



Immunology Questionnaire (ImmunoQ)

Control for the ImmunoCDGQ

This study is part of a research project entitled *“Deciphering immunological aspects of Congenital Disorders of Glycosylation (CDG) using a multidisciplinary approach”*. This is the PhD thesis of the researcher Rita Francisco (more about her [HERE](#)).

Before deciding to participate or not participate, it is important that you understand **why this study is being done, who is conducting it, what are its aims, how you can benefit from it and potential associated risks**.

By agreeing to participate, you are agreeing with the terms and conditions explained in this document.

What are CDG?

CDG – which stands for **Congenital Disorders of Glycosylation** – are a group of rare metabolic diseases. CDG children and adults face many challenges, as they often suffer from various and complex medical issues. Moreover, most CDG do not have a curative treatment. CDG have been widely overlooked and little is known about these conditions, which leads to enormous difficulties for health professionals, families and patients.

The complications related to the IMMUNE SYSTEM are one of the worst known clinical signs in CDG.

Instructions and Informed Consent for Participants

The questionnaire

This is an **ANONYMOUS** online questionnaire aimed to gather data on immune-related signs and symptoms among the general population. It was created by adaptation of the Immunology and CDG questionnaire (ImmunoCDGQ).

Aims

- 1) **The main aim of the questionnaire is to serve as a control and a validation tool for/of the ImmunoCDGQ** (more information [HERE](#)). Hence, it will not only allow us to understand the overall prevalence and distribution immune system complications, but also to better frame and interpret the data collected among the CDG community.
- 2) Adopt, improve and validate a patient-centric research approach.

Structure of the ImmunoQ

This questionnaire focuses on the **physical, functional aspects** as well as on the **impact on quality of life of immune system dysfunction** by assessing the main signs, symptoms, and management of immunological alterations.



It is divided in the following sections:

- 1) Immune-related problems;
- 2) Infections;
- 3) Autoimmune diseases;
- 4) Allergies, and;
- 5) Vaccination

Time commitment: 10 to 20 min (depending on the immunological involvement)

This questionnaire will be administered online through the platform **Survey Monkey** (<https://www.surveymonkey.com/>).

NOTE THAT you don't have to fill in the entire questionnaire all at once. You can stop at any point, how many times you need and finish it when it's convenient to you as long as it is done within the deadline of the project. To ensure that you can return to the question you were at when you left the survey, **MAKE SURE** you use the **SAME DEVICE** (e.g. computer or phone) and **INTERNET BROWSER** (e.g. Google Chrome).

Also, the questionnaire will be made available in the following **LANGUAGES**:



The Team

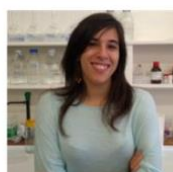
This questionnaire is a joint effort of CDG & Allies – Professionals and Patient Associations International Network (CDG & Allies – PPAIN), NOVA University of Lisbon, the research centers UCIBIO and CEDOC, UZ Leuven and of the Portuguese Association for CDG.



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Who can participate?

You can participate if you are at least 18 years-old. However, we are mainly looking for children (till 10 years-old). Hence, **we encourage adults to fill in the questionnaire about their children.**

Your participation is voluntary; no one can force you to participate against your will. You will not be harmed or hurt in anyway (medically, socially) if you decide not to participate. At any stage of the questionnaire you can stop filling it out. You don't need to justify your decision and that won't affect you in anyway.

Will my information be published?

This survey is anonymous. No personal information will be published.

Your participation is protected by the applicable laws of data protection. Multiple entries from the same individual will be avoided by selecting the SurveyMonkey option "the questionnaire cannot be answered several times from the same device".

Personal data collection abides the Law of Personal Data Protection (EU directive 2016/680, 27th April).

Procedures and Protocols

A) Risks associated with your participation

None, as all data given by you is treated confidentially and collectively. No interventive measures will be done.

B) Benefits associated with your participation

By sharing your experience with immune-related issues with us, we will be able to:

- 1) Gain an overall understanding of the prevalence and type of immune problems present in the general population;
- 2) Compare these problems and their prevalence with those found in the CDG community;
- 3) Define future research priorities and design research tasks accordingly;
- 4) Develop more accurate and tailored care guidelines;
- 5) Collect robust data in a reliable and fast manner;
- 6) Consolidate and validate patient-centered research methodologies;
- 7) Improve the care of CDG Patients;
- 8) Advance knowledge in the glycoimmunology field.



C) Remuneration of the research team

The team responsible for the development of this questionnaire is not receiving any payment for this research work. Rita Francisco is a PhD student, who has been awarded a research scholarship to perform her research project.

D) Study results communication and dissemination

The collected data in this study will be treated collectively and anonymously. It's planned to be:

- Presented at targeted conferences/congresses;
- Published in a peer-reviewed journal;
- Made available on the CDG & Allies-PPAIN website <http://www.researchcdg.com>.

Participant Information

Before you start the questionnaire, please....

Make sure you have your LAST/RELEVANT BLOOD TEST with you

Download the mini & thematic GLOSSARIES of scientific terms explained in Lay-language

[HERE](#)

All the questions asked in this questionnaire are related to the participant. You can report yourself and/or any child under your care.

1 Questionnaire = 1 Participant

- Please answer all questions based on what you believe is the most appropriate answer and on your direct experience or your experience as a caregiver (direct observation of the participant's behavior and reactions) or as patient (your direct experience).
- For some questions you may want to rely on the information you have received from the treating physician. You may want to ask your doctor about some of the results or questions in this survey, or for helping you to answer some of the questions.

Contacts

Who can I contact if I have doubts?

If you have any questions while taking part in this questionnaire or need additional information or clarification please write to the following address: rab.francisco@campus.fct.unl.pt