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ORIGINAL RESEARCH

Jordanians' Perspectives On Open Consent In Biomedical Research

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Introduction: The informed consent process is an integral step in biomedical research. However, the emergence of biobanks and the need for open consent (also called "broad" or "blanket" consent) create challenges to this process.

Aims and methodology: A survey was used to examine Jordanians' perspectives on open consent and reuse of stored samples in future research.

Results: The majority of participants had positive perceptions of informed consent and its importance. In addition, they appreciated the challenges that are associated with multiple uses of their biospecimens. About 55% agreed to provide open consent for reuse of their donated biospecimens. Participants (75–80%) also agreed that issues such as the possibility of sharing samples with international research centers, storage duration, and use of biospecimens after their death should be clarified as part of open consent. The inconvenience of the re-contact process, trust in the research team, and the importance of biobanks were all associated with participants' willingness to provide open consent ($P<0.05$). On the other hand, privacy and confidentiality, doubt about future use of samples, unknown storage period, and the possibility of cross-border sample sharing were significantly associated with participants' reluctance to provide open consent.

Conclusion: The majority of Jordanians accept the idea of open consent. Clarification of issues such as international sample sharing, duration of storage, domains of intended research, confidentiality, and privacy can provide more support for the use of open consent.

Keywords: open consent, sample storage, sample reuse, biobank, human ethics, human research

Introduction

The consent process sets out to actively document, usually in writing, participants' willingness to be involved in a specific study.[1] A valid consent process requires participants to be provided with adequate and thorough information about the nature of the study and the possible implications of their participation. As such, each study has a separate informed consent process and requires the participants to sign a new consent form.[2]

In the era of biobanking, samples may be stored and reused for different research purposes, raising the question of whether a new consent process is required. Re-contacting sample donors before each new study may overwhelm the research process, owing to the time and effort involved, as well as the likelihood of having to exclude some samples because the donors have become unreachable.[3]

The open consent model is considered an acceptable way to avoid such problems. It gives more weight to the importance of the general public perception of research, while preserving individuals' rights to choose whether to provide their open consent.[4]

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According to this model, donors to biobanks agree that their samples may be reused for future research purposes. The donors thus authorize local review board committees and biobank authorities to take decisions on their behalf regarding the use/reuse of their samples and data records for research purposes. However, this process can create some ethical controversies related to loss of privacy and confidentiality, as well as respect for the participant's autonomy.[5–7] Nevertheless, despite these concerns, open consent is widely used and supported by various experts and organizations when precautions such as data de-identification are applied.

Several studies have investigated participants' preferences regarding reuse of collected biospecimens and health information and their perspectives on the open consent model; this is particularly important, given the recent interest in developing biobanks around the world.[8–10] Therefore, the aims of this study were to explore and understand Jordanians' perspectives on the open consent model and to explore expectations and concerns. The results should inform the design of an effective consent policy and help to establish new policies to promote scientific research while taking into consideration participants' rights and preferences.[11,12]

Materials And Methods

Study Design And Study Population

This cross-sectional, survey-based study was approved by the Institutional Review Board (IRB) committee at King Abdullah University Hospital. In total, 500 questionnaires were obtained from Google forum; 24 of these were excluded from the analysis as they were not filled in correctly. Questionnaires from participants older than 18 years were accepted and were representative of Jordanian socioeconomic and demographic classes. Recruitment of participants was done using social media such as Facebook and WhatsApp. Recruitments were performed between May and June 2017.[13]

Study Instrument

The study instrument was a questionnaire composed of serial questions that focused on participants' perspectives on the importance of obtaining informed consent and their attitudes toward using the open consent model. Factors that might affect the attitudes of participants toward open consent were also included in the questionnaire. These include sharing samples with foreign research centers, storage duration, biospecimen use after participants' death, the convenience of the re-contact process, trust in the research team, the importance of biobanks, privacy and confidentiality, doubt about future use of samples, and the prospect of cross-border collaborations.

A preliminary questionnaire was tested with a few participants to confirm the questionnaire's validity and clarity. A final version of the questionnaire was then developed and distributed to participants using Google forums over 2 months in 2017. The questionnaire was initially written in English and then translated to simple Arabic language. Before each section/domain, a short paragraph was added to provide a brief explanation of the surveyed topic and the terms used.

The following information was given to participants before they were asked about their perspectives on the informed consent process:

Before participation in research, researchers must document participants' approval for participation, and individuals who enroll in the study are asked to sign a specially designed form, the "informed consent form.

> The informed consent process protects participants by providing participants with all the necessary information regarding their participation. It determines the objectives, the importance, the potential benefits, and the potential risks of participation. If the study involves biospecimen collection, the consent form determines the type and the quantity of the sample to be collected. The consent form must also place emphasis on protecting the privacy and confidentiality of the participants' personal information and confirming the participant's right to withdraw from the research when they demand to do so.

For the final section in the questionnaire, the following paragraphs were displayed to participants before they were asked about their perspective on the open consent process:

> There are different models to obtain participants' informed consent: the consent model applied in biobanks is called the open consent model, where individuals agree in advance to store and reuse their collected biospecimens for future research that is not yet determined without re-contacting them.
>
> There is a controversy over obtaining this type of consent; some experts believe that researchers should not be allowed to obtain individuals' consent for future studies that are not yet defined, out of concern over possible threats to participants' autonomy.
>
> Others believe that participants' open consent should be taken as allowing researchers to conduct studies on their samples without re-contacting them, to develop, facilitate, and advance scientific research.

This careful design was necessary because the pilot sampling indicated a lack of participant knowledge in this area; therefore, the validity of their answers might have been jeopardized without such explanations.

Participants' attitudes toward and perspectives on the concept of signing an open consent form were evaluated using a 5-point Likert scale. Participant identification was not requested, but they were asked to provide their consent using a mandatory agreement page regarding participation in the study before being able to open the questionnaire or answer any question.

The questionnaire's sections about the open consent model were composed of four major domains: (1) demographic and socioeconomic characteristics; (2) previous research experience; (3) perspectives on the value of informed consent; and (4) perspectives on the open consent model.

Statistical Analysis

Data were analyzed using SPSS® version 17. Simple descriptive statistics were used to report participants' characteristics, and their frequencies and distribution. Cross-tabulation (Pearson Chi-square) was used to assess the relationship between participants' characteristics and their attitudinal statements. Correlations between responses within each statement and the overall willingness to provide open consent for future research were assessed by calculating the Spearman rho correlation coefficient (non-normally distributed scale).

Results

The study sample had almost equal proportions of each gender (52% female, 48% male). Approximately 50% of the participants had never participated in research before this study, while the other half had either participated in research before (~46%) or had been invited but refused to participate (3.6%). Slightly more than half of the participants (~60%) reported that they had no experience or prior knowledge of the term "informed consent," and around 40% indicated that they did have such prior knowledge.

Participants' Perspectives On Open Consent

The majority of participants showed positive perceptions of the informed consent process and agreed that obtaining consent before research participation would make the research credible and ethical, and provide good protection of their rights (Table 1).

About 80% of the participants agreed that, before they took part in research, they would need to know the specific research purposes for which their biospecimens would be used (Figure 1). However, when respondents were asked about their attitudes toward requiring researchers to contact participants for every single use of their stored samples (Table 2), 67% agreed that this might create extra strain. Prior participation in research was significantly associated with the latter statement (χ^2=19.54, P=0.012).

Figure 1 shows the respondents' perspectives on the open consent model. Around two-thirds of participants thought that open consent might not give them adequate control over the future use of their biospecimens, adequately protect their rights, or show them sufficient respect and that the process might not provide them with enough information to give meaningful consent. The latter statement showed a strong statistically significant association with prior knowledge of research (χ^2=24.2, P=0.002) and a higher level of education (χ^2=22.77, P=0.004).

Nonetheless, 55% of the participants agreed that they would provide open consent for storage and reuse of their donated biospecimens; 66% of the participants were more willing to give their open consent to study a specific disorder or a list of related disorders (Figure 1).

Table 3 shows respondents' attitudes towards the options that could be provided on informed consent forms regarding the collection and future use of blood samples. About 80% of the participants agreed with the need for consent forms to provide an option to determine whether the sample could be transferred to another country, and 88% of the participants stated that an open consent form should provide participants with options regarding the duration of storage of the collected biospecimens. About 80% of the participants agreed that options for the use of samples after the death of participants should be provided. Moreover, 82% of the participants agreed that they should be given adequate knowledge and have the choice to sign either a single consent or an open consent form before any study.

Correlation Of Various Factors With Willingness To Provide Open Consent To Allow Storage/Reuse Of Biospecimens For Future Research

The Spearman rho correlation coefficient was used to determine which factors correlate with willingness to provide open consent to allow storage/reuse of donated specimens in future research. Table 4 shows perspectives

Table 1 Participants' Perspectives On The Informed Consent Process

Participants' View On The Consent Process (%)		Helps Make The Research Credible And Ethical					Provides Greater Protection For Participants' Rights					Provides The Participants With A Certain Level Of Control If The Researchers Breached The Agreed Terms					Participants' Consent Should Always Be Obtained For Any Future Research				
		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Gender	Female	54.1	42.6	2.0	1.2	0.0	60.7	36.1	3.3	0.0	0.0	52.9	43.0	2.9	0.8	0.4	58.8	33.3	4.1	2.5	1.2
	Male	50.5	44.6	4.1	0.9	0.0	51.1	41.7	6.3	0.9	0.0	50.5	42.3	6.8	0.5	0.0	51.8	36.9	7.7	3.2	0.5
	χ^2 (P-value)	2.071 (0.558)					7.257 (0.064)					5.022 (0.285)					4.998 (0.287)				
Age (years)	18–29	54.7	40.6	3.2	1.4	0.0	55.8	39.6	4.7	0.0	0.0	51.4	43.5	4.3	0.4	0.4	52.5	36.3	6.8	3.2	1.1
	30–39	52.2	42.4	4.3	1.1	0.0	62.4	30.1	6.5	1.1	0.0	58.1	35.5	5.4	1.1	0.0	68.1	28.6	2.2	1.1	0.0
	40 and Over	45.3	53.7	1.1	0.0	0.0	50.5	45.3	3.2	1.1	0.0	45.7	47.9	5.3	1.1	0.0	51.6	37.9	6.3	3.2	1.1
	χ^2 (P-value)	7.166 (0.306)					8.098 (0.231)					4.939 (0.764)					9.499 (0.302)				
Education level (degree)	High school/ lower	46.4	50.0	3.6	0.0	0.0	60.7	32.1	7.1	0.0	0.0	53.6	39.3	7.1	0.0	0.0	48.1	48.1	0.0	3.7	0.0
	Undergraduate	51.9	43.7	3.2	1.3	0.0	55.5	38.2	6.0	0.3	0.0	51.1	42.9	5.4	0.3	0.3	52.5	36.4	6.6	3.2	1.3
	Graduate	55.0	41.7	2.5	0.8	0.0	56.7	41.7	0.8	0.8	0.0	52.9	42.9	2.5	1.7	0.0	65.0	28.3	5.0	1.7	0.0
	χ^2 (P-value)	1.357 (0.968)					6.675 (0.352)					5.143 (0.742)					10.463 (0.234)				
Residence	Town	44.7	50.5	4.9	0.0	0.0	50.5	41.7	7.8	0.0	0.0	48.0	43.1	7.8	0.0	1.0	51.5	33.0	10.7	2.9	1.9
	City	55.1	41.2	3.0	0.7	0.0	57.8	38.8	2.6	0.7	0.0	53.0	44.0	2.6	0.4	0.0	58.3	33.8	5.3	1.9	0.8
	Capital	54.3	41.5	1.1	3.2	0.0	58.5	34.0	7.4	0.0	0.0	53.2	37.2	7.4	2.1	0.0	53.2	39.4	2.1	5.3	0.0
	χ^2 (P-value)	10.778 (0.095)					9.071 (0.170)					14.946 (0.060)					13.160 (0.106)				
Monthly income JOD	<500	52.2	43.8	2.5	1.5	0.0	54.2	41.9	3.4	0.5	0.0	52.7	42.4	3.9	0.5	0.5	52.7	37.8	5.0	3.5	1.0
	500–1000	50.0	45.3	3.4	1.4	0.0	55.7	38.9	5.4	0.0	0.0	49.0	44.3	6.7	0.0	0.0	55.7	34.2	5.4	3.4	1.3
	>1000	55.0	41.3	3.7	0.0	0.0	59.6	33.0	6.4	0.9	0.0	52.8	41.7	3.7	1.9	0.0	58.7	33.0	7.3	0.9	0.0
	χ^2 (P-value)	2.521 (0.866)					4.536 (0.604)					6.816 (0.557)					4.981 (0.760)				

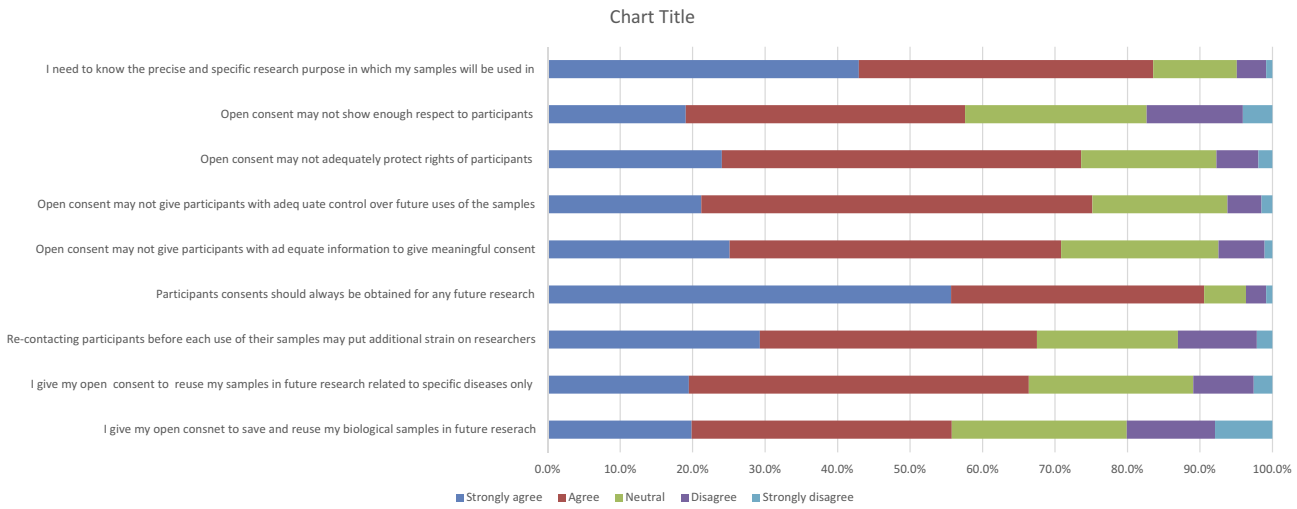

Figure 1 Participants' perspectives on open consent model.

on re-contact with participants before every use of stored biospecimens, which was considered as inconvenient to participants (r_s=0.379, P<0.001), a factor that puts extra strain on researchers (r_s=0.293, P<0.001), and a factor that would increase the likelihood of disclosure of participants' information (r_s=0.292, P<0.001). Trust in the medical research team had a positive influence on the willingness to provide open consent for future research on stored samples (r_s=0.356, P<0.001). As expected, willingness to provide open consent was associated with willingness to donate samples for establishing biobanks and for reuse in future research (r_s=0.222, P<0.001).

Willingness to provide open consent for future research also had a statistically significant negative correlation with many factors, including fear of negative effects of research on participants' privacy and confidentiality (r_s=−0.218, P<0.001), participants' lack of knowledge about the exact purposes of future studies (r_s=0.153, P<0.001), and the unknown storage period of samples (r_s=−0.127, P<0.01). Participants' reluctance to provide open consent was also correlated with fear of the possibility of cross-border collaborations and lack of trust in the intentions of researchers from other countries (r_s=−0.119, P<0.01) (Table 4).

Notably, even though a quarter of participants agreed that open consent is not a meaningful form of consent and that it does not adequately protect their rights or show them respect, none of these statements showed a significant positive or negative association with willingness to provide open consent (Table 4).

Discussion

Our study provides some insights into Jordanians' perceptions of an important aspect of advancing biomedical research: the willingness to provide open consent. Our participants were representative of Jordan's general population and major socioeconomic subgroups; owing to shared social and cultural backgrounds, they might also be representative of neighboring countries.

As we demonstrated, 40% of the participants indicated that they had some prior knowledge of the term "informed consent." The majority of participants showed positive perceptions of the informed consent process and agreed that obtaining consent before research participation would make the research credible and ethical and provide good protection of their rights. Prior knowledge of the informed consent process was significantly associated with participants' positive attitudes toward and perceptions of this consent process.

This clearly indicates the value of public education about research in general and, in particular, about the concepts of ethical and valid research practices.

Another interesting issue for between-studies comparison is the effect of trust on enthusiasm and willingness to provide open consent. In our study, trust appeared to have a major positive influence on the aforementioned aspects of research. Trust is an integral part of the advancement of biomedical research.[14–16] Numerous studies have found a positive correlation between the level of trust and readiness of individuals to donate biospecimens and provide open consent for biobanking.[16–18]

Table 2 Participants' Perspectives On Continuous Contact Regarding Their Storage Samples

Perspectives On Continuous Contact With Participants (%)		Continuous Contact With Participants Regarding Their Stored Sample Might Put Additional Strain On Researchers			Continuous Contact With Participants Regarding Their Stored Sample Might Be Inconvenient To Participants								Continuous Contact With Participants Regarding Their Stored Sample Might Increase The Likelihood Of Disclosure Of Participants' Information			
		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Gender	Female	27.9	37.3	20.9	12.3	1.6	18.9	28.7	28.7	19.7	4.1	23.8	39.8	27.5	7.8	1.2
	Male	31.2	38.5	17.6	10.0	2.7	22.1	38.3	20.7	14.4	4.5	24.5	44.5	23.2	5.5	2.3
	χ^2 (P-value)		**2.31 (0.679)**					**8.69 (0.069)**					**3.16 (0.531)**			
Age (years)	18–29	28.8	36.0	21.6	10.8	2.9	20.5	30.2	25.9	19.1	4.3	25.9	39.2	26.3	7.2	1.4
	30–39	33.7	33.7	18.5	13.0	1.1	23.7	31.2	25.8	15.1	4.3	23.9	41.3	27.2	6.5	1.1
	40 and Over	26.6	47.9	13.8	10.6	1.1	16.0	44.7	21.3	13.8	4.3	18.3	51.6	21.5	5.4	3.2
	χ^2 (P-value)		**8.28 (0.406)**					**8.03 (0.430)**					**6.90 (0.547)**			
Education level (degree)	High school	35.7	35.7	7.1	21.4	0.0	14.3	57.1	14.3	10.7	3.6	14.3	53.6	32.1	0.0	0.0
	Undergraduate	29.1	39.6	20.3	9.5	1.6	21.8	30.9	26.8	16.7	3.8	26.0	39.4	25.7	7.6	1.3
	Graduate	28.6	33.6	20.2	13.4	4.2	17.6	34.5	22.7	19.3	5.9	21.0	46.2	23.5	5.9	3.4
	χ^2 (P-value)		**10.92 (0.206)**					**10.52 (0.230)**					**9.75 (0.282)**			
Residence	Town	35.0	30.1	18.4	16.5	0.0	26.2	31.1	23.3	15.5	3.9	28.4	40.2	26.5	4.9	0.0
	City	28.2	39.8	20.3	9.4	2.3	17.6	35.6	24.3	18.0	4.5	22.2	44.7	22.9	7.9	2.3
	Capital	27.7	40.4	17.0	10.6	4.3	22.3	28.7	27.7	17.0	4.3	25.5	37.2	29.8	5.3	2.1
	χ^2 (P-value)		**3.124**					**0.926**					**2.759**			
Monthly income (JOD)	<500	32.2	35.6	18.3	10.4	3.5	23.2	28.6	28.1	15.3	4.9	25.2	40.1	28.2	5.0	1.5
	500–1000	26.4	41.2	18.9	13.5	0.0	17.6	35.8	25.7	16.9	4.1	23.1	43.5	23.8	8.2	1.4
	>1000	28.4	38.5	20.2	10.1	2.8	19.3	38.5	17.4	21.1	3.7	23.9	43.1	22.9	7.3	2.8
	χ^2 (P-value)		**7.71 (0.462)**					**8.97 (0.345)**					**3.79 (0.875)**			
Prior participation in research	Yes	33.5	34.9	17.7	13.0	0.9	22.2	30.1	23.6	20.4	3.7	25.1	42.8	24.2	7.0	0.9
	No	26.3	41.8	19.8	9.5	2.6	19.4	36.2	25.9	13.4	5.2	24.2	41.1	26.4	5.6	2.6
	Refused	18.8	18.8	37.5	12.5	12.5	6.3	31.3	31.3	31.3	0.0	6.3	50.0	25.0	18.8	0.0
	χ^2 (P-value)		**19.54 (0.012*)**					**10.15 (0.254)**					**8.70 (0.368)**			

Notes: * Significant at $P < 0.05$.

Table 3 Participants' Perspectives On Adding Specific Options To The Open Consent Form

	Clarification About Storage Period Of Samples	Clarification About Sample-Sharing With International Centers	Options For Sample Usage After Death	Options To Restrict Future Use Of Samples To A List Of Specific Diseases	Two Options Regarding Preferable Consent Model
Cumulative %	87.4	82.4	79.9	65.7	81.6
Gender					
Female	83.1	86	83	69.2	85.6*
Male	73.4	78.5	76	62.1	77.3
Age (years)					
18–29	75.6	80.5	78.3	65.5	80.2
30–39	83.4	81.6	82.5	64.9	84.9
40 and Over	82	88.4*	80.6	67	82.1
Education level (degree)					
High school	77.8	66.6	70.3	74.1	85.7
Undergraduate	78.8	83.9	80.1	65.7	80.2
Graduate	77.3	81.5	80.3	63.3	84.2
Residence					
Town	73.8	80.8	76.7	58.8	71.9
City	81.5	83.5	81.8	67.8	82.8
Capital	75.5	80.4	77.4	66.7	89.3*
Monthly income (JOD)					
<500	73.8	79.2	76.1	63.7	82.7
500–1000	80.3	87.1	81	69	79.2
>1000	83.4	80.7	83.4	64.2	83.5
Prior participation in research					
Yes	78.6	82.9	80.8	65	84.8
No	77.9	82.3	79.1	66.8	78.4
Refused	87.6	81.3	75.1	62.5	87.6
Knowledge of consent important					
Yes	76.5	80.8	77.3	65.9	80.3
No	80.7	84.7	82.8	63.9	81.9

Note: *Significant at P<0.05.

Regarding informed consent, 95% of the respondents agreed or strongly agreed with the importance of the consent process and its role in making the research ethical, credible, and more trustworthy. Ninety percent of participants agreed on the importance of a consent process before participation in research. Our results are consistent with those of other international studies, such as those done in the UK[19] and Japan,[20] where over 90% of the respondents agreed with the importance of the consent process in their decision to participate in a research study. Our results contradict those of the study by Ahram et al,[21] in which a majority of Jordanian respondents did not seem to be concerned about the existence of informed consent.

In our study, 55% of the participants were willing to provide their open consent to store and reuse their biological material for future research; this was lower than the percentage obtained by Ahram et al,[21] who found that more than 75% of the participants preferred the open consent model over the others. The willingness of participants to give their open consent was positively correlated

Table 4 Factors Affecting Participants' Willingness To Accept The Open Consent Model

Factors Correlated Positively With Participants' Willingness To Give Open Consent	r_s (P)	Factors Correlated Negatively With Participants' Willingness To Give Open Consent	r_s (P)	Factors Uncorrelated With Participants' Willingness To Give Open Consent	r_s (P)
Re-contacting participants before each use of their samples may be an inconvenience to participants	0.379**	Fear of the negative effects of research on privacy and confidentiality	−0.218**	Obtaining open consent may not show enough respect to participants	−0.048 (0.305)
I trust medical researchers to use/reuse my health information or biological samples	0.356**	Exact study purpose is not well defined	−0.153**	Obtaining open consent may not adequately protect the rights of participants	−0.016 (0.727)
Re-contacting participants before each use of their samples may put additional strain on researchers	0.293**	Unknown storage period of samples	−0.127*	Obtaining open consent may not give participants adequate control over future uses of the samples	0.036 (0.44)
Continuous contact with biospecimen donors increases the likelihood of disclosure of participants' information	0.292**	Possibility of transferring samples to another country	−0.119*	Obtaining open consent may not give participants adequate information to give meaningful consent	
Support for establishment of biobanks in Jordan	0.222**				

Notes: *Statistically significant at P<0.01. **Statistically significant at P<0.001.

with a lack of enthusiasm for continuous contact about their stored biospecimens and considering re-contact as a threat to privacy and confidentiality. No correlation was found between readiness to provide open consent and considering open consent as unmeaningful or disrespectful to participants. Based on the responses, although participants seemed to discriminate between various aspects of biobank participation, they exhibited a stronger feeling about some aspects than others.

In our study, 87% of the participants believed that there should be a time limit for sample storage, and options to choose the preferred consent model; these two factors contributed negatively to participants' willingness to provide open consent. In addition, participants had concerns regarding the sharing of samples with international centers. This concern was also discussed in previous studies, and complexities can emerge because of increasing international collaborations and differing national positions.[4]

Conclusions

Based on our results, enthusiasm to participate in biobanking and to provide open consent were associated with sociodemographic characteristics of participants, particularly age, education level, and previous knowledge of biobanks and informed consent. Thus, it is necessary to take these factors into consideration when discussing specific information with potential donors.[15] Our results suggest that using broad consent may affect participants' decision to participate in biobanks.

This study had several limitations. No response rate could be calculated, as our recruitment method depended on social media networks to collect responses from different geographical areas in Jordan. We also depended on participants' self-reported attitudes and hypothetical scenarios, rather than actual behavior, and we did not ask participants about their perspectives on dynamic consent.

Disclosure

The authors report no conflicts of interest in this work.

References

1. Iltis A. Lay concepts in informed consent to biomedical research: the capacity to understand and appreciate risk. *Bioethics*. 2006;20(4):180–190. doi:10.1111/biot.2006.20.issue-4
2. Townsend D. Informed consent in biomedical research. *Conf Proc IEEE Eng Med Biol Soc*. 2006;1:4085–4087.
3. Hallinan D, Friedewald M. Open consent, biobanking and data protection law: can open consent be 'informed' under the forthcoming data protection regulation? *Life Sci Soc Policy*. 2015;11:1. doi:10.1186/s40504-014-0020-9
4. Dhai A, Mahomed S. Biobank research: time for discussion and debate. *S Afr Med J*. 2013;103(4):225–227. doi:10.7196/SAMJ.6813
5. Master Z, Nelson E, Murdoch B, Caulfield T. Biobanks, consent and claims of consensus. *Nat Methods*. 2012;9(9):885–888. doi:10.1038/nmeth.2142

6. Abou-Zeid A, Silverman H, Shehata M, et al. Collection, storage and use of blood samples for future research: views of Egyptian patients expressed in a cross-sectional survey. *J Med Ethics*. 2010;36(9):539–547. doi:10.1136/jme.2009.033100
7. Hansson MG, Dillner J, Bartram CR, Carlson JA, Helgesson G. Should donors be allowed to give broad consent to future biobank research? *Lancet Oncol*. 2006;7(3):266–269. doi:10.1016/S1470-2045(06)70618-0
8. Joly Y, Dalpe G, So D, Birko S. Fair shares and sharing fairly: a survey of public views on open science, informed consent and participatory research in biobanking. *PLoS One*. 2015;10(7):e0129893. doi:10.1371/journal.pone.0129893
9. Husedzinovic A, Ose D, Schickhardt C, Frohling S, Winkler EC. Stakeholders' perspectives on biobank-based genomic research: systematic review of the literature. *Eur J Hum Genet*. 2015;23(12):1607–1614. doi:10.1038/ejhg.2015.27
10. Sanderson SC, Brothers KB, Mercaldo ND, et al. Public attitudes toward consent and data sharing in biobank research: a large multi-site experimental survey in the US. *Am J Hum Genet*. 2017;100(3):414–427. doi:10.1016/j.ajhg.2017.01.021
11. Barr MP, Souan L, MacGabhann P, et al. The establishment of an ISO compliant cancer biobank for Jordan and its neighboring countries through knowledge transfer and training. *Biopreserv Biobank*. 2014;12(1):3–12. doi:10.1089/bio.2013.0072
12. Grady C, Eckstein L, Berkman B, et al. Broad consent for research with biological samples: workshop conclusions. *Am J Bioethics*. 2015;15(9):34–42. doi:10.1080/15265161.2015.1062162
13. Makhlouf H, Alrabadi N, Khabour OF, Alzoubi KH, Al-Delaimy W. Population's perspectives toward biobanks in scientific research: a study from Jordan. *Pharmacogenomics Pers Med*. 2019;12:23–32. doi:10.2147/PGPM.S187657
14. Winickoff DE, Winickoff RN. The charitable trust as a model for genomic biobanks. *N Engl J Med*. 2003;349(12):1180–1184. doi:10.1056/NEJMsb030036
15. Hansson MG. Building on relationships of trust in biobank research. *J Med Ethics*. 2005;31(7):415–418. doi:10.1136/jme.2004.009456
16. Beskow LM, Dean E. Informed consent for biorepositories: assessing prospective participants' understanding and opinions. *Cancer Epidemiol Biomarkers Prev*. 2008;17(6):1440–1451. doi:10.1158/1055-9965.EPI-08-0086
17. Ahram M, Othman A, Shahrouri M. Public perception towards biobanking in Jordan. *Biopreserv Biobank*. 2012;10(4):361–365. doi:10.1089/bio.2012.0010
18. Trauth JM, Musa D, Siminoff L, Jewell IK, Ricci E. Public attitudes regarding willingness to participate in medical research studies. *J Health Soc Policy*. 2000;12(2):23–43. doi:10.1300/J045v12n02_02
19. Riordan F, Papoutsi C, Reed JE, Marston C, Bell D, Majeed A. Patient and public attitudes towards informed consent models and levels of awareness of electronic health records in the UK. *Int J Med Inform*. 2015;84(4):237–247. doi:10.1016/j.ijmedinf.2015.01.008
20. Asai A, Ohnishi M, Nishigaki E, Sekimoto M, Fukuhara S, Fukui T. Attitudes of the Japanese public and doctors towards use of archived information and samples without informed consent: preliminary findings based on focus group interviews. *BMC Med Ethics*. 2002;3:E1. doi:10.1186/1472-6939-3-1
21. Ahram M, Othman A, Shahrouri M. Public support and consent preference for biomedical research and biobanking in Jordan. *Eur J Hum Genet*. 2013;21(5):567–570. doi:10.1038/ejhg.2012.213