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Willingness to share anonymised routinely collected clinical health data in Switzerland: a cross-sectional survey

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Summary

AIMS OF THE SURVEY: Routinely collected health data (or real-world data) from hospitals is becoming increasingly important to advance medical progress. Anonymisation of these data facilitates data sharing processes. This allows stakeholders of the healthcare system to compliantly access this anonymised data to address epidemiological questions, advance precision medicine, support drug development or address other medical needs. As the willingness of the general Swiss population to share anonymised health data has been uncertain, a survey was conducted to better understand their perception of sharing such data for research purposes. The present survey focused on the re-use (secondary use) of hospital-derived health data in anonymised form.

METHODS: A cross-sectional survey was conducted in a representative random sample (n = 1006) of the general Swiss population. The general population was contacted by phone between 14 September and 3 October 2020. The survey was also conducted in an additional population with chronic disease (n = 225) via an online panel. An independent research organisation (gfs-zürich) was commissioned to conduct the survey. The survey participation was anonymous and voluntary. The demographic composition of the interviewed participants from the general population was specifically constructed to be representative of the 18+-year-old French- and German-speaking population of Switzerland, according to the quota features gender, age and language region. Representativeness of the chronic disease population is unclear.

RESULTS: 71% of the general population and 81% of the chronic disease group reported that they would share their anonymised health data for medical research. The drivers were mainly of an altruistic nature. Hurdles concern mainly data protection issues, potential misuse or disadvantages, e.g., by health insurers. About 56% of the general population would like to be better informed about the use of their personal health data, and 69% spontaneously reported health authorities as the stakeholder responsible for providing such information.

CONCLUSIONS: The survey showed that the Swiss population is willing to share anonymised health data given that some key concerns are addressed. Our findings underline that a better understanding of the standards and processes around health data privacy and transparent data usage is important to build trust in the public eye. An open dialogue is required to develop a common consent on data governance for Switzerland, which would allow health data sharing with third parties. This open dialogue should involve all stakeholders of the healthcare system, so as to strive towards both a more personalised and a more sustainable Swiss healthcare system.

Introduction

Routinely collected health data reflect the “real world” and are often referred to as real-world data; yet there is no uniform definition of the term "real-world data". According to the major regulatory bodies US Food and Drug Administration (FDA) and European Medicines Agency (EMA), real-world data are defined as data relating to a patient's health status and deriving from sources reflecting the real-world setting [1, 2]. Real-world data play an important role in driving medical advances and innovation, as well as in the realisation of precision medicine to increase clinical benefit for patients. Additionally, real-world data are pertinent to ascertain efficient and sustainable healthcare systems. Possible sources of real-world data include: electronic health records; health insurance data; disease registries; patient-generated data (e.g. collected through mobile devices such as health trackers) or health insurance data [1, 2]. The present manuscript focuses on routinely collected health data collected in hospitals; hospitals own the richest health data resources to address a large variety of health-related questions. Hence, the present survey focused on the re-use (secondary data use) of these hospital derived data in anonymised form. For the sake of clarity in this manuscript, routinely collected clinical data will be called “health data”.

Substantial progress in the digitalisation of healthcare has resulted in a vast amount of health data, which is continuously generated every day [3]. Nonetheless, most of these

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data remain "siloed" within the respective healthcare institutions with limited or no access for medical research [4, 5]. Of the numerous healthcare system stakeholders, only a few have access to routinely collected health data. Nevertheless, health data has become increasingly important for third parties such as governmental bodies or stakeholders from the private sector. The reasons why third parties need access to health data are either for research purposes or to make informed decisions. Examples here include addressing epidemiological questions (e.g., National Cancer Registry [6] or the COVID-19 pandemic), advancing personalised medicine, drug development, assessing safety and supporting evidence for submission to health authorities [2]. For these purposes, health data of individual patients (patient-level data) are of substantial importance, and the data should be anonymised as third parties have neither the right nor the interest in re-identifying individual patients.

To bring the role of anonymised health data into the right context within the Swiss setting, it is important to understand the different steps towards anonymisation. In figure 1, we describe a simplified data flow-example from routinely collected health data to anonymized data, which then can be shared with third parties:

- Step 1: at the healthcare institution where patients are treated, the patient is informed about the further use of her/his routinely collected health data and the right to object ("Widerspruchsrecht"); finally, the patient signs an informed consent form, for example, the Swiss general consent form ("Generalkonsent" [7]).
- Step 2: to re-use (also called secondary-data use) the routine collected health data (e.g., to address a research question), patient-level data are then usually transferred to a centralised database within the same healthcare institution or an associated research institution (e.g., registry), where the data are pseudonymised (coded/encrypted). Coding enables the continuous (longitudinal) feed of new patient data to centralised databases. Consequently, these data can be considered identifiable as a "decryption key" is available.
- Step 3: an additional anonymisation step of the database can then take place (e.g., when study data collection is completed) and would, by enhancing data protection, allow broader sharing with third parties. The correct process of anonymisation makes the re-identification of patients practically impossible unless disproportionate effort is applied.

The simplified dataflow described in figure 1 does not display technical requirements or any data governance features, but it is in accordance with the Swiss legal framework when anonymising health data. The Swiss data protection regulations and the legal architecture that defines the process of handling health data is complex. However, recent activities by Swissethics and Unimedsuisse (harmonisation of the general consent form [7]), a new Swiss cancer registration act ("Krebsregistrierungsgesetz"; KRG [6]) and the Swiss Personalised Health Network (SPHN) initiative [8, 9] have brought further clarity on how to process routinely collected health data for secondary data use, including anonymisation. The harmonised version of the Swiss general consent covers all requirements (it informs about data collection, right to object, re-use of the data in coded/encrypted or anonymised form), allowing routinely collected data to be re-used for research or to be anonymised for sharing with third parties [7]. The recently introduced Swiss cancer registration act (KRG) has contributed to the importance of the anonymisation process as its accompanying documents define, to some extent, the requirements for anonymisation of health data and the importance of making data from the national registry available for research [10]. For more details about the legal framework in Switzerland, the complexity of the data protection laws and the relevant *lex specialis* has been summarised comprehensively in a recently published article in *Swiss Medical Weekly* [11]. From an ethical perspective, health data sharing with private entities is possible, if a list of requirements are met according to the recently published Swiss guidance. If these requirements are fulfilled to address community needs, data sharing between public and private entities is ethical [12]. This is a good starting point to make anonymised data available for third parties.

It is important to understand that the technical requirements for anonymisation are not regulated under Swiss law. Compared with the United States, where according to Health Information Portability and Accountability Act (HIPAA) principles as alternative to an expert determination [13], a list of eighteen predefined variables have to be removed so that the data are considered as anonymised. The situation in Switzerland is not as clear and therefore data users are accountable for ensuring an anonymisation process considering all means reasonably likely to be used to preserve data privacy at all times. Since the technical requirements are not defined in the Swiss law, this room for interpretation remains contentious and leads to ambiguity and controversy. The complexity of the concept of anonymisation has been comprehensively described elsewhere for the Swiss [11] and the European contexts [14, 15].

Establishing a sustainable data ecosystem requires the acceptance and willingness of each individual to share health data [16]. In other words, data sharing in Switzerland starts with the permission of the patient. Whether routinely collected health data can be systematically collected for research and be anonymised depends on the patient's decision in the first step of the above-mentioned dataflow (figure 1). Therefore, it is important to understand the drivers and potential barriers influencing their willingness to share their health data. A recently published Swiss Survey by Brall et al. found that over 53% of the Swiss citizens would agree to participate in a personalised health research project [17]. This extensive and well-conducted survey generated valuable insight into sharing health data for use in personalised health research projects in the clinical trial setting. Neither the routine care setting nor anonymisation was addressed by Brall et al., and hence it does not cover the above-mentioned third step of the data flow (figure 1)

Objective of the survey

The willingness to share anonymised health data of the general Swiss population is unclear. Therefore, Roche (Pharma) Switzerland Ltd commissioned an independent research organisation, gfs-zürich, to conduct a survey among the general Swiss population and patients with a chronic disease in Switzerland to assess the current national standing of patient and public opinion towards sharing anonymised patient-level data for medical research with a variety of healthcare system stakeholders.

Materials and methods

Population

This survey focused on two populations in Switzerland, the general, adult (≥18 years) population (sample 1) and patients with a chronic disease (sample 2). For sample 1, the sample size calculations were based on the usual assumptions of gfs-zürich. Based on the typically used quotas gender, age and language region in Switzerland, 1000 interviews were conducted to assure that at least 30 interviews are contained in the smallest cell (in Switzerland: woman 50% X French-speaking 26% X older 64 years 23% = 3%). Above the number of 30 interviews the response behaviour is considered to change to a normal distribution. The resulting theoretical precision of a sample size of n = 1006 corresponds to an error margin of ±3.2% by confidence level of 95%. Eighty percent of sample 1 were randomly drawn from the publicly available telephone directory (landlines) of the German- and French-speaking parts of Switzerland. Another 20% of the sample were contacted on their mobile telephone numbers via random digit dialing. The survey of the sample of the general population was conducted from 14 September to 3 October 2020. The demographic composition of the sample was specifically constructed to be representative of the 18+-year-old French- and German-speaking population of Switzerland according to the predefined quota features: gender, age and language region. This survey was not conducted in the Italian-speaking (around 4% of the total population [19]) and Rhaeto-Romanic (around 0.5% [20]) parts of Switzerland because of resource restraints. The educational level was categorised as high (university or university of applied science), medium (final secondary school examination, higher vocational training) and low (mandatory school).

Sample 2 of chronic disease patients (cancer, multiple sclerosis, arthrosis, eye diseases or chronic back pain) were drawn from a Swiss online panel (Bilendi GmbH, Berlin, Germany). The number of available patients defined the sample size, where 225 patients and a confidence level of 95% resulted in an error margin of ±6.7%. Patients with cancer or multiple sclerosis were contacted first and preferentially included. The survey was conducted online from 15 to 28 September 2020. Subgroup analyses of the survey responses were performed only for the patients with cancer, multiple sclerosis and arthrosis owing to the limited size of the groups with eye diseases or back pain.

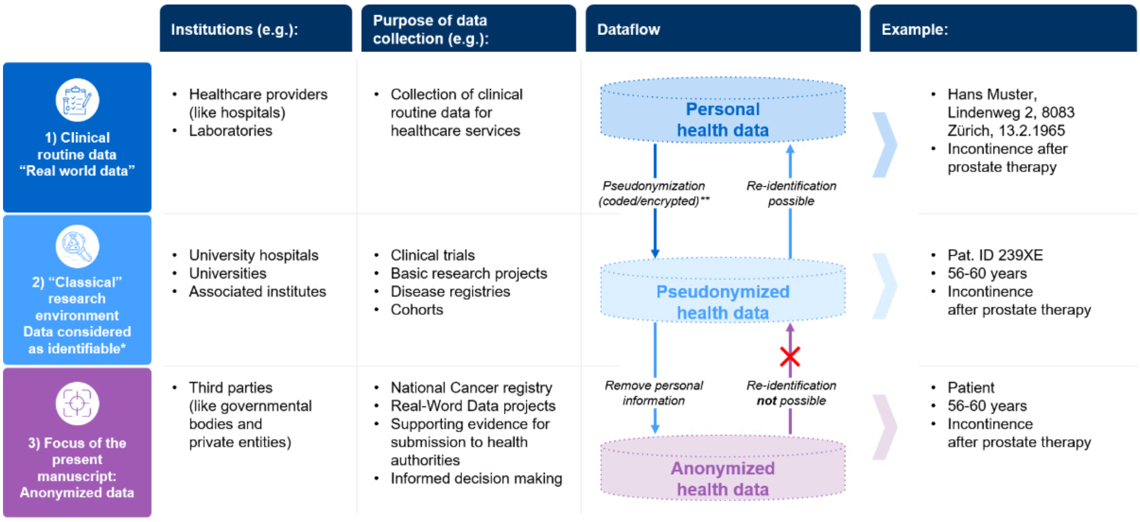
Questionnaire

The questionnaire consisted of 10 questions about data sharing, covering aspects of potential willingness to share anonymised health data and potential barriers that prevent data being shared, based on the scenario of a hospital visit including a request by the hospital for anonymised data for medical research. Two questions assessed the importance of trust in data collecting institutions and the preferred institution to inform on the topic of handling health data. Seven questions were closed-ended questions (four with five-point Likert scales, two with binary options and one to choose a statement out of four). Information on demographic details included age, gender, education level and purchasing power. Questions about drivers and barriers on sharing anonymised health data were first formulated as open-ended questions to receive an unbiased response on potential drivers and barriers, followed by two closed-ended questions to assess the agreement with preselected answer options describing potential drivers and barriers. The sample of the general population was asked whether they or someone close to them are affected by a chronic disease, and if so how. The questionnaire is available in the pdf version of the article.

Interviews

The surveys were conducted by gfs-zürich, Markt- und Sozialforschung (Zurich, Switzerland). The questions were

Figure 1: Dataflow: from personal to anonymised health data. Abbreviation: PHC, personalised healthcare.



	Institutions (e.g.):	Purpose of data collection (e.g.):	Dataflow	Example:
1) Clinical routine data "Real world data"	Healthcare providers (like hospitals) Laboratories	Collection of clinical routine data for healthcare services	Personal health data Pseudonymization (coded/encrypted)** Re-identification possible	Hans Muster, Lindenweg 2, 8083 Zürich, 13.2.1965 Incontinence after prostate therapy
2) "Classical" research environment Data considered as identifiable*	University hospitals Universities Associated institutes	Clinical trials Basic research projects Disease registries Cohorts	Pseudonymized health data Remove personal information Re-identification *not* possible	Pat. ID 239XE 56-60 years Incontinence after prostate therapy
3) Focus of the present manuscript: Anonymized data	Third parties (like governmental bodies and private entities)	National Cancer registry Real-Word Data projects Supporting evidence for submission to health authorities Informed decision making	Anonymized health data	Patient 56-60 years Incontinence after prostate therapy

* Patient could be directly or indirectly (via for example with decryption key) identified
** Preconditions: patient is informed about the further use of her/his health data, the right to object and with signed informed consent
Abbreviations: e.g., exempli gratia "for example"; Pat. ID, patient identifier.

designed to take a maximum of 13 minutes, worded in lay language (German and French for the two language regions, respectively), pre-tested with five volunteers and, if needed, adapted prior to starting the survey. The questions were developed in German and translated into French by a professional translation office. The English version was generated to complement this manuscript and it was not used for the survey. The German, French and English versions of the questionnaire are available in the pdf version of the article.

The telephone interviews were conducted by professional and experienced interviewers, trained for interview research. All interviewers received specific instruction for the present survey. They were using a professional software for telephone interviews, ensuring consistent questioning as well as the correct usage of filters and randomisation of questions and items. At least one supervisor was constantly present for quality control. Additionally, randomly selected audio records (10% of all telephone surveys) were checked for correct execution and transcription of the call. When interviewer mistakes were found, all interviews of this interviewer were checked. For quality reasons, in sample 2 online surveys that were completed in less than one third of the median time for completion (so called “speeders”) were discarded.

Analyses

Answers to open-ended questions were categorised using a verbatim-based codeplan. Results of open-ended and closed-ended questions were summarised descriptively (n, %, mean) and graphically (bar-charts), stratified by predefined subgroups (age group, gender, education level, language region) (IBM SPSS statistics software, IBM, NY, USA). Means of subgroups were compared using an independent t-test or chi-square test, and a Bonferroni correction was applied for multiple testing. Assessment of correlations between the willingness to share anonymised health data and different variables was done by Pearson’s bivariate analysis with r-values of ±0.3 to 0.5 suggesting a moderate correlation.

Ethics

The underlying survey does not fall under the regulations of the Swiss Human Research Act, hence this survey was not submitted to an ethics committee and no written informed consent was collected. Before the interview was started, the respondents were informed verbally that their participation is voluntary and anonymous, and that the survey is about “handling of personal data”. The respondents of the online panel were informed accordingly in the invitation, which was sent via email. No incentives were offered to the respondents of the telephone interviews for their participation.

Results

Survey participants, sample description and demographics

In total, 1006 surveys of participants from the general Swiss population and 225 surveys from patients with a chronic disease were evaluable and analysed. The general population interviewed was representative of the French- and German-speaking Swiss population, that is, structurally identical or with a very similar distribution of age groups, gender and regional distribution (table 1, full overview of demographic data in supplementary material 1 in the appendix). Among the patients with a chronic disease, the representativeness for the individual chronic diseases was not investigated. The total number of randomly dialed phone numbers, non-responders, occupied sign, individuals who refused until the final number of participants is reported in supplementary material 2 in the appendix.

Willingness to share data about their person

The first question explored the participants’ willingness to share any data about their person (not limited to personal or anonymised health data). Among the four ranking options that ranged from keeping data as secret as possible to happy sharing data, 73% of the general population tended to be rather cautious when sharing their data about their person (combining the two categories “I don’t like my data being collected and therefore keep it as secret as possible” and “I don’t like it when my data are collected, but sometimes I am forced to give it.” in figure 2A. More detailed results are presented in supplementary material 3 in the appendix). Younger participants (18–39 years) and those from the German-speaking regions were more willing to share their data than the others. Among patients with chronic diseases, 35% tended to be rather cautious when sharing data about their person (supplementary material 3 in the appendix).

Table 1:
Demographic characterisation of survey participants.

Population	18–39 y	40–64 y	>64 y	Male	Female	DE	FR
CH total[1]	35%	42%	23%	50%	50%	74%	26%
General Swiss population (N = 1006)	35%	43%	22%	50%	50%	75%	25%
Chronic disease population[2] (N = 225)	21%	49%	30%	43%	57%	67%	33%
– Cancer (n = 85)	8%	52%	40%	41%	59%	58%	42%
– MS (n = 43)	49%	49%	2%	26%	74%	74%	26%
– Arthrosis (n = 56)	9%	57%	34%	48%	52%	71%	29%
– Eye disease (n = 24)	38%	25%	38%	50%	50%	71%	29%
– Back pain (n = 17)	35%	41%	24%	71%	29%	71%	29%

CH: Switzerland; DE: German-speaking part of Switzerland; FR: French-speaking part of Switzerland; MS: multiple sclerosis.

[1] Percentages refer to distribution across the indicated categories and not the entire Swiss population.

[2] Representativeness of patients with a chronic disease is unclear.

The second question assessed the willingness to share health data that were collected during hospital visits in anonymised form for medical research. Seventy-one percent of the general population and 81% of the chronic disease patients expressed a positive attitude to providing their anonymised health data for medical research (fig. 2B). Willingness to share anonymised health data increased with educational level but did not differ substantially between age, gender and purchase power categories (supplementary material 4 in the appendix). Among those who were reluctant or cautiously pragmatic about sharing general personal data, 28% and 40%, respectively, stated full commitment to share anonymised health data for research (supplementary material 5 in the appendix).

The third question assessed the willingness of sharing different types of health data: 74–83% of the general population agreed to potentially share anonymised laboratory values, medical history, biological samples or results of genetic analyses, and of the chronic disease group 81–89% (supplementary material 6 in the appendix).

Identification of potential drivers to share anonymised health data

The willingness to share anonymised health data for medical research was assessed with an open-ended question. Well-intentioned purpose and guaranteed anonymity were most often mentioned (table 2). Further potential drivers that were mentioned addressed trustworthy/transparent institutions and guaranteed data security.

The following closed-ended question assessed the agreement with potential drivers to share anonymized health data (agreement ranged from “1 agree not at all” to “5 fully agree”, fig. 3). In the general population, highest agreement was reported for the drivers “better treatments for others” (86%), and “data protected from misuse” (85%), followed by “decrease in Swiss healthcare costs” (67%) and “knowing the exact research purpose” (64%). Only 9% of the general population agreed that potential direct financial compensation could be a driver. These findings are very similar in the chronic disease groups (supplementary material 7 in the appendix), except for direct financial compensation, where the agreement was higher (37%) in the chronic disease group than in the general population.

Identification of reasons (potential barriers) against sharing anonymized health data

With an open-ended question, the reasons against sharing anonymised health data were investigated. The most frequently mentioned reasons “fear of misuse or unintended use” and “concerns about anonymity” were reported by 26% and 15% of the general population and 13% and 8% of the chronic disease group, respectively (table 2). Other concerns mentioned comprised “general uneasiness”, “data security” and “other reasons”. Thirty percent of the general population were not able to give a reason against sharing anonymised health data for medical research (32% of the chronic disease group; table 2).

Based on the closed-ended questions, the general population reported agreement with the following barriers:

Figure 2: Willingness to share data. A General personal data. B Anonymised health data for medical research. The different categories are presented in percentages.

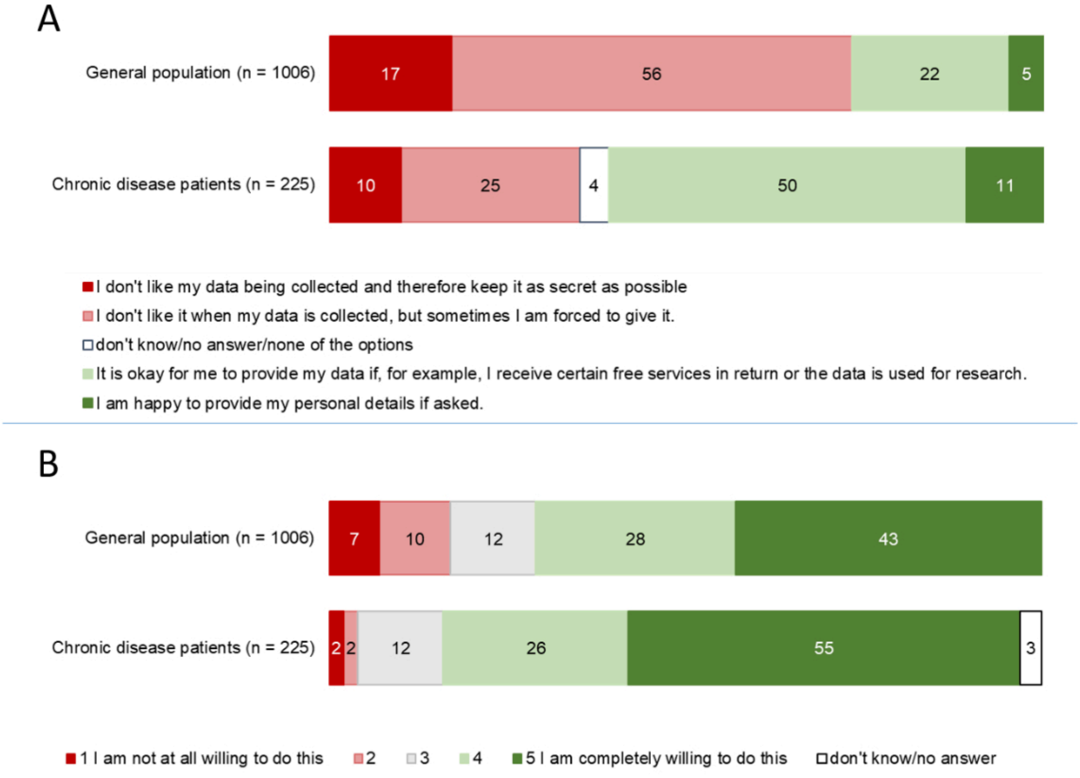


Table 2:
Frequency of requirements mentioned (potential drivers or barriers) affecting the attitude to sharing anonymised data for medical research[1].

	General Swiss population (N = 1006)	**Chronic disease population [2] (N = 225)**
Requirements to share anonymised health data		
Well-intentioned purpose	35%	25%
Anonymity must be guaranteed	30%	20%
Trusted/transparent institutions	17%	9%
Data security must be guaranteed	13%	8%
Personal incentives	3%	5%
Other	4%	6%
Nothing, will not share at all	3%	1%
Nothing, will do anyway	–	5%
Don't know / no answer	19%	41%
Reasons against sharing anonymised health data		
No reasons against	30%	32%
Fear of misuse or unintended use	26%	13%
Concerns about anonymity	15%	8%
Concerns about data security	6%	5%
General uneasiness	11%	4%
Other	6%	7%
Don't know / no answer	19%	40%

[1] Open-ended question, multiple selection possible.

[2] Representativeness is unclear for Swiss population with chronic diseases.

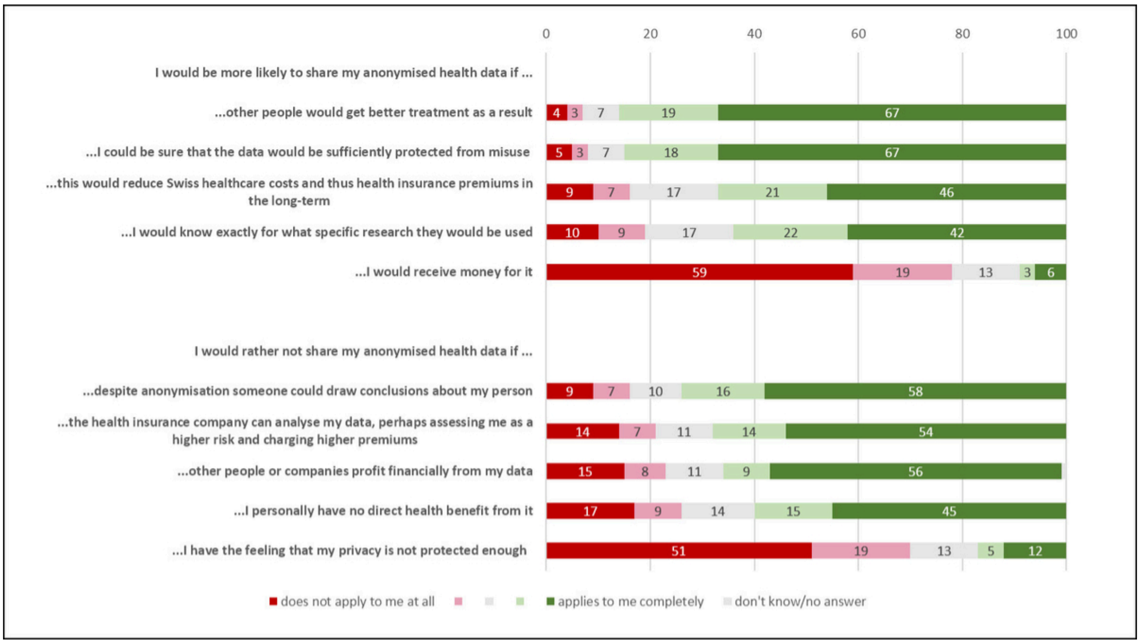
"concerns about privacy" (74%), "potential identification despite anonymization" (68%), "risk of higher health insurance premium" (65%) and "financial benefits for other people/companies" (60%) (figure 3). Only 17% agreed with the barrier "no personal health benefit". The chronic disease group reported similar agreements (supplementary material 7 in the appendix).

Comparisons between gender or age groups did not reveal any noteworthy differences (supplementary material 8 in the appendix).

Trust in institutions using anonymised health data for medical research

With a closed-ended question, participants were asked to rate their trust in institutions using anonymised health data for medical research in the interest of patients. In the general population, trust was highest for hospitals (67%) and universities (66%) and lowest for the health insurance (19%) and pharma sectors (19%). Trust in the Swiss Federal Office of Public Health (FOPH) was 56%. The trust in these institutions was rated higher by the chronic diseases population: 72% for hospitals, 72% for universities, 30% for health insurances and 29% the pharmaceutical sector. Only the Swiss Federal Office of Public Health was rated lower (49%). Trust-ratings were stratified by

Figure 3: Agreement to potential drivers and barriers affecting the willingness to share health data for medical research (general population, N = 1006). The different categories are presented in percentages.



gender and age groups (supplementary material 9 in the appendix).

Information about the handling of health data

The participants were asked (closed-ended question) whether they would like to be better informed about the handling of health data. Fifty-six percent of the general population and 78% of the chronic disease patient group would like to be better informed. The last question (open-ended) assessed who the participants see in charge of informing about the topic; 44% of the general population and 69% of the chronic disease population mentioned government bodies (e.g., FOPH) as being responsible for informing about this topic. Physicians, health insurers and hospitals were mentioned by 8%, 9% and 5%, respectively, of the participants of the general population, and by 18%, 12% and 11%, respectively, of the chronic disease group.

Discussion

The results of this survey show that more than two thirds of the French- and German-speaking Swiss population are willing to share anonymised health data for medical research. The willingness to share anonymised health data was even higher among patients with chronic diseases. The two interviewed populations (the general population and chronic disease patients) responded similarly in most cases and no major deviations were discovered. It is unclear to what extent the chronic disease group is representative for patients with cancer, multiple sclerosis, arthrosis, eye disease or back pain. The tendency of the chronic disease population to marginally higher willingness to share their anonymised health data might be explained by the willingness to participate in online panel surveys, for which the chronic disease patients have subscribed and hence already have a certain openness to share information. Moreover, as a patient, they have already been confronted with this topic in the hospital, be it in relation to a request for study participation or when signing consent forms (such as the Swiss general consent).

From the literature, reported willingness to share health data for research varies from 50% to 90% across western European countries [21–24]. Based on this survey, Switzerland is within this range (71%). Apart from different methodological approaches to conducting the surveys, the willingness to share health data depends on the legal requirements, data protection laws, healthcare system and cultural aspects of the respective countries. Hence, we will focus rather on literature from Switzerland in this discussion. A recent Swiss survey (Brall et al.) assessed the willingness of the general Swiss population to participate in studies on personalised health research with the focus on sharing personal health data (compared with anonymised health data in the present article) [17]. Brall et al. reported that 53.6% of the population were willing to participate in a personalised health research study. Compared with the present survey (71% willing to share their anonymised health data), this is considerably less and cannot be explained by different population characteristics, such as gender, age, education level, etc.. Nevertheless, there are other possible explanations for this discrepancy. First, Brall et al. focused on the clinical research setting and not on the real-world setting like the present survey. Second, the survey by Brall et al. used a different methodological approach (regular mailing with scope and background information, possibility to answer online or on paper, sending out reminders, questions with increased complexity, including the Italian-speaking region) for their investigation. With the letter-based approach, the participants had more time to reflect on their responses compared with telephone interviews, where they had to answer faster and in a more spontaneous way. Third, the survey by Brall et al. was conducted just before the COVID-19 pandemic. Because of the public discussion on lack of digitalisation in healthcare settings or contact tracing during the pandemic, this might have led to an increased acceptance of sharing health data in the present survey. Fourth, the Swiss population differentiates between personal data and anonymised data, wherein the population is more willing to share anonymised health data than personal data (i.e., identifiable data). In this case, anonymisation of data could be considered as a driver to sharing health data. However, the reason for the discrepancy remains unanswered, and future research could assess the potential impact of COVID-19 or anonymisation on the willingness to provide health data. Similarly to Brall et al., the present survey identified population characteristics, such as younger age or higher educational level, to be associated with higher willingness to share data, but in a real world setting.

The present survey showed that the main drivers of the willingness to share anonymised health data are mainly of an altruistic nature, namely “that other people get better treatment”. Only 9% of the participants expected a financial incentive or direct health benefit. The altruistic motivation of the Swiss population is encouraging and supports the current practice of health research where normally no incentives are given to trial participants. A narrative review of publications on attitudes towards the use of health data for research purposes showed similar qualitative results, reporting main drivers for sharing health data such as “sharing for the common good” or “returning own benefits incurred from research” [12]. Although the above-mentioned Swiss survey by Brall et al. did not report on potential drivers, they reported concerns about sharing health data, mainly data protection/security issues and fear of misuse, and hence very similar findings to the present survey. One concern in Brall et al., which stood out, “worried data used to discriminate against me or my family”, is comparable to potential fear from disadvantages by health insurance in the present survey. The concerns identified in the present survey or by Brall et al. have a large overlap with the qualitatively assessed barriers in the narrative review from Kalkman et al. [23]. Kalkman et al. reported the following reasons against sharing anonymised health data: data protection issues, such as data misuse, anonymity and data security. Interestingly, Kalkman reported that lack of public trust in data-sharing activities or lack of trust in data-handling institutions is negatively influencing the willingness to share data, similar to the findings of the present survey.

Data protection and data security concerns of the general Swiss population are understandable, and underline the need for a better public understanding of health data and its usage. This highlights the need for more information or education within the population. Although the legal architecture in Switzerland is complex, the handling of sensitive data (personal health data) and the surrounding accountabilities are sufficiently covered by the different laws and regulations [11]. As mentioned in the introduction, the Swiss legal framework does not define the technical requirement to anonymise data and some people might interpret this as lack of clarity. It is important to understand that anonymisation is a technical instrument and it does not replace data governance or supersede the accountability of the data users [14]. Anonymisation should be considered as part of the data governance. Even if data are anonymised, they should be handled in a securely protected manner to avoid potential re-identification of an individual patient in the future [11, 14, 25].

More than half of the survey participants wished to be better informed about the handling of health data, i.e., to have a better understanding of the appropriate measures taken to protect their personal rights and freedoms as guaranteed by such laws. This knowledge gap could be the reason for the general concerns regarding data protection and security of data. A recent Swiss survey, commissioned by the Swiss Federal Office of Public Health (FOPH), assessed knowledge gaps on the Human Research Act, which became effective in 2014 [21]. This FOPH report revealed that 50–61% of the population would like to know more about legal regulations related to human research. This finding goes in the same direction as our survey assessing whether participants would like to be better informed about the data topic. This raises the question “who is responsible for informing the general public about this topic?"

It was not surprising that in the present survey, the participants clearly see the authorities, i.e., FOPH, to be responsible for educating the Swiss population. This result might be biased because the present survey was conducted during the COVID-19 pandemic (September to October 2020), when the FOPH was proactively informing about current evolutions of the Covid-19 pandemic. After the Swiss authorities, physicians, health insurances and hospitals were frequently mentioned as responsible for informing about health data. As the health data topic becomes increasingly important, the authorities (or other independent bodies) could play a central role to improve the basic knowledge within the general population, which in turn would facilitate the informed consent process of the data-collecting institutions. From the legal perspective, the data-collecting healthcare institutions are obliged to inform the patients if their data is going to be re-used for research [26, 27] and hence the healthcare professionals already play an important role by explaining to their patients consent forms such as the “general consent” for the re-use of health data [28]. To disperse the fears and barriers around data protection issues and potential misuse of health data, informing patients should not be limited to the “data-collecting” institutions, the “data-using” institutions (universities, other third parties, etc) should also inform proactively and transparently about the purpose and their interests in re-using the health data. Consequently, all stakeholders of the healthcare system may play an important role in informing about re-using health data.

The present survey assessed the level of trust in five institutions/stakeholders by asking “how is your trust that this institution uses your anonymized health data for research in the interest of the patients?”. Notably, only two thirds of the general population expressed trust in hospitals or universities, half of the population expressed trust in the Swiss authorities, and less than a fifth trusted in health insurers or the pharmaceutical industry. This low trust in industry has also recently been observed in a survey conducted in The Netherlands and Germany [29]. Trust in an institution correlates with the willingness to share health data (supplementary material 10 in the appendix), hence the lack of trust results in lower willingness to share health data. Transparency is needed to build trust and transparent communication would be an important first step, mainly done by the data-collecting institutions, as explained above, but the other data-using stakeholders of the healthcare system also play an important role. Ideally, the data flow could be displayed from data collection, to coding and anonymisation until final research results. Disclosure of who has access to what data at which time point would increase the trust and decrease the fear of possible data protection issues. Besides the full disclosure of the data flow, the final last step should be to inform the patients about the findings of a research project where they agreed to share their data, as it has been reported by the participants in the survey from Brall et al. [17].

The low level of trust sharing anonymised health data with the pharmaceutical industry shows that the role of the pharmaceutical industry within the healthcare system is not fully understood. Pharmaceutical industry plays an important role in advancing medical research and is the key driver for medical innovation in Switzerland. The pharmaceutical industry needs to raise awareness about its contribution to advancing medical research and how anonymised healthcare data can be used in this context. An open and proactive public engagement is necessary 1) to understand the roles of the different stakeholders in the healthcare data ecosystem and 2) to increase the trust in the general population.

This survey has several strengths. First, the topic of using anonymised health data for medical research has not been investigated yet in Switzerland. Second, the telephone interviews were conducted anonymously, and this was explained to the participants at the beginning of the interview; therefore, it can be expected that the broad concept of anonymisation was understood by most participants. Third, the survey was conducted with short telephone interviews with a simple structure and included open questions allowing spontaneous responses. Fourth, the short and simple structure of the telephone interviews assured the completeness of responses. Fifth, despite their limited representativeness, including a population with chronic diseases provides valuable insights. On the other hand, telephone interviews were time limited, which did not allow to include complex and sophisticated questions. Hence, several topics were not addressed because it was too complicated for the short telephone interviews, including, process of providing informed consent, data governance, exchange of health data between different institutions, willingness to share identifiable (e.g., coded) data vs anonymised data, and different legal theories around anonymisation. Another possible limitation of this survey is that participants who agreed to join a survey might be biased since they tend to be more open to sharing their information than those who refused to participate. This applies also to the sample of chronic disease patients as already mentioned above.

Conclusion

The anonymisation of health data is an important step in unleashing the benefits of a connected healthcare data ecosystem for improved patient care and health system efficiency, and to accelerate data-driven biomedical research and development. Enabling access to health data for third parties, such as the pharmaceutical industry, governmental bodies and others, who usually have no access to routine health data, will be key to ensuring that all stakeholders and ultimately society as a whole can benefit. The present survey showed that the Swiss population is willing to share their anonymised health data, although substantial concerns regarding data protection and security have been raised. To address these concerns, educational efforts to increase understanding and to raise awareness of data sharing and re-use within the general population is needed. Therefore, transparent communication about the use of health data throughout the data journey is crucial. In addition, an ppen dialogue is required to develop a common consent on data governance for Switzerland. This open dialogue should involve all stakeholders of the healthcare system, including patients and third parties such as the pharmaceutical industry. The stakeholders need to declare their interests, needs and preconditions for a fair exchange of value to ultimately foster the trust of the general public towards transparent health data exchange and ultimately towards a more personalised and more sustainable Swiss healthcare system.

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We thank the participants in this survey and the only panel for their participation which allowed us to gain this novel insight into the perception of sharing their anonymised health data. We would like to thank the agency SFL Regulatory Affairs & Scientific Communication GmbH for the medical writing support. Finally many thanks to William Archey, Ingo Bühner, Jean-Marc Häusler, Damian Page, Alexandra Schmid and Florian Zabel for their valuable contributions to the present work.

Conflicts of interest
FP and DG are employed by Roche Pharma Schweiz AG and are stakeholders of Roche. KML works as a project manager at gfs-zürich. Roche Pharma Switzerland AG commissioned an independent research organization, gfs-zürich, to conduct this survey. All authors fulfill the ICMJE criteria for authorship by providing substantial contributions to conception and design of the work (DG, FP, KML), data acquisition and analysis (KML), interpretation of the data (DG, FP, KML), drafting the manuscript (DG, FP). DG, FP and KML have approved the final version of the manuscript and are accountable for the final content of the manuscript. The data of this survey was further used by KML for her independently conducted master thesis (Master of Advanced Studies UAS Zurich) at the ZAHW School of Management and Law. KML has no other potential conflict of interest.

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Supplementary material 1

Demographic characteristics of survey participants

	Age			**Gender**		**Language region**		**Purchasing power**				**Education**		
	18-39 y	**40-64 y**	**>64 y**	**male**	**female**	**DE**	**FR**	**Low**	**Medium low**	**Medium high**	**High**	**Compulsory**	**Secondary**	**Tertiary**
CH total*	35%	42%	23%	50%	50%	74%	26%	Not available	Not available	Not available	Not available	19%	45%	36%
General Swiss population (N=1006)	35%	43%	22%	50%	50%	75%	25%	7%	37%	44%	9%	7%	38%	54%
Chronic disease population (N=225)	21%	49%	30%	43%	57%	67%	33%	17%	43%	32%	3%	Not applicable	Not applicable	Not applicable
Cancer (n=85)	*8%*	*52%*	*40%*	*41%*	*59%*	*58%*	*42%*							
MS (n=43)	*49%*	*49%*	*2%*	*26%*	*74%*	*74%*	*26%*							
Arthrosis (n=56)	*9%*	*57%*	*34%*	*48%*	*52%*	*71%*	*29%*							
Eye disease (n=24)	*38%*	*25%*	*38%*	*50%*	*50%*	*71%*	*29%*							
Back pain (n=17)	*35%*	*41%*	*24%*	*71%*	*29%*	*71%*	*29%*							

CH Switzerland, DE German-speaking part of Switzerland, FR French-speaking part of Switzerland, MS multiple sclerosis.
* Percentages refer to distribution across the indicated categories and not the entire Swiss population.

Supplementary material 2

Survey flow

Sample 1

N* of calls (by random calling, incl. random digit dialing)	138’245
N of individuals who did not respond	96’630
Occupied sign or answer machine	15’681
N individuals who refused to participate	13’128
Quota complete, respondent out of target group	2’923
Phone number inexistant, fax, business number	7’902
Appointments - Not reachable during field time	425
Language problems	550
N of individuals included considered for final results	**1006**

*N=Number

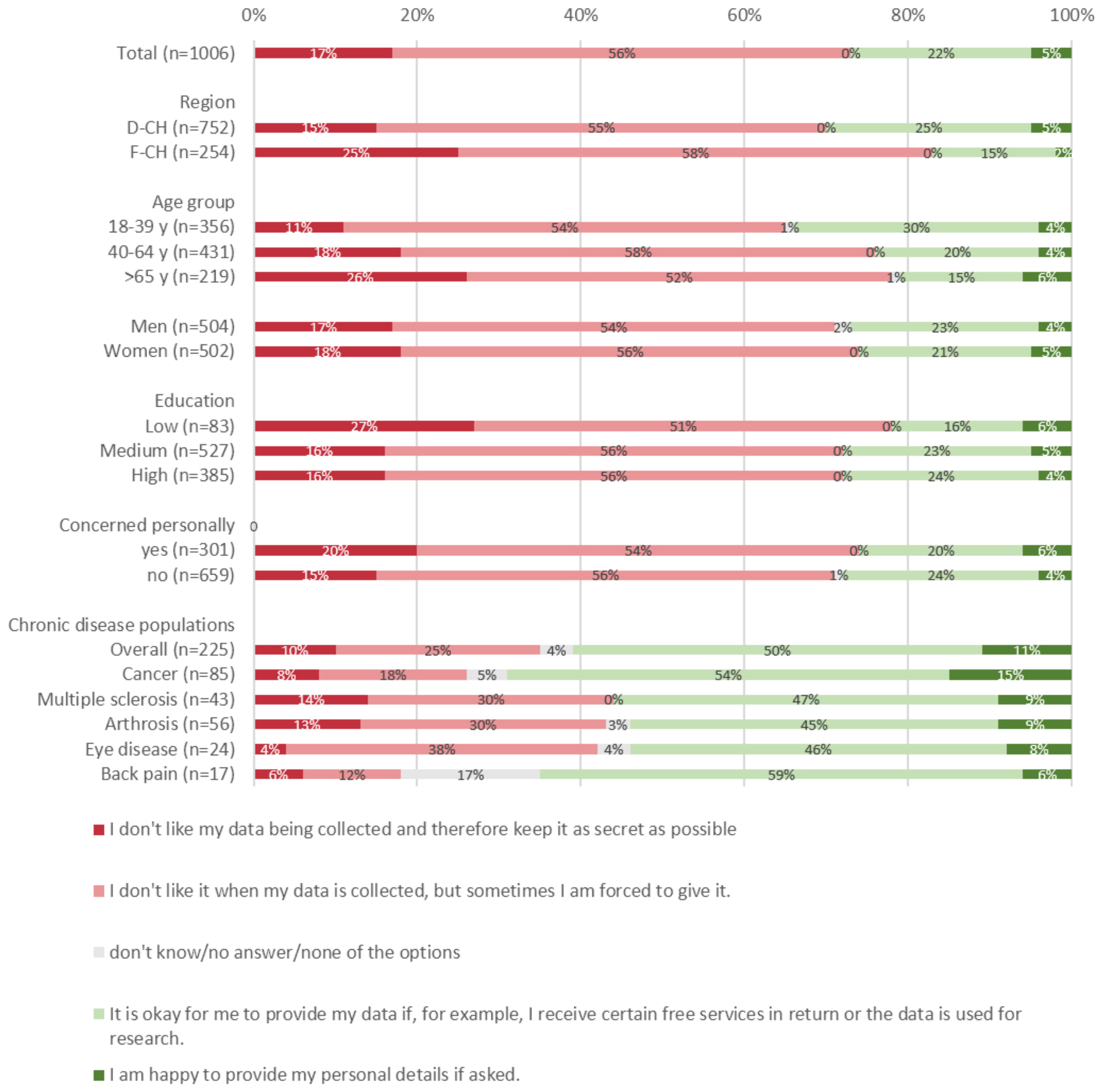
Sample 2

N* of contacts in online panel (target group nr. 2)	885
Screen outs / out of target group	72
Conducted interviews	235
Deleted for quality reasons	10
N individuals included for final results	**225**

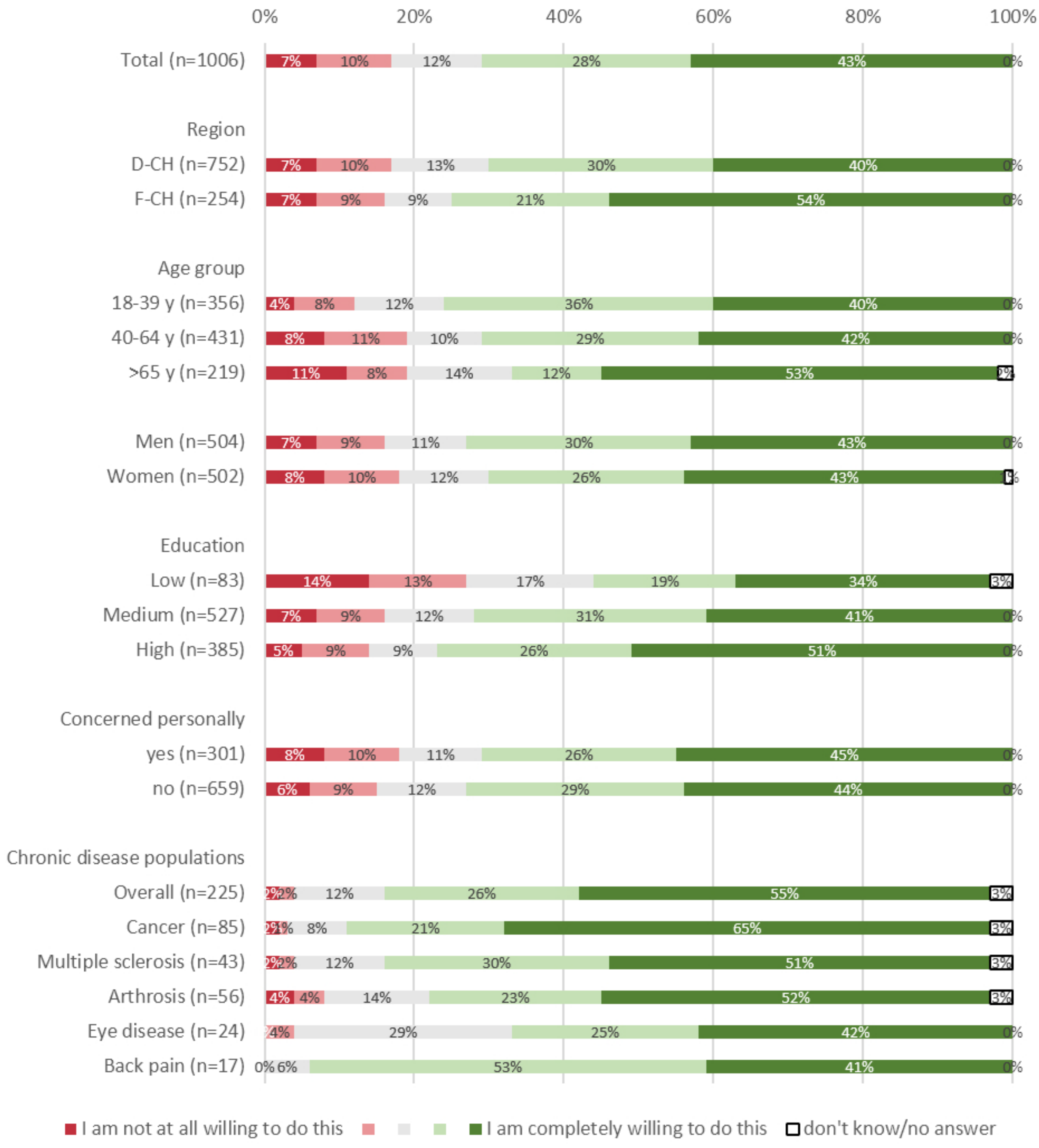
*N=Number

The “number of calls” might appear large, but the resulting response rate of 7.1% is within a common range for this methodological survey approach. Please note, comparing response rate to other surveys using other approaches, like sending out letters, is only partially possible. Moreover, it is also not comparable with a screening process for clinical trials.

Supplementary material 3



Supplementary material 4

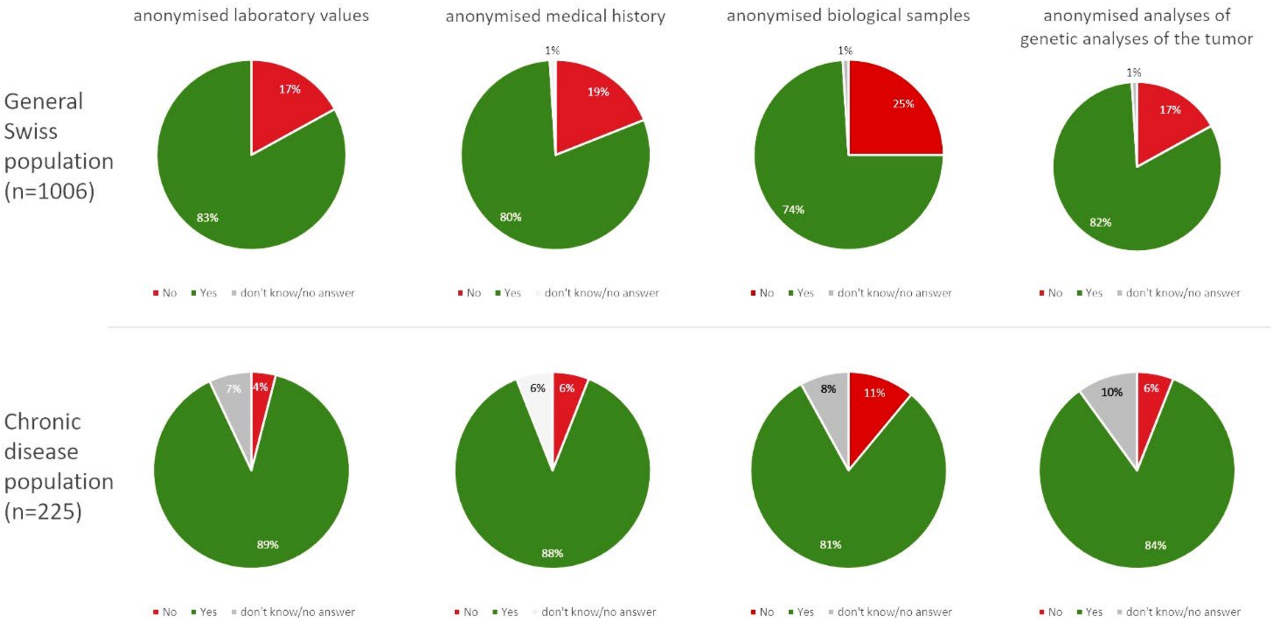


Supplementary material 5

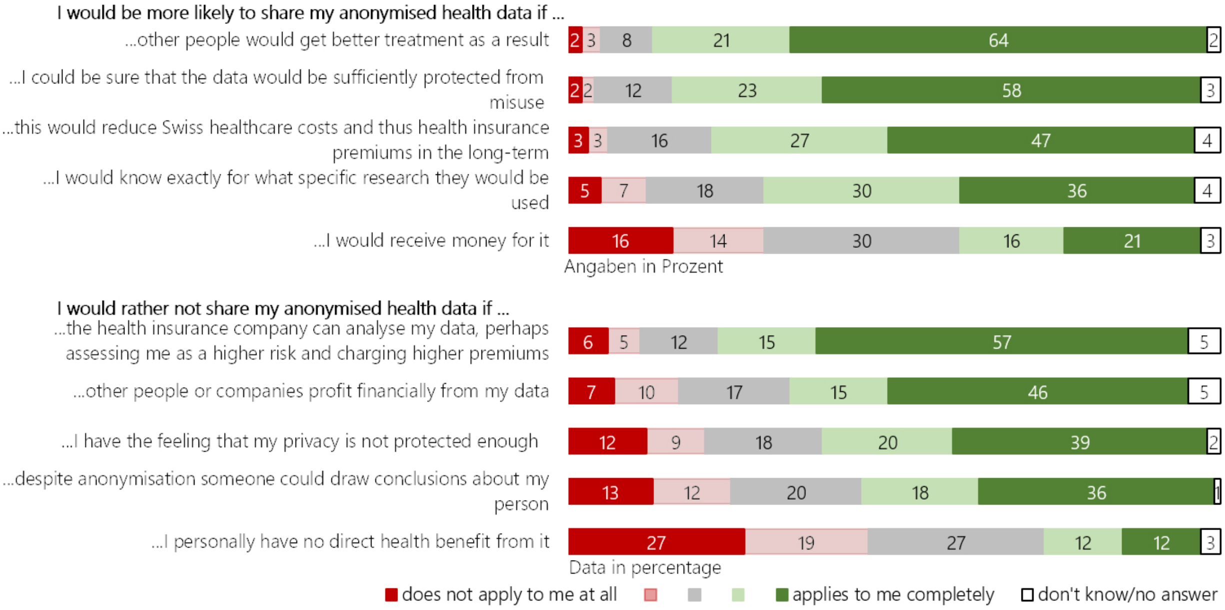
Table of general data vs anonymized health data

		Willingness to share general personal data.			
		I don't like my data being collected and therefore keep it as secret as possible	I don't like it when my data is collected, but sometimes I am forced to give it.	It is okay for me to provide my data if, for example, I receive certain free services in return or the data is used for research.	I am happy to provide my personal details if asked.
Willingness to share anonymized health data for medical research.	I am not at all willing to do this	21%	5%	2%	7%
	…	21%	9%	3%	4%
	…	9%	15%	7%	4%
	…	20%	31%	32%	9%
	I am completely willing to do this	28%	40%	57%	74%
	don't know/no answer	0	0	0	2%

Supplementary material 6

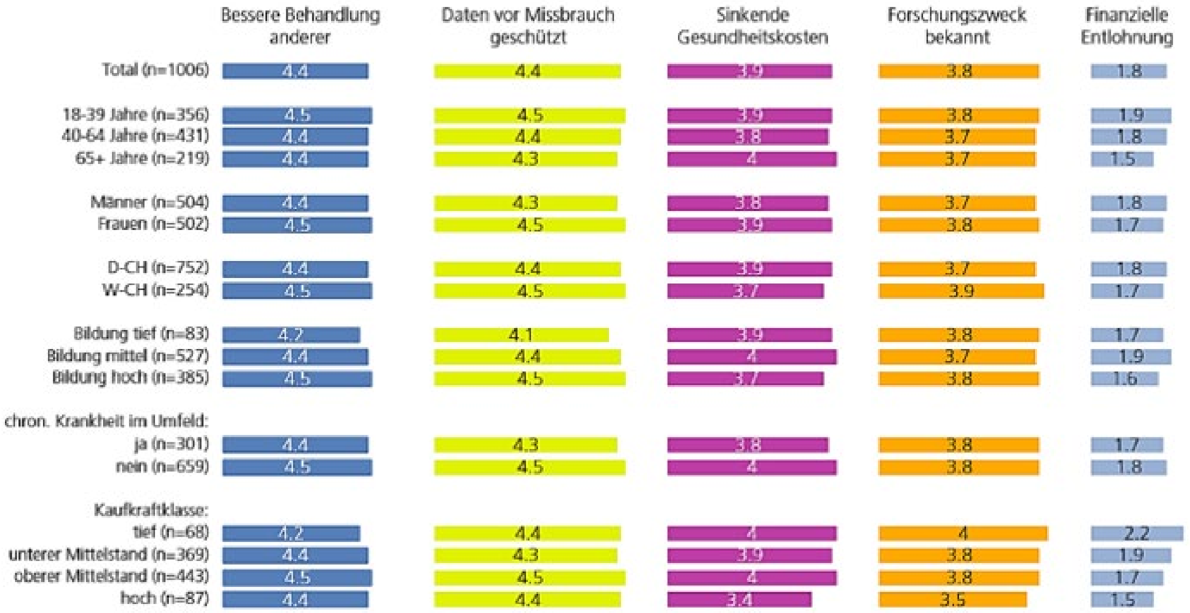


Supplementary material 7

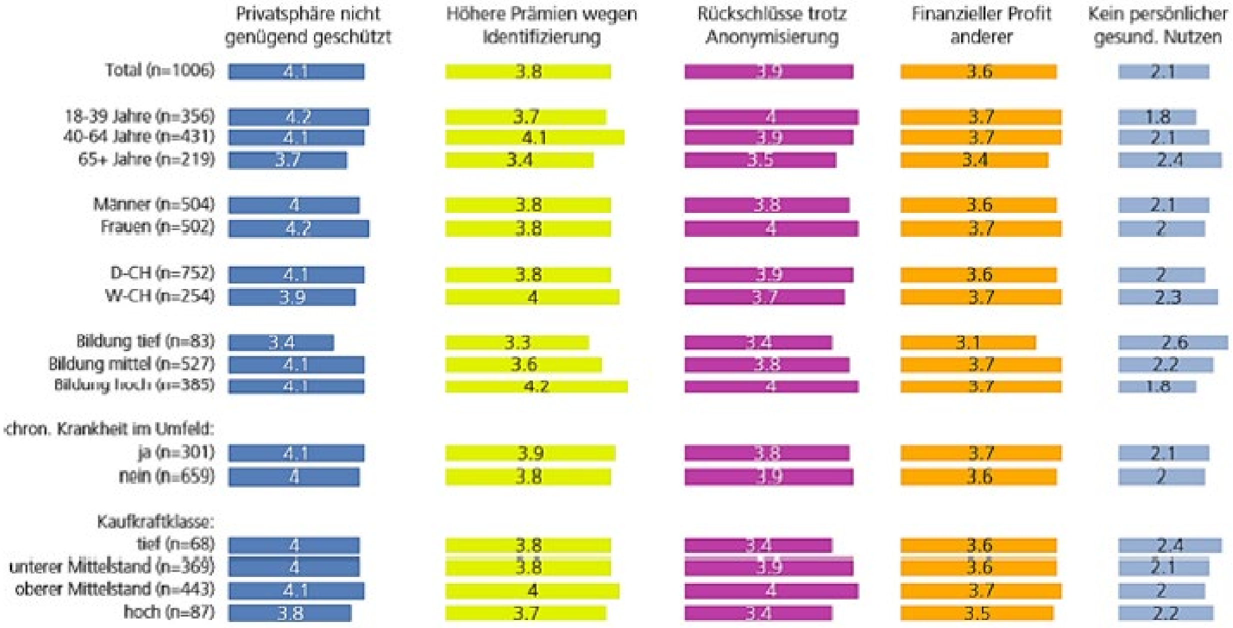


Supplementary material 8

G7: Ich lese Ihnen nun einige Gründe vor, mit denen andere Leute begründet haben, warum sie ihre Gesundheitsdaten **eher** der medizinischen Forschung zur Verfügung stellen würden. Wie stark treffen die Aussagen auf Sie zu von 1 «trifft gar nicht auf mich zu» bis 5 «trifft voll und ganz auf mich zu»?
Stichprobe 1, telefonische Bevölkerungsbefragung: n=1006



G8: Ich lese Ihnen nun einige Gründe vor, mit denen andere Leute begründet haben, warum sie ihre Gesundheitsdaten **eher nicht** der medizinischen Forschung zur Verfügung stellen würden. Wie stark treffen die Aussagen auf Sie zu von 1 «trifft gar nicht auf mich zu» bis 5 «trifft voll und ganz auf mich zu»?
Stichprobe 1, telefonische Bevölkerungsbefragung: n=1006



Supplementary material 9

Mean trust ratings stratified by gender and age

	Mean rating[1]			**Mean rating[1]**					
	male (A)	**female (B)**	***p-value[2] (A vs. B)***	**18-39 years (A)**	**40-64 years (B)**	**65+ years (C)**	***p*-value[2] (A vs. B)**	***p*-value[2] (A vs. C)**	***p*-value[2] (B vs. C)**
Trust in universities	3.8	3.8	.503	4.0	3.7	3.6	.001	.000	.224
Trust in hospitals	3.8	3.8	.873	4.0	3.7	3.7	.000	.002	1.000
Trust in pharma sector	2.5	2.5	.790	2.5	2.4	2.5	1.000	1.000	1.000
Trust in Swiss authorities	3.5	3.6	.575	3.9	3.4	3.2	.000	.000	.113
Trust in health insurers	2.4	2.6	.020	2.5	2.4	2.5	.616	1.000	.827

[1] Mean rating on 5-point Likert scale

[2] Means of subgroups were compared using independent t-test or Chi-Square-Test, and Bonferroni correction was applied for multiple testing.

Supplementary material 10

Correlation of trust in an institution and willingness to share clinical data for medical research

Institution	**Correlation (Pearson)**	**Significance (two-sided)**	**n**
Universities	0.458	0.00	991
Hospitals	0.439	0.00	1000
Pharmaceutical industry	0.290	0.00	994
Swiss authorities	0.341	0.00	997
Health insurances	0.248	0.00	998
Pearson’s bivariate analysis with r-values of ± 0.3 to 0.5 suggesting a moderate correlation.			

[English Version not used for survey. Translation done with DeepL for publication in peer-reviewed journal]

Questionnaire: Willingness to share health data
Client: confidential
Project number: 20218
Method: CATI adhoc
Date: 7 September 2020
Version 8_after pretest

Hello Mr/Mrs XX, my name is XXX from gfs-zürich, the Institute for Market and Social Research. We are conducting a current survey on the topic of handling personal data. The survey will take about 10 minutes.

closed
C1. Please enter gender: Man = 1, Woman = 2

alterNUM
C2. May I ask how old you are? (INT: Please write your age in years)

G1. What is your attitude towards providing others with your personal information? I am going to read you four statements; please tell me which one applies most to you.
READ OUT / ONLY ONE ANSWER

1. I don't like my data being collected and therefore keep it as secret as possible. 1

2. I don't like it when my data is collected, but sometimes I am forced to give it. 2

3. It is okay for me to provide my data if, for example, I receive certain free services in return or the data is used for research. 3

4. I am happy to provide my personal details if asked. 4

Not applicable / don't know / no answer9

G2. In the course of examinations in hospital, you might be asked whether you would be willing to have your health data anonymised and thus made available for medical research. Anonymisation means that personal data, such as your name or date of birth, are deleted and no conclusions can be drawn about your person.

How willing are you in principle to have your personal health data anonymised and made available for medical research? Please answer from 1 "I am not at all willing to do this" to 5 "I am completely willing to do this", with the values in between you can grade your judgement.

Scale value 1-5/ _____/

G3. Would you give consent for your following data to be anonymised and made available for medical research? Please answer "yes" or "no" in each case.
READ OUT / RANDOMISE

Laboratory values, e.g. from blood tests/ _____/
Medical history, e.g. the course of an illness/ _____/

Biological material such as blood or urine samples that are no longer needed for diagnosis/ _____/
Genetic testing of a cancer disease/ /_____

G4. What are the reasons against consenting to anonymise your health data and make it available for medical research? Please name any that come to mind.
OPEN QUESTION

G5. On a scale from 1 = "very low" to 5 = "very high", how high is your trust in the following institutions that they would use the anonymised health data for medical research in the interest of patients?
READ ALOUD / ONE ANSWER PER LINE / RANDOMISE ITEMS

Universities/ _____/
Hospitals/ /_____
Pharmaceutical industry/ _____/
Swiss authorities/ /_____
Health insurance sector/ _____/

G6. What conditions would have to be met for you to agree to anonymise your health data and make it available for medical research? Please tell me all the ones that are important to you.
OPEN QUESTION

G7. RANDOMISE G7 AND G8
I am now going to read you some of the reasons other people have given as to why they would be **more likely to make** their health data available to medical research. How strongly do the statements apply to you from 1 "does not apply to me at all" to 5 "applies to me completely"? You can use the values in between to grade your judgement.
READ ALOUD / ONE ANSWER PER ITEM / RANDOMISE ITEMS

I would be more likely to share my anonymised health data if...

... I would receive money for it/ _____/

... this would reduce Swiss healthcare costs and thus health insurance premiums in the long term/ _____/

... other people would get better treatment as a result/ _____/

... I would know exactly for what specific research they would be used/ _____/

... I could be sure that the data would be sufficiently protected from misuse/ _____/

G8. I am now going to read you some of the reasons other people have given as to why they would **rather not make** their health data available to medical research. How strongly do the statements apply to you from 1 "does not apply to me at all" to 5 "applies to me completely"?
READ OUT / RANDOMISE ONE ANSWER PER ITEM / ITEMS

I would **rather not** share my anonymised health data if...

... despite anonymisation someone could draw conclusions about my person/ _____/.

... the health insurance company can analyse my data,
perhaps assessing me
as a higher risk and charging higher premiums/ /_____

... other people or companies profit financially from my data/ _____/

... I personally have no direct health benefit from it/ _____/.

... I have the feeling that my privacy is not protected enough/ _____/

G10. Would you like to be better informed about the handling of personal health data?
DO NOT READ OUT / ONLY ONE ANSWER

Yes 1
No2
don't know/no answer9

G11. Who do you think is responsible for educating the population on the subject of health data?
DO NOT READ OUT / MULTIPLE ANSWERS POSSIBLE

Doctors1
The authorities, such as the FOPH or the health directorates2
The person who collects the data3
Health insurers 4
Media (newspapers, television, online media, etc.) 5
Public institutions such as universities 6
Patient protection organisations, associations 7
Pharmaceutical sector 8
Schools 9
Hospitals 10

Other, who:___________________________ 98
don't know/no answer99

G12. Thank you very much for your answers. Now we just have a few questions about yourself. What is the highest school level you have completed?
ONLY ONE ANSWER

Compulsory schooling (9 years: Real-, Sekundar-, Bezirks-,
Orientierungsschule, Pro-, Untergymnasium, Sonderschule) 1
Preparatory courses (nursing professions, social year, arts and crafts school...)
Intermediate year, apprenticeship2
Vocational apprenticeship or vocational school3
Matura school, vocational baccalaureate, diploma school4
Higher technical and vocational training (e.g. Federal Certificate of Proficiency, Federal Diploma of Proficiency
and Master Craftsman Diploma, Higher Commercial Comprehensive School
(HKG), Technical School (TS) 5
University of Applied Sciences (FH, HTL, HWV, HFG, HFS) 6
University (ETH), University7
No answer9

G13.In which purchasing power class do you consider yourself to be?
READ OUT / ONLY ONE ANSWER

Low means1
Lower middle class2
Upper middle class3
Well off4
Answer refused9

G14.Do you or someone close to you currently suffer from a chronic illness that permanently restricts you in your everyday life? You can answer "yes" or "no", or you can choose not to answer.
ONLY ONE ANSWER

Yes1
No2
Don't know / no answer9

Thank you very much for your information, that brings us to the end. Have a nice day/evening.

Fragebogen:	Teilbereitschaft von Gesundheitsdaten
Auftraggeber:	vertraulich
Projektnummer:	20218
Methode:	CATI adhoc
Datum:	7. September 2020
	Version 8_nach Pretest

Guten Tag Herr/Frau XX, mein Name ist XXX von gfs-zürich, dem Institut für Markt- und Sozialforschung. Wir führen eine aktuelle Studie zum Thema Umgang mit persönlichen Daten durch. Die Umfrage dauert ca. 10 Minuten.

geschlF
C1. Bitte Geschlecht eintragen: Mann = 1, Frau = 2

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alterNUM
C2. Darf ich fragen, wie alt Sie sind? (INT: Bitte Alter in Jahren eintragen)

G1. Wie ist Ihre Einstellung dazu, anderen Ihre persönlichen Daten zur Verfügung zu stellen? Ich lese Ihnen vier Aussagen vor; bitte sagen Sie mir, welche am ehesten auf Sie zutrifft.
VORLESEN / NUR EINE ANTWORT

1. Ich mag es nicht, wenn meine Daten gesammelt werden und halte sie deshalb möglichst geheim. 1

2. Ich mag es eher nicht, wenn meine Daten gesammelt werden, aber manchmal bin ich gezwungen dazu, sie anzugeben. 2

3. Es ist für mich in Ordnung, meine Daten anzugeben, wenn ich dafür z.B. gewisse Gratisleistungen erhalte oder die Daten für die Forschung verwendet werden. 3

4. Ich gebe meine persönlichen Daten gerne an, wenn danach gefragt wird. 4

Nicht zutreffend / weiss nicht / keine Antwort 9

G2. Im Rahmen von Untersuchungen im Spital könnten Sie gefragt werden, ob Sie bereit wären, Ihre Gesundheitsdaten anonymisieren zu lassen und somit für die medizinische Forschung zur Verfügung zu stellen. Anonymisieren heisst, dass personenbezogene Daten, wie zum Beispiel Ihr Name oder Geburtsdatum, gelöscht werden und keine Rückschlüsse auf Ihre Person mehr möglich sind.

Wie hoch schätzen Sie grundsätzlich Ihre Bereitschaft ein, Ihre persönlichen Gesundheitsdaten anonymisieren zu lassen und für die medizinische Forschung zur Verfügung zu stellen? Bitte antworten Sie von 1 «bin überhaupt nicht bereit dazu» bis 5 «bin voll und ganz bereit dazu», mit den Werten dazwischen können Sie Ihr Urteil abstufen.

Skalenwert 1-5 /_____/

G3. Würden Sie die Einwilligung geben, Ihre folgenden Daten zu anonymisieren und für die medizinische Forschung zur Verfügung stellen? Bitte antworten Sie jeweils mit «ja» oder «nein».
VORLESEN / RANDOMISIEREN

Laborwerte, z.B. von Blutuntersuchungen /_____/
Krankengeschichte, z.B. den Verlauf einer Krankheit /_____/
Biologisches Material wie Blut- oder Urinproben, die nicht mehr für die Diagnose benötigt werden /_____/
Genetische Untersuchungen einer Krebs-Erkrankung /_____/

G4. Welche Gründe sprechen gegen die Einwilligung, Ihre Gesundheitsdaten zu anonymisieren und für die medizinische Forschung zur Verfügung stellen? Bitte nennen Sie mir alle, die Ihnen in den Sinn kommen.
OFFENE FRAGE

G5. Wie hoch ist Ihr Vertrauen in die folgenden Institutionen, dass diese die anonymisierten Gesundheitsdaten für medizinische Forschung im Sinne der Patienten anwenden würden, auf einer Skala von 1 = «sehr niedrig» bis 5 = «sehr hoch»?
VORLESEN / EINE ANTWORT PRO ZEILE / ITEMS RANDOMISIEREN

Universitäten /_____/
Spitäler /_____/
Pharma-Branche /_____/
Schweizer Behörden /_____/
Krankenversicherungs-Branche /_____/

G6. Welche Voraussetzungen müssten erfüllt sein, damit Sie damit einverstanden wären, Ihre Gesundheitsdaten zu anonymisieren und für die medizinische Forschung zur Verfügung zu stellen? Bitte nennen Sie mir alle, die Ihnen wichtig sind.
OFFENE FRAGE

G7. **G7 UND G8 RANDOMISIEREN**
Ich lese Ihnen nun einige Gründe vor, mit denen andere Leute begründet haben, warum sie ihre Gesundheitsdaten **eher** der medizinischen Forschung zur Verfügung stellen würden. Wie stark treffen die Aussagen auf Sie zu von 1 «trifft gar nicht auf mich zu» bis 5 «trifft voll und ganz auf mich zu»? Mit den Werten dazwischen können Sie Ihr Urteil abstufen.
VORLESEN / EINE ANTWORT PRO ITEM / ITEMS RANDOMISIEREN

Ich würde meine anonymisierten Gesundheitsdaten eher teilen, wenn…

… ich dafür Geld erhalten würde /_____/

… dadurch die Schweizer Gesundheitskosten und damit langfristig die Krankenversicherungsprämien sinken würden /_____/

… andere Leute dadurch eine bessere Behandlung erhalten würden /_____/

… ich genau wüsste, für welche konkrete Forschung sie verwendet würden /_____/

… ich sicher sein könnte, dass die Daten vor Missbrauch genügend geschützt werden /_____/

G8. Ich lese Ihnen nun einige Gründe vor, mit denen andere Leute begründet haben, warum sie ihre Gesundheitsdaten **eher nicht** der medizinischen Forschung zur Verfügung stellen würden. Wie stark treffen die Aussagen auf Sie zu von 1 «trifft gar nicht auf mich zu» bis 5 «trifft voll und ganz auf mich zu»?
VORLESEN / EINE ANTWORT PRO ITEM / ITEMS RANDOMISIEREN

Ich würde meine anonymisierten Gesundheitsdaten **eher nicht** teilen, wenn…

… trotz Anonymisierung jemand Rückschlüsse auf meine Person machen könnte	/_____/
… die Krankenversicherung meine Daten analysieren kann, mich dann vielleicht als höheres Risiko einschätzt und höhere Prämien verlangt	/_____/
… andere Leute oder Unternehmen finanziell von meinen Daten profitieren	/_____/
… ich persönlich keinen direkten gesundheitlichen Nutzen davon habe	/_____/
… ich das Gefühl habe, dass meine Privatsphäre nicht genug geschützt ist	/_____/

G10. Wären Sie gerne besser informiert zum Thema Umgang mit persönlichen Gesundheitsdaten?
NICHT VORLESEN / NUR EINE ANTWORT

Ja	1
Nein	2
weiss nicht/keine Antwort	9

G11. Wer ist Ihrer Meinung nach zuständig dafür, die Bevölkerung über das Thema Gesundheitsdaten aufzuklären?
NICHT VORLESEN / MEHRERE ANTWORTEN MÖGLICH

Ärzte	1
Die Behörden, wie z.B. das BAG oder die Gesundheitsdirektionen	2
Derjenige, der die Daten erhebt	3
Krankenversicherer	4
Medien (Zeitungen, Fernsehen, Online-Medien usw.)	5
Öffentliche Institutionen wie Universitäten	6
Patientenschutzorganisationen, Verbände	7
Pharma-Branche	8
Schulen	9
Spitäler	10
Andere, wer: ___________________________	98

weiss nicht/keine Antwort	99

G12. Herzlichen Dank für Ihre Antworten. Jetzt haben wir nur noch ein paar Fragen zu Ihrer Person. Welches ist die höchste Schulstufe, die Sie abgeschlossen haben?
NUR EINE ANTWORT

Obligatorische Schulzeit (9 Jahre: Real-, Sekundar-, Bezirks-, Orientierungsschule, Pro-, Untergymnasium, Sonderschule)	1
Vorbereitungskurse (Pflegeberufe, Sozialjahr, Kunstgewerbeschule…) Zwischenjahr, Anlehre	2
Berufslehre oder Berufsschule	3
Maturitätsschule, Berufsmatura, Diplommittelschule	4
Höhere Fach- und Berufsausbildung (z.B. eidg. Fachausweis, eidg. Fach- und Meisterdiplom, höhere kaufmännische Gesamtschule (HKG), Technikerschule (TS)	5
Fachhochschule (FH, HTL, HWV, HFG, HFS)	6
Hochschule (ETH), Universität	7
Keine Antwort	9

G13. In welche Kaufkraftklasse schätzen Sie sich ein?
VORLESEN / NUR EINE ANTWORT

Wenig bemittelt	1
Unterer Mittelstand	2
Oberer Mittelstand	3
Gut situiert	4
Antwort verweigert	9

G14. Leiden Sie oder jemand aus Ihrem nächsten Umfeld momentan an einer chronischen Krankheit, welche Sie in Ihrem alltäglichen Leben dauerhaft einschränkt? Sie können mit «ja» oder «nein» antworten oder auch keine Antwort geben.
NUR EINE ANTWORT

Ja	1
Nein	2
Weiss nicht / keine Antwort	9

Herzlichen Dank für Ihre Angaben, damit sind wir am Ende angelangt. Ich wünsche Ihnen noch einen schönen Tag/Abend.

Fragebogen:	Teilbereitschaft von Gesundheitsdaten
Auftraggeber:	vertraulich
Projektnummer:	20218
Methode:	CATI adhoc
Datum:	7. September 2020
	Version 8_nach Pretest

Bonjour Monsieur/Madame XX, mon nom est XXX de gfs-zürich, l'Institut d'études de marché et de recherche sociale. Nous réalisons une étude d'actualité sur le thème de l'utilisation des données personnelles. La durée de l'interview est d'environ 10 minutes.

geschlF

C1. Merci d'indiquer le sexe: homme = 1, femme = 2

alterNUM

C2. Puis-je vous demander votre âge? (INT: Merci de saisir l'âge en années)

G1. Quel est votre point de vue en ce qui concerne la divulgation de vos données personnelles à d'autres? Je vous lis quatre affirmations et vous demande de me dire laquelle vous correspond plutôt.

LIRE/UNE SEULE REPONSE

1. Je n'aime pas que mes données soient collectées et par conséquent je les garde si possible confidentielles.	1
2. Je n'aime plutôt pas que mes données soient collectées mais parfois je suis obligé de les indiquer.	2
3. Pour moi, communiquer mes données ne me cause aucun problème, si je reçois pour cela p.ex. des prestations gratuites ou que mes données soient utilisées pour la recherche.	3
4. Je communique volontiers mes données personnelles si elles me sont demandées.	4
Ne me concerne pas / ne sais pas / pas de réponse	9

G2. Dans le cadre d'examens à l'hôpital, il se pourrait que l'on vous demande si vous êtes disposé à accepter d'anonymiser vos données de santé et de les mettre ainsi à disposition de la recherche médicale. Anonymiser veut dire que les données à caractère personnel comme par exemple votre nom ou votre date de naissance sont supprimés et toute identification avec votre personne est ainsi totalement exclue.

A combien évaluez-vous en principe votre disponibilité à accepter que vos données personnelles de santé soient anonymisée et mises à disposition de la recherche médicale? Merci de répondre en utilisant une échelle de 1 «ne suis pas du tout disposé» à 5 «suis tout à fait disposé», les valeurs intermédiaires vous permettent de nuancer votre point de vue.

Valeur de l'échelle 1-5 /_____/

G3. Donneriez-vous votre accord pour anonymiser vos données suivantes et les mettre à disposition de la recherche médicale? Merci de répondre à chaque fois par « oui » ou par « non ».

LIRE / RANDOMISER

Résultats de laboratoire, p.ex. des analyses de sang /_____/
Antécédents médicaux, p.ex. évolution d'une maladie /_____/
Matière biologique comme test de sang ou urine qui ne sont plus nécessaires pour le diagnostic /_____/
Analyses génétiques d'un cancer /_____/

G4. Quelles raisons plaident contre l'accord d'anonymiser vos données de santé et de les mettre à disposition de la recherche médicale ? Merci de citer toutes celles que vous viennent à l'esprit.
QUESTION OUVERTE

G5. Quel est le niveau de confiance que vous accordez aux institutions suivantes qui utiliseraient les données de santé pour la recherche médicale au bénéfice des patients. Merci de répondre en utilisant une échelle de 1 «très faible » à 5 « très élevé »?
LIRE / UNE REPONSE PAR LIGNE / RANDOMISER LES ITEMS

Universités /_____/
Hôpitaux /_____/
Industrie pharmaceutique /_____/
Autorités suisses /_____/
Secteur de l'assurance maladie /_____/

G6. Quelles conditions devraient être remplies pour que vous acceptiez d'anonymiser vos données de santé et de les mettre à disposition de la recherche médicale? Veuillez me citer toutes celles que vous considérez comme étant importantes pour vous.
QUESTION OUVERTE

G7. RANDOMISER G7 ET G8
Je vous lis maintenant quelques raisons formulées par d'autres personnes comme arguments qui les auraient **plutôt** incitées à mettre à disposition leurs données de santé pour la recherche médicale. Dans quelle mesure les affirmations suivantes vous concernent sur une échelle de 1 «ne me concerne absolument pas» à 5 « me concerne pleinement ». Les valeurs intermédiaires vous permettent de nuancer votre jugement.
LIRE / UNE REPONSE PAR LIGNE / RANDOMISER LES ITEMS

Je partagerais **plutôt** mes données de santé anonymisées, si …

… je recevais de l'argent en contrepartie /_____/

… de ce fait, les coûts suisses de la santé et les primes d'assurance maladie diminuaient sur le long terme /_____/

… de ce fait, d'autres personnes pouvaient bénéficier d'un meilleur traitement /____/

… je savais précisément pour quelle recherche concrète elles étaient utilisées /____/

… je pouvais être certain-e que les données soient suffisamment protégées contre toute utilisation abusive /____/

G8. Je vous lis maintenant quelques raisons formulées par d'autres personnes comme arguments pour **ne plutôt pas** mettre leurs données de santé à disposition de la recherche médicale. Dans quelle mesure les affirmations suivantes vous concernent sur une échelle de 1 «ne me concerne absolument pas» à 5 « me concerne pleinement ».
LIRE / UNE REPONSE PAR LIGNE / RANDOMISER LES ITEMS

Je ne partagerais **plutôt pas** mes données de santé anonymisées si…

… malgré l'anonymat quelqu'un pouvait établir une quelconque relation avec ma personne /____/

… l'assurance maladie peut analyser mes données, et alors m'évalue peut-être comme personne à plus haut risque et augmente les primes /____/

… d'autres personnes ou entreprises profitent financièrement de mes données /____/

… je n'en tire personnellement aucune utilité directe en termes de santé /____/

… j'ai le sentiment que ma sphère privée n'est pas suffisamment protégée /____/

G10. Aimeriez-vous être mieux informé sur le thème de l'utilisation des données personnelles de la santé?
NE PAS LIRE/UNE SEULE REPONSE

Oui	1
Non	2
Ne sais pas / pas de réponse	9

G11. Qui, à votre avis, est responsable d'informer la population sur le thème des données de santé?
NE PAS LIRE / PLUSIEURS REPONSES POSSIBLES

Médecins	1
Les autorités comme p.ex. l'OFSP ou les directions de la santé	2
Celui qui recueille les données	3
Assureur maladie	4
Médias (journaux, télévision, médias en ligne etc.)	5
Institutions publiques comme les universités	6
Organisations pour la protection des patients, associations	7

Industrie pharmaceutique	8
Ecoles	9
Hôpitaux	10
Autre, qui: ___________________________	98
Ne sais pas / pas de réponse	99

G12. Un grand merci pour vos réponses. Voici encore quelques questions se rapportant à votre personne. Quel est le plus haut niveau d'étude que vous avez achevé?
UNE SEULE REPONSE

Ecole obligatoire (9 ans: école primaire, secondaire, de district, cycle d' orientation, progymnase/ pré-gymnase, école spéciale)	1
Cours préparatoires (professions de soins, année sociale, école des arts et métiers...) année de transition, préapprentissage	2
Apprentissage ou école professionnelle	3
Maturité, maturité professionnelle, école de degré diplôme	4
Haute formation spécialisée et professionnelle (p.ex. diplôme fédéral, maîtrise/brevet fédéral, école supérieure de gestion commerciale (ESGC), école technique (ET)	5
Haute école spécialisée (HES, ETS, ESCEA, EAA HSG)	6
Haute école (EPF), Université	7
Pas de réponse	9

G13. Dans quelle classe de pouvoir d'achat vous classeriez-vous?
LIRE/UNE SEULE REPONSE

Modeste	1
Moyenne inférieure	2
Moyenne supérieure	3
Aisée	4
Réponse refusée	9

G14. Souffrez-vous ou quelqu'un de votre proche entourage souffre-t-il en ce moment d'une maladie chronique qui vous/qui le limite dans ses activités de la vie quotidienne de manière permanente? Vous pouvez répondre par «oui» ou par «non» mais aussi ne pas donner de réponse.
UNE SEULE REPONSE

Oui	1
Non	2
Ne sais pas / pas réponse	9

Nous sommes arrivés au terme de cette enquête, merci beaucoup pour vos réponses. Je vous souhaite une belle journée/une bonne soirée.