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General consent: a mixed-method and patient-inclusive approach to explore and optimise information strategies

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Summary

STUDY AIMS: Little is known about the factors influencing patients' response and decision rates to requests for general consent, designed to cover the use of health-related personal data and biological samples, in tertiary university hospitals. As such, we first sought to evaluate different general consent administration modes implemented at Lausanne University Hospital between December 2012 and April 2022, based on the following indicators (i) information rates, (ii) response rates and (iii) consent rates. The second objective of the study was to assess patients' understanding, preferences, needs and expectations regarding the content, form and mode of administration of general consent.

METHODS: This mixed-methods study comprised two phases. First, we analysed retrospective administrative data and general consent-related information from 178,223 adult patients who had been informed about general consent. Second, we analysed 2445 anonymised questionnaires mailed to patients as well as 4737 patient communications, and conducted 32 semi-structured telephone interviews.

RESULTS: The information-provision mode and clinical context influence patients' response to general consent.Oral information given by healthcare providers within medical departments is the most effective way of informing patients and making them reach a decision about granting general consent. However, 73.3% of questionnaire respondents considered that written information supported by a hotline is sufficient. Patients referred to the emergency room, following an accident for example, are less likely to respond to and grant general consent. Even though most respondents claim to fully grasp the information material, some topics seem less well understood and require additional explanations, such as the use of health-related personal data and biological samples in external institutions and the consequences of not replying to general consent.

CONCLUSIONS: The study provides an accurate data-driven depiction of how general consent administration methods and clinical contexts impact patients' response and decision rates, as well as an assessment of patients' understanding and needs concerning general consent information. These data allow us to confirm the validity of several practices, draw lessons and propose pragmatic recommendations to optimise general consent administration in hospitals, specifically: 1) Promote general consent information provision before or during the hospital visit or stay, 2) If a patient has not replied to general consent, repeat the information in a more favourable clinical context, 3) Diversify information channels and explore digital options for more-personalised and adapted information, 4) Simplify, clarify and illustrate general consent documentation with concrete examples of research enabled by general consent.

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Introduction

General consent for research is a form of informed consent by which individuals grant permission for the secondary use of their health-related personal data and biological samples in yet-to-be-defined research projects. General consent covers all data and samples collected during hospital visits and stays (both before and after accepting and signing the consent form), but precludes the collection of additional samples for research for which additional and specific informed consent is necessary. Even though researchers are legally required to provide participants with information and consent documents that are clear and understandable, these documents are often lengthy and complex, hindering patients' understanding, informed choice and recall of their decision [1–6]. General consent has the particularity that future studies are not yet defined, and therefore the information provided at the time of the consent request can only be generic.

General consent has been implemented at Lausanne University Hospital (CHUV) since November 2012 [7] and in the other Swiss university hospitals since 2014, as a consequence of the entry into force of the Federal Act on Research involving Human Beings (Human Research Act / SR 810.30) [8]. At CHUV, the current general consent form includes two questions: the first is about secondary use of health-related personal data and biological samples, the second is about participation in the genomic biobank of the hospital (supplementary document 3 in the appendix). Regardless of its evolution over time, the aim of general consent at CHUV has remained the same, namely to facilitate research, while providing patients with sufficient clear information to allow them to make an informed decision. However, the modes of general consent administration and the forms used to document patients' general consent have undergone several modifications.

There is evidence that medical and demographic factors influence the way patients respond to general consent [9], including some ambiguous findings. In an early analysis conducted in 2017, CHUV reported that the consent rate was declining progressively with age. Moreover, women, patients born outside Switzerland and patients admitted through the emergency ward were less likely to consent [7]. More recently, Zurich University Hospital also observed that women are less likely to grant general consent, whereas age, a higher frequency of hospital visits and multiple diagnoses were associated with an increased decision rate [10]. Similar results were reported in Geneva University Hospital: people more prone to grant general consent were older, had more comorbidities, were of higher socioeconomic status and were more often of Swiss nationality [11]. We observed that the number of patients informed about general consent and response rates also fluctuated depending on the modes of administration. However, overall, evidence regarding the impact of the mode of general consent administration on patients' decision-making is limited [12]. Our study aims to fill this knowledge gap and illustrate the influence of the clinical context.

The first objective of the study was to identify the factors impacting the response and the rate of general consent, in particular the influence of general consent administration modes implemented at CHUV between December 2012 and April 2022. The second objective was to evaluate patients' understanding, preferences, needs and expectations concerning the content, format and administration of general consent. Overall, the results of this study provide a solid base on which pragmatic recommendations can be drawn on how to optimise general consent content and how the information is administered.

Materials and methods

This was a mixed-methods study, including quantitative and qualitative analysis.

Data sources

The evaluation of factors impacting the response and consent rate to general consent relies on administrative data and general consent-associated data from 178,223 adult patients informed about general consent, collected at CHUV from December 2012 to April 2022. Data were extracted from three existing institutional administrative databases by the CHUV IT division team. During this period, general consent was gradually implemented in adult hospital departments, culminating in 2019 with systematic general consent information provided to adult inpatients and outpatients, except for those visiting the Psychiatric Department. A single research database was created after an iterative process of data extractions and data management, a check of data consistency and removal of duplicates. Random spot checks were undertaken to ensure data quality after this process. Before the statistical analysis, it became clear that certain variables had a very large number of categories, some of which had very few observations. As a result, the categories of certain variables

were grouped. Subsequently, during logistic regression modelling, several observations had to be excluded and variables dropped in order for model assumptions to be respected and to ensure that the models could converge. In particular, all variable categories with fewer than 50 observations were dropped as the odds ratios for these categories were very unstable.

The database created for this study will be kept on CHUV's secure server for 20 years after the publication of the study, then destroyed.

The assessment of patients' understanding, preferences, needs and expectations regarding general consent is based on data collected via three channels: 2445 anonymous questionnaires, 32 semi-structured interviews and 4737 patient communications:

Questionnaire: A 36-item 6-page questionnaire was developed by the study team. It was sub-divided into 3 sections: demographic information; self-assessed comprehension; and needs and expectations relating to the information (supplementary document 1 in the appendix). Question types were multiple-choice, scale and open-ended. During a 3-month period (1 March 2022 – 3 June 2022), the paper questionnaire was added to the general consent documents that are systematically mailed to adult patients who visit CHUV. An electronic form was also available via a QR code. The French version of the questionnaire was mailed and various languages were available upon request (German, Italian, English, Spanish and Portuguese). Only the English version was requested. The questionnaire explored respondents' understanding as well as their needs and expectations regarding the content, format and administration of general consent. Data from the paper questionnaires were manually entered into an electronic REDCap® database. The questionnaire was anonymous.

Semi-structured interviews: Given that individuals not returning a general consent decision (non-responders) were very unlikely to answer the questionnaire, a random sample of individuals who did not fill in the general consent form after the reminder was selected based on their age, sex and whether they received general consent information before or after the hospital visit/stay. These individuals were invited to participate, on a voluntary basis, in a semi-structured phone interview during which researchers probed participants about their recall of the information received, their understanding, and their needs and expectations about this information. In total, 32 interviews were conducted in July and August 2022 and in May and June 2023, with 15 women (6 aged 18–42, 9 aged 43–67) and 17 men (6 aged 18–42, 10 aged 43–67 and 1 aged 68–90). Discussions were conducted according to the interview guide (supplementary document 2 in the appendix), recorded, transcribed verbatim and anonymised. All recordings were destroyed and the transcripts were archived.

Patient communications (hotline phone calls, e-mails and patient letters) received at the Research Consent Unit are systematically summarised in a dedicated database.We extracted the notes taken during the period from 15 May 2020 to 7 March 2023, and analysed them.

Data analysis

Quantitative analyses

Quantitative analyses were conducted on the retrospective dataset (December 2012 – April 2022) to identify factors impacting response and decision about general consent using logistic mixed-effect regression models.

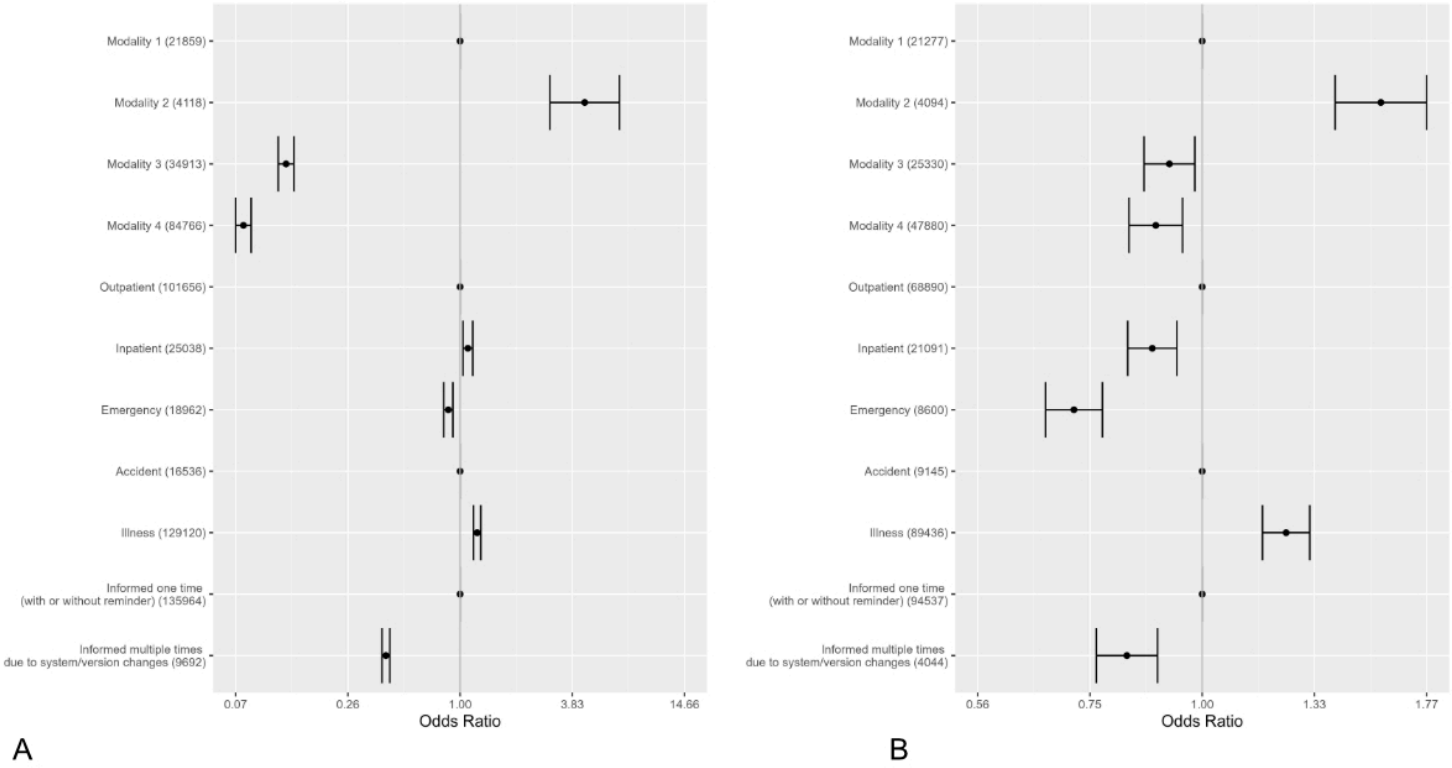
The modalities of general consent administration were as follows:

- Modality 1: general consent oral presentation by staff dedicated to general consent (Dec 2012 – Oct 2016),
- Modality 2: general consent oral presentation by medical doctors, nurses or administrative staff within the wards (Since Sep 2014),
- Modality 3: Information by mail *before* visit/hospitalisation, with or without reminder letter (Since Oct 2016),
- Modality 4: Information by mail *after* visit/hospitalisation, with or without reminder letter (Since Oct 2016).

General consent modality, version, status for information reiteration (once or more than once), age, sex, marital status, religious affiliation, country of citizenship, type of visit (outpatient, inpatient or emergency), reason for care (illness or accident) were introduced as fixed effects, and medical units as a random effect. After relevant groupings, small categories (fewer than 50 patients) were excluded (corresponding to 315 participants). Forest plots of odds ratios and 95% confidence intervals are presented. It was assumed that the effect of each variable is the same across all categories. We assumed that there are no interactions between the different variables in the model. No correction for multiplicity of tests was applied. Due to the large number of variables and for reada-

bility reasons, only those relevant to the discussion are displayed in figure 1. All analysed variables are available in figure S1 in the appendix. Missing values were considered to occur completely at random.

Figure 1: Logistic regression of response rate among informed patients (A) and consent rate among responders (B). The number of values for each category is shown in brackets. References are visible on the figure with an odds ratio value of 1 and no confidential interval. Response rate was modelled among informed patients and consent rate was modelled among patients who responded to general consent. Modality 1: General consent oral presentation by staff dedicated to general consent; Modality 2: General consent oral presentation by medical doctors, nurses or administrative staff within wards; Modality 3: Information by mail *before* visit/hospitalisation, with or without reminder letter; Modality 4: Information by mail *after* visit/hospitalisation, with or without reminder letter.



Descriptive statistics were performed to present the results of the questionnaire, applied to answers to queries and Likert scale data; mainly counts and percentages. All quantitative statistical analyses were performed with R 4.1.3 and 4.5.1. No weighting for underrepresentation of certain groups of patients was applied.

Qualitative analyses

Qualitative data collected via the questionnaire, semi-structured interviews and patient communications were analysed using the thematic content analysis method of Braun V and Clarke V [13], chosen for its flexibility and suitability in capturing complex, subjective experiences. This method entails an iterative process in which two researchers independently familiarise themselves with the data prior to coding them to identify interesting recurring content. To enhance the credibility and trustworthiness of the findings, discrepancies between coders were resolved through discussion and consensus. Data coding and analysis were performed using MAXQDA (Analytics Pro 2022) to help organise data and facilitate interdisciplinary exchange between researchers. In the Results section, the number of occurrences per theme are indicated as well as the total number of occurrences for one question. The total number of occurrences excludes answers with no relevance to the question. This clarification is provided to ensure methodological transparency and prevent any misinterpretation of the results.

Ethics approval and consent to participate

This study was conducted in compliance with the Helsinki Declaration. According to its aims, the study is a quality project and so falls outside the scope of the Swiss research legislation (the Human Research Act), which applies to research concerning human diseases, and the structure and function of the human body (see article 2). As such, Swiss research legislation and institutional guidelines waive the requirement for approval by an Ethics Committee.

Furthermore, to process this monitoring study, the dataset constituted with mainly administrative data of patients was anonymised to comply with the applicable data protection legislation. Given the type of study and the anonymisation of data, patient consent was not required. Data concerning patients' understanding and opinions about general consent documents and modalities were collected on a voluntary basis through anonymised questionnaires and interviews.

The institutional Legal Department formally confirmed that this study is exempt from Ethics Committee authorisation in compliance with Swiss legislation and institutional guidelines, as well as from patient consent.

Nonetheless, before starting, we informed the cantonal ethics committee for research involving humans (CER-VD) about this study.

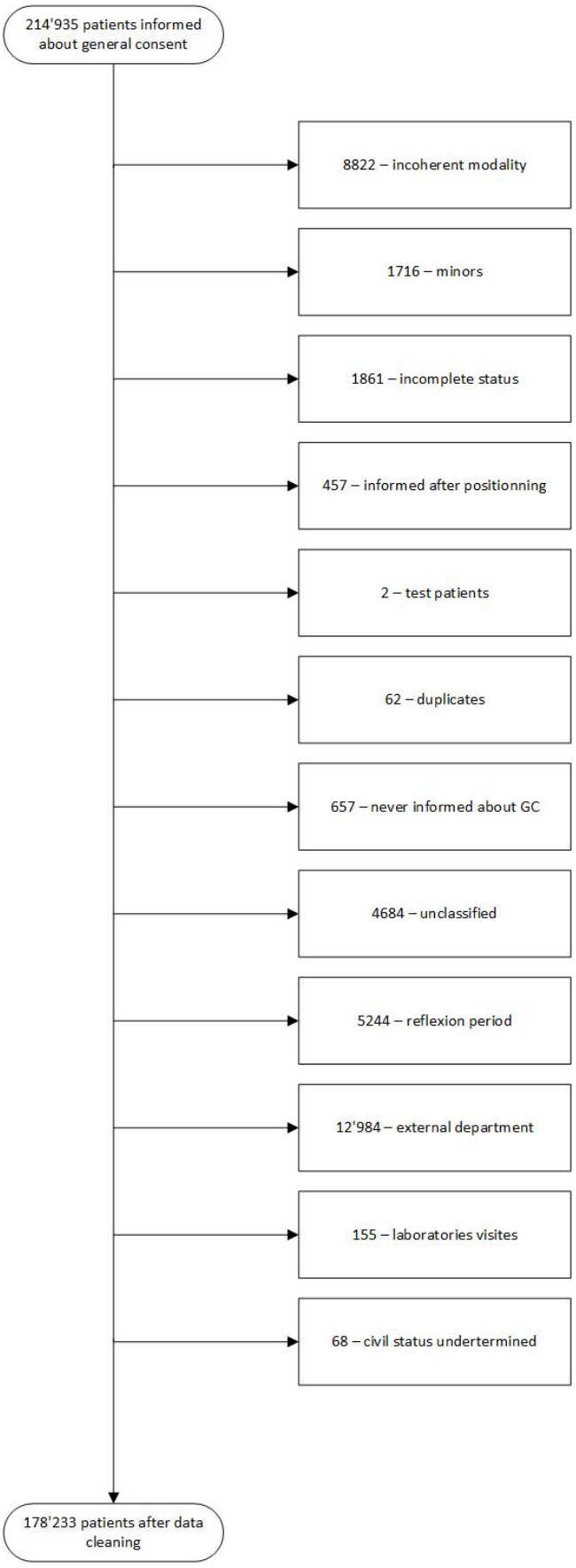
Results

Patient characteristics

Sample for the evaluation of factors impacting the response and consent rate to general consent

To be able to determine the factors influencing the response and consent rate, a database was created as described in "Materials and methods". Several observations were excluded, as shown in the patient selection chart (figure 2). This results from complexities associated with how data were recorded and anomalies in the information process. In total 36,712 (17%) observations were excluded from the initial extraction file (n = 214,935) for various reasons, resulting in the final database containing 178,223 observations. The descriptive analysis of the database is available in table S1 in the appendix.

Figure 2: Patient selection chart used to create a single research database containing 178,223 observations for the quantitative analysis. In total, 36,712 (17%) observations were excluded resulting from data cleaning from the initial extraction file (n = 214,935); exclusion was linked to various reasons resulting in a database. A summary of the reasons for exclusion of variables is provided in the flowchart.



Questionnaire sample

The questionnaire was mailed to 13,798 adult patients of CHUV between 1 March and 3 June 2022. The research team accepted returned questionnaires (paper 92% and electronic 8%) until 3 August 2022. During this period, 2616 questionnaires were returned (response rate: 19%). In comparison, the response rate to general consent forms over the same period (i.e. individuals who provided a response to the general consent request) was 46%. Among the returned questionnaires, 6.5% (171) had to be excluded (incomplete electronic records [n = 86]; only the administrative part of the questionnaire completed [n = 75]; fewer than 5 items of the questionnaire filled in [n = 9]; questionnaire completed by a minor [n = 1]), which resulted in the inclusion in the analysis of 2445 questionnaires of different levels of completeness (providing a consolidated response rate of 18%). Among questionnaire respondents, 36% identified as male, 48% as female and 16% did not specify sex. The average age was 51 and most questionnaire respondents were identified as patients (80%). The descriptive table of questionnaire respondents as well as questionnaire results are extensively reported in tables S2 and S5 in the appendix.

Based on the responses to question 8 of the questionnaire (How did you fill in/do you think to fill in general consent form), we observed that patients who stated in the questionnaire that they responded to or intended to respond to the general consent request were overrepresented. This overrepresentation was particularly pronounced for individuals who stated that they would agree to the secondary use of their health-related personal data and biological material: 70% of the questionnaire respondents indicated that they intended to or had consented while the observed actual consent rate among those informed about general consent in the same period is 34%. In contrast, questionnaire respondents who stated they did not intend to respond to general consent (2% of questionnaire respondents) or would refuse (5% of questionnaire respondents) were drastically underrepresented, when compared to the population who received the questionnaire accompanying general consent documents (54% non-respondents and 11% refusers) (table S6). Due to this lack of representation of non-respondents, a random sample of individuals who did not fill in the general consent form was selected and interviewed, as described in the "Materials and methods" section. Although individuals who declined general consent were underrepresented among questionnaire respondents, engaging this group was not feasible, as it would have required contacting those who had refused general consent.

Factors influencing response and consent rate

The quantitative analyses conducted on factors influencing patients' response revealed that most variables related to general consent administration, to hospital visit/stay and to patient demographics impact the odds for responding to general consent and consenting to secondary use of health-related personal data and biological samples (figure S1, tables S3 and S4 in the appendix).

The way general consent information is administered is associated with various response and consent rates. In-person oral presentation by staff of the unit/ward (modality 2) is associated with the highest odds for responding and consenting to the secondary use of health-related personal data and biological samples (compared to modality 1: oral presentation by dedicated staff): adjusted odds ratio (aOR) = 4.44, p <0.001, for responding and aOR = 1.58, p <0.001) for consenting. In contrast, written information sent by mail before (modality 3) or after (modality 4) the visit/hospitalisation is associated with the lowest odds for responding and consenting: modality 3 vs modality 1, aOR = 0.12, p <0.001 for responding and aOR = 0.92, p = 0.018 for consenting; and modality 4 vs modality 1, aOR = 0.07, p <0.001 for responding and aOR = 0.89, p <0.001 for consenting (figure 2A illustrates the logistic regression of response rate among informed patients, and figure 2B illustrates consent rates among responders).

Inpatients are more likely to respond to general consent than outpatients (aOR = 1.10, p = 0.001) and emergency patients (aOR = 0.87, p <0.01); however, outpatients are the most likely to grant general consent. Emergency patients are less prone to respond and grant general consent. This is related to the fact that patients whose type of visit/stay is categorised as "illness" are more prone to respond to and grant general consent than those categorised as "accident" (aOR = 1.23, p <0.001 and aOR = 1.24, p <0.01, respectively) since these patients often enter via the emergency room.

Compared to patients informed once (with the first mailing +/- the reminder letter), those informed multiple times are less prone to respond (aOR = 0.41, p <0.02) and grant general consent (aOR = 0.83, p <0.001). Patients were informed multiple times because *either* they did not respond before April 2019 and were informed again when the new general consent management application was implemented *or* they did not reply to the first version of general consent and were in-

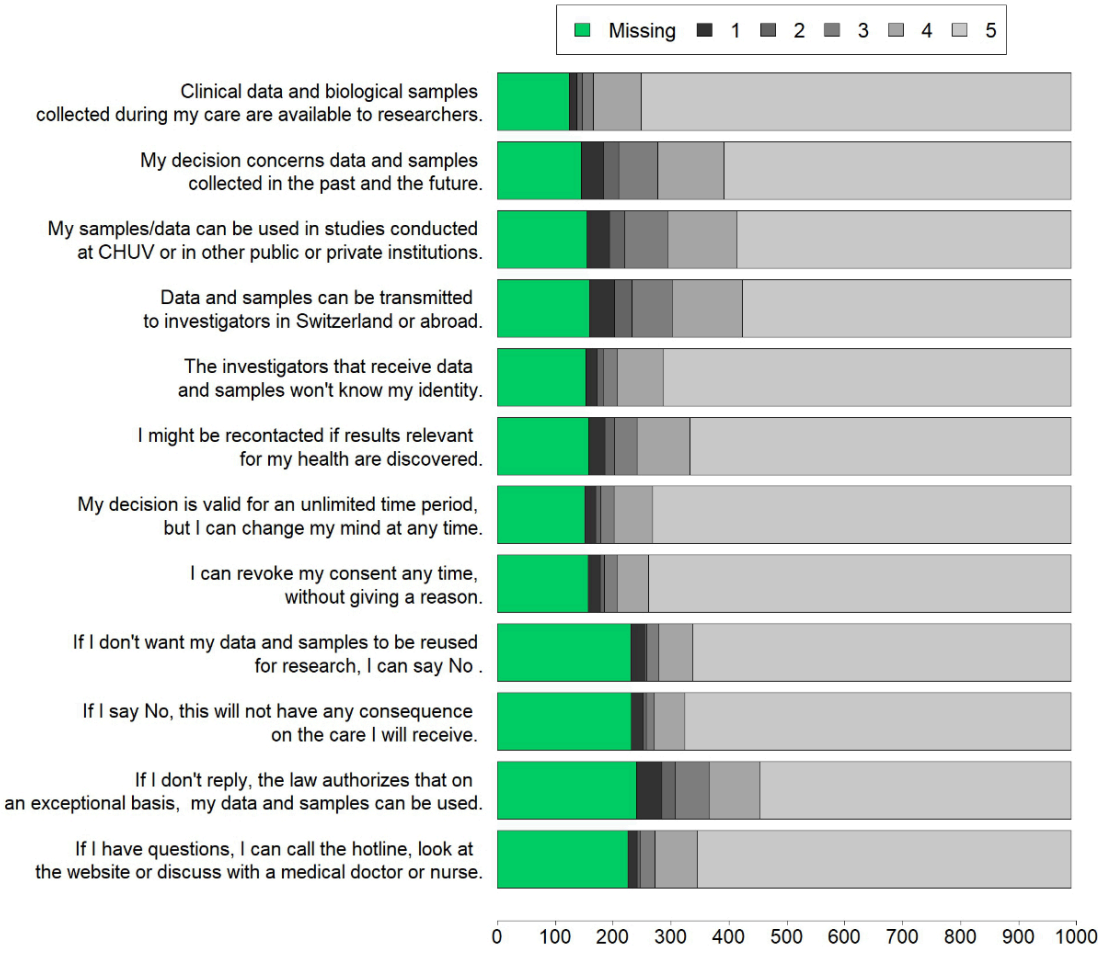
formed again when the version changed. The same trend in response and consent rate is observed when analysing the effect of the reminder letter. During the period from January 2018 to April 2020, 39% of patients made their decision after receiving the information by a single mail. In May 2020, a reminder letter was introduced and sent 6 weeks after the initial information letter if the patient had not responded. During the following period, 55% of patients made their decision when receiving general consent information by mail, which suggests that despite a lower overall consent rate in responders during the latter period (76% vs 81%), the reminder mailing was followed by a 16% increase in overall response rate among informed patients.

Patients' self-assessed comprehension of general consent information

Using a series of 12 statements (questions 9–10 and 14–23; questions 11–13 concerning the genomic biobank are not discussed in this article), questionnaire respondents were asked to indicate the extent to which they understood the information provided on a Likert scale of 1 "I didn't understand" to 5 "I understood". Most questionnaire respondents (60%, n = 1454) indicated that they understood all these statements, rating a score of 5 for each statement. Similarly, when asked on a scale of 1 to 10 whether they easily understood the general consent documents (Q25), 89% (n = 2060) of respondents gave a rating greater than 8, with 59.7% (n = 1378) giving the maximal score (table S5 in the appendix). An analysis to compare the understanding of acceptors', refusers' and non-responders' groups was not statistically possible, since the questionnaire return rate of the non-responders and refusers was too low.

While most questionnaire respondents self-assessed complete understanding of general consent information, we identified some topics with varying levels of understanding (figure 3). The greatest variability in understanding is related to (i) the use of health-related personal data and biological material collected in the past and the future, (ii) the use of samples and data by public and private entities, and (iii) the use of samples and data in Switzerland and abroad. The possibility that, in cases of non-response, health-related personal data and biological samples may exceptionally be used for research under Article 34 of the Swiss Human Research Act – outlining how permission to use data and samples from non-respondents can be granted – remains a subject for which patients' and questionnaire respondents' understanding is limited.

Figure 3: Self-assessed comprehension of general consent information. Using a series of 12 statements (questions 9–10 and 14–23; questions 11–13 concerning the genomic biobank are not illustrated in this figure), questionnaire respondents were asked to indicate the extent to which they understood the information provided on a Likert scale of 1 "I didn't understand" to 5 "I understood". Ratings of people who did not rate 5 to all comprehension questions are illustrated (n = 991 patients). "Missing" means no response.



Examination of the 4737 patient communications data revealed several recurring questions from patients: 350 people asked why they had received this consent form, 320 needed help understanding the information and completing the form and 220 asked whether they had to complete the general consent form considering they felt too old, too sick or misunderstood the scope of the consent. Individual interviews confirmed that the reason why a patient receives general consent needs to be better explained as well as the existence of a provision whereby data may still be used in specific circumstances in case of non-response (i.e. that under Article 34 of the Swiss Human Research Act, permission to use the data may still be granted in some cases).

Main sources of concern for patients

When questionnaire respondents were asked whether they were concerned about some aspects of general consent information (Q31), the majority responded that they were not (91.4%, n = 2149) (table S5). Among respondents who indicated having concerns (8.6%, n = 203), 3 themes recurred in the comments. The first concern was the use of health-related personal data and biological material in the private sector (59/175 occurrences). The second concern was the fact that biological samples and health-related data could be shared with institutions in a foreign country (32/175 occurrences). The third concern was data protection (how data are stored, the level of protection, the risk of hacking, ...) with 25/175 occurrences.

Preferences about general consent information modalities and timing

When asked about the best way to receive information about general consent (Q29), 73.3% of the questionnaire respondents (n = 1677) stated that the printed materials, the website and support options offered by the hospital are sufficient to make an informed decision, while 26.7% (n = 611) of respondents would appreciate an oral presentation. When asked who should provide oral information, the preference goes to a medical doctor (38.2%), followed by a general consent team member (26.6%), a nurse (25.9%) and, lastly, a member of the admission office (14.3%) (table S5).

Concerning the best moment to receive general consent information (Q33), opinions vary. We observe a slight preference for the option "during the stay or visit" compared to "after the stay or visit" and "before the stay or visit" (33.3% of questionnaire respondents vs 29.8% and 24.5%, respectively) (table S5). When examining the reasons why respondents prefer to receive the information during their stay or visit, the main motivations are that it is the best moment to ask/clarify certain points with hospital staff (98/227 occurrences) and that patients have time while waiting at the hospital (77/227 occurrences).

Evaluation of the layout and presentation of general consent information

Questionnaire respondents were asked to rate the presentation and layout of general consent information on a scale of 1 to 10 (Q24). The majority rated the presentation and layout positively, with 88% using scores of 8 or more (n = 2038).

Respondents were also probed on whether they felt any information was missing from the documentation (Q26). The overwhelming majority, 93.1% (n = 2137), considered that there was no information missing from the documentation. Among respondents indicating that information was missing, comments were made on the type of research to be conducted with their health-related personal data and biological material, as well as on the need to show examples of research being done with general consent (31/110 occurrences). Some respondents mentioned that they would like to have more information on research being done in the private sector and abroad (15/110 occurrences). Details on how health-related data and biological samples are protected would also be appreciated (14/110 occurrences).

During individual interviews, several suggestions for improvement were raised, such as simplifying the information to make it more understandable and accessible, illustrating the importance of general consent by referring to concrete examples of research projects carried out within the framework of general consent and clarifying the consequences of not responding to general consent.

Most questionnaire respondents (94.4%, n = 2241) stated that general consent documents were sufficient to make a decision (Q28). Of those who needed more information (n = 132), 45.4% (n = 60) indicated that they wanted to discuss the topic with a relative and 20.5% (n = 27) wanted to discuss it with their doctor or nurse (table S5).

Willingness to participate in research and overall satisfaction with information received

When asked to rate the importance of contributing to research on a scale from 1 "Not at all" to 10 "It's essential" (Q34), an overwhelming majority of questionnaire respondents (89.1%, n = 2068) answered towards the positive end of the scale (greater than 8).

When asked why it is important to contribute to research, the two most prevalent reasons were civic duties (567/647 occurrences) and a personal involvement in medical research (student, physician, researcher in the family, ...) (47/647 occurrences).

88% (n = 2044) of the respondents were satisfied with the information received on general consent, rating satisfaction at more than 8 on a scale from 1 to 10 (Q35). Two questions sought suggestions on enhancing the clarity and comprehensibility of the documents (Q27) and improving how patients are informed about general consent (Q36). Among 406 suggestions, 130 emphasised the need to simplify the documents and make them more concise. While 86 respondents would like to have oral information during their visit/stay at the hospital and have human contact, 34 respondents were interested in a more electronic process. In line with observations reported above, 19 respondents emphasised the importance of providing examples of research conducted within the framework of the general consent.

Discussion

Factors predicting response and consent

Our quantitative analyses spanning over a decade of general consent practice at a university tertiary hospital reveal that information modalities, as well as the context of the patient's visit, influence response and consent rates.

The quantitative analyses highlight that oral information provided by hospital unit staff during the patient's stay/visit is associated with the highest likelihood of responding to and granting general consent. The questionnaire data also show a slight preference for receiving general consent information during the hospital stay/visit as it provides an opportunity to ask questions, and because patients often have waiting time in hospital that could be used wisely to be informed about general consent. These results are aligned with previous studies demonstrating that patients' preferences regarding the use of their samples and health-related data in research is influenced by relational considerations [4].

Patients whose visit/stay is classified as emergency and patients whose visit/stay is related to an accident are less likely to grant general consent than patients presenting at the hospital for a scheduled appointment and patients whose visit is related to an illness. The unforeseen situation, concomitant stress and possibly a temporary incapacity to discern create an unfavourable context for making decisions regarding general consent. This may be a barrier to a representative engagement of patients in research conducted in critical care or emergency units. Repeating general consent information in a more favourable clinical context may increase the chances of obtaining a response to general consent request.

A decision to participate in research initiatives depends on the patients' trust towards the hospital and their staff [9, 14–16]. Over time, the trust relationship of a patient with the hospital may change, as well as the context of their care or the reason for the visit (transition from an acute episode to a chronic illness, repeated hospital stays, scheduled versus emergency stay, etc), their interest in research and general consent might change accordingly.

We also observed that the probability of responding and granting consent is influenced by the patient's sociodemographic profile (sex, age, religion, nationality and marital status), which will not be discussed in more detail as it has been described in several previous studies [7, 9–11]. It does, however, question the representativeness of people included in research projects conducted using data covered by general consent. As previously reported, the extent to which patients understand information and consent documents influences the response and consent rates [17]. Offering multiple ways to inform patients about general consent might be a solution to better reach the diverse patient profiles and increase the variety of patients responding to general consent. Several studies reported that users' comprehension improved when an e-consent medium was used [18]. The potential of digital solutions that provide flexible and tailored information for patients, such as dynamic consent platforms [19], needs to be explored with the help of patients and researchers. However, digitisation of the consent process should be thought of as a complement to improve patient autonomy and understanding, not as a substitute for human interaction [20].

Patients' preferences about general consent documents

Most questionnaire respondents stated that the printed material, website and support options offered (hotline and e-mail) are sufficient to help them make their decision. However, the analysis of the questionnaires, interviews and patient communications reveals that the information brochure should be more concise, easier to understand and more attractive. Examples of research made possible by general consent would also be greatly appreciated. Additionally, individual interviews showed that the reason why patients receive general consent and the consequences of not responding need to be better explained.

Furthermore, the questionnaire revealed that the questions concerning the use of health-related personal data and biological material by the private sector and/or abroad were also those that raised most concerns. As previously reported, the main concerns when deciding whether to grant general consent are lack of trust, data privacy and an objection to profit-making through the use of health-related data [21–24]. Emphasising the patient-centred benefit of this third-party use of health-related personal data and biological material, as well as better communication about the means used to protect privacy may help patients feel more comfortable about sharing their data with researchers from the private sector or abroad [25]. Furthermore, digital dynamic consent platforms offering transparency and more consent choices may offer patients greater confidence and peace of mind in their choices [24, 26].

We should keep in mind that, even though a random sample of individuals that did not fill in the general consent form was selected for interviews, most respondents in the three qualitative models were favourable towards general consent, meaning that the interpretation of the data discussed must be taken with caution.

Limitations of the study

The large sample size gives the results their strength, but it could also lead to some effects appearing statistically significant without representing an operationally relevant difference. In addition, data are based on administrative data extracted from hospital databases. Although efforts have been made to ensure that these data are collected accurately (through iterative quality checks), some inaccuracies may persist due to data entry errors, despite careful data consistency and data cleaning checks when deriving the analysis dataset.

The extended duration of data collection – over 10 years – cannot exclude a time effect. Intercurrent events, such as the SARS-CoV-2 pandemic, could have influenced perceptions of the healthcare system and biomedical research, and therefore the reception of information on general consent by patients [24] .

Questionnaire respondents displayed a recruitment bias: patients who responded to general consent were overrepresented, particularly those who granted general consent. In contrast, non-respondents to general consent and general consent refusers were severely underrepresented, something that cannot be compensated for by statistical methods. Furthermore, the questionnaire was distributed only via mailings to patients receiving general consent via modality 1, which may influence some responses. Therefore, the data collected via the questionnaire must be interpreted with caution as respondents' profile reveals a specific population that is generally favourable towards research and general consent.

Conclusion

The results presented in this study are based on a substantial volume of information. These data allowed us to confirm the validity of several practices, draw lessons from more than ten years of experience in the field of general consent and propose four practical recommendations for general consent practice:

- Promote general consent information before or during the hospital visit or stay, whether in written or oral form.
- If a patient has not replied to the general consent request, repeat the information in a more favourable clinical context.
- Diversify information channels and explore digital options to offer more-personalised and adapted information.
- Simplify, clarify and illustrate general consent documentation with concrete examples of research carried out using general consent.

These recommendations should help increase the number of patients properly informed and therefore patients who complete the general consent form. Indeed, if modalities of general consent administration are adapted according to patients' needs and preferences, and if the content and format of the information allow for better understanding of general consent, we assume that the response rate will increase and, more importantly, so will the rate of truly informed and autonomous decisions.

This study focused on patients' perspectives on general consent information within a broader institutional approach to patient and public involvement and engagement. The relatively high response rate to the questionnaire suggests that many patients value the idea of improving understanding of the consent request and legitimise its informed and well-understood nature. It is essential to involve patients in the development of general consent and in the establishment of guidelines relating to its administration.

Availability of data and materials

The datasets generated and analysed during the current study were deposited under restricted access in the institutional repository of CHUV due to the sensitive nature of the data. Metadata are publicly available on Zenodo and accessible via the DOI provided in the dataset reference (https://doi.org/10.5281/zenodo.15683552). Access to the data may be granted upon reasonable request to the Principal Investigator and is subject to a data transfer and use agreement.

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Author contributions: BS, MF and CA contributed to the conception and the supervision of the study. BS, MF, CA, NK and JZ were involved in designing the methodology. NK, JZ and MJC collected and processed the data. NK, JZ, MJC and MM analysed and interpreted the data. JZ and CA reviewed the literature. NK, CA, MM and BS wrote the first draft of the manuscript. All the authors were involved in the revision of the manuscript.

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Potential competing interests

All authors have completed and submitted the International Committee of Medical Journal Editors form for disclosure of potential conflicts of interest. No potential conflict of interest related to the content of this manuscript was disclosed.

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Appendix

Supplementary Table 1: *Statistic description of the sample for the evaluation of factors impacting the GC response and consent rate*

	Modality 1 (N=25134)	Modality 2 (N=4666)	Modality 3 (N=41706)	Modality 4 (N=106717)	Overall (N=178223)
GC positioning					
No	1685 (6.7%)	32 (0.7%)	12030 (28.8%)	47588 (44.6%)	61335 (34.4%)
Yes	23449 (93.3%)	4634 (99.3%)	29676 (71.2%)	59129 (55.4%)	116888 (65.6%)
Consent secondary use					
No	3906 (15.5%)	568 (12.2%)	5364 (12.9%)	13196 (12.4%)	23034 (12.9%)
Yes	19543 (77.8%)	4066 (87.1%)	24312 (58.3%)	45933 (43.0%)	93854 (52.7%)
Missing	1685 (6.7%)	32 (0.7%)	12030 (28.8%)	47588 (44.6%)	61335 (34.4%)
Age					
Mean (SD)	57.9 (19.1)	58.0 (17.6)	51.9 (18.3)	47.8 (19.0)	50.4 (19.2)
Median [Min, Max]	60.0 [18.0, 102]	60.0 [18.0, 104]	52.0 [18.0, 104]	46.0 [18.0, 121]	50.0 [18.0, 121]
Age category					
18-29	2419 (9.6%)	396 (8.5%)	5658 (13.6%)	21889 (20.5%)	30362 (17.0%)
30-39	2872 (11.4%)	409 (8.8%)	6516 (15.6%)	21012 (19.7%)	30809 (17.3%)
40-49	3049 (12.1%)	576 (12.3%)	6519 (15.6%)	16260 (15.2%)	26404 (14.8%)
50-59	4082 (16.2%)	899 (19.3%)	7781 (18.7%)	17335 (16.2%)	30097 (16.9%)
60-69	4674 (18.6%)	985 (21.1%)	6771 (16.2%)	12931 (12.1%)	25361 (14.2%)
70-79	4541 (18.1%)	916 (19.6%)	5732 (13.7%)	10764 (10.1%)	21953 (12.3%)
>80	3497 (13.9%)	485 (10.4%)	2729 (6.5%)	6526 (6.1%)	13237 (7.4%)
Gender					
F	11748 (46.7%)	2585 (55.4%)	23036 (55.2%)	59445 (55.7%)	96814 (54.3%)
M	13386 (53.3%)	2081 (44.6%)	18670 (44.8%)	47272 (44.3%)	81409 (45.7%)
Civil status					
Single	4790 (19.1%)	983 (21.1%)	12386 (29.7%)	40359 (37.8%)	58518 (32.8%)
Divorced	3794 (15.1%)	754 (16.2%)	5251 (12.6%)	11680 (10.9%)	21479 (12.1%)
Married	12544 (49.9%)	2314 (49.6%)	20148 (48.3%)	45902 (43.0%)	80908 (45.4%)
Separated	819 (3.3%)	144 (3.1%)	1215 (2.9%)	2908 (2.7%)	5086 (2.9%)
Widowed	3171 (12.6%)	466 (10.0%)	2592 (6.2%)	5387 (5.0%)	11616 (6.5%)
Missing	16 (0.1%)	5 (0.1%)	114 (0.3%)	481 (0.5%)	616 (0.3%)
Type of visit					
Out patient	8739 (34.8%)	3181 (68.2%)	40282 (96.6%)	71188 (66.7%)	123390 (69.2%)
Inpatient	15655 (62.3%)	1349 (28.9%)	1267 (3.0%)	10977 (10.3%)	29248 (16.4%)
Emergency	76 (0.3%)	36 (0.8%)	67 (0.2%)	24539 (23.0%)	24718 (13.9%)
Missing	664 (2.6%)	100 (2.1%)	90 (0.2%)	13 (0.0%)	867 (0.5%)
Reason for care					
Accident	2479 (9.9%)	60 (1.3%)	4108 (9.9%)	15310 (14.3%)	21957 (12.3%)
Illness	21972 (87.4%)	4505 (96.5%)	36651 (87.9%)	89407 (83.8%)	152535 (85.6%)
Missing	683 (2.7%)	101 (2.2%)	947 (2.3%)	2000 (1.9%)	3731 (2.1%)
Department					

DAL_207	2459 (9.8%)	286 (6.1%)	9935 (23.8%)	19074 (17.9%)	31754 (17.8%)
DC_202	5944 (23.6%)	687 (14.7%)	7150 (17.1%)	12666 (11.9%)	26447 (14.8%)
DCI_225	8426 (33.5%)	811 (17.4%)	547 (1.3%)	25018 (23.4%)	34802 (19.5%)
DCV_212	3517 (14.0%)	77 (1.7%)	2836 (6.8%)	6100 (5.7%)	12530 (7.0%)
Admin. DPT	2 (0.0%)	0 (0%)	23 (0.1%)	1783 (1.7%)	1808 (1.0%)
Psychiatric DPT	12 (0.0%)	199 (4.3%)	72 (0.2%)	125 (0.1%)	408 (0.2%)
DFME_213	1598 (6.4%)	561 (12.0%)	4125 (9.9%)	13297 (12.5%)	19581 (11.0%)
DM_200	1107 (4.4%)	709 (15.2%)	9879 (23.7%)	16215 (15.2%)	27910 (15.7%)
DMLP_210	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
DNC_208	1457 (5.8%)	1082 (23.2%)	3468 (8.3%)	5178 (4.9%)	11185 (6.3%)
DO_209	481 (1.9%)	59 (1.3%)	2541 (6.1%)	2105 (2.0%)	5186 (2.9%)
DRM_211	129 (0.5%)	134 (2.9%)	708 (1.7%)	4380 (4.1%)	5351 (3.0%)
Missing	2 (0.0%)	61 (1.3%)	422 (1.0%)	776 (0.7%)	1261 (0.7%)
Confession					
Other + invalid codes	552 (2.2%)	111 (2.4%)	1720 (4.1%)	4126 (3.9%)	6509 (3.7%)
Catholics	9547 (38.0%)	1758 (37.7%)	14206 (34.1%)	32707 (30.6%)	58218 (32.7%)
Jewish	69 (0.3%)	18 (0.4%)	93 (0.2%)	286 (0.3%)	466 (0.3%)
Muslims	1262 (5.0%)	176 (3.8%)	2595 (6.2%)	7836 (7.3%)	11869 (6.7%)
Orthodox	423 (1.7%)	67 (1.4%)	886 (2.1%)	2167 (2.0%)	3543 (2.0%)
Protestants	8434 (33.6%)	1486 (31.8%)	10348 (24.8%)	21312 (20.0%)	41580 (23.3%)
None	2578 (10.3%)	604 (12.9%)	6233 (14.9%)	18664 (17.5%)	28079 (15.8%)
Jehovah's witness	77 (0.3%)	20 (0.4%)	121 (0.3%)	240 (0.2%)	458 (0.3%)
Missing	2192 (8.7%)	426 (9.1%)	5504 (13.2%)	19379 (18.2%)	27501 (15.4%)
Citizenship					
African	541 (2.2%)	70 (1.5%)	1336 (3.2%)	3758 (3.5%)	5705 (3.2%)
American	456 (1.8%)	73 (1.6%)	823 (2.0%)	2758 (2.6%)	4110 (2.3%)
Asian	410 (1.6%)	60 (1.3%)	1285 (3.1%)	3470 (3.3%)	5225 (2.9%)
European	5734 (22.8%)	929 (19.9%)	9859 (23.6%)	29035 (27.2%)	45557 (25.6%)
Oceania	11 (0.0%)	2 (0.0%)	18 (0.0%)	56 (0.1%)	87 (0.0%)
Other/Stateless	2 (0.0%)	0 (0%)	2 (0.0%)	11 (0.0%)	15 (0.0%)
Switzerland	17936 (71.4%)	3518 (75.4%)	28232 (67.7%)	67038 (62.8%)	116724 (65.5%)
Missing	44 (0.2%)	14 (0.3%)	151 (0.4%)	591 (0.6%)	800 (0.4%)
Number of GC information					
1	25134 (100%)	4613 (98.9%)	37259 (89.3%)	100639 (94.3%)	167645 (94.1%)
2+	0 (0%)	53 (1.1%)	4447 (10.7%)	6078 (5.7%)	10578 (5.9%)
GC Version					
GC 2020	0 (0%)	438 (9.4%)	23550 (56.5%)	93340 (87.5%)	117328 (65.8%)
GC CHUV	24649 (98.1%)	4225 (90.5%)	18156 (43.5%)	13377 (12.5%)	60407 (33.9%)
Missing	485 (1.9%)	3 (0.1%)	0 (0%)	0 (0%)	488 (0.3%)

***Supplementary Table 2**: Statistic description of the sample of questionnaire respondents*

	Overall (N=2445)
Age	
Mean (SD)	51.0 (18.8)
Median [Min, Max]	51.0 [18.0, 99.0]
Missing	514 (21.0%)
Gender	
Female	1181 (48.3%)
Male	882 (36.1%)
Missing	382 (15.6%)
Education	
Other	81 (3.3%)
Federal certificate or diploma, ES (specialist school)	239 (9.8%)
Federal Certificate of Competence (CFC)	534 (21.8%)
Compulsory schooling	238 (9.7%)
HES (University of Applied Sciences), University, EPF (Federal Institute of Technology)	740 (30.3%)
Maturité (secondary school diploma)	182 (7.4%)
Missing	431 (17.6%)
Category	
Other	45 (1.8%)
Patient	1946 (79.6%)
Friend or relative	25 (1.0%)
Missing	429 (17.5%)

Supplementary Figure 1: *Logistic regression of response rate among informed patients (A) and consent rate among responders (B)*

The number of values for each category is shown between brackets.

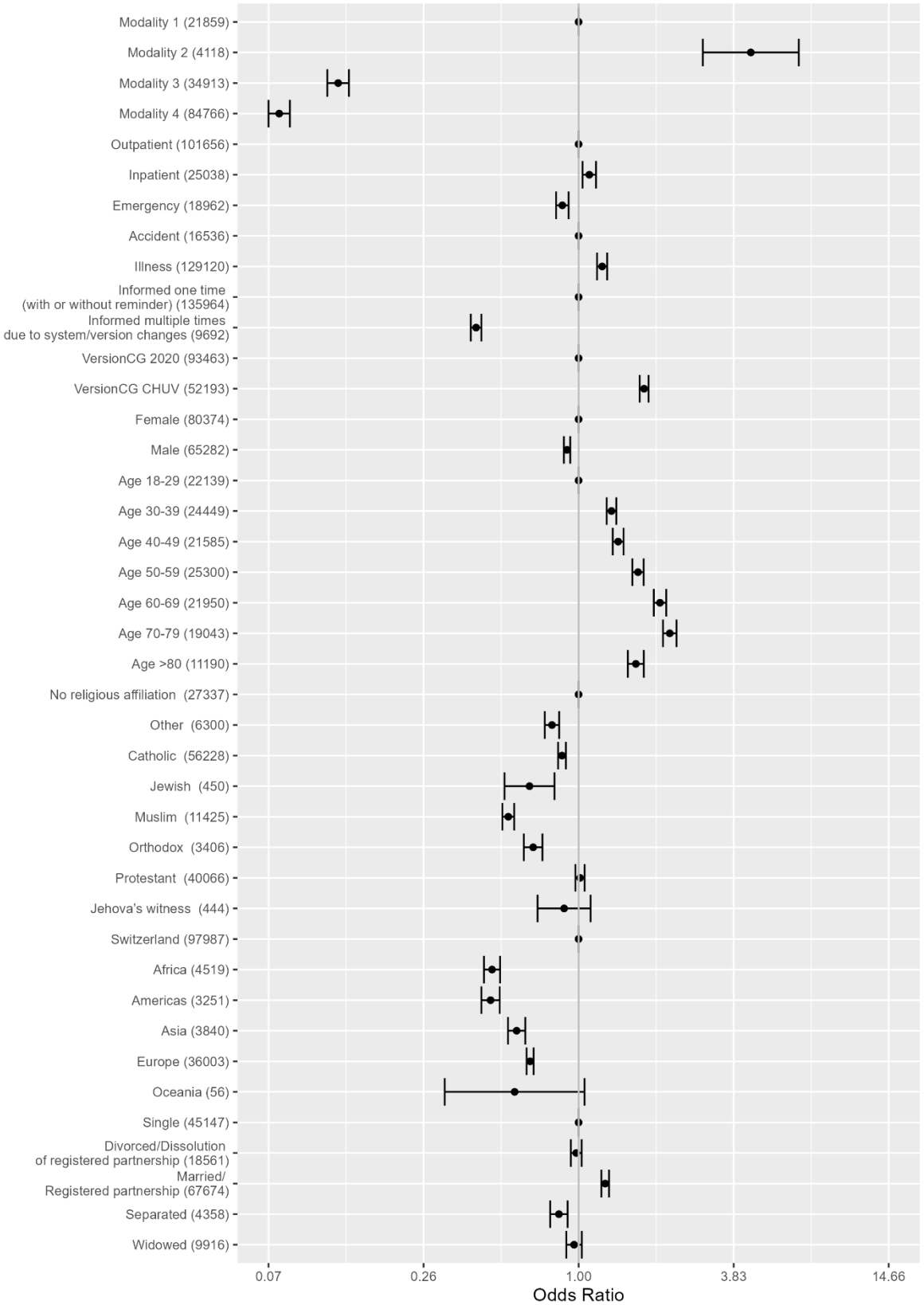
Modality 1: GC oral presentation by GC dedicated collaborators,

Modality 2: GC oral presentation by medical doctors, nurses or administrative collaborators within the wards,

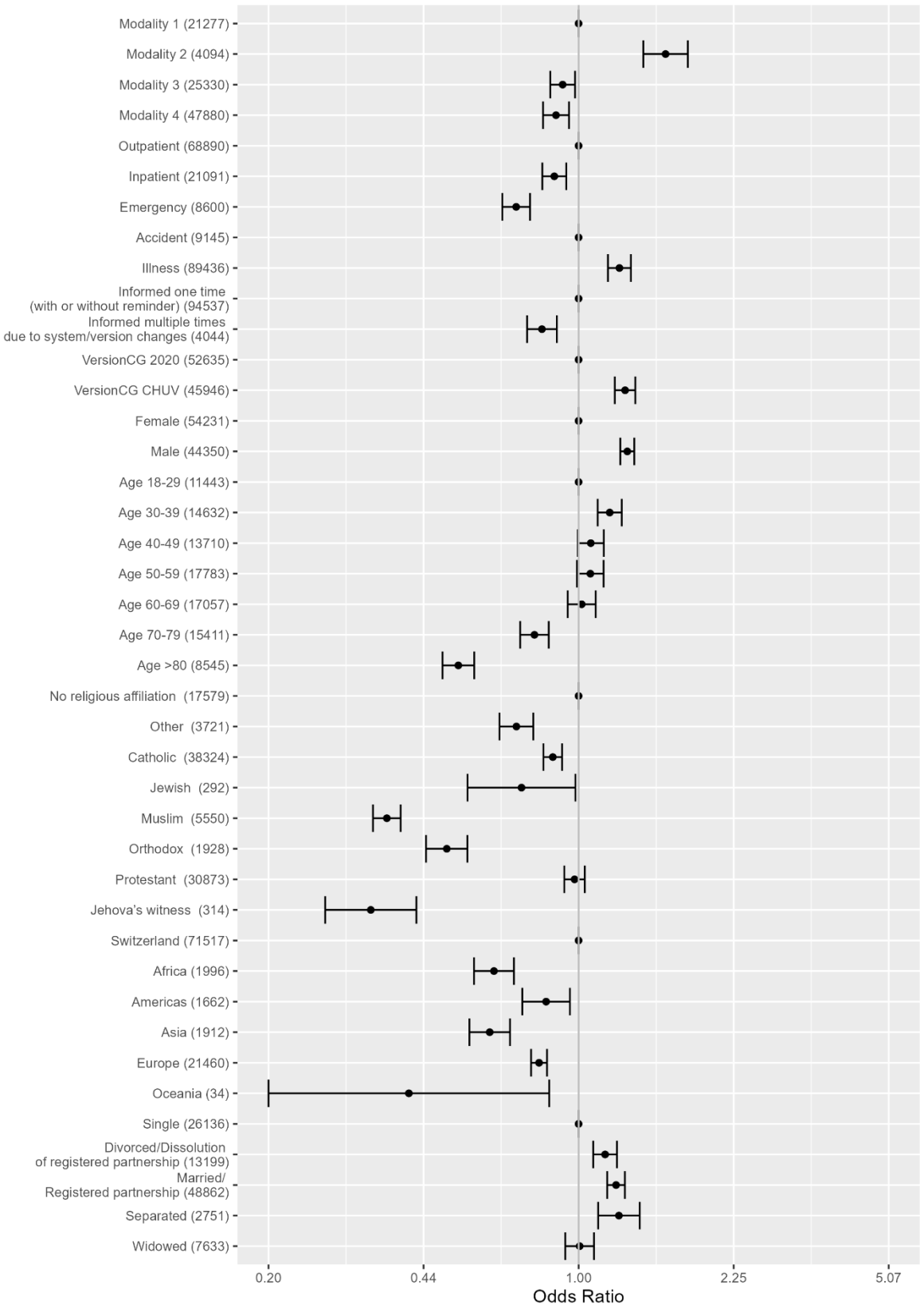
Modality 3: Information by mail prior to visit/hospitalization, with or without reminder letter,

Modality 4: Information by mail after visit/hospitalization, with or without reminder letter.

A.


Modality 1 (21859)
Modality 2 (4118)
Modality 3 (34913)
Modality 4 (84766)
Outpatient (101656)
Inpatient (25038)
Emergency (18962)
Accident (16536)
Illness (129120)
Informed one time (with or without reminder) (135964)
Informed multiple times due to system/version changes (9692)
VersionCG 2020 (93463)
VersionCG CHUV (52193)
Female (80374)
Male (65282)
Age 18-29 (22139)
Age 30-39 (24449)
Age 40-49 (21585)
Age 50-59 (25300)
Age 60-69 (21950)
Age 70-79 (19043)
Age >80 (11190)
No religious affiliation (27337)
Other (6300)
Catholic (56228)
Jewish (450)
Muslim (11425)
Orthodox (3406)
Protestant (40066)
Jehova's witness (444)
Switzerland (97987)
Africa (4519)
Americas (3251)
Asia (3840)
Europe (36003)
Oceania (56)
Single (45147)
Divorced/Dissolution of registered partnership (18561)
Married/ Registered partnership (67674)
Separated (4358)
Widowed (9916)
0.07
0.26
1.00
3.83
14.66
Odds Ratio

B.


Modality 1 (21277)
Modality 2 (4094)
Modality 3 (25330)
Modality 4 (47880)
Outpatient (68890)
Inpatient (21091)
Emergency (8600)
Accident (9145)
Illness (89436)
Informed one time (with or without reminder) (94537)
Informed multiple times due to system/version changes (4044)
VersionCG 2020 (52635)
VersionCG CHUV (45946)
Female (54231)
Male (44350)
Age 18-29 (11443)
Age 30-39 (14632)
Age 40-49 (13710)
Age 50-59 (17783)
Age 60-69 (17057)
Age 70-79 (15411)
Age >80 (8545)
No religious affiliation (17579)
Other (3721)
Catholic (38324)
Jewish (292)
Muslim (5550)
Orthodox (1928)
Protestant (30873)
Jehova's witness (314)
Switzerland (71517)
Africa (1996)
Americas (1662)
Asia (1912)
Europe (21460)
Oceania (34)
Single (26136)
Divorced/Dissolution of registered partnership (13199)
Married/ Registered partnership (48862)
Separated (2751)
Widowed (7633)
0.20
0.44
1.00
2.25
5.07
Odds Ratio

Supplementary Table 3: *Logistic regression of response rate among informed patients.* Odds ratios, 95% confidence interval lower bounds (cinf) and 95% confidence interval upper bounds (csup) are described. Number in brackets represent the total number of patients within each category.

Variable	odds	cinf	csup
Modality 1 (21859)	1.00	1.00	1.00
Modality 2 (4118)	4.44	2.93	6.74
Modality 3 (34913)	0.12	0.11	0.14
Modality 4 (84766)	0.07	0.07	0.08
Outpatient (101656)	1.00	1.00	1.00
Inpatient (25038)	1.10	1.03	1.16
Emergency (18962)	0.87	0.82	0.92
Accident (16536)	1.00	1.00	1.00
Illness (129120)	1.23	1.17	1.28
Informed one time (with or without reminder) (135964)	1.00	1.00	1.00
Informed multiple times due to system/version changes (9692)	0.41	0.39	0.43
GC version 2020 (93463)	1.00	1.00	1.00
GC version CHUV (52193)	1.76	1.70	1.83
Female (80374)	1.00	1.00	1.00
Male (65282)	0.90	0.88	0.93
Age 18-29 (22139)	1.00	1.00	1.00
Age 30-39 (24449)	1.33	1.28	1.39
Age 40-49 (21585)	1.41	1.34	1.48
Age 50-59 (25300)	1.67	1.59	1.76
Age 60-69 (21950)	2.02	1.92	2.14
Age 70-79 (19043)	2.20	2.08	2.33
Age >80 (11190)	1.64	1.53	1.76
No religious affiliation (27337)	1.00	1.00	1.00
Other (6300)	0.79	0.75	0.85
Catholic (56228)	0.87	0.84	0.90
Jewish (450)	0.65	0.53	0.81
Muslim (11425)	0.54	0.52	0.57
Orthodox (3406)	0.67	0.62	0.73
Protestant (40066)	1.01	0.97	1.05
Jehovah's witness (444)	0.88	0.70	1.11
Switzerland (97987)	1.00	1.00	1.00
Africa (4519)	0.47	0.44	0.51
Americas (3251)	0.47	0.43	0.50
Asia (3840)	0.58	0.54	0.63
Europe (36003)	0.66	0.64	0.68
Oceania (56)	0.57	0.31	1.05
Single (45147)	1.00	1.00	1.00
Divorced/Dissolution of registered partnership (18561)	0.98	0.94	1.03
Married/Registered partnership (67674)	1.26	1.22	1.30
Separated (4358)	0.84	0.78	0.91
Widowed (9916)	0.96	0.90	1.03

Supplementary Table 4: *Logistic regression of consent rate among responders.* Odds ratios, 95% confidence interval lower bounds (cinf) and 95% confidence interval upper bounds (csup) are described. Number in brackets represent the total number of patients within each category.

Variable	odds	cinf	csup
Modality 1 (21277)	1.00	1.00	1.00
Modality 2 (4094)	1.58	1.40	1.77
Modality 3 (25330)	0.92	0.86	0.98
Modality 4 (47880)	0.89	0.83	0.95
Outpatient (68890)	1.00	1.00	1.00
Inpatient (21091)	0.88	0.83	0.94
Emergency (8600)	0.72	0.67	0.78
Accident (9145)	1.00	1.00	1.00
Illness (89436)	1.24	1.17	1.32
Informed one time (with or without reminder) (94537)	1.00	1.00	1.00
Informed multiple times due to system/version changes (4044)	0.83	0.76	0.89
GC version 2020 (52635)	1.00	1.00	1.00
GC version CHUV (45946)	1.28	1.21	1.35
Female (54231)	1.00	1.00	1.00
Male (44350)	1.29	1.24	1.34
Age 18-29 (11443)	1.00	1.00	1.00
Age 30-39 (14632)	1.18	1.11	1.25
Age 40-49 (13710)	1.07	1.00	1.14
Age 50-59 (17783)	1.06	0.99	1.14
Age 60-69 (17057)	1.02	0.94	1.09
Age 70-79 (15411)	0.79	0.74	0.86
Age >80 (8545)	0.53	0.49	0.58
No religious affiliation (17579)	1.00	1.00	1.00
Other (3721)	0.72	0.66	0.79
Catholic (38324)	0.87	0.83	0.92
Jewish (292)	0.74	0.56	0.98
Muslim (5550)	0.37	0.34	0.39
Orthodox (1928)	0.50	0.45	0.56
Protestant (30873)	0.98	0.93	1.03
Jehovah's witness (314)	0.34	0.27	0.43
Switzerland (71517)	1.00	1.00	1.00
Africa (1996)	0.64	0.58	0.71
Americas (1662)	0.84	0.74	0.96
Asia (1912)	0.63	0.56	0.70
Europe (21460)	0.81	0.78	0.85
Oceania (34)	0.41	0.20	0.86
Single (26136)	1.00	1.00	1.00
Divorced/Dissolution of registered partnership (13199)	1.15	1.08	1.22
Married/Registered partnership (48862)	1.22	1.16	1.27
Separated (2751)	1.24	1.11	1.38
Widowed (7633)	1.01	0.93	1.08

***Supplementary Table 5**: Responses to the questionnaire*

–	**Overall respondents**
I authorize that clinical data and biological samples collected during my care are made available to researchers (Q9).	
1 – I haven't understood	13 (0.6%)
2	10 (0.4%)
3	19 (0.8%)
4	82 (3.5%)
5 – I understood	2197 (94.7%)
Missing	124
My decision concerns data and samples collected in the past and the future (Q10).	
1 – I haven't understood	39 (1.7%)
2	25 (1.1%)
3	68 (3%)
4	114 (5%)
5 – I understood	2054 (89.3%)
Missing	145
My data and samples can be used in studies conducted at CHUV or in collaboration with public or private institutions (Q14).	
1 – I haven't understood	39 (1.7%)
2	25 (1.1%)
3	75 (3.3%)
4	120 (5.2%)
5 – I understood	2031 (88.7%)
Missing	155
Data and samples can be transmitted to investigators in Switzerland or abroad, if the same level of data protection is ensured (Q15).	
1 – I haven't understood	44 (1.9%)
2	29 (1.3%)
3	70 (3.1%)
4	121 (5.3%)
5 – I understood	2022 (88.5%)

Missing	159
The investigators that receive data and samples won't know my identity (Q16).	
1 – I haven't understood	19 (0.8%)
2	11 (0.5%)
3	25 (1.1%)
4	78 (3.4%)
5 – I understood	2159 (94.2%)
Missing	153
I might be recontacted if results relevant for my health are discovered. At that time I could decide whether I would like to learn more about these results (Q17).	
1 – I haven't understood	28 (1.2%)
2	17 (0.7%)
3	38 (1.7%)
4	92 (4%)
5 – I understood	2112 (92.3%)
Missing	158
My decision is valid for an unlimited time period, but I can change my mind at any time (Q18).	
1 – I haven't understood	19 (0.8%)
2	9 (0.4%)
3	23 (1%)
4	66 (2.9%)
5 – I understood	2177 (94.9%)
Missing	151
I can revoke my consent any time, without giving a reason (Q19).	
1 – I haven't understood	21 (0.9%)
2	7 (0.3%)
3	22 (1%)
4	54 (2.4%)
5 – I understood	2184 (95.5%)
Missing	157
If I don't want my data and samples to be reused for research purposes, I can refuse point A of the general consent (Q20).	
1 – I haven't understood	24 (1.1%)

2	4 (0.2%)
3	21 (0.9%)
4	59 (2.7%)
5 – I understood	2107 (95.1%)
Missing	230
If I refuse secondary use of my data and samples for research purposes, this will not have any consequence on the care received at CHUV (Q21).	
1 – I haven't understood	20 (0.9%)
2	6 (0.3%)
3	14 (0.6%)
4	53 (2.4%)
5 – I understood	2121 (95.8%)
Missing	231
If I do not fill in the consent form, the law authorizes on an exceptional basis that my data and samples may be used, if the competent ethics committee grants special autorisation (Q22).	
1 – I haven't understood	44 (2%)
2	23 (1%)
3	58 (2.6%)
4	89 (4%)
5 – I understood	1991 (90.3%)
Missing	240
If I have questions about general consent, I can call the hotline and/or look at the website and/or discuss with a medical doctor/nurse during my visit (Q23).	
1– I haven't understood	16 (0.7%)
2	6 (0.3%)
3	25 (1.1%)
4	73 (3.3%)
5 – I understood	2100 (94.6%)
Missing	225
How do you rate the layout and presentation of the information leaflet and GC declaration? (Q24)	
1 – Not clear at all	13 (0.6%)
2	10 (0.4%)
3	13 (0.6%)

4	25 (1.1%)
5	44 (1.9%)
6	57 (2.5%)
7	115 (5%)
8	340 (14.7%)
9	324 (14%)
10 – Perfectly clear	1374 (59.4%)
Missing	130
How do you rate the understanding of information and GC declaration content? (Q25)	
1 – Not understandable	10 (0.4%)
2	10 (0.4%)
3	12 (0.5%)
4	21 (0.9%)
5	54 (2.3%)
6	38 (1.6%)
7	103 (4.5%)
8	317 (13.7%)
9	365 (15.8%)
10 – Perfectly understandable	1378 (59.7%)
Missing	137
Is any information missing from the information leaflet and GC declaration? (Q26)	
No	2137 (93.1%)
Yes	158 (6.9%)
Missing	150
Were the received documents sufficient to make your decision? (Q28)	
No, I needed to clarify some aspects using other information supports	132 (5.6%)
Yes	2241 (94.4%)
Missing	72
If no, specify: hotline	
Unchecked	123 (93.2%)
Checked	9 (46.8%)

If no, specify: e-mail at info.cg@chuv.ch	
Unchecked	125 (94.7%)
Checked	7 (5.3%)
If no, specify: website	
Unchecked	114 (96.3%)
Checked	18 (13.6%)
If no, specify: I spoke with a close relative	
Unchecked	72 (54.5%)
Checked	60 (45.4%)
If no, specify: I spoke with a MD/nurse	
Unchecked	105 (79.5%)
Checked	27 (20.5%)
If no, specify: other	
Unchecked	115(87.1%)
Checked	17 (12.9%)
How would you prefer to be informed about GC? (Q29)	
GC documents, website, hotline and email are sufficient	1677 (73.3%)
An oral information would be appreciated	611 (26.7%)
Missing	157
An oral information by a nurse	
Unchecked	569 (74.1%)
Checked	199 (25.9%)
Missing	1677
An oral information by a medical doctor	
Unchecked	475 (61.8%)
Checked	293 (38.2%)
Missing	1677
An oral information by a collaborator of the admission desk	
Unchecked	658 (85.7%)

Checked	110 (14.3%)
Missing	1677
An oral information by a collaborator of the GC dedicated team	
Unchecked	564 (73.4%)
Checked	204 (26.6%)
Missing	1677
An oral information by others	
Unchecked	722 (94%)
Have you been worried about some information concerning GC (Q31)	
No	2149 (91.4%)
Yes	203 (8.6%)
Missing	93
Is contributing to research important to you? (Q34)	
1 – No at all	28 (1.2%)
2	6 (0.3%)
3	11 (0.5%)
4	14 (0.6%)
5	75 (3.2%)
6	41 (1.8%)
7	79 (3.4%)
8	213 (9.2%)
9	180 (7.8%)
10 – It is essential	1675 (72.1%)
Missing	123
How did you receive GC documents? (Q7)	
By post, BEFORE visit	436 (21.4%)
By post, AFTER visit	1492 (73.4%)
By MD/nurse DURING visit	32 (1.6%)
Admission desk	1 (0%)
Other	51 (2.5%)
Several	21 (1%)
Missing	412
How did you fill in/do you want to fill in GC documents? (Q8)	

A: Yes/ B:Yes	1435 (76.3%)
A: Yes/ B:No	283 (15.1%)
A: No/ B:No	129 (6.9%)
I don't think to fill in the GC form	8 (0.4%)
I don't know	25 (1.3%)
Missing	565
How do you prefer to consent? (Q30)	
In writing	1830 (81.2%)
Orally	369 (16.4%)
Without preference	54 (2.4%)
Missing	192
Was the moment when you received GC information appropriate? (Q32)	
1 – Not appropriate	57 (2.5%)
2	28 (1.2%)
3	58 (2.5%)
4	42 (1.8%)
5	123 (5.4%)
6	107 (4.7%)
7	96 (4.2%)
8	215 (9.4%)
9	190 (8.3%)
10 - Appropriate	1367 (59.9%)
Missing	162
What would have been the best moment for you to receive information about GC? (Q33)	
Before my visit/hospitalization	482 (24.5%)
During my visit/hospitalization	654 (33.3%)
After my visit/hospitalization	586 (29.8%)
Other	100 (5.1%)
several	143 (7.3%)
Missing	480
What's your overall satisfaction rate concerning the GC information received? (Q35)	
1 – Not satisfactory	11 (0.5%)

2	2 (0.1%)
3	12 (0.5%)
4	12 (0.5%)
5	60 (2.6%)
6	68 (2.9%)
7	113 (4.9%)
8	339 (14.6%)
9	444 (19.1%)
10 – Very satisfactory	1261 (54.3%)
Missing	123

Some questions were omitted in the table since they concerned administrative aspects (1-6), were referring to the CHUV genomic biobank (11-13) or were collecting free text comments (27 and 36).

***Supplementary Table 6**: GC status of questionnaire recipients and declared GC status of questionnaires respondents*

	Questionnaire Recipients			**Questionnaire Respondents**		
	Response on general consent form			Response to Q8* of the questionnaire		
	N	% of total	% of return decision	N	% of total	% of consistent answer
AGREED general consent	4750	34%	75%	1718	70%	93%
REFUSED general consent	1548	11%	25%	129	5%	7%
Did not return consent form[a]	7500	54%				
Don't know/Don't intend to answer[b]				41	2%	
Missing/No answer selected[c]				404	17%	
Incoherent responses[c]				153	6%	
Total	13798	100%	100%	2445	100%	100%

**Q8: How did you fill in/do you think to fill in GC form?*

[a] This answer could not be evaluated in the questionnaire. As the questionnaire was anonymous it was not possible to determine if a questionnaire respondent sent back their GC form.
[b] This answer in the questionnaire is considered as equivalent to a non-response to GC
[c] These answers concern only the questionnaire. Missing or incoherent responses to GC form were not registered in the database which contains only the final response.

Supplementary Document 1: *Questionnaire*

Have you received the documentation on broad consent? **Tell us what you think.**

We are currently running a study with the aim of producing recommendations to improve our broad consent documentation, so that it meets patients' needs and expectations as closely as possible.

Your opinion is valuable and will help us to improve the understanding and the presentation of our documentation, as well as how we provide information.

How can I share my views?

Once you have familiarised yourself with the broad consent form and the accompanying information, please complete the questionnaire below, which is in three parts:

1. Your personal details.
2. Your understanding of the essential elements of broad consent.
3. Your needs and expectations about the content, format and distribution of the broad consent documentation.

You can choose whether to share your views:

Online (available in French only)

Scan the 2D bar code or visit the page
www.chuv.ch/enquete-cg

In writing

Complete the attached questionnaire and place it in the "Questionnaire anonyme" envelope. Seal the envelope and fold it in two. Then place it in the postage-paid envelope. Add your declaration of consent (or not), at your discretion, and post the envelope back to us.

The questionnaire is anonymous. It will not be possible for us to link your answers to your identity. All answers will be entered into a secure database hosted by CHUV.

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1/6

Your personal details

1. Are you

☐ Male ☐ Female ☐ Other

2. How old are you? _____

3. What is your mother tongue?

☐ French ☐ German ☐ Italian ☐ English ☐ Spanish ☐ Portuguese

☐ Other. Please give details: _____

4. How would you assess your understanding of English?

Not good at all 1 2 3 4 5 6 7 8 9 10 Excellent

5. Are you

☐ A patient

☐ A friend or relative. Please give details: _____

☐ Other. Please give details: _____

6. What is your highest level of qualification?

☐ Compulsory schooling

☐ CFC (Federal Certificate of Competence)

☐ Maturité (secondary school diploma)

☐ Federal certificate or diploma, ES (specialist school)

☐ HES (University of Applied Sciences), University, EPF (Federal Institute of Technology)

☐ Other. Please give details: _____

7. How did you receive the documentation on broad consent?

☐ By post before my stay in hospital/consultation

☐ By post after my stay in hospital/consultation

☐ From a doctor/other health professional when I was in hospital

☐ From the counter in the central reception area at CHUV

☐ Other. Please give details: _____

8. How did you complete/are planning to complete the broad consent form?

☐ YES to the reuse of my data/samples (point A) and YES to contributing to the Genomic Biobank (point B)

☐ YES to the reuse of my data/samples (point A) and NO to contributing to the Genomic Biobank (point B)

☐ NO to the reuse of my data/samples (point A) and NO to contributing to the Genomic Biobank (point B)

☐ I am not intending to return my completed declaration of consent

Please explain why: _____

☐ I don't know

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Your understanding of broad consent

By answering YES to point A of the broad consent form:	I didn't understand				I understood
9. I give permission for the medical data and biological samples collected during my care to be made available to researchers.	1	2	3	4	5
10. This includes my data and/or samples collected in the past and in the future.	1	2	3	4	5

By answering YES to point B of the broad consent form:	I didn't understand				I understood
11. I give permission for a blood sample to be collected for the CHUV Genomic Biobank (BGC).	1	2	3	4	5
12. My blood sample will allow the BGC to carry out genetic analyses for research.	1	2	3	4	5
13. No other collection of additional samples/data will be authorised apart from the sample collected for the CHUV Genomic Biobank.	1	2	3	4	5

By answering YES to points A and B, or only point A of the broad consent form:	I didn't understand				I understood
14. My data/samples can be used in studies conducted at CHUV or in partnership with **public or private** institutions.	1	2	3	4	5
15. Data and samples can be sent to researchers **in Switzerland and abroad** if the same level of data protection is guaranteed.	1	2	3	4	5
16. The researchers who access my data and samples will not know my identity.	1	2	3	4	5
17. I may be contacted again if any results relevant to my health are found. At that point, I will be able to decide if I want to know more.	1	2	3	4	5
18. My decisions are valid indefinitely but I can change my mind at any time.	1	2	3	4	5
19. I may withdraw my consent at any time, without having to give a reason.	1	2	3	4	5
20. If I don't want my data and samples to be used for research purposes, I can answer 'no' to point A of the declaration of consent form.	1	2	3	4	5
21. If I do not agree to my data and samples being reused for research or to contribute to the BGC, there will not be any consequences for the care I receive at CHUV.	1	2	3	4	5

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22. If I do not return my declaration of consent, the law provides that my samples and data can be used for research on an exceptional basis, subject to the approval of the relevant ethics committee	1	2	3	4	5
23. If I have any questions about broad consent, I can phone the hotline and/or check the broad consent (CG) website and/or discuss my concerns with a doctor/other health care professional when I visit CHUV.	1	2	3	4	5

Your needs and expectations about the content, format and distribution of the broad consent form

The questions below will help you assess the information leaflet, the declaration of consent form and the ways in which the broad consent form is distributed.

24. How clear is the layout and presentation of the information leaflet and declaration of consent form? (organisation of text, font size, format, etc.)

Not clear at all 1 2 3 4 5 6 7 8 9 10 Completely clear

25. How easy is it to understand the content of the information leaflet and declaration of consent form? (choice of vocabulary, simplicity of sentences, etc.)

Not easy to understand at all 1 2 3 4 5 6 7 8 9 10 Completely understandable

26. In your opinion, is there any information missing in the information leaflet and declaration of consent form?

YES ☐ NO ☐

If **YES**, what:

_____

_____

27. Do you have any suggestions to make our documentation clearer and easier to understand?

_____

_____

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28. Were the documents you received enough for you to make a decision?

☐ Yes

☐ No, I felt the need to clarify certain points with help from other sources (multiple answers allowed):

- ☐ Hotline
- ☐ E-mail to info.cg@chuv.ch
- ☐ Broad consent website
- ☐ I discussed it with a friend or relative. Please give details: _____
- ☐ I discussed it with a doctor or other health care professional.
  Please give details: _____
- ☐ Other. Please give details: _____

29. How do you think information about broad consent should be provided?

☐ The printed documents and website along with the hotline/email address are sufficient

☐ An oral presentation would be appreciated

If applicable, state who you think should provide this information:

- ☐ A nurse
- ☐ A doctor
- ☐ A member of staff from admissions
- ☐ A member of the team responsible for broad consent
- ☐ Other. Please give details: _____

Why?

_____

_____

30. Would you prefer to authorise the reuse of your data:

☐ in writing, by confirming your agreement in a document that you sign

☐ orally, by confirming your agreement to the professional who has provided you with the information. He or she will then record your decision in your file. You will therefore not sign any document

31. Have you been worried by any information regarding broad consent for research?

YES ☐ NO ☐

If **YES**, please give details:

_____

_____

32. Do you think that the point at which you received the broad consent form was:

Not at all appropriate 1 2 3 4 5 6 7 8 9 10 Appropriate

33. What would have been the best time for you to receive information on broad consent?

- ☐ Before my stay/consultation at CHUV
- ☐ During my stay/consultation at CHUV
- ☐ After my stay/consultation at CHUV
- ☐ Other. Please give details: _____

Why?

_____

_____

34. Is contributing to research important to you?

Not at all 1 2 3 4 5 6 7 8 9 10 It's essential

Why?

_____

_____

35. What overall satisfaction score would you give to the information received about broad consent as a whole?

Unsatisfactory 1 2 3 4 5 6 7 8 9 10 Very satisfactory

36. Do you have any general suggestions that would help us improve how we inform patients about broad consent?

_____

_____

If you would like to explore these questions in more detail in an individual telephone interview or focus group, you can contact us on 021 314 18 78 (Monday to Thursday from 8.00 to 12.00 and 13.00 to 16.00) or by email at info.cg@chuv.ch

Thank you for taking part!

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Supplementary Document 2: *Interview guide*

Entretiens avec personnes informées non-positionnées

Critères de sélection

- Ont reçu les 2 courriers CG (1er envoi et rappel) et min. 8 - max. 20 semaines se sont écoulées depuis le 1er envoi
- Diversité âge et genre
- Diversité modalité de réception du courrier (avant/après visite à l'hôpital)

Prise de contact

1. SMS
2. Puis appel téléphonique

SMS :

Bonjour/Bonsoir,

Je m'appelle |xxx| et je suis |chargée de recherche| au sein de l'unité du consentement à la recherche du Centre hospitalier universitaire vaudois (CHUV).

Le CHUV vous a récemment envoyé des documents relatifs au consentement général pour la recherche. Vous n'avez pas encore répondu. Les raisons pour lesquelles vous ne l'avez pas fait et votre point de vue nous intéressent en vue d'améliorer notre processus et le taux de réponse.

Auriez-vous un peu de temps à m'accorder pour un entretien de 30 minutes ? J'essaierai de vous téléphoner le X (j) à X (h). Si cet horaire ne vous convient pas, n'hésitez pas à répondre à cet sms ou à m'écrire par email : | xx.xxx @chuv.ch | pour me faire part de vos disponibilités.

Répondeur :

Bonjour Madame, Monsieur, X,

C'est xxx, chargée de recherche à l'Unité de consentement à la recherche du Centre hospitalier universitaire vaudois (CHUV). Je vous ai envoyé un SMS vendredi pour vous annoncer mon appel. Si vous aviez un moment plus tard, n'hésitez pas à me rappeler au xx xx xxx ou à m'envoyer un SMS et je vous rappellerai selon vos disponibilités. Une belle journée.

TELEPHONE :

Suite SMS (éléments à développer lors du premier appel téléphonique)

Bonjour Madame, Monsieur, X,

C'est |xxx|chargée de recherche| au sein de l'unité du consentement à la recherche du Centre hospitalier universitaire vaudois. Je vous ai envoyé un SMS vendredi pour annoncer mon appel. Auriez-vous un peu de temps à me consacrer maintenant pour vous expliquer ma démarche ?

Si NON :

Convenir d'un autre moment.

Si OUI :

Le CHUV vous a récemment envoyé des documents relatifs au consentement général pour la recherche. Vous n'avez pas encore répondu. Vous n'avez peut-être pas trouvé le temps d'y répondre, ou peut-être avez-vous été dérangé.e par un aspect de ce consentement. Votre point de vue et les raisons pour lesquelles vous n'avez pas répondu nous intéressent afin de nous améliorer.

En tant que chargée de recherche au sein de l'équipe de l'unité du consentement à la recherche, mon rôle est celui d'une chercheuse. Je ne suis pas personnellement impliquée dans les activités opérationnelles de l'unité et n'y ai pas d'enjeu. Mon objectif est de comprendre les raisons pour lesquelles les patients ne se positionnent pas sur le consentement, afin d'identifier si cela est lié au processus ou à la forme du consentement lui-même qui pourrait alors être amélioré OU si le non-positionnement des patients est le résultat d'une autre problématique.

En l'absence de prise de position, le cadre légal suisse prévoit que les échantillons et les données recueillis dans le cadre de soins peuvent être utilisés dans le cadre de la recherche. Il tient cependant à cœur à l'unité que chaque personne qui reçoit la demande de consentement général puisse prendre position afin que sa volonté soit respectée.

C'est dans ce contexte que je souhaiterais vous rencontrer pour un entretien d'au maximum 30 minutes pour discuter autour du consentement général, de son processus et de sa documentation. Je serais heureuse de me déplacer et de vous rencontrer en personne ou, si cela vous convient mieux, de vous rencontrer par vidéoconférence ou d'en parler par téléphone.

Seriez-vous d'accord de participer à cet entretien ?

Si NON :

Je vous remercie pour le temps que vous m'avez accordé et vous souhaite une très bonne journée.

Si OUI : planifier un rendez-vous ou, si demandé, mener l'entretien directement.

Guide d'entretien :

Merci pour votre temps / d'avoir accepté de me rencontrer (de me parler) aujourd'hui.

J'ai préparé quelques questions pour guider notre échange. Vous êtes libre de ne pas répondre à l'une ou l'autre des questions. Vous pouvez également demander à interrompre l'entretien à tout moment. Mes questions ne sont ni des jugements ni des reproches. Vos réponses nous permettront de nous améliorer.

Je souhaiterais enregistrer l'entretien afin de ne pas avoir à prendre trop de notes et de pouvoir mieux me concentrer sur notre échange. Si vous acceptez, je retranscrirai l'entretien et rendrai son contenu anonyme, puis je détruirai l'enregistrement. Aucune information ne pourra être mise en relation avec votre identité ou avec votre suivi médical.

Par ailleurs, si vous le souhaitez, vous pourrez relire la transcription de notre entretien.

Est-ce que vous acceptez que notre entretien soit enregistré ?

Si NON :

Pas de problème. Je vais prendre des notes pendant notre discussion.

Si OUI :

Merci, je vais débuter l'enregistrement maintenant.

Comme mentionné, je souhaiterais discuter avec vous du consentement général qui vous a été envoyé et de vos idées à ce sujet.

Avant que je ne vous appelle, vous n'aviez pas répondu ou pas encore répondu à ce consentement.

Environ **40** % des patient.e.s qui reçoivent le consentement général n'y répondent pas.

Seriez-vous d'accord de me parler des raisons qui vous ont retenu-e de renvoyer le consentement général ?

|SI LA PERSONNE NE DÉVELOPPE PAS APRÈS LA PREMIÈRE QUESTION :|Est-ce la modalité d'information par courrier qui n'était pas, n'est pas, la bonne pour vous ? Ou est-ce le moment choisi pour envoyer la documentation qui n'était pas approprié ? Peut-être est-ce le sujet, la recherche, qui ne vous a pas parlé ? Ou, si vous avez eu l'occasion de consulter la documentation relative au consentement, c'est peut-être cette documentation qui vous a découragé, sa forme, ses contenus ou son volume ?

Lancer quelques pistes mais après, laisser parler l'enquêté-e #

Chemin faisant, aborder :

- **Modalité :**
  - Quelle modalité aurait été préférable de votre point de vue ? Une présentation orale, par exemple, lors d'une visite au CHUV ou...

- **Moment :**
  - Quand auriez-vous souhaité recevoir le consentement général ?
  - Qu'avez-vous ressenti lorsque vous avez reçu le courrier du consentement général ? (Inquiétude, agacement, étonnement…)
- **Documentation :**
  - Avez-vous eu l'occasion de consulter et/ou d'examiner la documentation associée au consentement général ?
  - Qu'en avez-vous pensé ?
  - Qu'avez-vous pensé de sa forme (par exemple longueur texte, mise en page) ou de son contenu (clarté du vocabulaire, points délicats) ?
  - Certains éléments de cette documentation vous ont-ils laissé perplexe, préoccupé, ou ennuyé ?
  - Avez-vous des suggestions pour améliorer cette documentation ?
- **Rapport à la recherche :**
  - Quelle est votre point de vue, en général, sur la recherche ? Avez-vous eu une expérience personnelle ou avez-vous un vécu avec la recherche ?
- **Rapport au CHUV** :
  - Quel est votre point de vue, en général, sur le CHUV, son personnel, votre prise en charge ?
- **Mesures d'accompagnement :**
  - Avez-vous des recommandations nous permettant d'améliorer notre démarche et mieux familiariser les patientes et patients du CHUV au sujet du consentement général ?

Avant que nous terminions l'entretien, y a-t-il quelque chose que vous aimeriez savoir ou ajouter à ce que nous avons discuté ensemble ?

Je vous remercie pour cet échange, cela nous est très utile. Je vais maintenant arrêter l'enregistrement.

[Si le/la participant-e continue à parler du consentement général, possibilité de demander de redémarrer l'enregistrement pour capturer les informations importantes]

N'hésitez pas à nous contacter si vous avez des questions par rapport à l'étude. Vous pouvez me joindre directement à /xx.xxx@chuv.ch/ou au /xx xx xx/.

Merci pour votre participation et votre temps. Je vous souhaite une belle suite de journée.

[*Fin de l'entretien*]

/La personne parle-t-elle couramment/bien le français ou l'échange en français est-il difficile ? La personne parle-t-elle un peu d'elle-même ? Voir pour en savoir plus sur sa formation/dernier diplôme, mais pas nécessaire/

Supplementary Document 3: *GC information and consent form for adult patients (English version)*

Participation in research

Information on the use of health data and samples for research purposes and general consent to research

Our ability to diagnose and treat diseases has made considerable progress over recent decades. This has been made possible thanks to the continued efforts of medical research, in which several generations of doctors, scientists and patients have played an active part.

A significant proportion of this research relies on the use of patients' clinical data found in medical files, such as the results of laboratory analyses, medical treatments or genetic predispositions. Any biological material (such as blood, urine or tissue samples) collected during a stay in hospital and which is no longer needed for the patient's care can also be extremely valuable for research purposes.

This document explains how you can contribute to medical progress. It also explains how we protect your data and your rights.

Thank you for your interest and attention.

How can you contribute to research?

You can make a contribution to research by agreeing that your data and biological samples that are no longer needed can be stored, passed on and reused for research purposes. Data and samples include those that have been collected in the past. They also include any that are collected for your care during current and future stays and consultations at CHUV.

Your consent is voluntary.

It remains in effect for an indefinite period, or until you withdraw it. You may withdraw your consent at any time, without having to give a reason. To do so, you simply need to inform the Research Consent Unit at the address shown on the back of this document.

If you decide not to particpate in research by ticking "NO" for statement A, your clinical data and biological samples cannot be used for research.

If you do not sign the consent form, i.e. if you do not respond, the law provides that samples and data can be used for research on an exceptional basis subject to authorisation from the relevant ethics committee. It is therefore important for you to make your wishes clear.

Your decision will not have any effect on your medical treatment.

CHUV 2021 | 5 2379

What happens if you withdraw your consent?

If you withdraw your consent, your data and samples kept for research will be destroyed, subject to legal requirements. They will no longer be available for new research projects. This does not apply to data and samples that have already been used.

How are your health data and biological samples protected?

Data are stored at the hospital and protected in accordance with the legal requirements in effect1. Only authorised hospital staff, such as the doctors in charge of your care, have access to your data and samples in a way that identifies you.

Your biological samples are stored in biobanks. This ensures that your samples are managed correctly and linked to the data contained in your medical file. Samples and data may be used for a variety of purposes, including research. They are subject to safety and quality standards (www.chuv.ch/consentement-general).

If your data and samples are used for a research project, they are coded or anonymised.

- The term "coded" means that any personal information (for example, your name or date of birth) is replaced by a code. The key that indicates which code corresponds to which individual is kept in complete safety by a person who is not involved in the research project. People who do not have access to the coding key are not able to identify you.

- The term "anonymised" means that the link between the biological material or associated data and the individual is permanently broken. According to the law, data are deemed to be anonymised when they cannot be linked to a particular person without excessive effort. In principle, it is no longer possible to identify the person concerned, though absolute anonymisation cannot be guaranteed. Once the data and samples have been anonymised, it is impossible to prevent their use, even if the person concerned withdraws their consent. It will also not be possible to inform them of any research results that may be relevant to their health. Similarly, anonymised samples or data are not destroyed if consent is withdrawn.

The majority of research projects use coded data, particularly if they might produce results that would be relevant for the health of the people concerned.

You have the same rights to data protection in relation to research as you do for your care, in particular, the right to access your personal information.

Who can use your health data and samples?

Data and samples can be used by researchers who have been granted authorisation by the relevant Research Ethics Committee. Research projects are carried out in the hospital or in conjunction with other public institutions (such as other hospitals or universities) and private entities (such as pharmaceutical companies) in Switzerland or abroad.

Projects may include genetic analyses for research purposes.

Data or samples can only be sent abroad for research purposes if the data protection conditions in the destination country are at least as stringent as those applied in Switzerland.

CHUV 2021 | 52379

* In particular, the Federal Act on Research involving Human Beings and data protection legislation.

Will you be informed of research results?

In principle, the research carried out using your samples and data will not reveal any individual information about your health. In rare cases, however, relevant results may be discovered, for which treatments or preventive actions are available. In this case, you would be informed. If you do not wish to receive such information, please contact the Research Consent Unit at CHUV, at the address indicated at the end of this document.

Will your participation involve any financial costs or benefits?

Your participation will not involve any additional costs for you or your insurance company. The law does not allow any commercial use of data or samples. There will therefore not be any financial benefit for you or the hospital.

The Genomic Biobank at CHUV (BGC) is a collection of blood samples donated by patients on a voluntary basis.

It was specially created to conduct genetic analyses for research purposes. The BGC links genetic data with the data in patients' medical files. This is a leading resource for carrying out research on developing new treatments and preventive measures.

If you answered "YES" for the reuse of your data and samples in statement **A**, please tell us whether you are also willing to contribute to the BGC by responding to statement **B**.

What does this mean for you in practical terms?

If you consent to contribute to the BGC, a 7.5 ml sample of blood may be taken. If possible, this will be done at the same time as a blood sample needed for your care, to avoid another needle prick. The blood sample is only taken once, even if you stay in the hospital on more than one occasion.

Your decision will not have any effect on your medical treatment.

Where are samples kept?

Samples are coded and stored safely in dedicated freezers at CHUV. The conditions governing access to the samples, their use and transmission are described in the biobank regulations, which can be found on the website indicated on the back of this document.

What happens if you withdraw your consent?

If you withdraw your consent, the blood sample collected specifically for the BGC is destroyed.

Is there a charge for the additional sample for the BGC?

No, there is never a charge for samples or analyses carried out for research purposes. They do not involve any additional costs for you or your insurance company.

CHUV 2021 | 5 2329

You can let us know your decision by completing and signing the consent form.

The consent form is in three sections:

- **A** Please complete your last name, first name and date of birth, and then indicate whether or not you agree to the use of your health data and samples for research purposes.
- **B** If you agree to the use of your health data and samples for research purposes (i.e. you have answered "YES" to statement A), please indicate whether or not you also wish to contribute to CHUV's Genomic Biobank.
- **C** Sign and date the form to confirm your decision.

Once you have completed the consent form, please return it to us at the address shown on the back of this document.

If you have any questions or if you wish to withdraw your consent, please don't hesitate to contact us.

By post:
CHUV-Département de la formation et recherche
Unité consentement général
Boîte aux lettres N°47
Rue du Bugnon 21
1011 Lausanne
info.cg@chuv.ch

By phone:
021 314 18 78
Mon-Fri 07:30-12:00 and 13:00-16:00

Further information
www.chuv.ch/consentement-general

CHUV 2021 | 5 2379

Consent form for use of health data and samples for research purposes

Last name and first name | Date of birth

A I consent to my health data and unused biological samples collected during care (outpatient consultations and hospital stays) being kept, passed on and used for research purposes.

☐ YES ☐ NO

If you ticked "YES", please respond to statement B. If you ticked "NO", please go directly to point C.

B I agree to donate an additional blood sample of 7.5 ml to CHUV's Genomic Biobank for genetic analyses for research purposes.

- An additional blood sample of 7.5 ml may be taken during my care at CHUV.
- This sample will be used to carry out genetic analyses for research purposes.

☐ YES ☐ NO

However you respond, please go to point C.

C Confirmation of my decision

I have understood:

- the explanations about the use of my clinical data and biological samples for research purposes, as detailed in the information leaflet;
- that I am free to contact the Research Consent Unit at CHUV using the details shown at the bottom of this form, or a health professional with responsibility for my care at CHUV, if I require any further information or explanations;
- that my personal data are protected and will only be used for research in a coded or anonymised form;
- that my data and biological samples may be used in national and international research projects, in the public and private sectors;
- that projects may include genetic analyses of my samples for research purposes;
- that I may be contacted again if any results relevant to my health are found;
- that my decision is voluntary and has no effect on my medical treatment;
- that my decision is valid for an unlimited period, unless I withdraw my consent;
- that I may withdraw my consent at any time, without having to give a reason;
- that if I tick "NO" for statement A when signing the form, my clinical data and biological samples cannot be used for research purposes;
- that if I do not sign the consent form (no response), the law provides that my data and samples may be used on an exceptional basis if the relevant ethics committee grants special authorisation.

Place and date

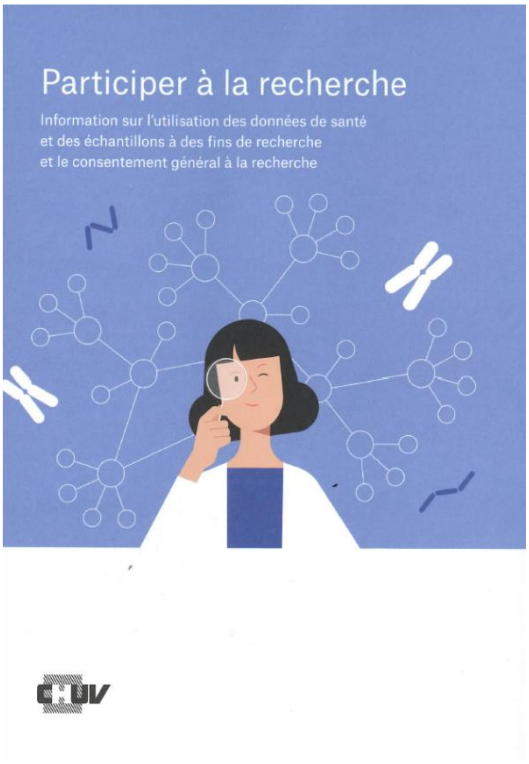
Patient's signature

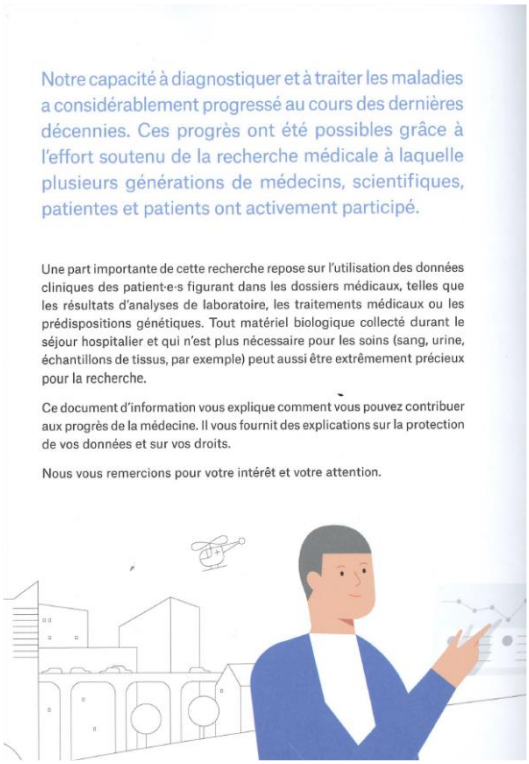
Please do not hesitate to contact us if you have any questions or comments.

Unité du consentement à la recherche
Rue du Bugnon 21, 1011 Lausanne
021 314 18 78 - info.cg@chuv.ch

CHUV V2.3 du 15 mars 2021

Supplementary Document 4: *GC information leaflet for adult patients (French version)*





Comment pouvez-vous contribuer à la recherche?

Vous pouvez contribuer à la recherche en acceptant que vos données et échantillons biologiques résiduels soient conservés, transmis et réutilisés à des fins de recherche. Les données et échantillons incluent ceux qui ont été collectés par le passé. Ils comprennent aussi ceux qui seront collectés pour vos soins durant vos séjours et consultations au CHUV, actuels et futurs.

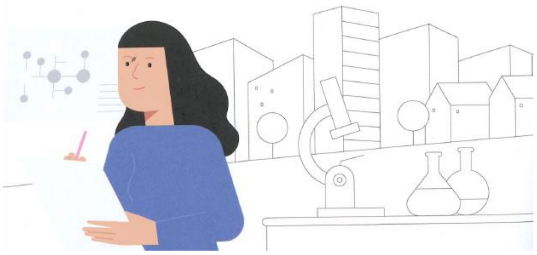
Votre consentement est volontaire.

Il reste valable pour une durée indéfinie ou jusqu'à un éventuel retrait. Vous pouvez retirer votre consentement en tout temps sans avoir à justifier votre décision. Pour cela, il suffit que vous en informiez l'Unité du consentement à la recherche à l'adresse indiquée au dos de ce document.

Si vous décidez de ne pas participer à la recherche en cochant «NON» au point A, vos données cliniques et échantillons biologiques ne pourront pas être utilisés pour la recherche.

Si vous ne signez pas le formulaire de consentement, c'est-à-dire en cas d'absence de réponse de votre part, la loi prévoit que les échantillons et données peuvent être utilisés à titre exceptionnel pour la recherche après autorisation par la commission d'éthique compétente. Il est donc important pour vous d'exprimer votre choix.

Votre décision n'a aucun effet sur votre traitement médical.



Que se passe-t-il si vous retirez votre consentement?

Dans ce cas, vos données et échantillons destinés à la recherche sont détruits, sous réserve des exigences légales. Ils ne sont dès lors plus disponibles pour de nouveaux projets de recherche. Cela ne concerne pas les données et les échantillons déjà utilisés.

Comment vos données de santé et vos échantillons biologiques sont-ils protégés?

Les données sont enregistrées à l'hôpital et protégées dans le respect des exigences légales en vigueur*. Seuls les collaborateurs autorisés de l'hôpital, des médecins en charge de vos soins par exemple, ont accès à vos données et échantillons sous forme identifiée.

Vos échantillons biologiques sont stockés dans des biobanques. Celles-ci assurent la bonne gestion des échantillons et leur lien avec les données contenues dans votre dossier médical. Ces échantillons et ces données peuvent être utilisés à des fins différentes, dont la recherche. Elles sont soumises à des normes de sécurité et de qualité (www.chuv.ch/consentement-general).

Si vos données et échantillons sont utilisés pour un projet de recherche, ils sont codés ou anonymisés.

- Le terme «codé» signifie que toutes les informations personnelles (par exemple votre nom ou votre date de naissance) sont remplacées par un code. La clé qui permet de savoir quel code correspond à quel individu est conservée en toute sécurité par une personne qui n'est pas impliquée dans le projet de recherche. Les personnes qui ne possèdent pas la clé de codage ne sont pas en mesure de vous identifier.
- Le terme «anonymisé» signifie que le lien entre le matériel biologique ou les données associées et l'individu est définitivement rompu. Selon la loi, des données sont dites anonymisées lorsqu'elles ne peuvent être mises en relation avec une personne déterminée sans engager des efforts démesurés.

* En particulier la loi sur la recherche sur l'être humain et la législation sur la protection des données.

En principe, il n'est plus possible d'identifier la personne concernée, même si une anonymisation absolue ne peut pas être garantie. Une fois les données et les échantillons anonymisés, leur utilisation ne peut pas être empêchée au cas où la personne concernée retire son consentement. Elle ne peut pas non plus être informée des éventuels résultats de recherche pertinents pour sa santé. De même, les échantillons ou données anonymisés ne sont pas détruits en cas de retrait du consentement.

La majorité des projets de recherche utilisent des données codées, en particulier lorsqu'ils peuvent générer des résultats pertinents pour la santé des personnes concernées.

Les droits relatifs à la protection de vos données dans le cadre de la recherche sont les mêmes que dans le cadre des soins, notamment le droit d'accéder à vos données personnelles.

Qui peut utiliser vos données de santé et échantillons?

Les données et échantillons peuvent être utilisés par des chercheurs·euses ayant reçu une autorisation de la commission d'éthique de la recherche compétente. Les projets de recherche sont menés dans l'hôpital ou en collaboration avec d'autres institutions publiques (d'autres hôpitaux ou universités, par exemple) et des entités privées (des compagnies pharmaceutiques, par exemple) en Suisse ou à l'étranger.

Les projets peuvent inclure des analyses génétiques à des fins de recherche.

La transmission de données ou d'échantillons à l'étranger à des fins de recherche n'est possible que si les conditions de protection des données dans le pays de destination sont au moins équivalentes à celles appliquées en Suisse.

Serez-vous informé.e des résultats de recherche?

La recherche menée avec vos échantillons et données ne révélera en principe aucune information individuelle pour votre santé. Dans de rares cas, il pourrait toutefois arriver que des résultats pertinents soient découverts, pour lesquels des traitements ou des actions de prévention sont disponibles. Dans ce cas, vous en seriez informé·e. Si vous ne souhaitez pas recevoir une telle information, veuillez contacter l'Unité du consentement à la recherche du CHUV à l'adresse indiquée à la fin de ce document.

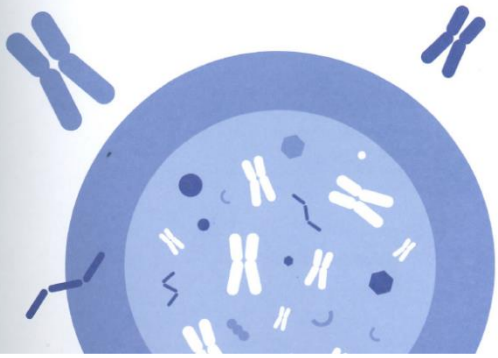
Votre participation engendre-t-elle des frais ou des bénéfices financiers?

Votre participation n'engendre aucuns frais supplémentaires pour vous ou votre assurance. La loi exclut la commercialisation des données et des échantillons. Ainsi, aucun avantage financier ne sera généré pour vous ou pour l'hôpital.

La Biobanque génomique du CHUV (BGC) est une collection d'échantillons de sang de patientes et patients volontaires.

Elle a été constituée spécialement pour effectuer des analyses génétiques à des fins de recherche. La BGC permet d'associer les données génétiques avec les données du dossier médical. C'est une ressource de premier ordre pour réaliser des recherches en vue de nouvelles thérapies et de mesures préventives.

Si vous avez répondu «OUI» pour la réutilisation de vos données et échantillons à la proposition **A**, merci de nous dire si vous acceptez de contribuer également à la BGC en répondant à la proposition **B**.



Concrètement qu'est-ce que cela implique pour vous?

Si vous consentez à participer à la BGC, un échantillon de 7,5 mL de sang pourra être prélevé. Le prélèvement sera réalisé si possible lors d'une prise de sang déjà prévue pour vos soins, afin de ne pas impliquer de piqûre supplémentaire. Le prélèvement de sang est effectué une seule fois, même en cas de séjours répétés.

Votre décision n'a aucun effet sur votre traitement médical.

Où les échantillons sont-ils conservés?

Ces échantillons sont conservés sous forme codée et sécurisée dans des congélateurs dédiés du CHUV. Les conditions d'accès aux échantillons, de leur utilisation et de leur transmission sont décrites dans le règlement de la Biobanque qui peut être consulté sur le site internet indiqué au dos de ce document.

Que se passe-t-il si vous retirez votre consentement?

Si vous retirez votre consentement, l'échantillon de sang spécifiquement collecté pour la BGC est détruit.

Le prélèvement supplémentaire pour la BGC est-il facturé?

Non, ce prélèvement et les analyses effectuées pour la recherche ne sont en aucun cas facturés. Ils n'entraînent aucuns frais pour vous ou votre assurance.

Vous pouvez nous communiquer votre décision en remplissant et en signant la déclaration de consentement.

La déclaration de consentement comprend trois étapes:

A Après avoir noté vos nom, prénom et date de naissance, indiquez si vous acceptez ou refusez l'utilisation de vos données de santé et échantillons à des fins de recherche.

B Si vous avez accepté l'utilisation de vos données de santé et échantillons à des fins de recherche (réponse «OUI» à la proposition **A**), indiquez si vous souhaitez ou non contribuer en plus à la Biobanque génomique du CHUV.

C Signez et datez la déclaration, afin de confirmer votre décision.

Lorsque vous avez complété la déclaration de consentement, vous pouvez nous la faire parvenir en la renvoyant à l'adresse indiquée au dos de ce document.

Si vous avez des questions ou si vous souhaitez retirer votre consentement, n'hésitez pas à nous contacter

Par courrier:
CHUV-Département de la formation et de la recherche
Unité du consentement à la recherche
Boîte aux lettres N° 47
Rue du Bugnon 21
1011 Lausanne
info.cg@chuv.ch

Par téléphone:
021 314 18 78
Lu-ve 7h30-12h et 13-16h

Informations complémentaires

www.chuv.ch/consentement-general

CHUV 10903 | Juin 2021