

Participant Information Sheet

The role of the Genetic Counsellor in the multidisciplinary team: the perception of geneticists.

Principal Researcher's Name and Contact Details:

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What is this study about? The rapid advances in genetics have led to an increase in the applicability of genetics in many aspects of healthcare. It is becoming increasingly important to create multidisciplinary teams that are able to respond to the changing needs of patients. The aim of this study is to investigate how a team should be composed when facing genetic disorders and in particular the role of the Genetic Counsellor from the geneticist's point of view.

Does this study concern me? If you are a medical geneticist registered to EBMG/ESHG, we would value your help with this study. We ask you to express your opinion from your own experience. We think it is important to carry out the research at European level in order to compare different contexts.

What am I being asked to do? If you exercise as a medical geneticist, and you volunteered to participate in this study we will ask you to complete an online survey. It will take 10 minutes of your time. The link will take you to a website with a questionnaire for you to complete.

Will I benefit from taking part to the study? The aim of this project is to investigate how a team should be composed when facing genetic disorders and in particular the role of the Genetic Counsellor. We believe that your involvement will be of benefit especially to patients who will be dealing with a team made up of qualified, appropriate staff with different, yet related, fields of activity. However, there might not be any direct benefit to you personally.

Are there any risks? You will not be disadvantaged in any way if you decide not to be involved in the study and if you decide not to participate this will not affect your relationship with the investigators in any way. Even if you agree to be involved, you can change your mind before or during the survey and you do not have to provide any specific reasons.

All your information will be treated confidentially. In the research paper, your name will not be linked to anything you tell us. At any time, you have the right to contact the researchers' employers to check this research project or make any complaint.

Thank you very much for your time and help. Please do not hesitate to contact us if you have any questions about this project. I would be very happy to answer any further questions you might have about the study before you decide about being involved. If you want to ask a question, please contact me by email francesca.catapano@student.unisi.it or Dr Christophe Cordier at christophe.cordier@synlab.com or by phone + 39 331.107.1304 / +41.79.177.55.95.

Finally, thank you for reading this information sheet.

Christophe Cordier and Francesca Catapano.