



Research article

Ethical issues in bio-sample sharing among the public in Jordan

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ABSTRACT

Background: Among the challenges of health research are sharing and the future use of human biological samples. Usually, participants show different opinions and ethical concerns regarding the usage and sharing of their biological samples. In this study, we investigated the perspectives of Jordanian participants regarding bio-samples collection, storage, use, and sharing.

Methods: The study is cross sectional, questionnaire-based, and involved 248 participants from Jordan. Data collected included demographic, qualitative, and quantitative information from research participants. The questionnaire was accomplished in the Arabic language and data were analyzed using SPSS version 22.0.

Results: Most of the participants (77%) supported providing samples for research purposes. Yet, they expressed concerns about the future use of their samples (27.8%), storage of their bio-samples after first use (19%), and export of the bio-samples outside of the country (27%). They further indicated that they will not mind if profits are generated from the samples (36.7%). On the other hand, about 18.5% would be very unhappy and would sue the researchers if their bio-samples were reused without their consent.

Conclusions and Recommendation: Participants showed strong views on specimen collection, storage, export, benefit sharing and future usage - most significantly on the consent process that permits free choices. Further research should be conducted to explore the concept of bio-samples donation and the benefit of sharing among researchers in Jordan.

1. Introduction

The development of biomedical research requires more access to important collections of biological and clinical databases in all fields of medical and health sciences. Consequently, medical and biological resources must be subjected to absolute traceability to ensure their compliance with researchers' work, leading to the development of infrastructures for collecting samples for research purposes (Verstuyft et al., 2018). However, several legal and ethical issues arise among research participants. Some believe that it is unethical to conduct future studies on stored biological samples, since it is unknown to the participant what type of research will be conducted and the type of research could produce religious and cultural concerns. On the other hand, other participants had no problem with the storage and use of their biological specimens, since research participants donated these specimens (Verstuyft et al., 2018).

Ethical committees were established to protect research participants from unethical research and unnecessary exploitation (JAMA, 2013). Research ethics committees have the authority to protect research participants' interests when it comes to the storage, ownership, export and confidentiality of samples with informed specific consent (Gibson et al., 2008). Examination of best approaches for use of biological resources begins with an investigation of participants' views and perceptions towards this process. This is an important step in realizing the complexity of the debate. A number of studies from developed countries have explored the views and perceptions of participants about sharing of samples, including France (Verstuyft et al., 2018), South Africa (Moodley et al., 2014), Canada (O'Doherty and Hawkins, 2010), United Kingdom (Trewick et al., 2009), the Netherlands (Vermeulen et al., 2009), and Sweden (Johnsson et al., 2008; Melas et al., 2010). However, few studies regarding public views on bio-samples sharing have been done in other developing countries (Igbe and Adebamowo, 2012; Wendler et al., 2005).

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There is strong support for broad consent in developed countries as it is occasionally difficult to re-consent participants (Petrini, 2010; Ruiz-Canela et al., 2009). Some presume that it is ethical to store samples and re-use them for future studies, since the specimens were donated and society will eventually benefit; thus, there is no need for controls on what research is conducted (Petrini, 2010). Others have considered the broad consent as pragmatic, but not an acceptable ethical solution (Ploug and Holm, 2020; Steinsbekk et al., 2013). In addition, there is still an argument regarding sharing the profits generated from bio-samples with research participants (Berg, 2001; NHMRC, 2011; Patrick, 2003). The aim of the current study was to explore the concept of samples ownership and the benefit of sharing bio-samples in a resource constrained country such as Jordan, in an effort to improve the consent process and respect participants' autonomy.

2. Methodology

This descriptive cross-sectional study was conducted over a one-month period (July 2019) in Jordan. A structured, pre-tested and self-administered questionnaire was designed to achieve the study objectives. Printouts of the questionnaire were prepared using the Arabic language, targeting a convenience sample of the general population in Irbid area - Jordan. For that purpose, study participants were approached at public places, open areas, parks, malls, etc. Once a participant provided a written informed consent, they were offered a copy of the questionnaire to complete. A well-trained research assistant was available all the time to answer any questions by the participants.

The researcher used G*Power software version 3.1.9.7 to calculate the sample size. A significance level of 0.05, a power of 0.95 and a medium effect size of 0.30 required the minimum number of subjects to be 220. Based on an anticipated dropout rate of 15%, the target number of participants was 253. The researcher performed an analysis of the data on 248 subjects.

All procedures, data collection and data coding were performed according to ethical guidelines and regulations. The study was ethically approved by the Jordan University of Science and Technology Institutional Review Board (IRB) committee. Participants were informed about the study objectives rationale, procedure, benefits, and re-contact information of the researchers before signing the informed consent form of the study.

The questionnaire of the current study was modified from Moodley et al. (2014). The questionnaire consisted of two sections: demographics and questions about the participants' relationship with data. The subjects were asked about their gender, marital status, education, and employment position, along with storage of samples, future use and export of specimens and the benefit of sharing. Subjects were asked about their attitudes and motivations for donating bio-samples for research. They were also requested to provide their opinion about the probability of storing their specimen and their feelings about future use of their samples. In addition, they were asked if they wanted to be contacted if their bio-sample was to be reused in the future. The questionnaire included a section about specimen sharing and export outside of Jordan. Finally, the participants' opinions were investigated regarding the possibility of researchers making financial profit from biological samples shared by others, and whether this is considered a criminal offense for which researchers should be held accountable.

The questionnaire was pilot tested to ensure quality and comprehensibility. Pilot samples were omitted from the final analysis. The reliability coefficient for all items of the survey was >0.6 . As for validity, the study survey was face validated via review by experts in the field including senior researchers in the areas of biology, pharmacology, public health, and research ethics. Additionally, to ensure content clarity and comprehension, subjects from the pilot sample were asked to provide comments about the way they understood each item of the survey. Data were recorded and coded in English for statistical analysis. Demographic factors, and participants' response were described using frequency and

percent analysis. Chi square test was used for statistical analysis via SPSS version 22.0 (SPSS, Inc., Chicago, IL, USA) in quantitative and qualitative forms.

3. Results

3.1. Demographic data

In total, 248 participants were enrolled in this study. Females were 68.1% of the participants. Most participants (81.4%) received a bachelor's degree and were single (84.3%).

3.2. Providing bio-samples and storage of specimens

Most participants (77%) felt they had a choice of providing bio-samples for the most recent research projects in which they volunteered to help others. On the other hand, 14.5% indicated that they wanted to give bio-samples willingly for their own good (i.e., participants' potential direct benefits from the research study such as free-of-charge diagnostic/laboratory tests, or therapeutic clinical trials). Only 8.5% said that they were instructed to provide the sample by a doctor (Table 1).

Participants were asked about their feelings toward the possibility of storing their specimens after the first round of tests had been carried out. Some participants (39.9%) agreed with the idea of sample storage. The most regularly cited reason was that once the bio-specimen had been collected, the storage would not spoil them. On the other hand, 16.9% wanted their samples to be coded for proper storage process, and 19% indicated that they should give permission for storing their samples and they should be provided with the reasons behind the storage. Meanwhile, 24.2% indicated that they are neutral regarding the idea of sample storage (Table 1).

3.3. Future use of specimens

Most of the participants –71.8%– expressed feelings of approval regarding the idea of re-using their specimen, despite the low percent who agreed with the idea of storage. Almost half of the sample 48% pointed out that they would want to be contacted once the sample was reused; the other half would permit a research ethics committee to consent on their behalf (Table 2).

3.4. Export of specimens and benefit of sharing

Only 29.4% would not mind at all if their specimens were exported outside Jordan. While a substantial proportion of participants 43.5% did not oppose the exportation of samples as long as the reasons for exportation were justified and mentioned in the consent form, 27% showed strong perturbation and disapproval for the exportation outside Jordan (Table 3).

A considerable proportion of participants in this study (44.8%) indicated that researchers must share a portion of the generated profits with them, because the specimens were theirs. Another proportion of participants 36.7% showed that they would not mind if profits were generated. A further 18.5% of participants pointed out that they would take legal action against the researchers if profits were generated, since the profits would be as a criminal offense, as they thought (Table 3).

Table 4 illustrates the relationship between participants' responses and demographic variables, namely, gender, education, and marital status. In terms of gender, female participants were more supportive of the reuse of bio-samples than male participants (p -value = 0.003). Additionally, single participants were more willing to donate bio-samples to help others, whereas married ones were more willing to donate bio-samples for their own good (p -value = 0.01). The level of education was not significantly associated with any of questions related to bio-samples sharing.

Table 1. Participants' opinion in regard of providing bio-samples and future storage of their specimens.

Item	Frequency	Percentage
Why did you provide a bio-sample for the research project you are enrolled in?		
a. Because it was for a good reason to help others	191	77.0
b. I gave it willingly for my own good	36	14.5
c. The doctors said they have to take my blood (I have no choice).	21	8.5
How do you feel about the possibility that your specimen could be stored?		
a. Comfortable. Once the sample has been donated, the storage would not affect me.	99	39.9
b. My sample should be coded	42	16.9
c. I should give permission for storage and I need reason for storage	47	19.0
d. Neutral (not interested)	60	24.2

Table 2. Opinion of participants in regard of future use of their bio-samples.

Item	Frequency	Percentage
Do you accept that your sample be reused?		
Yes	178	71.8
No	69	27.8
If yes, Do you want to be contacted each time the sample will be re-used?		
Yes	119	48.0
No	129	52.0
Should the possibility of re-using the sample be explained in the consent form?		
Yes	174	70.2
No	74	29.8

Table 3. Participants' opinion about exporting their bio-samples and sharing benefits.

Item	Frequency	Percentage
Do you have a problem if your specimen has been exported out of Jordan?		
a. I don't have a problem at all	73	29.4
b. I don't mind if it is justified and mentioned in the consent form	108	43.5
c. Yes, I do. I don't want my samples to be analyzed outside Jordan	67	27.0
Would you mind if profits were generated from specimen sharing?		
a. I have no problem	91	36.7
b. They must share a portion of the profit with me because it is my blood.	111	44.8
c. I will be unhappy. I will sue them.	46	18.5

4. Discussion

In Jordan, multiple studies have been published reporting on different ethical issues (Al Zou'bi et al., 2020; Alkaraki et al., 2020; Rababah et al., 2020). However, this is an original study that investigates the perspectives of the public regarding providing, storage, sharing and future use of bio-samples, which has not been the focus of a study.

Obtaining participants' perspectives is a crucial part of community participation in research including specimen collection, storage, export, or future usage. However, in developing new therapeutic and diagnostic procedures, it is crucial to emphasize the collection of biological data. Jordanian community engagement is critical to clarifying understanding of the concepts in biological samples sharing. However, the views of researchers must also be induced and justified by participant views in the best interests of science and society.

Based on the data generated by the current study, results illustrate interesting perspectives on sample storage, re-use, export and the benefit of sharing. Despite that participants support the ideas of sample collection and storage, which agrees with available literature (Igbe and Adebamowo, 2012; Moodley et al., 2014; Tindana et al., 2012), they indicated different views about re-use, export, and the benefit of sharing. Current data showed that 77% of participants were in favor of providing their specimens to research projects for the reason of helping others.

Likewise, the study by Moodley K et al. (Moodley et al., 2014) in South Africa revealed that 77.5% of participants provide their samples for research projects to help others or willingly for their own good (van Schalkwyk et al., 2012).

Less than half of participants (39.9%) were pleased with the idea of storing their samples, in contrast to the findings in South Africa (van Schalkwyk et al., 2012) where most participants (77.5%) were interested and comfortable with the idea of sample storage. The rest of the participants indicated that they would inquire about reasons for sample storage and would want to give permission. In the current survey, participants clearly expressed a feeling of ownership of their samples. However, this is incompatible with the concept of donation. It is therefore important to clarify and reinforce the concept of donation with research participants during recruitment to assess and improve the consent process.

Just like the studies in South Africa (Moodley et al., 2014; van Schalkwyk et al., 2012), the current study indicated that 44.8% expressed a desire for sharing profits while 55.2 % had no interest in sharing. This finding is slightly higher than in Egypt (Abou-Zeid et al., 2010) where 32.8% of participants would like to share in profits. This view of benefit sharing is a matter of interest given that most consent forms related to specimen collection indicate that royalties might be paid to researchers or sponsors who would not plan to share any possible royalty with participants (Secko et al., 2009). The debate between what

Table 4. Cross tabulation analysis for public responses with some demographic variables.

Item	Category	Gender		Education			Marital	
		Male	Female	Less than high school	Bachelor degree	Master degree	Single	Married
Why did you provide a bio-sample for a research project?	Because it was for a good reason to help others	62 (78.4%)	129 (76.3%)	13 (65.0%)	158 (80.2%)	20 (64.5%)	166 (79.8%)	25 (62.5%)
	I gave it willingly for my own good	12 (15.2%)	24 (14.2%)	5 (25.0%)	22 (11.2%)	9 (29.0%)	24 (11.5%)	12 (30.0%)
	The doctors said they have to take my blood (I have no choice).	5 (6.4%)	16 (9.5%)	2 (10.0%)	17 (8.6%)	2 (6.5%)	18 (8.7%)	3 (7.5%)
	P value	0.707		0.061			0.010	
How do you feel about the possibility that your specimen could be stored?	Comfortable. Once the sample has been donated, the storage would not affect me.	35 (44.3%)	64 (37.9%)	5 (25.0%)	82 (41.6%)	12 (38.7%)	85 (40.9%)	14 (35.0%)
	My sample should be coded	15 (19.0%)	27 (16.0%)	5 (25.0%)	30 (15.2%)	7 (22.6%)	32 (15.4%)	10 (25.0%)
	I should give permission for storage and I need reason for storage.	8 (10.1%)	39 (23.1%)	5 (25.0%)	38 (19.3%)	4 (12.9%)	38 (18.3%)	9 (22.5%)
	Neutral (not interested)	21 (26.6%)	39 (23.1%)	5 (25.0%)	47 (23.9%)	8 (25.8%)	53 (25.5%)	7 (17.5%)
P value	0.117		0.676			0.345		
Do you accept that your sample be reused?	Yes	66 (84.6%)	112 (66.3%)	17 (11.0%)	3 (4.9%)	23 (74.1%)	151 (72.6%)	27 (69.2%)
	No	12 (15.4%)	57 (33.7%)	138 (89.0%)	58 (94.1%)	8 (25.9.6%)	57 (27.4%)	12 (30.8%)
	P value	0.003	0.368	0.667				
Do you want to be contacted each time the sample will be re-used?	Yes	37 (46.8%)	82 (48.5%)	12 (60.0%)	89 (43.0%)	18 (58.1%)	98 (47.1%)	21 (52.5%)
	No	42 (53.2%)	87 (51.5%)	8 (40.0%)	108 (57.0%)	13 (41.9%)	110 (52.9%)	19 (47.5%)
	P value	0.805		0.219			0.532	
Should the possibility of re-using the sample be explained in the consent form?	Yes	54 (68.4%)	120 (71.0%)	13 (65.0%)	139 (67.1%)	22 (70.9%)	150 (72.1%)	24 (60.0%)
	No	25 (31.6%)	49 (29.1%)	7 (35.0%)	58 (32.9%)	9 (29.1%)	58 (27.9%)	16 (40.0%)
	P value	0.671		0.870			0.125	
Do you have a problem if your specimen has been exported out of Jordan?	I don't have a problem at all.	28 (35.5%)	45 (26.6%)	8 (40.0%)	55 (26.5%)	10 (32.3%)	64 (30.8%)	9 (22.5%)
	I don't mind if it is justified and mentioned in the consent form.	28 (35.5%)	80 (47.4%)	7 (35.0%)	86 (56.6%)	15 (48.4%)	88 (42.3%)	20 (50.0%)
	Yes, I do. I don't want my samples to be analyzed outside Jordan.	23 (29.0%)	44 (26.0%)	5 (25.0%)	56 (26.9%)	6 (19.3%)	56 (26.9%)	11 (27.5%)
	P value	0.186		0.672			0.538	
Do you mind if profits were generated from specimen sharing? (knowing that research was conducted for a good cause)	They must share a portion of the profit because it is my blood.	34 (43.0%)	77 (45.6%)	8 (40.0%)	93 (44.7%)	10 (32.3%)	97 (46.6%)	14 (35.0%)
	I have no problem.	32 (40.5%)	59 (34.9%)	6 (30.0%)	70 (33.6%)	15 (48.4%)	74 (35.6%)	17 (42.5%)
	I will be unhappy. I will sue them.	13 (16.5%)	33 (18.6%)	6 (30.0%)	34 (16.3%)	6 (19.4%)	37 (17.8%)	9 (22.5%)
	P value	0.667		0.340			0.396	

consent forms may indicate, what Helsinki's declaration intends, and what participants presume, should be carefully considered by REC members and researchers alike.

While most participants felt comfortable with future use of their specimens, strong opinions were apparent from 48% of respondents who expressed a need to be contacted once their samples would be reused. Current findings are slightly higher than the study in Egypt, where 39% of the 600 participants desired the consent option for future usage. On the other hand, 95% of participants in Uganda had no problem for samples re-use if the future usage was approved by the Institutional Review Board (IRB) (Wendler et al., 2005).

The medical research environment and approach to participation in clinical studies seems to be different in developed versus developing countries (Mahafzah et al., 2020; Makhoulf et al., 2019). This could be related to cultural differences, strong religious influences or concerns that are likely to impact decisions related to bio-samples sharing (Abuhammad et al., 2020; Alemayehu et al., 2018; Shehata et al., 2017). Based on the results of the current study, and given the participants' views on the future use of samples in Jordan, it is imperative to allow participants to indicate their choice in consent forms regarding future use of samples.

One limitation of the current work is that majority of study participants were educated and single. The relatively young and well-educated population of Jordan could explain the trend. Notably, the median population age in Jordan is 23.8 years and a literacy rate of more than 99% (Arouri et al., 2015; Department of Statistics, 2018). Yet, more studies regarding factors that contribute to willingness of study subjects to provide bio-samples are needed that consider a broader scope of demographics characteristics.

5. Conclusions

The verifiable findings of this study serve to underline the fact that participants exhibit a wide range of views concerning the use of biological samples for research purposes. Participants showed valid views on export, benefit sharing, future use and most importantly on the consent process that permits choices. Further research should be conducted to study the concept of donation and benefit sharing among different communities, to respect participant rights and privacy. Community enrollment to clarify these concepts is important. Moreover, the perspectives of researchers with respect to the concept of donation and benefit of sharing should also be explored and considered with participant views for the behalf of science and society.

Declarations

Author contribution statement

A. K. Alkaraki: Conceived and designed the experiments; Performed the experiments; Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.

L. Al-Ebbini: Conceived and designed the experiments; Performed the experiments; Analyzed and interpreted the data.

O. F. Khabour: Conceived and designed the experiments; Wrote the paper.

K. H. Alzoubi: Contributed reagents, materials, analysis tools or data; Wrote the paper.

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Data availability statement

The authors do not have permission to share data.

Declaration of interest statement

The authors declare no conflict of interest.

Additional information

No additional information is available for this paper.

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