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RESEARCH UPDATES

French cohorts and genetic research: Towards an alternative model

Cohortes françaises et recherche en génétique : vers un modèle alternatif

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Cohorts are an important source of biological samples and data already required for genetic research, and soon, for AI development [1,2].

Cohorts involve the development of networks for sharing biological samples, data and/or information of various kinds between the various people and the principal structures involved. In France, the people concerned are mostly participants and/or patients producing or sharing health data or other data of interest, the physicians enrolling the participants in the network and the researchers responsible for generating additional data from the samples, combine data and transforming them into valuable information.

These processes are facilitated by dedicated public academic structures, or private academic structures of recognized public utility, such as research centres or hospitals, but also by dedicated data storage facilities, such as the SNIIR-AM, the database of the French national health insurance system. Various means of electronic communication (smartphones, computer tablets, computers) can be used to produce, share and transform data, but they are not used systematically.

In France, the production of genetic data, by physicians and public or private laboratories with the necessary approval from French regulatory authorities (which is not the case for 23andMe, for example), is authorized only in a judicial, care or research framework. Moreover, in the context of research, the specific focus of this article, the data generated are generally limited to a specific theme (diabetes, cancer, rare disease, etc.), informed consent is recorded on paper and limited to that theme and the funding for the study is obtained from public sources.

We have, therefore, identified at least three major obstacles to the development of cohorts and genetic research in France: research goals restricted to one or a few topics, static informed consent collected on paper, and funding almost exclusively from public sources. We believe that these factors prevent the scientific and financial self-renewal of cohorts over space and time, and, thus, the production and scientific use of genetic data, in France. We support a cohort model based around three major points that conforms to the new European directives [3] and should make it possible to overcome these three obstacles.

Firstly, cohorts for genetic research should explicitly aim to combine human genome analysis with investigations based on multitopic questionnaires that can be modified over time, exclusively online. French law stipulates that the aim of the study must be defined in advance. However, it does not specify that this aim should be limited over time or to a few topics. In the absence of jurisprudence, this approach is entirely acceptable today and should be widely used, because these questionnaires can deal with an almost infinite number of phenotypic characteristics, from cancer or diabetes to caffeine tolerance or face shape. This approach would make scientific self-renewal possible, significantly increasing the production and scientific use of data.

Secondly, such an aim for genetic research would require a new type of consent: ''dynamic electronic informed consent'' [4]. Indeed, if research themes are to change over time, then the best solution would be to use an electronic informed consent system, with dynamic content. This would have the advantage of enabling participants to choose, whenever and wherever they wish, through responses to questionnaires, the genetic research in which they wish to participate or for which they wish to follow the progress and results, almost in real time.

It would also be of benefit to the study, as it would make participants more active and make it possible to bring together different cohorts temporarily so as to attain a critical mass for a new study, with the consent of the participants, thereby significantly increasing the production and scientific use of data, particularly for genetic data.

Finally, most of these cohorts are organized for publicly funded research. Private funding is incidental, and some research may have no private funding at all. However, the private sector is very interested in the data generated by these cohorts, particularly those of a genetic nature [5]. These data are, thus, a non-negligible potential source of funding that could be more important than public sector funding in terms of both its magnitude and duration.

We support the following idea: with the conscious and informed consent of the participants, whole-exome or whole-genome sequencing could be funded by interested private companies, which could then be provided with access to a copy of the study data, the principal data remaining freely accessible to researchers. The cohort would, therefore, no longer be dependent on state funding for its existence and would be less dependent on the state in terms of the choice of research subjects.

Of course, the idea is not to strip French academic research laboratories of public funding, particularly as this would provide them with the possibility, for whatever reason, to fund the sequencing of exomes or genomes of interest for their research independently. However, the chief advantage of such cohorts for these laboratories would be a considerable gain of time, because they would no longer have to manage recruitment and requests for regulatory and legal authorization. Financial and scientific self-renewal would also be improved, together with the production and scientific use of data.

Incidentally, this model of multi-thematic research topics and the use of electronic and dynamic informed consent was recently (March 28, 2018) highlighted by the French politician and mathematician Cedric Villani (recipient of the 2010 Fields Medal) in his report on artificial intelligence commissioned by French Prime Minister Édouard Philippe [6]. We are convinced that this cohort model is currently one of the best ways to develop genetic research in France, in the best interests of all and with respect for all concerned, including the participants.

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Disclosure of interest

GV, AA, HCS, OCB and VT are involved in the promotion of this model with various promoters, and would like to see all French cohorts adopt this model, making it possible to set up megacohorts by regrouping participants, with their consent.

P. Charlier and C. Hervé have not supplied their declaration of competing interest

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