

Perspectives, Attitudes, and Willingness to Participate Toward Biobank Research of the Public in the Arab Region

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Abstract

Population-based genomics studies have proven successful in identifying genetic variants associated with diseases. High-quality biospecimens linked with informative health data have made such studies possible. However, the success of biobanks depends on the willingness of the public to participate in biobank research. We aimed to explore the views of the Arabic public regarding their willingness to participate in biobank research. We used a validated questionnaire to assess the public's perceptions, attitudes, and willingness to participate in biobank research in four Arab low-middle income countries: Egypt, Jordan, Morocco, and Sudan. We recruited 967 participants in this survey. More than half of the respondents did not have prior awareness of biobanks. Although most aspects associated with biobanks had little influence on respondents' decision to participate in biobank research, two appeared to be pivotal. These included the prospects of sharing biospecimens and medical information with international researchers and the possibility that biobanking research would improve the personal health of donors. Participants expressed concerns regarding the privacy of medical information when shared with physicians and researchers and many did not trust individuals in charge of biobanks. Their willingness to donate biospecimens and medical information was less than 10%. Predictors of willingness to participate in biobank research included previous involvement in research and positive attitudes toward biobanks. Perceptions of biobanks had a negative influence on willingness to participate in biobank research. We conclude there should be additional efforts to raise public awareness, enhance perceptions, and engage the public in all aspects of biobanking research.

Introduction

Population-based biobanks have proven invaluable in the conduct of genomic research. The UK Biobank serves as an excellent example, as it has facilitated the identification of numerous genetic variants associated with chronic and widespread diseases such as cardiovascular diseases, diabetes, and Alzheimer's disease [1–3]. Genetic research has also been pivotal in identifying the association of lifestyle with certain conditions [4, 5]. Similar advancements have also been reported from the Qatar Genome Project, where genetic variants have been identified at the population level, some of which are associated with ethnic-specific risk of disease development or drug metabolism [6–9]. In addition to these population-based biobanks, there are also disease-specific and project-specific biobanks.

A crucial factor for biobanks' success is the public awareness and acceptance of the importance of biobanks and their willingness to donate their biospecimens and associated health information. It is therefore essential to recognize factors that influence the willingness of individuals to participate in biobank research. Such factors are highly influenced by various ethical and legal issues that include: the determination of types of future research performed on the donated samples, the extent of biospecimen and data sharing, the nature of commercialization and data ownership, the extent to which results are returned to participants, data security, privacy, and trust. Several studies indicate that demographic variables, such as gender, education level, and socioeconomic status might play a role in the willingness to donate [10–12].

Altruism, trust, and personal benefits are also commonly reported drivers of participation in biobanking [13–16]. Other factors have also been described, such as knowledge of biobanks and genomic research and the method of informed consent [17, 18]. The type of informed consent to participate in biobanks has served as a contentious issue ([19, 20]. Broad consent is commonly used in biobanks [21], which entails donating specimens for unlimited research projects with little restriction. Thompson and McNamee have proposed six possible models of informed consent that biobanks can implement, namely, verbal consent, blanket consent, broad consent, meta consent, dynamic consent, and waived consent. [22].

Population-based biobanks have been limited to high-income countries and have infrequently been established in low- and middle-income countries (LMICs). This deficiency is primarily due to the high cost of maintaining such biobanks as well as concerns with the extent of privacy protection and data sharing. Several studies have reported public willingness to participate in biobank research in several low- and middle-income countries in the Middle East, specifically Egypt, Jordan, and Morocco [23–26]. Ahram et al. reported that although there was little knowledge of biobanks among Jordanians, a considerable proportion indicated their willingness to donate samples and data for biobanks [12]. However, these studies failed to examine the impact of trust, privacy, and data sharing on participants' decisions. Accordingly, investigations are warranted to further explore the perceptions and attitudes of the public toward biobanking and their willingness to participate in biobank research. Using a previously validated questionnaire [27], we aimed to explore these issues in several low- and middle-income countries in the Middle East

Methodology

Study design

This was a cross-sectional study conducted between September 2020 to January 2021.

Study population

We recruited the general populations from Egypt, Jordan, Morocco, and Sudan.

Questionnaire: We used a previously validated questionnaire [27]. The beginning of the questionnaire included a list of terms with their definitions. These terms included: biobanks, DNA, genetic or hereditary disease, privacy, scientific research, research ethics committee, clinical trials, consent, and protection of informational privacy.

Subsequently, the questionnaire included a sociodemographic section and additional sections representing the following constructs: a) perceptions about biobanks; b) aspects of biobank research that affect willingness to donate; c) attitudes toward biobank research; d) attitudes toward trust and privacy, and e) willingness to participate in biobank research. A copy of the questionnaire is included in Supplementary File S1.

Recruitment Methods

In Egypt, Morocco, and Jordan, we distributed the questionnaires through different social media platforms, e.g., Facebook, LinkedIn, and WhatsApp. Social media advertisements were also purchased to recruit participants in Egypt, reaching over 100,000 individuals. In Sudan, participants were recruited face-to-face in the markets and from health facilities.

After explaining the study and obtaining informed consent, participants proceeded to complete the questionnaire. The target audience was adults 18 years and older of both genders and all educational backgrounds and economic statuses. Participants were informed that their participation was voluntary, that they could withdraw at any time, and that they could omit any question.

Sample Size

The sample size was calculated based on the percentage of potential participants who expressed willingness to participate in biobanking reported from a previous population-based study conducted in Jordan [12]. The sample size was determined using Epi info, version 3.5.1, 2008. Based on the confidence level of 95%, a power of 80%, and the 64% of participants who would show a willingness to participate in biobanking [12], a design effect of 2, and 20% missing responses the required minimum sample size was calculated to be 850 participants.

Statistical analysis: We calculated a total score for each construct included in the questionnaire. Responses regarding perceptions consisted of a 3-point scale (yes, no, not sure). A score of 3 points was given to responses that reflected the accepted factual reality of biobanks. For example, 3 points were given to a “yes” response to: “biobank research can lead to better medical treatments for future generations,” while only 1 point was given to a “yes” response to “biological samples will be used for the production of biological weapons.” A score of 3 points was given to a “not sure” response if the current reality was contested; for example, “personal medical information stored in a biobank will remain private.” The total score was calculated by the simple addition of the responses from the study population. Total scores ranged from 3-to 39 with higher scores reflecting more accurate perceptions.

Responses to the construct regarding “aspects of biobank research that affect willingness to donate” consisted of a 5-point Likert scale and the points given to the responses were as follows: very important = 5 points, important = 4 points, moderately important = 3 points, slightly important = 2 points, and not important = 1 point. Total scores ranged from 10 to 50 with higher scores reflecting a higher “aspect” score.

Responses of the constructs regarding “attitudes toward biobank research” and “attitudes toward trust and privacy” consisted of a 6-point (strongly agree, agree, no opinion, disagree, strongly disagree, and I do not understand). Scores ranged between 1-and 5 with 1 point assigned to “strongly disagree” and 5 points assigned to “strongly agree.” Negatively worded statements that did not reflect a positive attitude were reverse coded. The total score for each section was calculated by the simple addition of the responses from the study population. Total scores ranged from 11–55 and 3–15, respectively with higher scores reflecting a more positive attitude. Data were summarized as frequencies and percentages and mean \pm standard deviation (SD) for the aggregate scores.

Responses to the construct “willingness to participate in biobank research” consisted of a 5-point Likert scale (definitely yes, probably yes, not sure, probably not, and definitely not. Scores ranged from 1–5 points with 1 point assigned to “definitely not” and 5 points assigned to “definitely yes.” Total scores ranged from 5-to 25 with higher scores reflecting a greater willingness to participate in biobank research.

We constructed a multiple linear regression model to identify the independent predictors of the willingness to participate in biobank research. All variables with p-values < 0.10 in the bivariate analysis were included in the model.

The Statistical Package for the Social Sciences (SPSS), version 20.0, for Windows was used. The tests were two-tailed, and p-values ≤ 0.05 were considered to indicate statistical significance.

Results

Demographics of the study population

We recruited 967 participants; the majority (61.3%) were from Egypt and 83% lived in urban areas. Males constituted 56.3% of the total sample. Of our participants, 56.5% were university graduates, 48.2 had never been married, and most (83.6%) did not have children. The majority indicated that they were Muslims (95.8%), and many thought they were somewhat religious (70.4%), while approximately 15% considered themselves to be “very religious”. As for health status, 86.6% of respondents described themselves as healthy and only 2.3% had a history of cancer. Regarding research participation, 16.2% previously participated in research and a majority (87.6%) had been involved in questionnaire/interview types of studies and 35.5% donated a sample for research purposes. Regarding awareness, when asked whether they ever heard of the term “biobank,” more than half (52.6%) of the respondents indicated they “never did,” less than one-third (29.9%) “previously did,” and 17.5% were not sure. See Table 1 for further details.

Table 1
Demographic characteristics of participant.s (n = 967)

Demographic variable	n	%
Country		
Egypt	593	61.3
Morocco	68	7.0
Jordan	123	12.7
Sudan	183	18.9
Gender		
Female	423	43.7
Male	544	56.3
Marital status		
Widowed	12	1.2
Divorced	27	2.8
Never married	466	48.2
Married	462	47.8
Children		
No	808	83.6
Yes	159	16.4
Medical Condition		
Healthy	837	86.6
Disease other than Cancer	108	11.2
Cancer	22	2.3
Residence		
Rural	164	17.0
Urban	803	83.0
Degree of religiosity		
Not religious at all	31	3.2
Not very religious	117	12.1

* Responses are not mutually exclusive

Demographic variable	n	%
somewhat religious	681	70.4
Very religious	138	14.3
Education		
No formal education	4	0.4
Less than primary	11	1.1
Middle school	39	4.0
Technical education	77	8.0
High school	152	15.7
Graduate	546	56.5
Post-graduate	138	14.3
Awareness of the term biobank		
Not sure	169	17.5
No	509	52.6
Yes	289	29.9
Previous participation in research studies		
No	872	83.8
Yes	169	16.2
Types of research studies of previous participation*		
Clinical trials	23	13.6
Sample donation	60	35.5
Gene study	32	18.9
Questionnaire/Interview	148	87.6
Do not know	20	11.8
Age		
Mean ± SD (Range)	33 ± 11 (18–73)	
* Responses are not mutually exclusive		

Perceptions About Biobanks

The total mean perception score was 28.83 ± 3.77 (maximum possible score of 38) reflecting a moderate perception of biobanking practices. This moderate score results from many participants answering “not sure” for many items. For example, regarding specific perceptions of respondents towards biobanks, almost three-quarters were not sure if biobank research would lead to better medical treatments in the future or improve an individual's health (78.9 and 72.3%, respectively). Regarding the storage of biospecimens, 35.9% were not sure if the biobank could sell biospecimens to anyone and most participants were not sure whether biospecimens could be shared with local researchers (66.2%).

In contrast, many replied “not sure” to items in which expert consensus does not exist. For example, many (67.9%) were “not sure” if research results would be shared with donors in case there was a risk of developing a disease 43.4% were “not sure” if donors would have the freedom to request their samples to be destroyed in the future, and 59.3% of respondents were “not sure” if the medical information of donors would remain private;

Finally, a sizable minority of the participants held inaccurate perceptions of biobanks. For example, 18.8% thought that biobank research would only benefit private drug companies and 32.4% indicated that people will spend monies to donate biological samples. Another inaccurate statement included the possibility that a human would be cloned from donated biospecimens, which was believed by 16.3% of respondents.

The possibility of revealing personal medical information stored in a biobank was indicated by 21.1% of respondents and 31.7% thought that researchers are more interested in making money from donated biological samples than doing good research. Almost one-third of respondents (32.9%) believed that biological samples could be used for the production of biological weapons. See Table 2 for further details.

Aspects Of Biobank Research That Affect Willingness To Donate

The mean score for this construct was 17.19 ± 6.10 (maximum possible score = 50) reflecting a less than moderate score. This score indicates that most respondents “indicated” that several “aspects” of biobanks were “not important” in a decision to donate. These included benefits of biobanks to the general healthcare of people in the future (54.1%), the approval of ethics committees to research (66.9%), the religious endorsement of research (70.1%), the strict control of the personal biospecimens and medical information (79.6 and 78.9%, respectively), and the receipt of personal genetic data (63.3%). In contrast, only 26.4% believed that the possible sharing of biospecimens and medical information with international researchers was not important. The converse is that 73.6% thought that data sharing with international researchers had some degree of importance. Furthermore, only 44.4% felt that biobank research had the possibility of improving the personal health of donors was “not important.” See Table 3 for further details.

Attitudes Toward Biobank Research

The mean score for “attitudes toward biobank research” was 21.91 + 6.03 (maximum possible score = 55) reflecting a less than moderate score for positive attitudes toward biobank research.

Table 2
Participants' perceptions about biobanks. (n = 967)

	Yes (n)	%	No (n)	%	Not sure (n)	%
Donation						
1. Biobank research can lead to better medical treatments for future generations.	172	17.8	32	3.3	763	78.9
2. Biobank research can lead to improvement in an individual's health.	200	20.7	68	7.0	699	72.3
3. People will have to spend monies to donate biological samples.	313	32.4	361	37.3	293	30.3
4. Biobank research will only benefit private drug companies.	182	18.8	464	48.0	321	33.2
Storage						
5. People who donate their biological samples will not be able to request to have their samples destroyed in the future.	285	29.5	262	27.1	420	43.4
6. Biological specimens given to a biobank can be sold to anyone.	233	24.1	387	40.0	347	35.9
Privacy						
7. Personal medical information stored in a biobank will remain private.	317	32.8	77	8.0	573	59.3
8. Personal medical information stored in a biobank might be revealed to unauthorized people.	204	21.1	443	45.8	320	33.1
Data Sharing						
9. Biological samples can be shared with researchers in other institutions in my country	232	24.0	95	9.8	640	66.2
Research						
10. Researchers are more interested in making money from donated biological samples than doing good research.	210	21.7	412	42.6	345	35.7
11. A person might be cloned if he/she donates a biological sample to a biobank.	158	16.3	432	44.7	377	39.0
12. Biological samples will be used for the production of biological weapons.	318	32.9	259	26.8	390	40.3
Return of results						
13. Researchers will contact people if the analysis of their biological specimens shows risk for disease.	247	25.5	63	6.5	657	67.9

	Yes (n)	%	No (n)	%	Not sure (n)	%
Total perception score (mean ± SD)	28.83 ± 3.77					

Table 3
Aspects of biobank research that affect willingness to donate. (n = 967)

	Very important	Important	Moderately important	Slightly important	Not important
Donation					
1. Future research on my biological samples could improve healthcare for people in the future.	19 (2.0)	31 (3.2)	120 (12.4)	274 (28.3)	523 (54.1)
2. Future research on my biological samples will be reviewed by an ethics committee.	22 (2.3)	19 (2.0)	70 (7.2)	209 (21.6)	647 (66.9)
3. My personal health will improve from my donation.	62 (6.4)	67 (6.9)	180 (18.6)	273 (28.2)	385 (39.8)
4. My religion approves of my donating biological samples.	40 (4.1)	37 (3.8)	63 (6.5)	149 (15.4)	678 (70.1)
Privacy					
5. My medical information will remain private.	15 (1.6)	20 (2.1)	41 (4.2)	128 (13.2)	763 (78.9)
6. if the analysis of my biological samples reveals any stigmatizing information about me, this will be kept private.	18 (1.9)	23 (2.4)	52 (5.4)	104 (10.8)	770 (79.6)
Data Sharing					
7. My biological samples and medical information will be shared with researchers who are from other countries.	165 (17.1)	102 (10.5)	216 (22.3)	227 (23.5)	257 (26.6)
8. Access to my biological samples and medical information in the biobank will be strictly controlled by an oversight committee.	26 (2.7)	25 (2.6)	71 (7.3)	202 (20.9)	643 (66.5)
9. Researchers outside of my institution will not receive any biological samples or medical information that directly identifies me.	43 (4.4)	47 (4.9)	95 (9.8)	210 (21.7)	572 (59.2)
Return of results					
10. I will be able to obtain the genetic results from the analysis of my biological samples.	38 (3.9)	31 (3.2)	77 (8.0)	209 (21.6)	612 (63.3)
Total Aspects score, mean ± SD	17.19 ± 6.10				

For example, less than 5% of respondents agreed that people should donate samples to improve the health of future generations. Also, less than 10% agreed that donated samples could be shared with researchers

outside their countries. While less than 5% agreed that researchers must maintain the privacy of a donor's medical information, only 24% agreed that legal authorities should have the right to access personal data, when necessary. Finally, less than 5% of the respondents agreed that research results should be returned to donors even if it reveals a treatable or untreatable disease. See Table 4 for further details.

Attitudes Toward Trust And Privacy

The mean score for this construct was 8.08 ± 2.38 (maximum possible points 15) reflecting a moderate score for having trust in biobanks and believing that privacy would be protected. For example, more than half of the respondents indicated a privacy concern with sharing their medical information with their physicians or researchers (50.2% and 56.7%, respectively) Regarding "trust", less than 20% strongly agreed or agreed that they trust individuals in charge of biobanks. However, many respondents (40.5%) did not have a definite response regarding the level of trust towards those in charge of biobanks, which probably reflects their previous low level of awareness of biobanks. See Table 5 for further details.

Willingness To Participate In Biobank Research

The total willingness score of 10.42 ± 5.17 (maximum possible points 25) reflects a low willingness to participate in research. Almost three-quarters of respondents indicated that they would refuse to give any type of sample to participate in research and 80.2% would refuse to provide medical information. See Table 6 for further details.

Table 4
Participants' attitudes toward biobank research. (n = 967)

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Donation					
1. People should donate biological samples to improve the health of future generations.	10 (1.0)	18 (1.9)	144 (14.9)	388 (40.1)	407 (42.1)
2. People should donate biological samples even if there will not be a direct health benefit to them.	37 (3.8)	129 (13.3)	206 (21.3)	339 (35.1)	256 (26.5)
3. People who donate biological specimens should receive financial compensation that is in addition to any travel expenses.	55 (5.7)	116 (12.0)	223 (23.1)	312 (32.3)	261 (27.0)
Storage					
4. If people change their minds, they should have the right to withdraw their consent for the use of their biological samples.	21 (2.2)	71 (7.3)	119 (12.3)	337 (34.9)	419 (43.3)
Privacy					
5. Researchers must maintain the privacy of a donor's medical information when they perform research.	3 (0.3)	14 (1.4)	82 (8.5)	178 (18.4)	690 (71.4)
Data Sharing					
6. It is acceptable for biological samples to be shared with researchers at other institutions in my country.	49 (5.1)	63 (6.5)	153 (15.8)	402 (41.6)	300 (31.0)
7. It is acceptable for samples to be shared with researchers at institutions in other countries.	81 (8.4)	141 (14.6)	195 (20.2)	346 (35.8)	204 (21.1)
8. The legal authorities should have the right to obtain my genetic results when necessary.	96 (9.9)	127 (13.1)	174 (18.0)	337 (34.9)	233 (24.1)
9. Researchers should receive governmental approval prior to exporting samples out of the country.	26 (2.7)	46 (4.8)	122 (12.6)	300 (31.0)	473 (48.9)
Return of results					
10. If the analysis of my biological specimens reveals a disease that can be treated or prevented, then either I or my doctor should be informed of these results.	11 (1.1)	11 (1.1)	76 (7.9)	222 (23.0)	647 (66.9)
11. Even if the analysis of my biological specimens reveals a genetic disease that cannot be treated or prevented, I still want to be informed of these results.	20 (2.1)	39 (4.0)	91 (9.4)	262 (27.1)	555 (57.4)
Total attitudes score, mean ± SD	21.91 ± 6.03				

Table 5
Participants' attitudes toward trust and privacy. (n = 967)

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1. I worry about the privacy of my medical information when I share it with my doctor.	192 (19.9)	293 (30.3)	141 (14.6)	217 (22.4)	124 (12.8)
2. I worry about the privacy of my medical information when I share it with researchers.	209 (21.6)	339 (35.1)	171 (17.7)	174 (18.0)	74 (7.6)
3. I trust the individuals in charge of biobanks	71 (7.4)	113 (11.7)	392 (40.5)	270 (27.9)	121 (12.5)
Total "trust/privacy" score, mean ± SD (Minimum-maximum)	8.07 ± 2.38 (3-15)				

Table 6
Participants' willingness to participate in biobank research. (n = 967)

	Definitely Yes	Probably Yes	Not Sure	Probably Not	Definitely Not
1. If you are asked to give your medical information for research, would you agree to do it?	40 (4.1)	48 (5.0)	103 (10.7)	353 (36.5)	423 (43.7)
2. If you are asked to give saliva for research, would you agree to do it?	60 (6.2)	70 (7.2)	100 (10.3)	326 (33.7)	411 (42.5)
3. If you are asked to give a urine sample for research, would you agree to do it?	59 (6.1)	84 (8.7)	98 (10.1)	318 (32.9)	408 (42.2)
4. If you are asked to give a blood sample for research, would you agree to do it?	72 (7.4)	82 (8.5)	113 (11.7)	310 (21.1)	390 (40.3)
5. If you are asked to participate in genetic research, would you agree to do it?	85 (8.8)	104 (10.8)	188 (19.4)	305 (31.5)	285 (29.5)
Total Willingness score, mean ± SD	10.42 ± 5.17				

Preferences For Types Of Informed Consent

Regarding the preference for the type of informed consent when donating a biospecimen, more than 60% favored two types of informed consent. One included the use of tiered consent with coded samples (59.9%), and the other was recontacting donors for future research (64.7%). Less than a majority favored a broad consent model whether the samples were coded or irreversibly anonymized (Fig. 1).

Correlations Between Scores Of The Different Constructs

Several correlations were found between these different constructs. There was an inverse relationship between accurate perceptions of biobanks with the following constructs: “aspects of biobank research that affect willingness to donate”, “attitudes toward biobank research”, and “willingness to participate in biobank research”. There were, however, strong associations of several constructs with the “willingness to participate in biobank research”. These included “aspects of biobank research that affect willingness to donate”, “attitudes towards biobank research”, and “attitudes toward trust and privacy”. See Table 7 for further details.

Associations Between Demographic Characteristics And The Different Constructs

There were significant associations between several of the demographic parameters and the different constructs. For example, higher scores regarding “perceptions about biobank research” were associated with females compared with males, having children than no children, and previous participation in research. Regarding “aspects of biobank research that affect willingness to donate”, lower scores on this construct were associated with being female, previous research participation, not healthy vs. healthy, and having a university degree and higher. None of the demographic variables showed significant associations with the construct “attitudes toward biobank research.” Significant associations for “attitudes regarding trust and privacy” were found with living in a rural area compared with urban living and having a degree below the level of a university degree compared with a degree at or higher than the university level. Willingness to participate in biobank research was associated with having children, not previously participating in research, being less than 40 years old, and having a less-than-university degree. See Table 8 for further details.

Table 7

Correlation between participants' scores in the different constructs: results of Pearson's Correlation coefficient (p-value). (n = 967)

	Perceptions about Biobank Research	Aspects of biobank research that affect willingness to donate	Attitudes towards biobank research	Attitudes toward trust and privacy	Willingness to participate in biobank research
Perceptions about Biobank Research	1	-0.06(0.049)	-0.18(< 0.001)	0.06(0.08)	-0.23(< 0.001)
Aspects of biobank research that affect willingness to donate		1	0.53(< 0.001)	0.14(< 0.001)	0.31(< 0.001)
Attitudes toward biobank research			1	0.14(< 0.001)	0.48(< 0.001)
Attitudes toward trust and privacy				1	0.07(0.04)
Willingness to participate in biobank research					1

Table 8

Association between participants' demographics and questionnaire domain scores.* (n = 967)

	Perceptions about Biobanks		Aspects of biobank research that affect willingness to donate biospecimens		Attitudes towards activities in biobanking research		Attitudes towards trust and privacy		Willingness to participate in research	
	Mean \pm SD	p-value	Mean \pm SD	p-value	Mean \pm SD	p-value	Mean \pm SD	p-value	Mean \pm SD	p-value
Area										
Rural	28.73 \pm 3.79	0.72	17.66 \pm 6.38	0.30	21.88 \pm 6.16	0.93	8.57 \pm 2.48	0.01	10.13 \pm 4.96	0.42
Urban	28.86 \pm 3.76		17.10 \pm 6.04		21.92 \pm 6.01		7.96 \pm 2.35		10.48 \pm 5.21	
Gender										
Female	29.11 \pm 3.58	0.04	16.42 \pm 5.38	< 0.001	21.88 \pm 5.71	0.87	8.23 \pm 2.37	0.06	10.58 \pm 5.11	0.41
Male	28.62 \pm 3.89		17.80 \pm 6.54		21.94 \pm 6.28		7.94 \pm 2.38		10.30 \pm 5.21	
Children										
Yes	28.85 \pm 3.83	0.69	17.26 \pm 6.81	0.73	21.84 \pm 5.93	0.72	8.07 \pm 2.29	0.97	10.82 \pm 5.28	0.03
No	28.82 \pm 3.72		17.13 \pm 5.43		21.98 \pm 6.13		8.06 \pm 2.45		10.09 \pm 5.06	
Previous Participation in Research										
Yes	28.87 \pm 3.96	0.71	16.37 \pm 5.30	0.04	21.37 \pm 5.82	0.20	7.87 \pm 2.35	0.27	9.13 \pm 4.56	< 0.001
No	28.83 \pm 3.73		17.35 \pm 6.23		22.02 \pm 6.07		8.10 \pm 2.39		10.68 \pm 5.25	
Age Group										
< 40	28.75 \pm 3.74	0.71	17.32 \pm 6.29	0.17	22.03 \pm 6.20	0.25	8.11 \pm 2.41	0.27	10.59 \pm 5.31	0.046
> 40	29.13 \pm 3.84		16.73 \pm 5.34		21.53 \pm 5.43		7.91 \pm 2.25		9.85 \pm 4.61	
Medical Condition										
Healthy	28.90 \pm 3.74	0.28	17.34 \pm 6.17	0.03	21.95 \pm 6.09	0.60	8.06 \pm 2.41	0.95	10.40 \pm 5.19	0.77
* p-values \leq 0.05 are bolded										

	Perceptions about Biobanks		Aspects of biobank research that affect willingness to donate biospecimens		Attitudes towards activities in biobanking research		Attitudes towards trust and privacy		Willingness to participate in research	
Non-Healthy	28.40 ± 3.89		16.22 ± 5.51		21.67 ± 5.65		8.08 ± 2.25		10.55 ± 5.09	
Education Level										
Less than University	28.67 ± 3.95	0.56	17.86 ± 6.54	0.04	22.47 ± 6.32	0.08	8.40 ± 2.51	0.01	11.18 ± 5.83	0.01
University and higher	28.90 ± 3.68		16.91 ± 5.89		21.69 ± 5.90		7.93 ± 2.31		10.11 ± 4.84	
Marital Status										
Never married	28.53 ± 3.84	0.02	17.21 ± 6.33	0.91	22.09 ± 6.12	0.37	8.10 ± 2.46	0.65	10.76 ± 5.39	0.045
Ever married	29.14 ± 3.67		17.17 ± 5.86		21.74 ± 5.95		8.03 ± 2.30		10.09 ± 4.92	
Degree of Religiosity										
Not and Less than very religious	28.86 ± 3.71	0.88	17.13 ± 5.97	0.51	22.03 ± 6.07	0.13	8.10 ± 2.36	0.23	10.49 ± 5.21	0.27
Very religious	28.7 ± 4.11		17.54 ± 6.81		21.21 ± 5.80		7.83 ± 2.48		9.99 ± 4.91	
Awareness of the term "biobank"										
No	28.82 ± 3.86	0.22	17.81 ± 6.39	0.001	22.35 ± 6.22	0.004	8.05 ± 2.47	0.98	10.86 ± 5.23	< 0.001
Not sure	28.46 ± 3.50		17.17 ± 6.63		21.90 ± 6.04		8.11 ± 2.20		10.80 ± 5.16	
Yes	29.08 ± 3.73		16.09 ± 5.21		21.13 ± 2.20		8.04 ± 2.30		9.41 ± 4.92	
* p-values ≤ 0.05 are bolded										

Predictors Of Willingness To Participate In Biobank Research

There were several predictors for "willingness to participate in biobank research". These included previous participation in research, individuals with children, "attitudes toward biobank research", and "aspects of

biobank research that affect willingness to donate”. Perceptions about biobank research had a negative influence on “willingness to participate in biobank research”. See Table 9 for further details.

Table 9
Predictors of willingness towards participation in biobank research. (n = 967)

Predictor	(95% confidence interval)	P-value
Age (1 year)	-0.01(-0.04-0.02)	0.48
Participants with children (Yes vs No)	0.89(0.17–1.61)	0.02
Previous participation in research (Yes vs No)	-1.02(-1.78-)-0.25()	0.01
Education (university and higher vs less than university)	-0.60(-1.23-0.02)	0.06
Marital status (Ever married vs Never married)	-0.33(-0.89-0.23)	0.24
Awareness of the term “biobank” (yes vs no/not sure)	-0.57(-1.20-0.06)	0.08
Perception of Biobanks (1 unit increase)	-0.20(-0.28-(-0.13))	< 0.001
Attitudes towards biobanking research (1 unit increase)	0.35(0.29–0.41)	< 0.001
Aspects of biobank research that affect willingness to donate (1 unit increase)	0.06(0.004–0.11)	0.04
Attitudes about trust and privacy (1 unit increase)	-0.003(-0.12-0.12)	0.96

Discussion

Our study involving several LMICs in the Middle East demonstrated that the public awareness of biobanks is low and that only a small proportion of our participants were willing to participate in biobank research. Several demographic variables were associated with a willingness to donate. These included younger age, having children, previous participation in research, locality (rural greater than urban area), and level of education (less than a university degree compared with having a university degree or higher). These results compare with Mezinska and colleagues who also reported that younger people in Latvia are more willing to donate biospecimens, but they also showed, in contrast with our study, that higher education levels were associated with a higher degree of donations [28]. Surveys of the public from Jordan and Morocco also found that younger age is correlated with a willingness to participate in research [12, 26]. In a recent study of university students in Jordan, willingness to participate in biobanks was 90% for genetic and biobanking research, which is much higher than the results obtained in this study, reaching [29].

We also showed a relationship between the willingness to donate biospecimens to a biobank and several of the investigated constructs. These constructs included the importance of certain aspects of biobank research that affect willingness to donate, attitudes toward biobanks, and attitudes toward trust and

privacy. Perceptions about biobanks, however, had a negative association with a willingness to participate in research. In other words, individuals who had an enhanced perception of biobanks were less willing to participate in biobank research.

Our results show a low level of willingness to participate in biobank research compares with other studies [30] but is significantly lower than previous studies conducted in Egypt, Jordan, and Morocco, which were 85.3, 84%/65%, and 80.7%; respectively [12, 23, 26, 31]. Higher results for these studies compared with the present study can be explained by differences in demographics regarding age, level of education, and locality (i.e., rural vs. urban).

The essence of biobanks is sharing of biospecimens and related information with other researchers. It is, therefore, crucial to determine which features of biobank research activities adversely affect individuals' willingness to donate. Of the aspects we explored in this study, we found that sharing biospecimens and data with researchers from other countries was "not important" to only 26.6% of our respondents. This result is consistent with our finding that approximately 60% of our participants "disagreed" with the attitude that it is acceptable for samples to be shared with researchers at other institutions.

The alleged concern with sharing data in the international context corroborates the finding of Abou-Zeid and colleagues who showed in a survey conducted in 2010 that Egyptians' reluctance to share biospecimens and data with Western countries was more than with researchers in Arab countries [32]. Similarly, in an international study, Middleton and colleagues showed that Egyptians were among the populations that resisted data sharing [14]. Furthermore, Jordanian university students were less eager to participate in a biobank managed by a non-Arab entity compared with the government or an Arab institution (but more than a private sector) [29]. Ahram and colleagues showed that among Jordanians there has been an apparent change of opinion regarding data sharing between 2010 and 2020. Specifically, approximately 60% in 2010 thought that the involvement of non-Jordanian researchers with their biospecimens and health data would not influence their decision to participate in biobanking research as only 15% thought it would have a negative influence [24]. However, in a follow-up study in 2020, over 80% of survey respondents thought that the possibility of transferring biospecimens outside the country would negatively affect their approval to give an open consent for biomedical research [33].

In contrast, studies from other regions demonstrate higher rates of approval of data sharing. For example, in a study exploring the public attitudes in Latvia, approximately 70% of the participants would favor sharing of biobank samples among EU countries [28]. This was also evident in a study conducted in South Africa in which more than 70% of respondents agreed to share their samples with institutions in foreign countries [34]. Other studies have shown that the public appreciates the importance of sharing and its role in enhancing scientific discoveries and improving healthcare [35–37]. This value of data sharing appears to be a global trend, as recently reported by the multi-national study of Middleton et al. [14]. In contrast, openness to data sharing was not found among the Swiss public, where only 11.7% of survey respondents were willing to donate their data freely [38].

Several factors might explain the reluctance to data sharing. For example, Shabani and colleagues analyzed 15 empirical studies investigating the attitudes of research participants and the public towards genomic data sharing through public databases [39]. Their results revealed a wide variety of interrelated concerns with data sharing, including the personal perceptions of controllability and sensitivity of data, potential risks, and benefits of data sharing at individual and social levels, and also governance considerations.

Pawlikowski and colleagues explored the associations between the willingness to donate samples to biobanks and selected psychological variables. These variables included trust in doctors and scientists, a tendency towards risk, certain personality traits, a sense of and searching for meaning in life, and preferred values such as work, helping others, travels, personal development, tradition, and knowledge [40].

Kalkman and colleagues performed a narrative review of the empirical evidence addressing patients' and public views and attitudes towards the use of health data for research purposes [41]. They showed that support for data sharing for health research is conditioned on the value of the research, risk minimization, protection of privacy, data security, transparency, trust, and accountability.

Trust appears to be a common factor in all of these studies. Our study corroborates the importance of trust regarding biobank research. Specifically, we showed that a majority of our participants did not trust doctors or scientists to protect the privacy of their information, and many did not trust individuals in charge of biobanks. Similarly, Iott and colleagues showed that patients' trust in physicians is associated with their information-sharing concerns or behaviors [42]. Dive and colleagues reported the results of the Australian public attitudes toward the networking and globalization of biobanks. Using quantitative and qualitative methods, they explored factors that may contribute to or threaten trust. Their results indicated a generally high level of trust in biobanks and medical research more broadly, but key factors that can reduce the perceived trustworthiness of biobanks involved issues related to commercialization and participation in global networking. They recommended that robust ethical oversight and governance standards can promote trust in global biobanking.

Other studies have found that trust towards researchers depended on the nature of the entity where they were employed. For example, concerns towards researchers working for commercial and private (e.g., for-profit) have been demonstrated in many studies [14, 37, 43–45]. However, the reluctance with data sharing with academic researchers has been variable. A high level of mistrust regarding academic researchers was shown in one study from the US [46]. In contrast, a high level of trust was reported in an Australian study [47] and in a study conducted in the US [48].

Trust and privacy are intimately related as trust plays a role in the willingness of individuals to share their private information. We showed that a majority of our participants did not trust doctors or scientists to protect the privacy of their information. For example, Abdelhamid and colleagues also demonstrated that privacy concerns had the most influence on individuals' intentions to share their "protected health information" electronically with health care providers [49].

Our result contrasts with other studies showing that health care providers are the most trustworthy individuals among the public [37, 44, 45]. Middleton et al. found similar findings whereby physicians received the highest level of trust [14]. In contrast to our study, Middleton and colleagues also revealed that Egyptians had the highest level of trust in their physicians.

A reluctance to data sharing could also be related to potential discrimination, confidentiality breaches, and misuse of data for commercial or marketing purposes [50]. These results are contrary to what has been reported in the US and Australia, where people were more comfortable with sharing their biospecimens and data with local researchers [43, 46]. The situation is also different among Canadians who were more welcoming to share their biospecimens and information with international researchers [51].

The importance of trust and privacy protection probably played a role in our respondents' choices for informed consent. Most selected either a biobank with the option of re-consenting every new secondary biospecimen research (study-specific consent) or a tiered consent model with coded samples (categorical consent). Both types of consent offer the most degree of autonomy and a high level of control compared with broad consent. In general, other studies have shown a lack of consensus on the preferred type of consent [48, 51], while others have shown a preference for broad consent [52]. The preference for broad consent among Australians was influenced by whether the biobank is in Australia or overseas [43]. In a US study involving an exploratory mixed methods design, Simon and colleagues showed that broad consent (i.e., research-unspecific consent) was preferred over categorical and study-specific consent models for purposes of approving future research use [53]. Studies conducted in the Arab region of the Middle East (Jordan and Morocco) showed a preference for broad consent [25, 26]. However, in a questionnaire study involving 600 Egyptians, many participants favored a tiered consent model or a preference for recontact [32]. An overview of the studies that assessed the public preference for consent forms for biobanks suggests no consensus even within the same population [18].

Inadequate perceptions might also play an essential role in an unwillingness to share biospecimens and data with international researchers. For example, a significant proportion of our respondents thought that biobank research might lead to human cloning (16.3%) or the manufacturing of biological weapons (32.9%). Such a misperception warrants efforts to inform the public of the actual risks and benefits of biobanking, as the lack of accurate information regarding biobanks can hinder participation in such research [13, 54, 55].

We found certain factors to be of little importance to the Arab public. These included receiving potential health benefits from their donation and obtaining research results from the analysis of their specimens. Returning research results were not found to promote the public to participate in biobanking research. However, in a recent study, many Jordanians were not in favor of receiving research results regardless of whether the results revealed a treatable or untreatable disease [56]. This is contrary to previous studies showing that Egyptians desired in having such information added to their medical files [23] and that most Jordanians expressed an interest in performing genetic testing to learn if they would develop cancer [57].

We demonstrated that the level of awareness of biobanks was not significantly associated with a willingness to participate in biobank research. This result compares with other studies investigating the views of the public toward biobanks. For example, Mezinska and colleagues surveyed the Latvia public regarding their awareness and attitudes toward biobanks and showed only a quarter of the participants were aware of biobanks and that awareness was significantly associated with education, income, residential status, and place of work [28]. These investigators also showed that despite a low awareness, most participants either would definitely or probably be willing to provide health information about themselves to a biobank. Similar results regarding awareness and willingness were shown in a study performed in Egypt [23]. Other studies from Europe have shown a high willingness to donate samples and information to a biobank despite low awareness.

Our participants' level of awareness (29.9%) regarding biobanking compares with other studies performed in the Middle East. For example, in a study performed in Jordan, only approximately 26% of a representative sample of the population knew what the term "biospecimen" represented [12]. This result is surpassed by newer studies from Egypt [23], Eastern Moroccans [26], and, more recently, Jordan [31], in which the rates of awareness were 53.7%, 32.4%, and 28/5%; respectively.

We found that the level of awareness about biobanks was not a predictor of a willingness to participate in biobank research. Accordingly, raising awareness alone would not be sufficient for promoting the willingness to donate samples and personal data [28]. One possible approach might consist of promoting collaborative biobank governance that involves "the different interests of patients/donors, (public) funding agencies, clinicians/researchers acting as stewards of the hosted biosamples" [58]. Such collaboration would preclude having scientists as the main responsible agent for the stewardship of the specimens [28]. As shown in the fields of business, a broader understanding of partnerships that moves towards active engagement of stakeholders can be highly beneficial in allowing researchers to focus on the needs of the public and enable them to understand what is valuable to these other stakeholders [59–62]. This approach of active collaborative engagement would ensure that the public is not a mere bystander in biobank activities [63].

Limitations

We recognize several limitations of our study. The most prominent limitation is that the findings cannot be generalized. Several reasons explain this limitation. First, the survey involved only four Arab nations and did not include others like Qatar, which has an established biobank. Although the four nations encompass a wide array of different Arab nationals, they did not include people from the affluent Gulf region like Saudi Arabia and Qatar. Second, most respondents were mainly educated individuals holding a bachelor's degree and higher and did not include many of those with lower educational backgrounds.

In contrast, one could argue that patients should be targeted instead of the public since they are the ones that are usually recruited for specific research projects or to donate to a specific biobank. In addition, responses do not reflect actual public participation, which may be influenced by many personal and social factors not covered in the survey. Another limitation is the degree of understanding of respondents to

health-related research, particularly in genomics, and the risks associated with data sharing. Another point worth mentioning is that the survey was distributed at the start of the COVID-19 pandemic, which may have influenced people's attitudes given the conflicting scientific information broadcasted to the public at that time and the harm inflicted on the credibility of biomedical research. Despite these limitations, the study adds a novel contribution to the literature that lacks information in this region and opens the door for further research.

Conclusions And Recommendations

Our study demonstrates challenges to enhancing participation in biobank research that involve addressing imperfect perceptions, misplaced attitudes, and other aspects that could be influential in participation. Specifically, some of these factors raise concerns about the future of biobanks in the Arab region.

We encourage the initiation of awareness campaigns and fostering communication with the public regarding biobank research. We recommend qualitative exploratory studies to understand better the cautious attitudes of the Arab public toward biobanking and genomic research. The establishment of biobanks in the Arab regions must consider the motivators of potential biobank donors and the challenges. Enhancing willingness will facilitate collaborative research with international researchers and adherence to international standards and regulations. In addition, the active engagement of the public is expected to promote a culture of scientific research in all disciplines.

Our results can be useful in building the social responsibility of biobankers and scientists, issuing more appropriate opinions by research ethics committees, and planning better communication strategies between the public and the stewards of biobanks.

Declarations

Ethics approval and consent to participate: All methods were carried out in accordance with relevant guidelines and regulations. This study received ethical approval from the following research ethics committees: The institutional Review Board, Jordan University Hospital, The University of Jordan, Amman, Jordan (Ref: 67/2019/5766; October 23, 2019); The Research Ethics Committee, Faculty of Medicine, Suez Canal University, Ismailia, Egypt (Ref: 3982; October 29, 2019); Faculty of Medicine, University of Khartoum (Ref: FM/DO/EC, January 22, 2020); Comité d'éthique hospitalo-universitaire de Fès (Ref: 13/19, November 28, 2019).

After accessing the link, participants would be presented with an information page that provided more details about the survey study including that participation was voluntary and that responses were collected anonymously. Subsequently, participants were given two options: "Agree" or "I do not agree." Choosing "Agree" indicated that participants provided their informed consent.

Consent for publication: Not applicable

Availability of data and materials: The datasets during and/or analyzed during the current study are available at https://osf.io/263vu/?view_only=2a1d02a68dcd4334a800a39cd01ef51d

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Figures

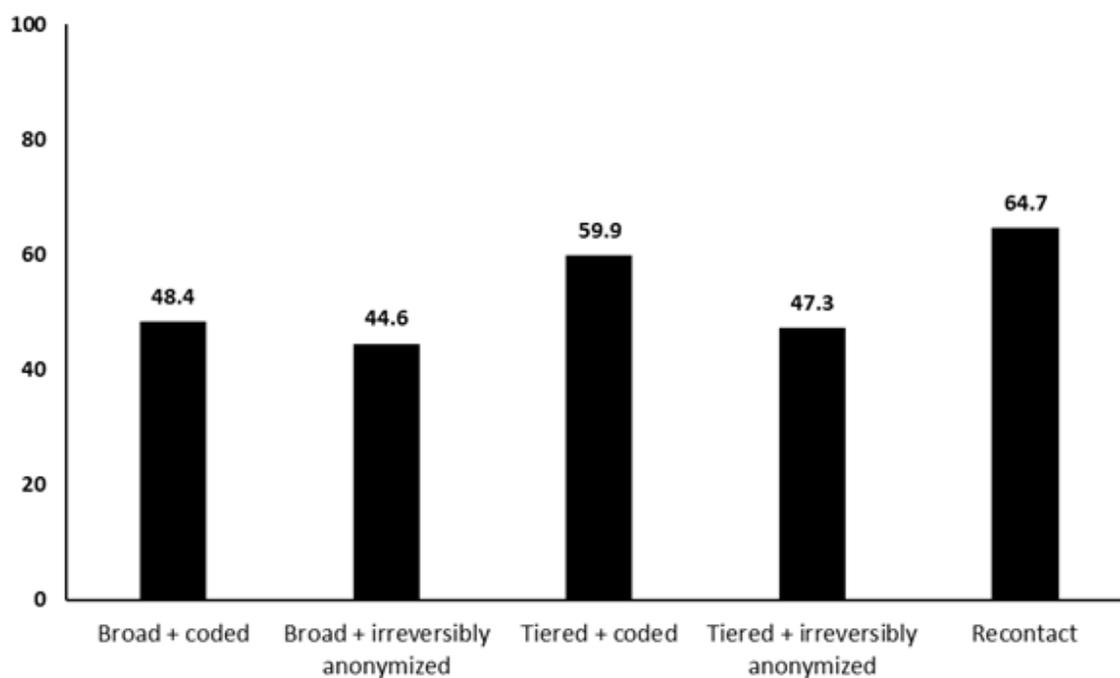


Figure 1

Participants' preferences towards types of informed consent (agree +strongly agree). (n= 967)

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