

What do I have to do?

At this time, we would like you to consider completing an online survey to learn more about the impact COVID-19 has had on your group. We are also interested in understanding more about how your group can be best supported in the future. The survey will take approximately 15 minutes to complete in full – we would appreciate partial answers if you only have time to complete a small component of the survey. The completed surveys will be stored in a safe environment that complies with national data security standards and will only be available to the three named researchers involved in the initial analysis. All future work will use summary data, which is anonymised.

How will the results be used?

Results from this project will be collated anonymously and used to help improve the accessibility of resources and addressing the needs of individuals affected by rare disease(s) in Northern Ireland.

We aim to:

- To perform an online survey with individual or collaborative rare disease groups.
- To explore the challenges rare disease groups have faced during the COVID-19 pandemic.
- To discover the impact COVID-19 has had on the services these groups are able to provide.
- To identify the long-term implications COVID-19 will have on such groups.
- To discover where resources need developed further to help groups support those with a rare disease at this time.

Are there any risks or disadvantages to taking part in the project?

Some people worry about being identified as someone taking part in the project. The chance of this happening by anyone outside the immediate contact team is very small, and we will do everything we can to prevent this from happening. We can only look at your data for approved scientific and healthcare purposes.

What are the advantages?

By taking part in this study you will be helping to identify where resources should be developed to most effectively support rare disease charity groups. We recognise the exceptional ongoing work from existing groups and by agreeing to take part in this study we hope to build resources further. There will be a £50 Amazon voucher provided to a single entry drawn at random from individuals who wish to be entered into the draw by providing their email address in the last question.

Will my taking part in this project be kept confidential?

We take information security very seriously. All electronic information from this project will be stored securely encrypted in computers within the Queen's University Belfast Centre for Public Health. Security levels on these computers meet national data security standards and no data will be stored in an unapproved location. Researchers cannot copy or take away any individual data from this storage area. If anyone reveals your data on purpose in a way that identifies you, it is a legal breach (in other words, they have broken their contract or they have broken the law). Any person, institution or company that does this could face criminal charges or substantial fines.

What do I do next?

If after careful consideration you are keen to proceed with the survey, please contact Dr Julie McMullan (Julie.mcmullan@qub.ac.uk) who will email you a link to the survey. If you have any further questions or wish to discuss anything related to rare disease please contact the study lead Dr Amy Jayne McKnight (a.j.mcknight@qub.ac.uk).

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION