CASE STUDY

GENEVA UNIVERSITY HOSPITALS

PATIENT ENGAGEMENT IN CLINICAL RESEARCH: GENEVA UNIVERSITY HOSPITALS' MODEL

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While the concept of patients as partners in clinical research is becoming increasingly prevalent, there is still room for improvement. The development and validation of partnership models to engage patients in the design and governance of clinical research programmes are still in the early stages, and approaches that can ensure substantial and effective patient contributions to research are needed. In this article, we describe the patient partnership model being developed at Geneva University Hospitals (HUG) to engage patients and their caregivers in the design of clinical research studies and to encourage research groups in their efforts to involve patients within their teams.

Patient engagement in clinical trials and other health research continues to gain momentum. Once regarded as passive "subjects" who had research performed on them, patients are now contributing across the spectrum of clinical development, including in the design and planning of research protocols, the selection of outcomes and endpoints, the development of recruitment strategies, and the dissemination of research results (see Uhlenbrauck et al.'s article in *Applied Clinical Trials* from 8 February 2018). Yet as recent research confirms, partnering with patients in clinical research needs to be improved (see Calaprice-Whitty et al.'s article in *Applied Clinical Trials* from 31 May 2017).

Research activities are an integral part of the mission of Geneva University Hospitals (**HUG**) and are carried out in close collaboration with the University of Geneva's Faculty of Medicine and Geneva's High School Health (HEds). For this reason, a model of patient engagement in clinical research, which is overseen by the Clinical Research Partnership Team (**PARTNER REC**), was developed in 2019 and is supported by the HUG General Directorate. The ultimate goal of the model is to enhance the speed and quality of clinical research at HUG.

PARTNER REC brings together patients, researchers, caregivers, doctors, members of the regional research ethics committee, and partnership professionals. The working group was originally designed to provide patients and research professionals with a toolbox, or methodological support, that informs researchers and patients on why, who, when, and how to involve patient partners in a research project protocol. This toolbox presents the following information for each step of a research project, from the identification of the research question to the dissemination strategy:

- examples of possible patient/public involvement for each stage (see **Table 1**)
- the value of such collaboration to the researcher
- the interest of the collaboration for the patient/member of the public.

In addition to developing the toolbox, since 2020 PARTNER REC has invited clinical researchers on a regular basis (every month) to present and discuss the possibilities of partnership with patients for the different stages of their projects. These sessions are led by patient partners, medical practitioners, and nursing professionals who are experts in research and partnership.

The partnership took a further step forward in 2021 by incorporating the contents of the toolbox into an information website for professionals and the general public (in French; will soon be available in English). Depending on their interests, level of knowledge, availability, and wishes, patients and the public can join a research team and participate in the following activities:

- developing a relevant research question
- preparing the study plan and presenting it to the general public
- recruiting participants
- collecting data, for example by interviewing patients
- interpreting research results.

Two key concepts for PARTNER REC are transparency and collaboration. Patients are considered more than just subjects of observation – they become full partners by contributing to one or more stages of the scientific knowledge production chain.

Table 1: Examples of possible patient and public involvement during clinical research stages

Clinical research stage	How patients and the public can be involved
Choice of the research topic	• Participate in surveys and focus groups on the relevance of the study topic • Propose a research theme or topic
Elaboration of the protocol	• Proofread, revise, and/or co-write parts of the study protocol • Discuss, advise on, and/or test the relevance of patient-centred outcomes • Proofread, edit, and/or co-write patient information
Conduct of the study	• Contact patient organisations to inform them about the study and facilitate the recruitment of interested patients • Liaise between the patients participating in the study and the research team in order to obtain feedback on their experiences and impressions
Interpretation of the results	• Discuss the appropriateness of intermediate or final results • Modify patient information, if necessary • Discuss the relevance of the results
Writing and publishing	• Participate in writing and proofreading the research article • Disseminate study results via patient organisation networks • Set up patient forums to inform others about the study results • Review documents that are intended for the public and/or published on HUG websites • Become involved in public events related to the research study
Implementation and change of practice	• Help develop recommendations for better hospital management • Advise on the practical aspects of implementing recommendations