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ABSTRACT

Background: Prospective studies with biobanks require participants' long-term commitment.

Aim: To assess participants' actual motivations for enrolment.

Methods: Participants of two German cohort studies, one ongoing and one in its pre-test phase, were surveyed about their decision to enroll.

Results: From the 623 completed questionnaires, the most common motive to enroll was “contributing to scientific knowledge”, followed by “learning about personal health status” and “receiving personal medical advice”, with variation of proportions between the studies.

Conclusion: While motivating participation through the gain of personal health information entails the risk of triggering undue expectations, focusing on the contribution to scientific progress seems appropriate to secure participants' long-term commitment and should therefore be further investigated in this setting.

INTRODUCTION

Individuals' enrolment and sustained participation are crucial for the success of prospective cohort studies with a biobank component. Understanding the motives underlying the decisions to enroll is necessary for developing adequate recruitment and retention strategies [1]. Studies have shown that individual decisions to enroll in biobank research are complex constructs, in which the prospect of personal benefit is often indicated as determinant [2-4]. Similarly, increased willingness to participate in research was found to be associated with the return of health information [5-11]. As discussed in the literature, the return of results (ROR) to participants includes individual health information, i.e. measurements from examinations, research results, and incidental findings, as well as generalized information obtained in the course of the study, i.e. aggregate research results [12].

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While returning aggregate research results is considered good practice [13], there are a lot of discussions around the return of individual health information. On the one hand, some argue that individual information should be returned out of “respect” for participants’ preferences [14,15]. Tenants of this position also argue for the researchers’ duty to return individual findings [15,16]. On the other hand, some have rejected the ethical foundation of such a duty [17,18] and have underlined its negative implications, among which the generation of misconceptions about research standards [19,20]. The likelihood that such misconceived expectations will not be fulfilled further entails the possibility that participants grow frustrated, and eventually decide to withdraw from the study [21].

Conceptually, the debates surrounding ROR and the possible duty to return individual results refer to different interpretations of the principle of reciprocity [22]. Broadly defined, reciprocity in the research context is “the recognition of the participation and contribution of the research participant” [23]. Specifically, reciprocity can be direct or indirect. Reciprocity is “direct” when benefits are addressed to the person who initially benefited the research, i.e. the return of information will benefit the participants. Reciprocity is indirect when benefits are not individual but generalized [24,25], i.e. when there is “an ongoing societal exchange where the individual contribution is expected to feed into a social whole that in the long run [could] let the individual benefit” [26].

As any study, cohort studies with an attached biobank are expected to define how reciprocity toward their participants will be implemented, i.e. whether and which results will be returned at recruitment or during the course of the study [27]. This qualification of the principle of reciprocity is required in order to frame the communication about the benefits attached to participation in the information provided to the individuals selected as potential participants. In this quantitative study, we explored how different elements, including the expectations of various forms of benefit, were involved in the participants’ decisions to join two longitudinal studies with attached biobanks: i) the German National Cohort (GNC) in its pre-test phase; (ii) the European Prospective Investigation into Cancer and Nutrition (EPIC)-Potsdam study in a reexamination after about 10 years of active participation.

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METHODS

Study settings and populations

The EPIC study is a multi-centric prospective cohort study with an attached biobank that was launched in 1992 in 23 study centers across 10 European countries, including Germany where two cohorts were established (Potsdam and Heidelberg). Details about study initiative, design, and aims are described elsewhere [28]. The EPIC-Potsdam study, affiliated with the German Institute of Human Nutrition Potsdam-Rehbrücke (DIfE), was set up from August 1994 to September 1998 involving a total of 27,548 participants (men from 40 to 65 years old and women from 35 to 65 years old) randomly drawn within an age strata from the population registers of municipalities adjacent to Potsdam. Recruitment procedures have been described in detail elsewhere [29]. All eligible participants were then re-contacted approximately every 2 years in active follow-up waves [30]. In spring 2013, a sample of about 800 EPIC-Potsdam participants (in the age range of 40 to 83 years) who attended an examination in 2010-2012 (including a blood draw) were re-invited. Our short questionnaire on the reasons for their enrolment was introduced after re-examination had started, which is why 513 EPIC-Potsdam participants were invited to complete it, of whom 96 percent did so (n=494). The mean age of the participants was 66 years (ranging from 40 to 83 years) and 54% were women. Because of the very high response rate, the age and gender distributions in our sample and the re-examination were identical. However, because the re-invitation examination happened 15 to 19 years after recruitment, which at that time focused on equal numbers across strata of age and gender, our study sample is not comparable to the sample originally recruited.

The GNC is a German-wide population-based prospective study launched in 2014. It foresees the recruitment of 200,000 participants in 18 centers across Germany, aged from 20 to 69 years old. Participants are invited to undergo a series of examinations (including the supply of biological samples which are then stored in a biobank) and to complete questionnaires. Regular active follow-up waves are planned over a period of 10 to 20 years. Further information about aims, design, and organization

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of the GNC are provided elsewhere [31]. In autumn 2011, participants of the pretest phase of the GNC [32] were invited to complete our questionnaire in two study centers in Berlin. Information about the recruitment and response rates of this phase of the GNC can be found elsewhere [33]. Among the GNC participants invited to complete our short questionnaire (n=201), 64 percent did so (n=129). The mean age of the participants was 49 years (ranging from 20 to 69 years) and 60% were men. Compared to the GNC study group in Berlin [33], our sub-sample is a little different: the proportion of women is lower (40%) than the proportion in the general study sample (69%). Furthermore, the mean age of our sample is higher (49 years) compared to the mean age of the whole group (41 years). The age range however is the same as for the pre-test phase.

Recruitment strategies and definition of reciprocity in each study settings

An overview of the written information provided in both settings is presented in [Table 1](#). Focused on indirect reciprocity, the EPIC-Potsdam study presents the support to the research endeavor as the main reason to join the reexamination and mention the provision to each participant of a summary of the aggregate research results in the form of a study report sent by post. In the documents available to prospective participants, the GNC indicated a benefit in the form of return of the results from the examinations as motivations for participation. In addition, a financial compensation was mentioned. Both studies indicate in similar ways that participation does not equate to a personal medical check-up.

Standardized questionnaire

The questions developed for our investigation were added to an existing questionnaire, which collected information on participants' satisfaction about their experiences in the study center and which was distributed to all participants at the end of their visit to the study center. To increase the chances of receiving honest answers, the satisfaction questionnaire was anonymous, i.e. unlinked to personal data. Age and gender were the only parameters collected in the questionnaire. Answering this questionnaire was voluntary and could be done directly in the study center. EPIC-Potsdam

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participants were also able to complete it at home (a pre-paid envelope to return it was provided) but almost all participants completed it at the study center.

Through 5 statements, participants were asked whether they considered the following aspects as motivations for enrolment: 1) contributing to scientific knowledge; 2) receiving personal medical advice; 3) learning about personal health status; 4) being exempted from regular check-up; 5) getting an insight into research practice. For each statement, participants were invited to express their level of agreement by ticking one of 3 boxes (yes; maybe; no). At the end of the questionnaire, a space was provided for the participants to add free text about other motivations for participation. These questions were adapted from the ones previously used in a study assessing expectations linked to participation in a German cohort study using MRI technology [19].

Statistical analysis

After exclusion of the questionnaires that did not contain participants' age or gender (n=4 in EPIC-Potsdam and n=3 in GNC), a sample of 616 completed questionnaires (n=490 EPIC-Potsdam; n=126 GNC) was available for analysis. Next to the 3 categories of answer for each question, a category "no answer" was created for the statements left unanswered so that we could use this missing data as a piece of information. Frequencies and proportions across categories of response were calculated, including the proportion of participants who did not answer, stratified by gender and age groups (EPIC: 40-65; >65; GNC: <40; 40-65; >65) using SAS (Version 9.4, Enterprise Guide 6.1, SAS Institute Inc., Cary, NC, USA). Qualitative data, i.e. open answers (n= 33 among EPIC-Potsdam participants and n=8 among GNC participants) were analyzed using qualitative content analysis as described by Schreier [34].

Ethical clearance

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Within the EPIC-Potsdam, approval was obtained from the Ethics Committee of the State Medical Association of Brandenburg (n°2110/NE). Within the GNC, approval for the activities included in the pre-tests was given by the Ethics Committee of the Charité-Universitätsmedizin Berlin (n°EA1/197/12).

RESULTS

Role of various expected benefits in the decision to enroll

As shown in [Table 2](#), 90.2% of EPIC-Potsdam participants and 72.2% of GNC participants, whereas 78% among women and 64.7% among participants older than 65 years, agreed to the statement “I want to contribute to scientific knowledge”. 35.3% of EPIC-Potsdam and 32.6% of GNC participants answered yes to the statement “I would like a doctor to give me some advices about my health”, with higher proportions among EPIC-Potsdam participants older than 65 years (39.1%) and GNC respondents younger than 40 years (45.2%). 36.1% of EPIC-Potsdam participants and 55.6% of GNC participants agreed with the statement “I will learn more about my health status”, with the highest proportions among GNC participants younger than 40 years (67.8%) and GNC female participants (62%). 78% of EPIC-Potsdam participants and 50% of GNC participants answered negatively to the statement “If I take part in this study, I don’t have to attend the regular check-up examinations”. Among the EPIC-Potsdam participants, the highest proportion of negative answer was observed for participants aged between 40 and 65 years (88.4%) where the lowest proportion of 69.2% was observed among participants older than 65 years. Within the GNC, the proportion of negative answers was higher among women (56%) than men (46.1%) and participants younger than 40 years (58.1%) than participants between 40 and 65 years (46.1%). About a third of all participants (29.3% of EPIC-Potsdam participants and 29.4% of GNC participants) answered positively to the statement “I wanted to get an insight into the research practice”, with the highest proportion among GNC respondents younger than 40 years (48.4%).

The proportion of “maybe” answers ranged from 6.5% (“If I take part in this study, I don’t have to attend the regular check-up examinations”) to 30.4% (“I will learn more about my health status”)

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among the EPIC-Potsdam participants and from 2.4% (“I want to contribute to scientific knowledge”) to 7.1% (“If I take part in this study, I don’t have to attend the regular check-up examinations”) among GNC participants. The proportion of “no answer” ranged from 5.9% (“I want to contribute to scientific knowledge”) to 13.8% (“I wanted to get an insight into the research practice”) among EPIC-Potsdam participants and from 24.6% (“I want to contribute to scientific knowledge”) to 45.2% (“I wanted to get an insight into the research practice”) among GNC participants.

Further motivations for enrolment provided in the open section at the end of the questionnaire

As shown in [Table 3](#), some contributions provided in the open part of the questionnaire confirmed answers described in the previous section referring to the expectation of personal health information or to the support for scientific progress. Other contributions highlighted further motivations such as altruism; support of for a specific research institution; a sense of duty; or a personal link to the diseases investigated by the study.

DISCUSSION

Our study showed that participants considered various aspects, including indirect and direct forms of reciprocity, as constitutive of their decision to enroll, confirming the complex nature of such decision [35]. Support for scientific progress was involved in the decision to enroll of a large majority of participants from both studies, possibly reflecting the fact that individuals who did not share this view are less likely to enroll in such research. We also saw that, in both studies, learning more about one’s own health status was commonly indicated as a motivation for enrolment, followed by the possibility of receiving personal medical advices, and the prospect of gaining insights into research practice. Younger GNC participants and older EPIC-Potsdam participants were the most likely to answer positively to these statements, perhaps reflecting the limited access (possibly due to time concerns or lack of opportunities) to regular check-ups among individuals younger than 40 years as well as increased health concerns among elderly persons. It is noticeable that uncertainty was present throughout the questionnaires, mainly in the form of non-response among GNC participants and, to a

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lesser extent, through the use of maybe answers among EPIC-Potsdam participants. This uncertainty was particularly manifest for the statement on the equivalence between research participation and medical health check: more than a third of GNC participants and a tenth of EPIC-Potsdam participants did not answer the statement. These proportions are important if we consider the recruitment strategies and their emphasis on the fact that research participation does not equate a personal medical check-up.

To a certain extent, our data confirm previous findings about the tendency to consider personal health information as a benefit attached to research participation and thus as a factor involved in the decision to enroll [2-7]. Differences observed between the two studies are not as strong as the reciprocal frames from each study could have implied, i.e. communication focused on indirect reciprocity within the EPIC-Potsdam and on direct reciprocity within the GNC. This confirms previous evidence showing that individual expectations of benefits are difficult to “shape” through the information provided by the study [36]. The limited differences observed between the studies could further be attributable to the stage of implementation for each study. Indeed, over the follow-up period for the EPIC-Potsdam study, it is legitimate to assume that participants who may have expected more in terms of direct benefit may have grown frustrated and therefore decided to discontinue participation or even withdraw, as hypothesized elsewhere in the literature [21].

Given the participants' sustained interest in personal benefits in the context of cohort studies with attached biobanks, it is important to reflect on the implications of the different reciprocal frames. On the one hand, promoting participation in a frame of direct reciprocity, i.e. emphasizing the return of individual health information as an advantage of participation, may appear as an effective approach for securing recruitment [37]. Still, it can be speculated that, in order to be effective in retaining participants over time, this approach would require strategies that clarify the exact nature of the direct benefits to be expected. For instance, and in reference to our specific settings, it should include a stricter emphasis on why the results provided by the study do not equate to a medical check-up.

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On the other hand, adopting of a frame of indirect reciprocity that precludes the return of personal information as a reason to enroll may appear perilous with regards to recruitment rates. Indeed, the initial participation rates in the EPIC-Potsdam study of about 20% [29] were low compared to participation rates of around 70% in various US studies during the same time period [38]. Nevertheless, a recruitment strategy focused on indirect reciprocity could bear valuable assets with regards to long-term commitment as it could contribute to the limitation of exaggerated expectations of personal benefit at the beginning of the study. In this regard, it is interesting to note that the retention rates of the EPIC-Potsdam study have been impressively high over the long-term: above 90% over the first 10 years of follow-up. This positive outcome could also be the result of continuing efforts to communicate research about standards, methods, and achievements.

CONCLUSION

On these premises, we suggest that adopting a frame of indirect reciprocity to motivate research participation should be further explored as particularly adequate for ensuring long-term commitment in cohort studies with biobanks. Furthermore, using such a frame is an incentive to continue reflecting on the forms of “care” that could be offered to participants as a return for their initial contribution to research [39], that could be alternatives to the return of health information, which can sometimes result harmful or confusing for participants [27], and that would be adapted to the context of epidemiological research [40]. We believe that it is in this reflection process on adequate return for research participation that the duty set under the principle of reciprocity as defined by the P³G’s guideline, i.e. “to promote trust between researchers and research participants” [27], could be best achieved.

STRENGTH AND LIMITATIONS

To our knowledge, this study is the first to have investigated participants’ decisions to enroll in two prospective cohort studies taken at different stages of their implementation, i.e. pre-test and re-examination. While this can be considered a strength as it provides a longitudinal perspective on the

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decision to enroll and to remain committed in a study, limitations in comparability exist due to the factors related to time: time spent in the study (just enrolled vs. long-standing contributor), selection over time, i.e. attrition bias, in the EPIC-study and timing of enrolment (shortly after the fall of the wall for the EPIC-Potsdam and a few years ago within the GNC). Although the levels of education, income, and generally social classes are comparable between Berlin and Potsdam, the GNC has a higher chance to recruit participants with a non-German socio-cultural background. Therefore we did not aim at systematically comparing the results between the studies. We rather aimed at contextualizing the two sets of data in their specificities, specifically regarding their recruitment strategies. It is also important to note that we did not investigate the broader context of the decision to participate. As presented elsewhere [41], the post- neoliberal context of scientific research could have played a role in the participants' decision to enroll in the studies but we did not gather data about this dimension in our study.

Regarding the methodological limitations, we decided to use descriptive statistics only and refrain from performing any statistical testing as we considered that the limited comparability between the two study populations did not warrant such testing. Consequently, we decided to treat the missing answers as piece of information rather than to transform them in order to be able to perform statistical testing (e.g. imputation, extrapolation or simulation). Although, we reached high response rates, we cannot exclude that we encountered some selection bias linked to the fact that about 7% of the participants invited (106 out of 714 participants; n=87 in the GNC and n= 19 in the EPIC Potsdam) did not complete the questionnaire. The low number of socio-demographic variables available to stratify the results can further be considered as a limitation of this study. Because we exclusively investigated the motives to enroll of actual participants, we did not tackle the similarly important issue of reasons for non-participation in this type of study, some insights into this question can be found elsewhere in the literature [4].

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SUMMARY POINTS (8-10)

- **Our survey study investigates various motives underlying participants' decision to enrol in two cohort studies with attached biobanks ongoing in Germany.**
- **Our data show that the wish to support science and the expectation of some form of personal health information are the most common reasons to enrol in these two studies.**
- **These two motivations reflect two distinct forms of benefit: direct (i.e. personal reward for their participation through personal health information) and indirect (i.e. contributing to the science progress, and indirectly to the greater good of society).**
- **These forms of benefits resonate with the principle of reciprocity that each study is bound to qualify in order to frame its policy about return (or not) of results to participants.**
- **As we could see that participants are receptive to both direct and indirect reciprocity, we reflect on the possible advantages and drawbacks of advertising participation from a perspective of direct or indirect reciprocity.**
- **A strategy based on direct reciprocity may secure recruitment rates while entailing the chance that some participants develop disproportioned expectations regarding the return of personal health information, which could, in turn, endanger their retention in the study.**
- **A strategy based on indirect reciprocity may appear riskier for recruitment but could also turn out to be better suited to promote long-term involvement in the study.**
- **Further research on the advantages and inconveniences of both approaches need to be pursued in the context of large cohort studies.**

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Literature of particular interest:

1. Mein G, Seale C, Rice H et al. Altruism and participation in longitudinal health research? Insights from the Whitehall II Study. *Soc Sci Med*, 75(12), 2345-2352 (2012). **

One of the few studies that investigate motives to remain committed in longitudinal studies, highlighting a complex understanding of the notion of reciprocity among participants.

2. Halverson CM, Ross LF. Incidental findings of therapeutic misconception in biobank-based research. *Genet Med*, 14(6), 611-615 (2012)*

In this study, the researchers unveiled some degree of misconception among biobank participants' expectations of results in the frame of their participation.

3. Fry CL. Research participation and internal normativity: understanding why people participate. *Am J Bioeth*, 8(10), 43-44 (2008).**

This is a short commentary that nicely nails down how participation ought to be considered as a “multi-dimensional construct” whose phenomenology needs to be explored.

4. Dixon-Woods M, Ashcroft RE, Jackson CJ et al. Beyond "misunderstanding": written information and decisions about taking part in a genetic epidemiology study. *Soc Sci Med*, 65(11), 2212-2222 (2007). **

The authors explored in a detailed way the role of written information in participants' decisions to cooperate in a research initiative.

5. Hobbs A, Starkbaum J, Gottweis U, Wichmann HE, Gottweis H. The privacy-reciprocity connection in biobanking: comparing German with UK strategies. *Public Health Genomics*, 15(5), 272-284 (2012).*

Nobile, H., Borry, P., Pischon, T., Steinbrecher, A., Boeing, H., Vigl, M., Bergmann, M.M. (2017). Participants' decision to enroll in cohort studies with biobanks: quantitative insights from two German studies. *PERSONALIZED MEDICINE*, 14 (6), 477-485. [doi: 10.2217/pme-2017-0049](https://doi.org/10.2217/pme-2017-0049)

In this study, the authors offer a comparative analysis of the different reciprocal strategies put into place in large biobank studies in the UK and in Germany.

6. Hoeyer K. Donors perceptions of consent to and feedback from biobank research: time to acknowledge diversity? *Public Health Genomics*, 13(6), 345-352 (2010). **

Through a review of the literature, the author argues in favour of a consideration of the context in order to discuss the specific dynamics between donor and biobank, consequently arguing for a tailored reciprocal “care” from the biobank to its donors.

7. Fryer-Edwards K, Fullerton SM. Relationships with test-tubes: where's the reciprocity? *Am J Bioeth*, 6(6), 36-38; author reply W10-32 (2006)*

In this piece, the authors question the assumption of reciprocity used to ground the duty to return results to participants, specifically arguing from the perspective of epidemiological studies.

Nobile, H., Borry, P., Pischon, T., Steinbrecher, A., Boeing, H., Vigl, M., Bergmann, M.M. (2017). Participants' decision to enroll in cohort studies with biobanks: quantitative insights from two German studies. *PERSONALIZED MEDICINE*, 14 (6), 477-485. doi: [10.2217/pme-2017-0049](https://doi.org/10.2217/pme-2017-0049)

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Table 1: Extracts from the information documents (invitation letter, information brochure and informed consent) provided to the participants of the pre-test of the German National Cohort (GNC) and the re-examination of the Potsdam cohort of the European Prospective Investigation into Cancer and nutrition study (EPIC-Potsdam).

<p>GNC</p> <p>IL : 1 page / IB: 12 pages / IC: 2 pages</p>	<p>EPIC-Potsdam</p> <p>IL : 1 page / IB: 3 pages / IC: 1 page</p>
<p>“The aim of this preliminary study is to test the different examination methods and questionnaires. The time required will be 1.5 - 4 hours depending on the size of your participation. You will receive a financial compensation between 10 and 60 euros. The most important results of the examinations will be sent to you by post [<i>highlighted in the original text</i>].” (IL)</p> <p>“Which benefit do I have from study participation? During your visit in the study center, different medical examinations will be performed. At a later time, we will send you an easily understandable letter by post. This letter will contain the most important results of the examinations and laboratory tests carried out with the results from the examinations and the laboratory measurements. If the findings indicate that it is advisable to consult a physician, we will explicitly point it out to you. However we want to emphasize that study participation cannot be compared with a general health check and that we do not establish medical diagnosis. You will only receive the most important results. We also point out that in the course of our study, you may learn about some pathological processes in your body which may be unknown to you (e.g. abnormal laboratory results) and which may require further medical clarification ("incidental findings "). (IB)</p>	<p>“As a participant of the EPIC-Potsdam cohort study, you recently joined additional examinations in our study center and thereby support the study in a significant way. We are currently scientifically analyzing this data and we will publish the results in international journals in the next years. We will update you about it in our “study report”.” (IB)</p> <p>“Why do we have to examine you a second time? We are inviting all individuals who have answered our first invitation to come back in our study center in order to repeat the collection of a blood sample as well as some examinations. (...) To ensure the success of this endeavor, it is important that as many already selected persons as possible respond to the second invitation.” (IB)</p> <p>“About which results are you going to be informed? The results of the blood analyses (so called biomarkers) can only deliver relevant information when used in the context of scientific research questions. These values are not appropriate to predict or diagnose diseases. Therefore it is not planned to return these results to you.” (IB)</p> <p>“I understand that the examinations will be used exclusively to answer scientific questions and therefore not [<i>highlighted in the original text</i>] in a medical purpose to preclude some diseases or to make a diagnosis.” (IC)</p>

GNC: German National Cohort

EPIC-Potsdam: Potsdam cohort of the European Prospective Investigation into Cancer and Nutrition

IB: Information brochure

IL: Invitation letter

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IC: Informed consent

Table 2: Survey respondents' characteristics by answers to survey statements

I decided to participate because:		EPIC-Potsdam					GNC					
		All	Gender		Age groups		All	Gender		Age groups		
			Men	Women	40-65	>65		Men	Women	< 40	40-65	>65
	n	490	226	264	224	266	126	76	50	31	78	17
1.	I want to contribute to scientific knowledge											
	yes	90.2	90.7	89.8	91.5	89.1	72.2	68.4	78.0	71.0	74.4	64.7
	maybe	3.5	4.4	2.6	3.6	3.4	2.4	1.3	4.0	3.2	2.6	0.0
	no	0.4	0.5	0.4	0.9	0.0	0.8	0.0	2.0	0.0	1.3	0.0
	no answer	5.9	4.4	7.2	4.0	7.5	24.6	30.3	16.0	25.8	21.7	35.3
2.	I would like a doctor to give me some advices about my health											
	yes	35.3	39.9	31.4	30.8	39.1	32.6	28.9	38.0	45.2	29.5	23.6
	maybe	26.7	28.3	25.4	31.7	22.6	7.1	5.3	10.0	12.9	2.6	17.6
	no	27.0	22.1	31.1	30.4	24.0	20.6	19.7	22.0	12.9	24.3	17.6
	no answer	11.0	9.7	12.1	7.1	14.3	39.7	46.1	30.0	29.0	43.6	41.2
3.	I will learn more about my health status											
	yes	36.1	36.3	36.0	35.7	36.5	55.6	51.3	62.0	67.8	52.6	47.0
	maybe	30.4	37.6	24.2	33.5	27.8	3.2	1.3	6.0	3.2	2.6	5.9
	no	22.7	18.1	26.5	23.7	21.8	9.5	9.2	10.0	3.2	11.5	11.8

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	no answer		10.8	8.0	13.3	7.1	13.9	31.7	38.2	22.0	25.8	33.3	35.3
4.	If I take part in this study, I don't have to attend regular check-up examinations												
	yes		4.3	3.1	5.3	1.8	6.4	3.2	2.6	4.0	6.4	2.6	0.0
	maybe	%	6.5	9.3	4.2	2.7	9.8	3.2	1.3	6.0	6.4	2.6	0.0
	no		78.0	78.8	77.3	88.4	69.2	50.0	46.1	56.0	58.1	46.1	52.9
	no answer		11.2	8.8	13.2	7.1	14.6	43.6	50.0	34.0	29.1	48.7	47.1
5.	I wanted to get an insight into the research practice												
	yes		29.3	24.8	32.9	24.6	33.1	29.4	30.3	28.0	48.4	20.5	35.3
	maybe	%	24.8	27.9	22.4	33.9	17.3	4.0	3.9	4.0	3.2	5.1	0.0
	no		32.1	36.3	28.4	32.1	31.9	21.4	13.2	34.0	19.3	23.1	17.6
	no answer		13.8	11.0	16.3	9.4	17.7	45.2	52.6	34.0	29.1	51.3	47.1

Nobile, H., Borry, P., Pischon, T., Steinbrecher, A., Boeing, H., Vigl, M., Bergmann, M.M. (2017). Participants' decision to enroll in cohort studies with biobanks: quantitative insights from two German studies. *PERSONALIZED MEDICINE*, 14 (6), 477-485. doi: [10.2217/pme-2017-0049](https://doi.org/10.2217/pme-2017-0049)

Table 3: Sample of the contributions provided in the open part of the questionnaire

Altruism	"To do something for the others" "My motivation to contribute my small part is the possibility to help a lot of people with the results" "To be useful for society"
Personal benefit	"My health is so important to me that it is worth all efforts" "Because my health status is currently bad" "Indications on the personal evaluation of my general condition" "Motivation to adopt a healthier lifestyle"
To support science progress	"As a small contribution to a better prevention of diseases" "To support research analyses so that certain diseases can be better treated"
To support a specific institution	"Connection with the [name of the institution], for more than 60 years" "To support the scientists and the [name of the institution]"
Consistency	"Because I have been participating for 19 years now" "Because I have been involved for so long, I don't want to interrupt the examinations and the results"
Familial history of disease	"There are cancer cases in our family. Maybe I can contribute through my participation to a gain of knowledge"
Duty	"To participate in a study on cancer is a civic duty"