European Journal of Human Genetics (2017) 25, 31–36

www.nature.com/ejhg

ARTICLE

Biobank attributes associated with higher patient participation: a randomized study

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The objectives of the study were to assess patients' intent to participate in a hospital-based biobank and to explore the factors associated with higher participation. A 23-item questionnaire was developed to survey a random sample of patients in a Swiss university hospital. Two vignettes describing hypothetical biobanks were incorporated in the survey and patients were asked whether they would agree to participate. Three factors were randomly manipulated in each vignette using a factorial design: cancer-oriented research *vs* general consent, one *vs* several reviews of the patient's chart, and genetic *vs* blood protein analyses (first vignette); blood sample *vs* oral swabbing, local *vs* international project, and a follow-up visit *vs* no visit (second vignette). Of the 1140 respondents, 73.6 and 69.6%, respectively, agreed to participate in the biobank. Biospecimen collection via oral swabbing, single chart review, and no follow-up were associated with higher participation. Participation was also higher among younger patients, Europeans, patients who had a positive opinion on research, and blood/organ donors. Biobanking was supported by a majority of patients, especially if biospecimens were collected through non-invasive techniques or if data collection was done once. The scope of consent, the scale of the project, or the tests performed on biospecimens did not influence participation.
European Journal of Human Genetics (2017) **25,** 31–36; doi:10.1038/ejhg.2016.132; published online 5 October 2016

INTRODUCTION

Genetic epidemiology relies increasingly on the availability of biobanks.[1] However, biobanks face several challenges related to the need to protect research subjects and to provide in return a societal benefit attributable to the research findings.[2,3] Patients are key actors in the development of a hospital-based biobank and their active support is an essential element for its success. Many biobanks obtain specimens from patients at the point of care, such as at the time of hospital admission. Although participation rates are typically high, the elements that make participation in the biobank attractive to patients are only partially understood.[4]

Several factors associated with the intent of patients to participate in a biobank have been studied previously. First, the scope of consent can influence participation. One-time consent compared to dynamic or tiered consent,[5,6] or general consent compared to specific consent[7] were associated with an increased intended participation. Patients expressed the possibility to withdraw consent even after inclusion in the biobank as important even if in reality this is a right and not an option.[5] Second, a one-time data collection from the medical chart and the absence of follow-up over time was associated with increased participation.[8] The type of biobank sample has not been specifically assessed in the literature; especially no study has compared the willingness to participate in a biobank that uses left-over blood after routine clinical visits compared with the *ad hoc* collection of blood samples or oral swabs. Because the latter procedures entail an additional burden to the patient, this factor may influence patient participation. Finally, individual characteristics can influence participation in a biobank, such as older age, being married or being a blood donor.[9]

This study aimed to assess the effect of several biobank attributes on intended participation among hospitalized patients. We performed an experimental survey among patients discharged from a university hospital in Switzerland based on two hypothetical vignettes presenting a biobank project. Each vignette tested three experimental factors that were randomly attributed to potential participants in order to control for the effect of various confounders.

MATERIALS AND METHODS

Study design, setting and participants

We designed a cross-sectional study in a random sample of patients hospitalized between 1 March and 31 March 2014, at the University of Geneva Hospitals of Geneva, a 2000-bed public teaching hospital located in Geneva, Switzerland, with >48 000 admissions per year, representing >670 000 hospitalization days. Participants were adults that had been hospitalized and who were identified through the administrative database. Exclusion criteria were residence outside Switzerland or lack of a home address (in-transit patients). A random sample of 2600 patients was selected and a survey package including an information letter, a questionnaire, and a stamped return envelope was sent by post mail 8–12 weeks after discharge. Two reminders were sent during the next 2 months.

The study protocol was submitted to the institutional review board, which exempted it from formal review because it carried minimal risk.

Questionnaire and clinical research vignettes

We developed a 23-item questionnaire that included three parts. The first part contained seven items assessing the respondents' opinion about participation in research. The second part presented four clinical vignettes, including two about a biobank project within the hospital (Supplementary Appendix 1A and B). Each clinical vignette tested three binary factors, which were randomly attributed using a factorial design, thus yielding 8 versions (A to H) of the

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Received 4 May 2016; revised 11 July 2016; accepted 5 August 2016; published online 5 October 2016

survey (Supplementary Appendix 2). The third part recorded participant characteristics (see independent variables below). Initial versions of the vignettes were pre-tested by six persons to assess the readability and ensure that they were easily understood by French speakers.

Primary outcome

At the end of each vignette, the respondents were asked to give their position about their hypothetical participation (primary outcome) on a 5-point Likert scale: (1) 'I would have certainly refused'; (2) 'I would have probably refused'; (3) 'I would have hesitated'; (4) 'I would have probably agreed'; and (5) 'I would have certainly agreed'.

Independent variables associated with the willingness to participate

For each vignette, the three experimental factors were the main predictors tested to explain the willingness to participate (Supplementary Appendix 2). In the first vignette, the factors tested were the scope of consent (general consent *vs* cancer-oriented research), one *vs* several reviews of the patient's chart, and the type of analyses done on the biospecimens (genetic *vs* blood protein analyses). In the second vignette, we tested the method used for collecting biospecimens (blood sample *vs* oral swabbing), patient follow-up visit (yes *vs*. no), and the scale of the biobank project (local *vs* international). We investigated also the following patient characteristics and their past behavior or opinion toward research: age; gender; country of birth; level of education; childbearing and marital status; self-rated health status; opinion on the utility of clinical research at the hospital and genetic research in particular; past participation in clinical research; and if they were blood or organ donors.

Sample size estimation

We anticipated that 70% of respondents would have a positive opinion toward a hospital-based biobank.[10] To obtain a 95% confidence interval (CI) of $\pm 2.5\%$ around 70%, 1300 patients were required. We expected that patient participation would be 50%, leading to a total number of 2600 patients or 325 per vignette version. This study size allowed detection of a 7% difference in positive opinion (70 *vs* 77%) between two categories of experimental factors at a power level of 80%.

Statistical analysis

The two vignettes were analyzed separately. For each vignette, we first estimated the intent to participate by grouping 'I would have certainly agreed' with 'I would have probably agreed' and estimated the 95% CI using the exact binomial method. We then assessed the two primary outcomes using the original 5-point Likert scale (ordinal format). We used an ordered logistic regression model for each vignette to estimate the association between the likelihood of participation as the dependent variable and the three dichotomous experimental factors as the independent variables. In a second step, we forced all the experimental factors into the models and added pre-specified individual characteristics. Age groups were categorized as <40, 40–59, 60–74 and $\geqslant 75$ years. Education levels were grouped as follows: 'elementary school and apprenticeship' *vs* 'secondary school' *vs* 'professional school and university' as the reference. Patient self-rated health status was ordered from 'poor' to 'excellent', then dichotomized as 'excellent/very good/good' *vs* 'fair/poor'. Patient opinion on clinical research was ordered from 'very negative' to 'very positive'. Patient opinion on genetic research was grouped in 'positive opinion' *vs* 'negative opinion' or 'no opinion'. All analyses were performed using Stata version intercooled 14 (StataCorp., College Station, TX, USA). Statistical significance was defined as $P<0.05$ (two-sided).

RESULTS

patient characteristics

Of 2600 randomly selected patients, 1140 (43.8%) returned the completed questionnaires (Table 1); 1118 of 1140 (98.1%) responded to at least one vignette about the biobank and were included in the current analysis. Reasons for non-participation were refusal ($n=32$), death ($n=22$) and failure to return the questionnaire ($n=1406$). More than 50% of the respondents were women (Table 1). Half of all respondents were born in Switzerland, 55.9% had completed elementary school or an apprenticeship, 53.6% were married, and 78.5% had at least one child. The mean age was 60 years. Respondents considered their health as excellent or very good in 23.2% of cases and 32.0% had been hospitalized in the last 6 months. One-quarter of respondents had participated in at least one clinical study in the past (Table 2). Respondents had a favorable global opinion about clinical research and genetic research in particular.

Experimental factors associated with willingness to participate

The first vignette was completed by 1108 (42.6%) patients, the second by 1102 (42.4%), and 1092 patients completed both (42.0%). The percentage of answers from a certain refusal to a certain agreement increased gradually from 5.2% to 43.6% in the first vignette (Figure 1a), and from 7.2 to 38.4% in the second vignette (Figure 1b). In the first vignette, 816 (73.6%; 95% CI: 70.9–76.2)

Table 1 Responders' characteristics

Variables	*Respondents* (n = *1118*[a])
Female gender, *n* (%)	614 (55.6)
Mean age (SD, median)	60.0 (±19.4, 63)
Categories of age (years), n *(%)*	
<40	209 (19.8)
40–59	267 (25.3)
60–74	287 (27.1)
⩾75	294 (27.8)
Country of birth, n *(%)*	
Switzerland	573 (52.0)
Other European countries	360 (32.7)
Other countries	169 (15.3)
Level of education, n *(%)*	
Elementary school	266 (24.2)
Apprenticeship	348 (31.7)
Secondary school	119 (10.9)
Professional school	141 (12.8)
University	224 (20.4)
Marital status, n *(%)*	
Married	590 (53.6)
Single, divorced, separated, widowed	510 (46.4)
Has children, n *(%)*	
Yes	863 (78.5)
No	236 (21.5)
Self-rated health status, n *(%)*	
Excellent	66 (6.0)
Very good	189 (17.2)
Good	517 (47.2)
Fair	250 (22.8)
Poor	74 (6.8)
Blood donor, n *(%)*	
Yes	361 (33.0)
Tried	99 (9.0)
No	636 (58.0)
Organ donor card, n *(%)*	
Yes	200 (18.2)
Not yet	145 (13.2)
No	752 (68.6)
Hospital stay in the last 6 months, *n* (%)	338 (32.0)

[a]Some data had missing values, % calculated on available data; missing data were excluded.

would have certainly or probably agreed to participate compared with 768 (69.7%; 95% CI: 66.9–72.4) in the second vignette. There were no differences between the eight groups of patients randomly allocated to the different versions of the vignettes for all covariates tested or in terms of the response rate (data not shown, available upon request).

Among the six experimental factors randomly manipulated in the vignettes, three were significantly associated with willingness to participate (Table 3). In the first vignette, a single review of the patient's chart (compared with several reviews) was independently associated with a greater likelihood to participate. The type of biological analyses performed on biospecimens or the scope of consent presented to patients were not associated with participation. In the second vignette, a higher willingness to participate was found if biospecimens were obtained by oral swabbing compared with a blood sample, or if the patients did not require a follow-up visit. Of note, willingness to participate was not associated with the scale of the project.

Individual predictors associated with willingness to participate

After adjustment for individual-level predictors, the associations between willingness to participate and the three experimental factors tested in each clinical vignette remained unchanged (Table 4). In both vignettes, we found similar independent associations between willingness to participate and the following individual predictors: younger respondents; individuals born in Switzerland or other European countries (vignette 2); those who had a positive opinion of clinical research or had participated in a clinical study in the past or had a favorable opinion on genetic research; blood donors and potential organ donors.

Table 2 Responders' opinion toward research

Variables	*Respondents* (n = *1118*[a])
Participation to clinical studies during the last hospital stay, *n* (%)	275 (25.0)
Past participations to clinical studies, *n* (%)	274 (24.9)
Research is an important mission of a university hospital, n *(%)*	
Very important	937 (84.5)
Rather important	154 (13.9)
Not important	18 (1.6)
Is it justified to ask patients to contribute to producing knowledge that will be useful to other persons? n *(%)*	
Definitively justified	876 (79.3)
Partially justified	199 (18.0)
Definitively unjustified	29 (2.6)
What is your opinion about clinical research among patients? n *(%)*	
Very positive	448 (40.6)
Rather positive	483 (43.7)
Neutral	150 (13.6)
Rather negative	17 (1.5)
Very negative	6 (0.5)
Opinion of genetic research, n *(%)*	
Favorable	765 (69.3)
Non expressed	303 (27.5)
Unfavorable	36 (3.3)

[a]Some data had missing values, % calculated on available data; missing data were excluded.

DISCUSSION

In this experimental study conducted in a sample of patients in a Swiss university hospital, the willingness to participate in a hypothetical research biobank was high with ~70% of positive answers. Intended participation was increased if the biospecimens were to be collected through oral swabbing (*vs* blood sample), if the patient was not followed over time, or if his/her medical record was consulted only once. We did not observe any influence of the scope of consent (general *vs* cancer-oriented), the use of genetic tests (*vs* blood protein analysis) on biospecimens, or the scale of the project (local *vs* international). Patient characteristics associated with willingness to participate in a biobank were a younger age (<75 *vs* ≥75 years) and Swiss or European nationality (*vs* nationality from other countries). Having a positive opinion on clinical research or genetic research, having participated to clinical studies in the past, or being a blood or organ donor were also independent predictors of intended participation in the biobank.

Attitudes of patients toward genetic research and biobanking[10–13] are often more favorable than the attitudes of the general population.[14–17] This patient bias may be explained by patients' belief that research findings would potentially benefit their own health.[10,18–21] However, willingness to participate in a hypothetical biobank may be lower than the actual participation because some determinants of behavior, such as altruism, trust or sense of duty are less implied in the decision process in a fictional situation.[5,20–23]

Some of our results confirmed previous reports, such as an increase in willingness to participate if data were collected once,[8]

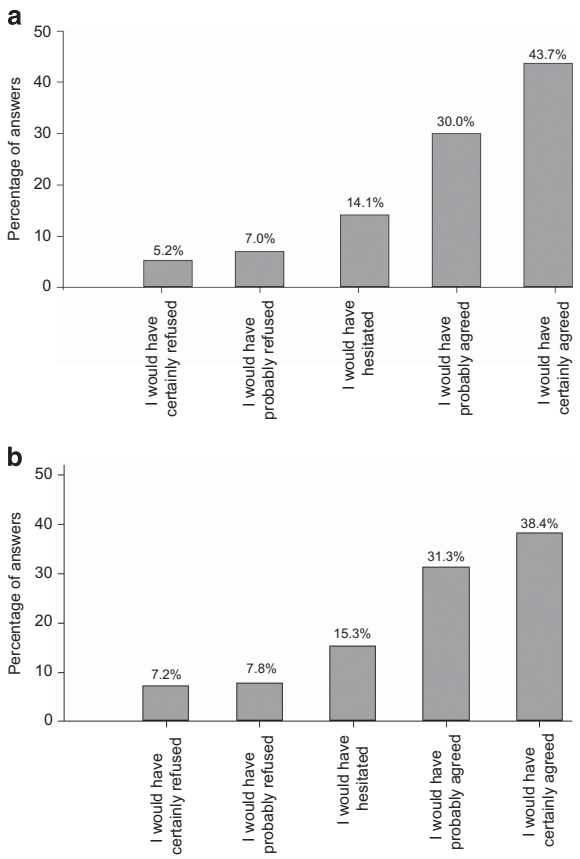

Figure 1 Distribution of the percentage of answers from certain refusal to certain approval in the first vignette (**a**) and second vignette (**b**).

Table 3 Independent associations of six experimental factors with willingness to participate in a biobank project

Experimental factors assessed in the two clinical vignettes	*Willingness to participate*[a]		
	Odds ratio	*95% CI*	P-*value*
Vignette 1			
Cancer-oriented consent (*vs* general consent)	0.90	0.72–1.12	0.35
Single review of the patient's chart or individual health data (*vs* several reviews)	1.35	1.09–1.68	0.007
Genetic analyses on the biospecimens (*vs* blood protein analysis)	1.11	0.89–1.38	0.35
Vignette 2			
Oral swabbing (*vs* blood sample)	1.35	1.09–1.67	0.007
No follow-up of patients (*vs* follow-up)	1.54	1.24–1.91	<0.001
Local project (*vs* international)	0.88	0.71–1.10	0.27

Abbreviation: CI, confidence interval.
[a]Obtained by ordinal logistic regression model. Willingness to participate was rated on a 5-point Likert scale.

Table 4 Multiple-ordinal logistic regression models per clinical vignette

Variables tested	*Vignette 1*[a]			*Vignette 2*[b]		
	Odds ratio	*95% CI*	P-*value*	*Odds ratio*	*95% CI*	P-*value*
Cancer-oriented consent (*vs* general consent)	0.95	0.74–1.20	0.68	—	—	—
Single review of the patient's chart (*vs* several reviews)	1.37	1.07–1.74	0.011	—	—	—
Genetic analyses on the biospecimens (*vs* blood protein analysis)	0.97	0.76–1.23	0.77	—	—	—
Oral swabbing (*vs* blood sample)	—	—	—	1.32	1.04–1.67	0.021
No follow-up of patients (*vs* follow-up)	—	—	—	1.36	1.07–1.73	0.012
Local project (*vs* international)	—	—	—	0.87	0.69–1.10	0.24
Categories of age (years), (*vs* ⩾75)			0.004			<0.001
<40	1.72	1.18–2.49	0.005	1.89	1.31–2.74	0.001
40–59	1.68	1.20–2.35	0.003	1.66	1.19–2.30	0.003
60–74	1.60	1.16–2.22	<0.001	1.80	1.30–2.48	<0.001
Male gender (*vs* female)	1.03	0.80–1.32	0.84	1.07	0.84–1.37	0.59
Country of birth (*vs* other country)			0.058			0.032
Switzerland	1.56	1.07–2.26	0.020	1.52	1.05–2.19	0.026
Other European countries	1.49	1.02–2.19	0.041	1.64	1.12–2.39	0.010
Level of education (*vs* elementary school/apprenticeship)			0.19			0.059
Secondary school	0.94	0.64–1.40	0.78	1.38	0.93–2.07	0.11
Professional school/university	1.29	0.99–1.70	0.06	1.33	1.02–1.74	0.034
At least one child (*vs* no child)	1.30	0.96–1.76	0.09	1.40	1.04–1.88	0.027
Excellent/very good health status (*vs* good/fair/poor)	0.90	0.68–1.19	0.47	0.97	0.74–1.28	0.84
Opinion on research (from 'very negative' to 'very positive')	1.82	1.53–2.17	<0.001	1.93	1.63–2.30	<0.001
Past participation in clinical studies (*vs* no participation)	1.71	1.28–2.29	<0.001	1.53	1.15–2.03	0.004
Positive opinion on genetic research (*vs* negative or no opinion)	3.29	2.47–4.38	<0.001	3.36	2.53–4.46	<0.001
Blood or organ donor (*vs* not)	1.53	1.19–1.97	0.001	1.90	1.47–2.44	<0.001

Abbreviation: CI, confidence interval.
[a]Among respondents, 989 of 1,108 (89.3%) had no missing data.
[b]Among respondents, 992 of 1,102 (90.0%) had no missing data.

if patients were not re-contacted[13] or if the biospecimens were collected through oral swabbing and not as a blood sample.[13] In contrast to previous findings,[6,24] we did not find any association between participation and the scope of consent. A similar lack of association was also recently reported in a survey conducted in the USA.[25] Two possible explanations can be proposed. First, the scope of consent may not be of concern to patients because they trust the research project investigators.[20] Alternatively, patients do not understand the implications of broad consent compared with disease-oriented consent or study-specific consent and this leads them to ignore this factor during the decision process.[26] In general, when broad consent is sought, its implications should be clearly stated in the information sheet distributed to potential participants. In particular, patients should understand that they will not be informed each time a new research project makes use of their biospecimens.

We expected that patients would feel less comfortable with genetic analyses than with other types of research, which would reduce their willingness to participate in a genetic biobank, but no such effect was found. We presume that this absence of association may be due to a lack of knowledge about the potential risks related to confidentiality in genetic research or the

consequences related to an incidental genetic variant discovery.[23] Similar to a US trial where 53% of respondents were willing to donate a blood sample because of a specific interest in genetic research, [16] the majority of participants (~70%) in our study were favorable to genetic research. Finally, the local *vs*. international scale of the biobank did not influence the respondents' willingness to participate.

The association between patient age and the willingness to participate in a biobank has been investigated on several occasions. In some studies, intended participation increased with age,[9,27,28] while the opposite was true in others.[8,18,29] This suggests that age in itself may be less important than other respondent characteristics that may vary with age, such as expectations or attitudes, or that the effect of age is sensitive to the type of biobank proposed. Similarly, the culture and attitudes toward research probably explain the effect of patient nationality on participation in the biobank. Finally, previous participation in a medical research study or the expression of a favorable opinion regarding research, particularly genetic research, are naturally associated with participation in a biobank as the attitudes, preferences and values required are essentially the same. Several studies have reported similar findings.[10,18,30,31] Being a blood donor or having an organ donation card are associated with a positive attitude toward genetic research[9,31,32] and these characteristics indicate also that a person is comfortable with making part of his/her body available for the benefit of others.

The main strength of this study is that we targeted patients who are directly concerned by the development of hospital-based biobanks. The experimental design of the study allowed to control for the effect of confounding on the association between the six factors tested and the intended participation of patients in biobanking. However, the limited participation in the survey may have caused a selection bias with respondents more motivated by the topic or more favorable to biobanks than non-participants.[28] Other limitations of our study deserve mention. First, we only tested factors assessing the logistics of a biobank. Because we were limited in the number of experimental factors we did not assess other potentially important factors, such as the return of individual genetic test results. Patient attitudes toward the return of incidental genomic results vary, and can be influenced by disease severity, disease treatability, carrier status, life expectancy, likelihood of response to treatment, and cost of the test.[33] It was also demonstrated that return of incidental findings was generally better accepted by the general population than by patients.[34,35] Similarly, the willingness to participate in a hospital-based biobank may be influenced by the possibility of sharing data between several data sets and also of disseminating the results through online publications.[36] Finally, factors related to culture and the local socio-political system, such as altruism, or the relative weight of individual versus societal interests were not assessed here. Surveyed populations from Northern European countries are often more motivated to participate in a biobank research than Southern European countries;[37] Switzerland is at the lower range of motivated countries. For these reasons, our results may not be generalizable to other cultures.

In conclusion, our results suggest that patients are more willing to participate in biobanks if the procedures are simple and non-invasive. Intent to participate in biobanking was not influenced by the scope of consent, the type of analyses done on the biospecimens, or the scale of the biobank project.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

ACKNOWLEDGEMENTS

We thank Rosemary Sudan for editorial assistance.

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Supplementary Information accompanies this paper on European Journal of Human Genetics website (http://www.nature.com/ejhg)