

Between data providers and concerned citizens: Exploring participation in precision public health in Switzerland

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Abstract

This empirical article explores the dynamics of exchange and reciprocity between cohorters, that is, study organizers, and cohortees, that is, study participants. Drawing on literature on bioeconomy and valuation, we analyze cohortees' expectations in return for the "clinical labor" they perform in the pilot phase of a Swiss precision public health study. Based on an ethnography of this cohort and data from seven focus groups with cohortees ($n=37$), we identified four positions: (1) the good citizen participant, (2) the critical participant, (3) the concerned participant, and (4) the self-oriented participant. These reveal that cohortees' participation, still framed in altruistic terms, nevertheless engages expectations about reciprocal obligations of the state and science in terms of public health, confirming the deep entanglement of gift-based, financial, and moral economies of participation. The different values emerging from these expectations—robust scientific evidence about environmental exposure and a socially oriented public health—provide rich indications about stake making which might matter for the future of precision public health.

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1. Introduction

“In Scandinavian civilization, and in a good number of others, exchanges and contracts take place in the form of presents; in theory these are voluntary, in reality they are given and reciprocated obligatorily” (Mauss, 2002: 3). In his essay on the gift, Mauss draws our attention to the rules of exchange underlying human transactions. Based on the context of ancient small-scale societies, his observations nevertheless help to understand how exchanges take place in research participation in the nation-state context of population-based and precision public health cohorts (Lee, 2021). The umbrella terms of “precision public health” (Khoury et al., 2016) and “personalized health” (Meier-Abt et al., 2018) refer to the use of different data—genomic, other *omics*, clinical, self-tracked—to improve the health of the population through the early detection of diseases and the development of targeted health strategies. Precision public health cohorts rely on large data sets which makes “participation” challenging. Participation in research has historically been framed as an act of altruism involving that the provision of samples and data is made “freely,” that is, under the condition that participants are informed sufficiently and have enough time to give their consent. Among others, this is justified by the ethical concern for undue inducement and biasing participation by attracting people through the prospect of financial incentives (Resnik, 2015).

An extensive body of Science and Technology Studies has shown, however, that even though framed in altruistic terms, participation in research contributes also to the bioeconomy of technoscience and generates other kinds of values relating to economic and national capitalization, which may lead to new forms of exploitation of the bodily work performed by donors of biological material or data (i.e. Tupasela, 2006). In parallel, and partly in response to these ethical concerns, public engagement initiatives have become overarching norms of the good governance in life sciences (i.e. Gottweis, 2008). Focusing on the ethics and politics of participation, they have been developed to address potential public mistrust toward science in regard to sensitive issues of general consent, return of research results, or data protection and privacy, and grant research participants a more important and symmetrical status in the governance of science and biomedicine. In line with international standards, the ELSI group (Ethical, Legal, and Social Issues) of the Swiss Personalized Health Network (SPHN)—a Swiss initiative aiming at developing infrastructure to enable a secured use and exchange of health data—recommends that strategies are developed to generate public trust, mutual respect, and reciprocity between research participants, research institutions, and the general public. Participation in scientific research is thus at the intersection of several economies—gift-based, financial, and moral—in which several kinds of values are generated and exchanged, and which may or may not align.

While reciprocity is one of the ethical values promoted in governance, its meaning and implications for scientists and research participants remain empirically underexplored: what is given, but also invested when people participate in public health research? What is expected in return both from the scientists and the state? Opening the black box of “participation” in precision public health provides an important entry point into questioning and understanding in more detail what is circulating among the different parties involved and what kinds of values are enacted. This is especially relevant in regard to the important status differentials at stake in precision public health, where the benefits of sharing tissues and data are unequally distributed (Desmond, 2021), risking reproduction of structural inequities and health disparities (Lee, 2021).

Drawing on the Science and Technology Studies literature on bioeconomy (Cooper and Waldby, 2014; Hoeyer, 2016) and valuation (Dussauge et al., 2015a), we propose an empirical exploration of participation in public health research in Switzerland which expands the literature on research participation often framed in bioethical terms (Vayena and Madoff, 2019). By unpacking the dynamics of exchange and reciprocity between *cohortees*, that is, cohort participants (hereafter CPs), and *cohorters*, that is, scientists and public health officers involved in the pilot phase of a large-scale precision public health cohort currently being developed in Switzerland, the *Swiss Health Study* (SHeS), we will shed light on “counter-gifts” expected by cohortees for their “clinical labor” and the “common good” they imagine should stem from such a cohort. This will allow us to show how different regimes of values are enacted and to which extent they align or misalign, revealing in this way how inequalities might be reproduced.

Participation in question

The term “participation” can refer to “scientific participation,” as the “population” under study, a collection of individuals providing data and biological samples for research purposes, but also to “public participation,” referring to the political body engaged in the governance of biomedical research (Bühler et al., 2019; Tupasela et al., 2015). Participatory approaches are part of a broader movement in biomedicine and public health that attempts to recognize citizens’ and patients “subject” status, their experiential knowledge (Rabeharisoa et al., 2014), and “civic epistemologies” (Jasanoff, 2012), thereby marking a shift away from biomedicalization toward a more integrative model of medicine (Abel et al., 2023; Panese, 2022). The rationales for public and patient involvement (PPI) are diverse and have evolved over time (Stilgoe et al., 2014), shifting from a deficit model interpreting debates and resistance to technological innovations and science in terms of lack of knowledge to an upstream engagement model promoting meaningful dialogue between experts and the “lay” public (Joly and Kaufmann, 2008). No public “out there” exists in itself, and these approaches can be seen as ways of constructing different versions of the public and performing a particular type of democracy (Voß and Amelung, 2016).

While PPI is considered to be effective in building trust between scientists and citizens, it is also criticized for playing an instrumental role in legitimizing medical and scientific endeavors, using social diversity to achieve predetermined goals, increasing participation rates in research, or as a mechanism for engineering consent and acceptability without fully acknowledging the concerns of participants who remain under-represented, and ignoring the political nature of the approach (Luna Puerta et al., 2020; Petersen, 2007; Van Oudheusden, 2014). According to Lee (2021), a reciprocity-based approach in precision public health is needed to address systemic inequalities and socio-political concerns that go beyond the issue of consent which remains caught in an individualistic framework. Drawing on the Maussian theory of gift (Mauss, 1992), Lee defines research participation as a “relational act that demands reciprocity” and engages the moral responsibility of the parties involved (Lee, 2021: 64). Consequently, Barazzetti and Bosisio (2021) argue for a better definition of what counts as the collective benefit of research to ensure that personalized health research is consistent with participants’ values and goals (see also Nowotny, 2014).

A recent survey investigating the Swiss public’s willingness, attitudes, and concerns toward personalized health found a majority of respondents to support the provision of health information and biological samples, in spite of concerns about discrimination, confidentiality, and misuse of data for commercial or marketing purposes (Brall et al., 2021). Another survey highlighted the predominance of altruistic motivations among the organizers of the study, as well as the people concerned by the purpose of the study (Rochat et al., 2020). Altruistic motivations are also very present among older Swiss adults who were willing to share data to contribute to a “greater good,”

such as scientific knowledge or medical research, without any expectation of reciprocity (Mählmann et al., 2017). This is in contrast with social studies in other contexts that illuminated the importance of reciprocity and the dynamics of gift/counter-gift in CPs' engagement over the long term and in building trust (i.e. Kerasidou, 2017; Ochieng et al., 2021; Sheikh and Hoeyer, 2018). It is therefore important to investigate qualitatively the form of exchange taking place between cohorters and cohortees and the kinds of values that are enacted through this.

The multiples values of participation

The concept of “clinical labor,” coined by Waldby and colleagues (Mitchell and Waldby, 2010), helps to understand the dynamics of exchange within the bioeconomy of precision public health and medicine. It is defined as “the regularized, embodied work that members of the national population are expected to perform in their role as biobank participants—in the creation of biovalue through biobanks” (Mitchell and Waldby, 2010: 334). This involves a transformation of population data and biosamples as a public resource into diverse forms of biovalue and biocapital. These studies show how the gift economy—premised on altruism, solidarity, and reciprocity—and the commercial economy—for profit, aimed at maximizing productivity, and generating capital value from “waste” tissues—are in practices deeply entangled (Degli Esposti and Pavone, 2019; Hauskeller and Beltrame, 2016). Indeed, both “public value”—such as the protection of human health—and “exchange value” in financial terms are co-produced in biomedical research. Moreover, as technoscientific endeavors are often inscribed in promissory regimes of expectations and hype (Audétat, 2015; Brown, 2003), the values they generate are speculative (Rajan, 2005) and associated with capitalization and assetization logics (Bühler and Herbrand, 2022) where temporality plays an important role. The commercialization versus gift narratives shadows the complexity of the exchanges taking place in tissues economies as Hoeyer demonstrated (Hoeyer, 2009, 2013), and there is a need to deepen the understanding of the valuation practices at stake in the economies of precision public health research.

The pragmatist approach of valuation studies defines values as “the precarious outcomes of contingent practices” (Dussauge et al., 2015b: 277) resulting from processes that make “things” (relations, ideas, etc.) valuable (Datta Burton et al., 2022). Broadening the definition of value beyond the financial sheds light on how “valuations of life are intermingled with values such as scientific reputation, profitability, fairness, economic efficiency, and accessibility of care” (Dussauge et al., 2015a: 1). This multiplicity entails processes of hierarchization, negotiation, and conflicts about which values matter. Accounting for the relational work needed to keep a register—for example, economic—separate from another, for example, scientific (Helgesson and Krafve, 2015; Lee, 2015), this approach enables us to deepen the analysis of the different regimes of values at stake in biomedicine, healthcare, and science where the specific value of scientific results is intertwined with assumptions about the values of life.

These analytical insights are relevant to understand the exchange dynamics taking place between cohorters and cohortees and the different kinds of values enacted in the Swiss cohort under study. We take the pilot phase of this cohort as a case study to explore what “good” is expected as a counterpart of participation. How do cohortees perceive their participation in the cohort, especially the clinical labor necessary for the production of data and samples? What do they expect in return? Finally, to what extent do these expectations align with the objectives and visions of cohorters? Addressing these questions empirically, we will show how cohortees' participation, while framed in altruistic terms—they do not expect financial compensation but want to contribute to something “bigger than themselves”—nevertheless engages expectations about reciprocal obligations of the state, public health, and science. The different values emerging from these expectations—science, public health as a specific field of medicine, scientific evidence of environmental exposures—provide rich indications

about stake making which might matter for the future of public health. This article provides thus an empirical contribution to both the critical literature on the bioethics and bioeconomy of research participation and to the Swiss debates about precision public health.

2. Methods and data collection

Study setting

Our data were generated in two studies: (1) the pilot phase of the SHeS and (2) the project *Development of Personalized Health in Switzerland: Social Sciences Perspectives* (DoPHiS) funded by the Swiss National Science Foundation (University of Lausanne), in which Bühler conducted an ethnography of the implementation of SHeS. The SHeS-pilot phase stems from a parliamentary motion submitted in 2008 to request a human biomonitoring program. Following an evaluation of the Swiss context and various exchanges with the scientific community, the Federal Council supported the concept of a pilot study leading to a national population cohort. The pilot phase took place between 2018 and 2021. Drawing on an exposome model of health (Wild, 2012), the scope of biomonitoring was expanded to include other environmental determinants of health, including lifestyle and nutrition. Publicly funded, the SHeS-pilot represents a hybrid project trying to combine the objectives of previous epidemiological studies and turned toward public health as a common good, while, at the same time, aiming to build infrastructure for future biomedical and public health research,¹ comparable to other national biobanks (Mitchell and Waldby, 2010; Tupasela et al., 2015). It brought together several federal offices, a federal biobanking institution, and two scientific teams based on academic public health research institutions in the French and German-speaking parts of Switzerland. The pilot cohort aims primarily (1) to build infrastructure for research, but has additional objectives; (2) a *surveillance goal*, to conduct human biomonitoring and investigate related sources of exposure as well as the nutritional status of the population; and (3) a *scientific goal*, to advance research on the exposome, gain a better understanding of health determinants, and identify relevant exposure biomarkers. Long term, it also has (4) a *governance goal*, to support evidence-based health policy and evaluate the impact of public health interventions.

Public involvement

Bühler contributed to the development of a PPI approach in collaboration with the SHeS team. Frahsa joined them at a later stage. The cohorters' initial objective was to reinforce the study design in preparation for the national study by understanding better the motivations and obstacles of research participation and exploring their perspective about sensitive ethical issues such as data sharing and protection, consent, or the implication of third parties with commercial interests. Cohortees were not involved in the design or the governance of the pilot study, but the aim is to reinforce this dimension for the scaling-up stages. The PPI approach adopted oscillates thus between a "study-focused model" and a "priority-setting" one (Greenhalgh et al., 2019) aiming to integrate the experiential knowledge of cohortees into the research setting (Knaapen and Lehoux, 2016). The final PPI approach has been constructed by the social scientists and the cohorters working at the Federal Office of Public Health, through discussions and exchanges about the needs, financial, temporal, and material constraints. The propositions this small group made were then submitted and discussed in the governing board of the cohort. The PPI approach results from interdisciplinary work and has evolved and been adapted over time in a pragmatic way.

Due to the pandemic, the focus groups, initially planned as face-to-face, were conducted online with fewer participants per discussion. The format was evaluated as convenient by participants

who could avoid transport and save time through this format. The online format reinforced the anonymity of cohortes, some using a pseudonym. Five focus groups were organized with French-speaking participants in March 2021 and two took place in October 2021 with German-speaking participants. The discussion was organized around three topics: (1) the experience and meanings of participation; (2) perspectives and concerns about consent and data protection; and (3) knowledge, concerns, and expectations about environmental health and public health. We tried to make the groups as diverse as possible in terms of age and gender. The French-speaking focus groups had 27 participants (16 women and 11 men) between 30 and 60 years. The German focus groups included 10 participants (4 women and 6 men), between 27 and 61 years of age, with half of them in their fifties. In all groups, participants were mostly from a high socio-economic background and were working in higher education, science, healthcare, health communication, information technology (IT), or public administration (see Supplemental Material for more information about the focus groups).

Data analysis

For this article, we draw mainly upon seven online focus groups with cohortes ($n=37$) that were part of this PPI initiative. We put into perspective these results with ethnographic data and interviews with the cohorters. Discussions were recorded, transcribed verbatim, and pseudonymized. We conducted narrative and reflexive thematic analyses (Braun et al., 2019) to identify, analyze, and report themes on specific aspects, such as perceptions of clinical labor, reciprocity, or understanding of the interplay between health and the environment. Bühler coded all French-language discussions, and Frahsa coded all German-language discussions. Codes and themes were discussed within the research team to check for accuracy in the process of analysis and credibility of the results. For trustworthiness of the data and communicative validation, co-authors discussed a draft thematic map and description of the themes as well as findings from the analysis.

3. Results

The results section starts by describing cohorters' concerns about participation and the kind of clinical labor expected from cohortes. The main body of the results is about four kinds of CPs' concerns and expectations and closes with presenting the valuation dynamics at stake in the cohort participation.

Clinical labor, or what is expected from cohortes

Since the beginning of the project, recruitment and participation rates have constituted a central scientific, political, and ethical concern for the team implementing the pilot study. The scientific value of a cohort depends on a high participation rate that would allow robust statistical analyses. Success in participation rates was also perceived as an indicator decisive to convince authorities and funding bodies of the feasibility of such a cohort. Cohorters therefore closely monitored participation as an indicator of the adhesion potential of the Swiss population to a future national cohort. In addition, cohorters were concerned that the high level of clinical labor required from cohortes might prevent them from participating, particularly given the length of several questionnaires, travel to the clinical research center, and the duration of health examinations. Cohorters were therefore interested in a more precise picture of the time, data, and samples cohortes were willing to invest. For this purpose, they created a questionnaire to evaluate their motivations, as well as facilitators and barriers for cohort participation. In addition, the PPI approach was implemented to explore in-depth cohortes' experiences, concerns, and expectations.

Clinical labor in this pilot study was intensive and condensed over a few weeks. Residents invited to participate by an official letter from the Federal Office of Public Health (FOPH) had to read and sign a detailed informed consent form. Then, their first task was to fill in five questionnaires on environment and lifestyle habits, nutrition, quality of life, medical history, and acceptance of biomedical research. It could be done at their own pace and own sequence. They could access an online dashboard indicating the progression of questionnaires. Upon completion, a study nurse contacted CPs for health examinations, including anthropometric data, blood pressure, lung function, bioimpedance, and handgrip strength, as well as urine and blood samples at the clinical research center. Some samples were analyzed in the respective hospital laboratories (clinical chemistry and hematology); other parts were stored for later metabolomic, epigenomic, and genomic analyses in a central biobank (study website). Additional questionnaire-based assessments on exposure and nutrition took place during the study visit. Cohortees also wore an accelerometer for 1 week to evaluate their physical activity and digitally recorded food consumption for eight consecutive days. If the pilot receives approval for scaling-up phases, these intensive phases of clinical labor will be repeated every 5–10 years.

The burden of clinical labor, although recognized by the cohortees in the focus groups, appeared not to be a main obstacle to participation. Cohortees appreciated the flexibility of filling out questionnaires at their own pace, and some even expressed disappointment at not being eligible for the study visits. Rather than a demanding clinical labor, they perceived these as opportunities they further advertised in their networks. However, the lack of flexible opening hours and the distance to the research center were mentioned as potential obstacles, in particular, having to take time off from work. Several cohortees perceived part-time or flexible work arrangements, such as home office, to allow for easier participation than full-time work. As the practical and temporal constraints of clinical labor might stratify access, and those with less low-paid work were under-represented in the pilot study (internal monitoring), it is particularly decisive to reflect upon how any unpaid time taken off from work to participate in research is valued. The relativization of the burden of clinical labor for cohortees also sheds light on what CPs anticipate in the medium to long term as the benefits gained from the study. Even though the literature on participation in Switzerland shows the great value granted to altruism (Brall et al., 2021; Rochat et al., 2020), the focus groups revealed that it was not sufficient for participation, and cohortees expected other benefits in return. The expectations detailed below reveal the moral values and directions cohortees think should orient public health research as a counterpart of their clinical labor.

4. What to expect in return? The “good” of participation in question

The “good” citizen: Identity politics and scientific research as a valuable good

Some CPs explained participation as a disinterested gesture that they perceive as “just normal.” They explained their willingness to participate as part of the reciprocal dynamics between society and themselves:

The reason is that you can give something back to society. I mean, I’m a computer scientist, so, usually, I’m not that socially engaged, and this was also an opportunity to give something back socially for once (man, fifties).

In line with the historical framing of research participation as altruistic, this revealed how scientific research is valued and part of a public good that any “good” citizen shall be willing to support. Although some CPs described their participation as devoid of self-interest and as an altruistic gesture made in

exchange for what “society” gives them, the high social value granted to research appeared to represent an incentive. The perception of research as a valuable good seemed to extend to some cohortees who were in turn valorized for taking part in such a laudable enterprise, saying they were excited to explore “the other side” or the “backstage” of science. Moreover, the valorization of scientific research as a common good might even take the form of a positive gesture toward one’s own country validating their Swiss citizenship:

I received a letter at home, and it will sound silly to you but I was proud to receive it, I was happy to know that I would be able to contribute to a study in Switzerland. You should know that I am not of Swiss origin, so it made my Swiss patriotism come alive for my new country, and it is true that I don’t belong to any major groups in the community. I am a woman without any children and perhaps there are not that many in the study, that was my motivation not to receive a small gift [such as a voucher] (woman, fifties).

This CP assigned value to representing a specific population sub-group. Considering her own socio-economic position with regard to norms of age and marital and family status, she wanted to provide the cohorters with health data and samples that might otherwise be difficult to find. She perceived clinical labor as a way of contributing to the cohort as a collective enterprise in which social diversity could be scientifically valued.

The research team presented CPs with a certificate of participation signed by the director of the FOPH, congratulating them on their pioneering gesture to valorize their engagement. However, it was not mentioned in the focus groups and, although recognizing officially CPs as “good citizens,” they more highly valued the informal contact with the scientists and the sense of belonging to a scientific enterprise considered a “noble cause,” “a good in itself,” as long as it is carried out by Swiss institutions perceived as reliable and legitimate for doing “good” science.

The critical participant: In defense of public health

Several cohortees perceived public health as a specific good to which they wanted to contribute. These CPs contrasted public health with biomedical, technocentric interventions that they tended to be critical of. For them, public health was associated with low-tech measures targeting the environment, broadly understood as the social and environmental determinants of health, defending the interests of the population, and promoting a holistic understanding of health.

The longitudinal and populational aspects of the cohort were perceived as a rare attempt and added value to its scientific interest. CPs perceived a long-term cohort to better serve the understanding of the health determinants in the population than a shorter study would do. This valorization was also based on an understanding of health determinants as dynamic and evolving over time. Cohortees also considered the sustainability of the healthcare system and its tendency to reproduce health inequalities:

I like the idea of having a study that allows us to advance prevention. The problem is that money is often spent more on treatment than on prevention, which is a pity in our health system [. . .] medicine that is also compatible with the environment and climate change, rather than a super-technical, high-tech medicine that serves one or two people and is very expensive, and that also has a significant negative impact on the environment, perhaps at the expense of the rest of society . . . I wonder about what kind of medicine we will need in the future? [. . .]. I want a medicine less intrusive in terms of impact and costs for tomorrow’s society and therefore I want to take time to go in this direction (woman, thirties).

There was no strong opposition against either prevention measures that targeted individual behavior or those that targeted the physical and social environment, which were deemed

complementary. However, there were expectations that such a cohort would support the development of measures sensitive to “conditions” favorable for health and would target structural elements, such as legal jurisdiction:

The current trend is to focus a lot on people's behavior and for me it is important to work on the influence that we can have on our health. However, it is even more important that we focus on the conditions that are favorable to health and not only on individual behavior; a real public health approach, and not just “you have to eat 5 portions of fruit and vegetables a day and then you won't be obese” (woman, forties).

If it could lead to recommendations for the general population, whether in regard to food or the environment, there may also be changes to the legislation because there are currently limits, but are they right, too high, too low? (woman, mid-thirties).

Critical participants were often well-informed about the health system due to their professional backgrounds and personal interests. Aware of some of the limits of the current health policies, their participation can be understood as a way of doing politics by other means to defend a more social version of public health.

The concerned participant: Environmental politics

The focus of the cohort on understanding the impact of the environment on health was a relevant incentive for cohortees who were concerned about anthropogenic climate change and the environmental crisis. They were particularly interested in participating in such a cohort and in advertising it more broadly in their networks and beyond.

Participation was to contribute to the production of scientific evidence on the health impact of the environment in a context perceived as full of doubts, contradictory sources of information, and fake news. Over recent years, Switzerland has witnessed a growing politicization of environmental issues—climate strikes, a “green wave” at elections, and votes on public initiatives aimed at prohibiting pesticides—which has turned environmental health into a sensitive issue, a phenomenon echoed in these cohortees' concerns. They expected to benefit from reliable information about the impact of various forms of environmental exposure:

In this period of fake news, where we hear that there is a resurgence of thyroid cancer, ah, it's Chernobyl, we hear so many things, and yet in other areas, like cosmetics, we hear nothing (woman, late forties).

The existing lack of Switzerland-based data was particularly highlighted:

It is precisely that we seem to be in a total blind spot whereas we are in a continuous chemical bath, and it is amazing that in a country like Switzerland we still do not have data on this type of bioaccumulation of exposure to the plethora of chemical products (man, forties).

On a health policy level, the role of the state was considered especially important for initiating prevention measures based on scientifically valid and reliable information. In the context of uncertainties surrounding exposure science and given the importance of industry lobbies, the state and public health institutions were seen as a guarantor entity capable of producing science devoid from private interests, countering the power of private interests to protect the health of the population:

It is an area [health] where the state must take back its rights and its role, because we are very much dictated to by private companies, all those who promote sugar, food, cosmetics. As an individual, I find it

difficult sometimes to make decisions with full knowledge because we don't have the data. I don't think that they hide it from us, but there is not necessarily an incentive to release certain data in my opinion. It is an area where we really need data from the state. There are things we can influence, but there is a whole part that we can't, like pesticides, heavy metals. And here the state must protect us [. . .] there is not enough funding and not enough interest, these huge companies have complete power and no responsibility. I find it completely imbalanced, and it is important to start working against it (woman, fifties).

Concerns about the impact of a polluted environment on their health were at the core of these cohortees' motivation. Sources of concern related to pesticides, but also included further aspects, such as 5G, electromagnetic waves, heavy metals, plastics, cosmetics, sugar, pesticides, pollution from cars, noise, climate change, or waste. However, clinical labor was inscribed in a reciprocity frame as those CPs expected health authorities to provide scientific evidence on these aspects and regulate them. The cohort was seen as a means to sort out "the truth" about sources of exposure and their impacts, enabling citizens to take a stance, but also to develop health policies to protect the health of the population from what is perceived as a constant yet diffuse and uncertain source of risk. This expectation is particularly important in regard to the historical neglect of industrial pollution and the way it often affects the lives of those who are already socio-economically precarious (Elsig et al., 2019; Henry et al., 2021).

The self-oriented participant: Self-monitoring and access to preventive care

These three expectations relate to individual values regarding vision of science, public health, and the environment, as moral and political causes to which cohortees wished to contribute. In the focus groups, the superior moral value granted to these causes was revealed when CPs apologized for being selfish and seeing their participation as a way of getting a free medical check-up. This reveals the normativity of altruism as the main frame through which participation is enacted. Two, sometimes intersecting, types of CPs expressed these personal expectations: the younger and the more precarious, a result confirming survey's findings (Rochat et al., 2020). They reflected about the situation of those without a GP (general practitioner)² and/or with a high insurance premium and limited financial means:

It might be a bit selfish, but with the high insurance premium we don't really have the opportunity to have regular medical check-ups, so I don't go to the doctor very often. I only go when I'm very sick, so it's less than once a year, so I was interested in having a health check-up, something I've never been able to do in my life, knowing that I've been a very heavy smoker since I was very young, and not only a cigarette smoker (man, thirties).

For most CPs, participation was an opportunity to know if their efforts to stay healthy—such as eating organic food, using essential oils, fasting, or physical activity and sport—had an actual positive impact on their health. They were interested in benchmarking comparisons to others' results, and receiving feedback on how to improve their health behaviors:

What could possibly be added for me. What is not in here now is feedback about me personally. So what are my risk factors? How am I doing on average? What could I do better? If you have looked at how I behave or move or what I eat etc. So there is little personal feedback, but it could be done relatively easily, if you have these parameters, then calculate what are your risk factors and what are the simple tips on how this person could now behave differently to improve their health (man, forties).

Others CPs aimed for information about currently unexplained personal health conditions, such as chronic fatigue or asthma. Moreover, some concerned participants about environmental exposure

did not only want to contribute to the study, but also expected future results to document their specific local exposure, creating an image of personalized biomonitoring. Beyond individual results, many wanted to be kept informed in accessible ways about results, reports, and publications.

5. Discussion

By empirically exploring the dynamics of exchange and reciprocity between cohortees and cohorters, we aimed to deepen our understanding of the moral and political economy of participation in precision public health. Implementing the pilot phase of a national cohort to study health is costly, especially for cohorters who worked for several years to develop work instructions, secure data flows, and manage the circulation of samples to the central biobank, not to speak about the political and institutional work needed for the governance of such cohort. It is also costly for cohortees who perform clinical labor for free and spend several hours answering questionnaires and undergoing health examinations in addition to their other professional activities. The recruitment of citizens and their enrollment in the study was a major concern for cohorters. Good rates of participation enabling the collection of data and samples represent scientific value. Therefore, recruitment and retention of cohortees are crucial issues that call for addressing the difficulties of participation as well as understanding potential reasons for dropping out. This raises tension about increasing the size of the “population” of the cohort for the sake of science, and the involvement of cohortees as agentic subjects with knowledge, concerns, and expectations that need to be considered seriously.

Researchers’ benefits to implementing such a cohort are diverse and can be read as forms of future capitalization about the personal, scientific, social, or institutional advantages they might gain in the future. Focusing on the benefits for cohortees, we identified four narratives among cohortees: (1) the good citizen participant, (2) the critical participant, (3) the concerned participant, and (4) the self-oriented participant. In the first narrative (1), scientific research is perceived as a valuable good. Contributing to the cohort is experienced as a citizen gesture; people are expected to perform as a counter-gift for what society provides them in terms of public services and other facilities. For some, it is also valorizing and reinforces the feeling of belonging to a whole, validating their sense of citizenship and nationality. In the second narrative (2), participation can be a way of “doing politics by other means.” Cohortees taking this position were well-informed and critical of the current health system. Their clinical labor gains value as an action defending a social vision of public health as opposed to biomedical endeavors. In the third narrative (3), often overlapping with the second one, cohorters are expected to advance the field of environmental health. Participation is seen as a contribution to the production of much-needed evidence about multiple sources of exposure. It also points to the moral obligation of the state to conduct research and implement policy on a topic of public concern.

The three first positions of cohortees are all inscribed in exchange dynamics between individual contribution to the cohort and a range of expectations about the collective benefits it would bring. These expectations are not seen as a direct personal return on their clinical labor but as important values that the cohortees want to personally protect and expect the cohorters to promote. Those positions highlight the perceived duty of the state to: (1) conduct high-quality scientific research, (2) develop a sustainable healthcare system oriented toward public health values, and (3) furnish Swiss residents with reliable evidence about the impact of exposure on health to develop appropriate health policies. Their expectations are turned toward the future, and their participation can be seen as an investment made in the present for a better health system. Moreover, a sense of personal gratification was sensitive when they expressed their motivation to participate in a scientific project aligned with their values. It seems that it gives personal meaning to their participation and clinical labor may become valorizing in itself.

The fourth narrative (4) is slightly distinct from the first three ones insofar as participation is work meriting something in return in the present. The normative enactment of altruism obscures the possibility that participation might provide access to preventive care, particularly for younger and more precarious cohortees or those paying a high insurance premium. In alignment with concerns about environmental exposures, there are also expectations about personal biomonitoring results and science as a resource for the daily navigation of risks. The Swiss health system is highly biomedicalized, and there is a lack of investment into public health research and policy development, especially in the field of prevention (Monod, 2022). Premiums of health insurances are very expensive and obligatory. People who find themselves in good health often opt for high out-of-pocket franchises. This is amenable to increase health inequalities (Remund et al., 2019). The expectations of self-oriented CPs about receiving the instant results of a medical check-up, information about their health habits and preventive advice, illustrate well two contemporary tendencies in health. First, it sheds light on health inequalities and shows how research can be a way of accessing preventive care, sometimes opportunistic and sometimes stemming from real financial difficulties. Second, it reveals the valuation of accessing data about one's own health reflecting the self-monitoring movement (Ruckenstein and Schüll, 2017) and the importance of concerns about environmental exposures.

Studies on the bioeconomy of participation and on valuation show how a nexus of different kinds of values is deeply entangled in the production of scientific knowledge. Our empirical analysis confirms the deep entanglement of the gift-based, financial, and moral economies of participation. It provides indications about how precision public health research should be oriented in the future to be aligned with the different values emerging from CPs' expectations: robust scientific evidence about environmental exposure and a socially oriented public health. It also points, however, to possible disjunctions between these and the actual endpoints of the cohort. On the cohortees' side, concrete translation from science to policy and interventions is expected. While science, public health, and environmental health emerge as shared values by cohorters and cohortees, the temporality in which research activities are inscribed might generate frictions. The scope of material, institutional, and political constraints to promote such valuable goals is postponed to a middle-long term future, while cohorters' main concern in the present is the valorization of the scientific value of the cohort and the financial and institutional securitization necessary to build up and expand it. This temporal lag has important implications in terms of trust building, willingness to participate and inclusivity.

While enacted in altruistic terms, participation relates to high expectations about the state and scientific counter-gift and moral responsibility. The general importance of public health values—concerns for health inequalities, chemical exposure, interventions targeting conditions for health and not only individuals—in CPs' expectations shall be taken into consideration when developing precision public health cohorts. As reciprocity is central for trust and the values cohortees expect to be defended so elusive, it seems also important to find ways of concretely integrating these values and to inform cohortees about what is done in the present. It indicates also that in spite of the many financial, temporal, and institutional constraints they face, cohorters should pursue their efforts and keep caring for participants' personal investments and expectations toward science and the state in terms of public health to support the relational ethics of public health research. This is not only to improve participation rates but also to make sure that research and results of the study's future uses are consistent with CPs' values and goals and to reach more inclusivity in research, as conflicting understandings of the social plus value or "common good" of precision for public health might arise.

Public health is traditionally characterized by concerns and strategies to mitigate health inequalities, and the value of a more social and just health system is present in the narratives of cohortees,

yet additional specific measures need to be implemented to make it really “for and from the public” and not only for privileged persons. In addition, this raises the question of public and patient involvement as the right tool to integrate more precarious and socially vulnerable population groups. Diversifying the means of reaching and integrating people and complementing with other qualitative and empirical studies is needed to explore the stakes of participation for people with lower socio-economic status and to address power imbalance and health inequities in public health research.

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Author contributions

N.B. designed the project and conducted it. She analyzed data and wrote the main body of this paper. A.F. contributed to the production of data, the analysis, and to the writing of this paper. R.M.B. and N.V.G. participated in the focus groups and revised this paper. M.B. made the interdisciplinary collaboration possible and revised this paper. F.P. is the grant holder of the project. He contributed to N.B.’s reflections about the overall conceptualization of the project and revised this paper. All co-authors approved the final version of this paper.


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Supplemental material

Supplemental material for this article is available online.

Notes

1. Data and biological samples are open to any researcher upon request and approval by the cohort’s steering committee.
2. In Switzerland, general practitioners - family doctors - are considered specialists doctors. Traditionally called « family doctors », these physicians work usually in private practice and are part of the primary line of care.

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