

# Views of University Students in Jordan towards Biobanking

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## Research article

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# Abstract

## Background

Biobanks are considered a primary mean of supporting contemporary research, in order to deliver personalized and precise diagnostics with public acceptance and participation as a corner stone for their success.

## Aims

This study aims to assess knowledge, perception, and attitudes towards biomedical research and biobanking among students at the University of Jordan.

## Methodology

An online questionnaire was designed, developed, and piloted. It was divided into 5 sections that included questions related to issues of biomedical research and biobanking as well as factors influencing decision to participate.

## Results

Responses from 435 students revealed that 52.9% previously heard of biobanks. There was overwhelming acceptance for participation in biomedical, genetic, and biobanking research. A blood sample was the most preferred for donation. Protection of privacy, a consent prior to donation, approval of an ethics committee, and trust towards researchers were the most important factors associated with willingness to participate. On the other hand, vagueness of the type of research performed on samples and not receiving research results had a negative connotation. There was no clear agreement on the type of consent preferred by students, but to be contacted and informed of research results was preferred by the majority. Students also preferred disposal of samples and information when deciding to withdraw from participation.

## Conclusion

There is strong enthusiasm among students to participate in biomedical research and biobanking with all rights reserved thus providing hope for a very promising future in Jordan.

# Background

Understanding the molecular etiology and distribution of specific diseases among groups of people of various ethnic backgrounds has necessitated the advent of biobanking. Biobanks are well established in high income countries, but are only beginning to emerge in low- and middle-income countries. The inclusion of low income countries in biomedical research can advance multiple aspects of disease distribution, diagnosis and treatment, particularly, considering genetic diversity [1, 2]. Jordan, located in

the central region of the Middle East, is often a preferred place to receive excellent health care due to its advanced medical system and renowned physicians. Jordan hosts a heterogeneous mixture of different and unique ethnic groups with a relatively similar cultural background. Thus, data generated from biomedical research are expected to provide an insight regarding public health in the region [3].

Biobanking refers to the process by which samples of bodily fluid or tissue are collected for research use to improve our understanding of health and disease. Biobanks allow for the availability of diverse biospecimens with associated data that would facilitate the achievement of precision medicine via the identification of disease biomarkers [4]. Moreover, biobanks have served in fighting and managing pandemics. AIDS Specimen Bank (ASB) of the University of California at San Francisco. The ASB was started in December 1982 in response to the early challenges of the AIDS epidemic for example, the UCSF AIDS specimen bank (ASB) provided investigators with high-quality biospecimens that contributed to the identification of the agents that cause AIDS and Kaposi's sarcoma [5]. We are now witnessing the international efforts and race for vaccine development for the COVID-19 pandemic, which further highlights the importance of patient sample [6].

For a successful biobank, a large and diverse number of individuals should be willing to participate via donating and sharing their biospecimens and information. Public participation is highly influenced by ethical, social and legal challenges. According to Hawkins (2010), the controversies that revolve around biobanks include issues of consent, privacy and confidentiality, return of results, and data-sharing. Thus, the concept of biobanking needs to be publicly discussed and challenges in recruiting potential donors should be unraveled at the national level [7, 8]. Indeed, cultural-social norms of the community play an important role in whether the community is willing to donate and contribute to medical research.

Previously, approximately two-thirds of Jordanians expressed willingness to participate in biobanks with correlation to younger age [9]. Herein, we targeted students at the University of Jordan from various disciplines and academic years in order to further explore their knowledge, attitudes, and practice towards biomedical research and biobanking. In addition, other aspects of biomedical research and biobanking such as the main factors that influence student willingness to participate and consenting in such as research were assessed. The University of Jordan is the largest university in Jordan encompassing 94 majors at the bachelor's degree level, is located in a hub of the capital, Amman, and is attended by students of various demographic background.

## Methods

### *Study design and data collection*

This is a cross-sectional study based on a questionnaire related to knowledge, attitude, and practice towards biomedical research and biobanking. To maintain confidentiality, the identity of the participant remains anonymous throughout the entire survey. The study was approved by the Institutional Review Board of Jordan University Hospital.

The questionnaire was developed by the authors taking into consideration the local ethical and cultural context. A pilot study was conducted first for 3 weeks in October 2019 to provide a valuable insight and feedback regarding the suitability and clarity of questions. Adjustments were made accordingly. The survey was distributed afterwards for a period of two months among online university groups and individual students.

The final questionnaire was composed of 5 sections. The first section included an introductory page that explained the purpose behind the questionnaire and whether they agreed to participate. The second section covered demographics data (gender, age, school, academic year (except first year), grade point average (GPA), religion, educational level of both parents, and monthly income of the family). The third section included questions regarding participating in a biomedical research and the influence of certain factors on decision to participate including time needed to provide a sample, type of sample, direct health benefit from participating, religious point of view regarding participating, privacy options, withdrawal options, financial benefit from participating, and trust in researchers. The fourth section included how (the concept of biobanking, donation of biospecimens, and the influence of certain biobanking related issues such as type of future research done, direct benefit from the results, the biobank-based institution re-contact, level of consent, and withdrawal) may influence and change decisions. Survey respondents had the chance to add a comment at the end of the survey.

### *Measures*

*Demographic data.* Participants were asked about their gender, age, faculty, educational year, GPA, religion, parents' education and income (1 Jordanian Dinar = \$1.41).

### *Attitude towards biospecimens.*

Initially, participants were asked if they had ever participated in a biomedical research before, what they thought of donating biospecimens for research purposes, and their willingness to contribute. Those attitudes were measured on a 5-point Likert scale with scores ranging from "very unlikely" to "very likely" in addition to a category of "don't know". Subsequently, participants were asked to indicate how important some factors were when donating a specimen and revealing personal and family-related information; analyzed factors were: time spent in donating, fear of needles/blood, existence of consent prior to participation, availability of direct medical benefit, religious views, confidentiality, right to withdraw from research, type of collected personal and family-based information, approval of an authorized ethics committee, type of research, impact of the research on public health, availability of general or personalized results, and identity of and level of trust towards researchers. Moreover, the respondents were asked to specify the type of biospecimen(s) they would be willing to donate giving them several options to choose from.

### *Attitude towards biobanking*

Participants were then asked if they were familiar with the concept of biobanking, followed by nine statements measuring the extent of participants' agreement on participating in a biobank, which included: the overall possibility of participating in a biobank or the possibility of participating under certain circumstances that included being unaware of the type of future research, lack of direct benefit, availability of general research result, and management of the biobank by either a governmental institution, an academic institution, a private institution, an Arab institution, or a non-Arab institution.

Participants were also asked if they preferred a limited or a wide consent regarding the donation of a biospecimen, flow of biospecimen coding, and re-contact. Finally, respondents were asked how, in case of withdrawal, the biobank should handle biospecimens and information of donors.

### *Data analysis*

Data were analyzed using the SPSS software program, version 22.0 (SPSS Inc., Chicago, IL, USA). Descriptive statistics were used to report sample characteristics in addition to frequencies and percentages. Pearson Chi-square was used to assess the relationship between individual responses within each statement with demographics. The correlations between responses within each statement and the overall willingness to participate in biobanking were also assessed. *P* values less than 0.05 were considered as significant.

## **Results**

The questionnaire reached 476 students, 435 of them consented to participate and 41 declined. Table 1 shows the sociodemographic characteristics of the sample. The majority of respondents were females (72.0%). Ages of the students ranged from 17 to 39 with a mean of 20.8. School categories were divided as medical versus non-medical, health versus non-health, and scientific (including health) versus non-scientific. The majority of responses came from scientific schools 83.4%, while the lowest included the non-scientific schools 16.6%. Medical students constituted 45.5% of the total study population. As for the academic year, students were divided into second, third, and fourth and above where the majority of responses (42.5%) belonged to students in the fourth year and above category and the lowest group constituted third-year students (22.1%). First-year students were not included since the study was conducted when they were in their first semester. Over 90% of students had a GPA of 2.5 and higher. Those with GPA of 2.0-2.5 constituted 9.0% and failing students with GPA below 2.0 were a minority (0.7%). Students with variable family income were well represented with the highest proportions was those with income of 500-999 JD (23.4%) followed by 2000 JD (20.9%) and above and the lowest proportion was students with income of less than 500 JD (8.7%) and 1500-1999 JD (9.2%).

Table 1. Sample characteristics

\*Missing data (n) = 98 (22.5%)

<b>Gender (N=435)</b>	<b>%</b>
Male (122)	28.0
Female (313)	72.0
<b>Age</b>	
17 (1)	0.2
18 (11)	2.5
19 (124)	28.5
20 (89)	20.5
21 (81)	18.6
22 (49)	11.3
23 (54)	12.4
24 and above (26)	2.1
<b>Mean= 20.8 (± 2.01; Min= 17; Max= 39)</b>	
<b>School Categories</b>	
Medical (198)	45.5
Non-medical (237)	54.5
Health School (318)	73.1
Non-health (117)	26.1
Scientific (363)	83.4
Non-scientific (72)	16.6
<b>Academic Years</b>	
Second year (154)	35.4
Third year (96)	22.1
Fourth year and above (185)	42.5
<b>GPA</b>	
<2.00 (3)	0.7
2.00-2.49 (40)	9.0

2.50-2.99 (106)	24.4
3.00-3.49 (144)	33.2
3.5-4.00 (142)	32.7
<b>Income (JD)*</b>	
<500 (38)	8.7
500-999 (105)	23.4
1000-1499 (71)	15.2
1500-1999 (40)	9.2
2000 and higher (92)r	20.9

### Knowledge, attitude, and practice towards biomedical research and biobanking

Students were asked if they had previously participated in biomedical research. Over a quarter of them (28.9%) indicated that they did (Table 2). A previous participation in research was found to be significantly high among students of the medical, health, and scientific schools ( $p < 0.001$ ). Students of higher academic years, and those with higher income also had a significant tendency ( $P < 0.001$  and  $0.01$ , respectively) to previously participate in biomedical research. As for GPA, students with intermediate GPA, i.e. 2.50-2.99, were the largest group to had previously participate in research ( $P < 0.01$ ).

Students were then asked if they agreed on the use of biospecimens in biomedical research. The majority either agreed (57.5%) or strongly agreed (38.9%) (Table 2). Students in medical, health, and scientific school significantly tended to strongly agree compared to other schools ( $P < 0.001$ ). As for income, those with an income of <500 JD or 1500-1999 JD tended to be less acceptable of the use of biospecimens in research ( $P = 0.023$ ).

Students were then asked of their willingness to participate in biomedical research or genetic research (Table 2). There is an overwhelming willingness to participate in both of them where approximately 95% of students were willing to participate in biomedical research in general and almost 90% of them were willing to participate in genetic research regardless of gender, academic year, or GPA. Students from medical, health, and scientific school were significantly more willing to participate in both compared to their counterparts. There is also a trend that students with a family income of <500 JD or 1500-1999 JD were found to be less enthusiastic towards participation, not only regarding research discipline being very significant ( $< 0.001$ ), but also participation in genetic research.

Table 2. Knowledge of biobanking, attitudes towards the use of biospecimen in research, and engagement in research. (<sup>1</sup> \*  $P < 0.05$ ; \*\*  $P < 0.01$ ; \*\*\*  $P < 0.001$ )

Questions	Responses				Significant factors associated with favorable response <sup>1</sup>		
	Yes (%)	No (%)					
Have you previously participated in medical research	112 (28.9)	276 (71.1)			Being in medical <sup>***</sup> , health <sup>***</sup> , or scientific <sup>**</sup> schools, 3 <sup>rd</sup> and 4 <sup>th</sup> year, GPA of 2.50-2.99 <sup>***</sup> , income >2000 JD <sup>**</sup>		
Have you previously heard of biobanks?	230 (52.9)	250 (47.1)			Being in medical <sup>***</sup> , health <sup>***</sup> , or scientific <sup>**</sup> schools, GPA of <sup>3</sup> 2.50*, income of 500-1500 and >2000 JD <sup>**</sup> , prior participation in biomedical research <sup>*</sup>		
			<b>Strongly Agree (%)</b>	<b>Agree (%)</b>	<b>Disagree (%)</b>	<b>Strongly disagree (%)</b>	
Do you generally agree with using biospecimen in medical research?	169 (38.9)	250 (57.5)	16 (3.7)	0 (0)			Being in medical <sup>***</sup> , health <sup>***</sup> , or scientific <sup>***</sup> schools, GPA of <sup>3</sup> 3.50*, income 500-1500 and >2000 JD <sup>**</sup> , prior participation in biomedical research <sup>**</sup>
How likely is it that you participate in biomedical research by providing biospecimen and personal/family information?	145 (35)	246 (59.4)	20 (4.8)	3 (0.7)			Being in medical <sup>*</sup> , health <sup>**</sup> , or scientific <sup>*</sup> schools, prior participation in biomedical research <sup>*</sup>

<b>How likely is it that you participate in genetic research?</b>	153 (36.9)	213 (51.3)	39 (9.4)	10 (2.4)	Being in medical <sup>*</sup> , health <sup>**</sup> , or scientific <sup>*</sup> schools, income 500-1500 and >2000 JD <sup>**</sup>
<b>Possibility of participating in future biobanking research</b>	99 (24.6)	271 (67.4)	25 (6.2)	7 (1.7)	Being in medical <sup>***</sup> , health <sup>*</sup> , or scientific <sup>*</sup> schools, income 500-1500 and >2000 JD <sup>*</sup> , prior participation in biomedical research <sup>**</sup>

Students were then asked if they had heard of biobanks before (Table 2). The concept of a biobank was defined to students when they were asked of their willingness to participate in a biobank. The majority of students (~90%) whether from health schools or non-health schools either strongly agreed or agreed to participate (Table 2). As expected, students of health schools were significantly more enthusiastic about participation in a biobank.

### **Preferred biospecimen donation for biomedical research**

Students were asked of the biospecimens they would prefer to contribute for research purposes. Options included blood, cheek swab, urine, saliva, stool, and tissue leftover (Figure 1). The most preferable sample was blood with 85.7% of students preferring to contribute for research purposes, followed by cheek swab with 66.7% and comparably saliva. On the other hand, stool was the least preferred biospecimen to be donated for research.

### **Factors influencing participation in biomedical research and preferred sample types**

Students were then asked about factors that might affect participation in biomedical research by ranking them according to the level of importance ranging from least level of importance to very important. There was also an option of “unsure”. The factors analyzed were: time spent to participate, fear of blood and needles, consenting prior to participation, gaining direct personal benefit, religious views in regards to participation, protection of privacy, availability of data, withdrawal, nature of provided information whether personal or family-based, approval of an authorized ethics committee, type of research conducted, positive impact on public health, personal gain of any profit, availability of general or personal results, trust toward researchers, and identity of researcher.

As detailed in Table 3, the most influential factors that were ranked as “very important” were protection of privacy (55.9%), followed closely by consenting prior to participation (54.3%), approval of an authorized

ethics committee (51.5%), and trust towards researchers (45.5%). On the other hand, the least important factors were personal gain of any profit (66.7%), fear of blood and needles and (65.3%), and identity of researchers (43.4%). Interestingly, religious views and time spent to participate were considered to be “important” by a considerable proportion of students (44.6%).

Table 3. Factors influencing participation in biomedical research.

	Least level of importance (%)	Slightly important (%)	Important (%)	Very important (%)	Unsure (%)
Time spent to participate	23 (5.3)	127 (29.2)	<b>194 (44.6)</b>	69 (15.9)	22 (5.1)
Fear of blood and needles	<b>284 (65.3)</b>	63 (14.5)	50 (11.5)	19 (4.4)	19 (4.4)
Consenting prior to participation	12 (2.8)	33 (7.6)	148 (34.0)	<b>236 (54.3)</b>	6 (1.4)
Gaining direct personal benefit	<b>137 (31.5)</b>	95 (21.8)	107 (24.6)	59 (13.6)	37 (8.5)
Religious view on participation	23 (5.3)	127 (29.2)	<b>194 (44.6)</b>	69 (15.9)	22 (5.1)
Protection of privacy	16 (3.7)	38 (8.7)	131 (30.1)	<b>243 (55.9)</b>	7 (1.60)
Ability of data withdrawal	67 (15.4)	<b>107 (24.6)</b>	<b>121 (27.8)</b>	<b>108 (24.8)</b>	32 (7.4)
Nature of provided information	35 (8.0)	86 (19.8)	<b>153 (35.2)</b>	<b>145 (33.3)</b>	16 (3.7)
Nature of family information provided	33 (7.6)	90 (20.7)	<b>148 (34.0)</b>	<b>150 (34.5)</b>	14 (3.2)
Approval of an authorized ethics committee	19 (4.4)	56 (12.9)	132 (30.3)	<b>224 (51.5)</b>	4 (0.9)
Type of research conducted	64 (14.7)	98 (22.5)	<b>138 (31.7)</b>	120 (27.6)	15 (3.4)
Positive impact on public health	9 (2.1)	75 (17.2)	<b>170 (39.1)</b>	<b>169 (38.9)</b>	12 (2.8)
Personal gain of any profit	<b>290 (66.7)</b>	70 (16.1)	21 (4.8)	7 (1.6)	47 (10.8)
Availability of general results	26 (6.0)	101 (23.2)	<b>171 (39.3)</b>	130 (29.9)	7 (1.6)
Availability of personal results	27 (6.2)	84 (19.3)	<b>170 (39.1)</b>	142 (32.6)	12 (2.8)
Trust towards researchers	11 (2.5)	61 (14.0)	153 (35.2)	<b>198 (45.5)</b>	12 (2.8)
Identity of researchers	<b>189 (43.4)</b>	85 (19.5)	74 (17.0)	39 (9.0)	48 (11.0)

## Influence of biobanking aspects on willingness to donate

To investigate how the impact of certain aspects related to biobanks would affect willingness to participate in a biobank, students were asked if they were willing to donate for a biobank under certain conditions including lack of benefits, not knowing the type of research, the managing body of the biobank (academic institution, governmental entity, private sector, an Arab entity, or a non-Arab entity) as shown in Table 4. There was a strong shift of willingness towards not participating when students were told that they would not know the type of research conducted where likeliness to participate dropped down to approximately 30% or they would not receive general results of the research where likeliness dropped down to less than half. Knowing that the biobank would be managed by an academic institution was a favorable indication especially when compared to a governmental entity, a private sector, an Arab institution, or a non-Arab institution (89.2% vs. 75.9% vs. 63.4% vs. 76.3 vs. 66.9, respectively.)

Table 4. Impact of certain aspects of biobanks on willingness to participate.

Possibility of participating in a biobank under different circumstances:	Strongly disagree (%)	disagree (%)	Agree (%)	Strongly agree (%)	Unsure (%)
Overall likelihood to participate:	7 (1.7)	25 (6.2)	271 (67.4)	99 (24.6)	33 (7.5)
a. without gaining benefits directly	13 (3.0)	36 (8.3)	242 (55.6)	111 (25.5)	33 (7.6)
b. without knowing the type of research	85 (19.5)	161 (37.0)	105 (24.1)	20 (4.6)	46 (10.6)
c. without being provided with general results	42 (9.7)	138 (31.7)	175 (40.2)	34 (7.8)	46 (10.6)
d. if managed by governmental entity	19 (4.4)	39 (9.0)	250 (57.5)	80 (18.4)	47 (10.8)
e. if managed by an academic institute	8 (1.8)	22 (5.1)	237 (54.5)	151 (34.7)	17 (3.9)
f. if managed by private health sector.	32 (7.4)	66 (15.2)	208 (47.8)	68 (15.6)	61 (14)
g. if managed by an Arab institute	16 (3.7)	46 (10.6)	249 (57.2)	83 (19.1)	41 (9.4)
h. if managed by a non-Arab institute	26 (6.0)	63 (14.5)	217 (49.9)	74 (17.0)	55 (12.6)

## Personal choices regarding biobanking aspects

Biobanks are associated with certain aspects in regards to type of consent, donor coding, re-contact, and means of sample handling at withdrawal. We, therefore, asked students about their preferences in

specific biobank operation. Students were given three options of consent: either an open consent allowing researchers to conduct any type of research on the biospecimens, a limited consent whereby specific type of research that is disease-specific, for example, can be conducted, or a consent that necessitates contacting donors every time a biospecimen would be used for research. As shown in Table 5, there was no clear preference over which type of consent is preferred where approximately one-third of students chose any one of the three types. In addition, half of the students preferred samples to be traceable back to donors, one quarter of them either preferred de-identifying samples either at time of collection or upon request at a later stage. As for re-contacting donors, two-thirds of students opted to be contacted whenever results specific to samples would be generated, whereas a quarter of them preferred to be re-contacted whenever results indicate the possibility of disease diagnosis ,8.5% wanted to be contacted if the disease could be treated, and only 1.1% never wanted to be re-contacted. Upon withdrawal, slightly more than half of students preferred to have their samples and data disposed and one-third of them would choose elimination of donor identity, but preserving samples and related information.

Table 5. Specific preferences in regards to biobanking-related aspects.

<b>Preferred level of consent when participating in a biobank and donating a biospecimen</b>	
Wide consent	138 (31.7)
Limited consent	166 (38.2)
A one-time consent with possible renewal	131 (30.1)
<b>Preferred procedure to protect donor identity when collecting samples</b>	
Just code samples and enable retrieval of donor identity	216 (49.7)
Ability to delete sample coding at a later stage upon request	120 (27.6)
Anonymize samples at time of collection	98 (22.5)
Doesn't really matter to me	1 (0.2)
<b>When to contact participants if specific results to their samples are generated</b>	
Re-contact under all circumstances	293 (67.4)
Re-contact me only in definite cases of having or increasing the possibility of having a disease	100 (23.0)
Re-contact me only in definite cases of having or increasing the possibility of having a treatable disease	37 (8.5)
Never contact me	5 (1.1)
<b>In case of deciding to withdraw from a biobank</b>	
Disposal of samples only	31 (7.1)
Deleting all data only	41 (9.4)
Disposal of both sample and data	225 (51.7)
Removing donor identity, but keep samples and data	138 (31.7)

## Discussion

The term “biobank” appears to be new to almost half of student respondents from all disciplines where only 52.9% of the students stated that they have a previous knowledge of the term. This figure is better than the 27% Saudi healthcare students [10], the 40% of Egyptian medical students [11], and the 20% of Russian students [12] who knew what the term means. However, it is less than students of the Italian

Padua University who a large percentage of them were able to select the right definition from a multiple-choice question [13]. It is expected that students of medical, health, and scientific colleges would know the term better compared with students of other disciplines. Knowledge is also correlated with previous participation in biomedical research.

In our study, an overwhelming majority of students expressed their willingness to participate in biomedical research (94.2%) and biobanking (92%). A high proportion of students (88.2%) were also willing to participate in genetic research. This enthusiasm to participate in a variety of biomedical research activities contrasts the attitude of Egyptian medical students who were by far less eager to engage in research [11]. Saudi healthcare students were similarly eager to donate for biobanks in association with prior tissue donation and testing, but not involvement in medical research [10]. We, however, found that willingness to participate was affected by prior participation in biomedical research as well as by school affiliation where students from health schools showed greater enthusiasm. Previous participation in biomedical research was also found to correlate with willingness to donate for biobanking among Egyptian students [11]. Sociodemographic status also did not influence students' willingness to participate in biobanking among university students in Russia [12]. On the other hand, the survey conducted among students in Italy showed that gender has a significant association on participation [13]. A previous study among the Jordanian population showed that positive responses correlated significantly with younger age and increasing education, but not gender [9].

Beside enthusiasm in participating in biobanks in our young generation, two major themes are found to play a major role in determining the likelihood of participation. The first is protection of personal integrity. This can be revealed by the importance, expressed by students, of protection of privacy, ability to withdraw data, the type of information provided to researchers including family information. Confidentiality could also be noticed by student preferences at the time of donation and in case of withdrawal from biobanks. Half of students preferred to either have the ability to remove personal identification of samples at a later stage of donation or at the time of donation. In addition, about half of students preferred disposal of both samples and data and 30% would rather biobanks keep samples, but dispose donor identity, upon withdrawal. Concern about confidentiality was one of the main reasons Saudi and Egyptian students were not willing to donate for biobanks [10, 11].

The other theme that influences student participation in biobanks is the type of research. A large number of students indicated that it was important for them to know what kind of research would be conducted on their samples and this was confirmed by the shift in willingness to participate in biobanking if they do not know this information. The study surveying Russian students [12] showed that the specific goal of the research had the greatest impact on one's decision to participate. Saudi and Egyptian students also expressed their concern of misuse of their samples to be a major determining factor to their participation [10, 11].

In addition, although students indicated that the type of researchers handling the samples was not important, willingness to donate for a biobank is influenced according to the entity operating this biobank

with an academic institution having the most trust and non-Arab and private biobanking having the least. This trend appears to be a common phenomenon as has been illustrated by two reviews of the literature on this topic covering different nations such as the U.S., Scotland, China, among many others [14, 15]. This attitude is not restricted to the general public, but also to healthcare professionals who expressed willingness to participate in biobanks affiliated with hospital, university and government research institutions and less likely with for-profit companies [16].

Importantly, fear of blood and needles was not a major factor in preventing students from participating in biomedical research, in addition, blood was selected as the most preferred biospecimen to donate followed by cheek swabs and saliva. Stool, on the other hand, was the least preferred. Similarly, fear of needles was one of the stated factors that would prevent Saudi and Egyptian students from participating in biobanks [10, 11], although blood and saliva were the most preferred biospecimens to be donated. Blood appears to be an acceptable biospecimen to be donated by the public in Egypt [17] as well as others [18, 19].

Informed consent is a cornerstone of biomedical research. A majority of students (88.4%) believe consenting prior to participation is an important factor for them to participate. However, there was no consensus on preferred type of consent with opinions divided almost equally among three choices: an open consent, a consent restricted to disease type, or a one-time consent with possible renewal. In two previous studies conducted in Jordan, the majority of the general population (75%) favored an open consent and only 4% would require reconsenting [20]; on the other hand, only half of patients of multiple sclerosis preferred an open consent and 37% would rather reconsenting [21]. These differences, particularly, in the proportion of individuals desiring to re consent for the use of their samples in research are probably due to eagerness to learn of the type of research to be conducted on their samples. Such curiosity was also expressed by a similar percentage of university students (39%) of the State of Michigan, USA, who wanted to be contacted again each time scientists want to use their leftover dried blood spots taken when they were newborn [22].

The purpose of re consenting and re contacting is tightly related to returning research results, which appears to be a strong incentive for students to participate in biobanking. More than two-thirds of students want to be contacted under all circumstances when research results are generated and one-third of them want to be contacted only if the result revealed a certain disease. Returning of research results has been found to strongly correlate with willingness to participate in biobanking initiative [23]. Returning research results has been under discussion for some time now and guidelines are needed to be established taking into consideration donor's rights and the logistics associated with this process [24].

There is also high sense of the importance of personal and ethical protection among the students. Although students enrolled in non-scientific disciplines are less aware of the terms questioned in the survey, a large proportion of them are still eager to participate in biomedical research initiatives. Those involved in biomedical research need to capitalize on this outcome in promoting biomedical research and in establishing a productive biobank.

## Conclusions

A major strength of this study is the inclusion of students of different disciplines with various demographic backgrounds representing a diverse group and, hence, providing credibility to the generated data. However, some limitations are worth noting. First, responses are based on a self-reporting, electronic questionnaire, a method that could jeopardized students' understanding of some items or may allow them to answer the questionnaire hastily. Additionally, using online data collection platforms could have prevented us from reaching a certain segment of students of the, i.e. those with lower academic standing (i.e. GPA) or from non-scientific disciplines..

The results presented herein offer a promising outlook for biomedical research and biobanking in Jordan illustrating high student interest in these initiatives. It is clear that there are certain issues that must be considered when attempting to involve the young generation in Jordan in biomedical research and biobanking. These issues include clarity regarding the concepts, purposes, and operational procedures of biobanks as well as outcome of research from a personalized perspective. Since there is no consensus regarding a preferred informed consents, it is a good idea to use a tiered consent that grants potential donors a form they prefer increasing trust in biobanks and, subsequently, participation.

## Abbreviations

GPA: Grade-point average

## Declarations

### *Ethics approval and consent to participate*

This study was approved by the Institutional Review Board of Jordan University Hospital. Participants of the online questionnaire were provided with the opportunity of not answering the questionnaire. In addition, participants could not be identified. An introductory paragraph explaining the nature of the survey was provided followed by a question asking for the electronic "written" consent of participants with two options to choose from: "Agree" or "I do not agree."

### *Consent for publication*

Not applicable

### *Availability of data and materials*

The datasets during and/or analyzed during the current study available from the corresponding author on reasonable request.

### *Competing interests*

The authors declare that they have no competing interests

### *Funding*

Non funding was needed for this research.

### *Authors' contribution*

All authors contributed to, data collection, data analysis, interpretation of the results, and manuscript writing and final approval; FK was responsible for manuscript writing and statistical analysis; DJ, JA, MAE, and SA were medical students who were primarily responsible for data collection and manuscript writing; MA conceived the idea, designed and supervised the study, and was responsible for critical revision of the manuscript.

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### *Authors' information (optional)*

Not applicable

## **References**

1. De Oliveira L, Dias MAB, Jeyabalan A, Payne B, Redman CW, Magee L, et al. Creating biobanks in low and middle-income countries to improve knowledge – The PREPARE initiative. In: Pregnancy Hypertension. 2018. p. 62–4.
2. Klingstrom T, Mendy M, Meunier D, Berger A, Reichel J, Christoffels A, et al. Supporting the development of biobanks in low and medium income countries. In: 2016 IST-Africa Conference, IST-Africa 2016. 2016. doi:10.1109/ISTAFRICA.2016.7530672.
3. Ahram M, Soubani M, Abu Salem L, Saker H, Ahmad M. Knowledge, Attitudes, and Practice Regarding Genetic Testing and Genetic Counselors in Jordan: A Population-Based Survey. J Genet Couns. 2015;24:1001–10.
4. Coppola L, Cianflone A, Grimaldi AM, Incoronato M, Bevilacqua P, Messina F, et al. Biobanking in health care: Evolution and future directions. J Transl Med. 2019;172.
5. De Souza YG, Greenspan JS. Biobanking past, present and future: Responsibilities and benefits. AIDS. 2013;27:303–12.
6. Vaught J. Biobanking During the COVID-19 Pandemic. Biopreserv Biobank. 2020;18:153–4.
7. Ahram M, Othman A, Shahrouri M. Public perception towards biobanking in Jordan. Biopreserv Biobank. 2012;10:361–5.

8. Bossert S, Kahrass H, Strech D. The public's awareness of and attitude toward research biobanks - A regional German survey. *Front Genet.* 2018;9:190.
9. Ahram M, Othman A, Shahrouri M. Public perception towards biobanking in Jordan. *Biopreserv Biobank.* 2012;10:361–5.
10. Merdad L, Aldakhil L, Gadi R, Assidi M, Saddick SY, Abuzenadah A, et al. Assessment of knowledge about biobanking among healthcare students and their willingness to donate biospecimens. *BMC Med Ethics.* 2017;18:32.
11. Ziady H, El Zeiny N, Sultan E, El Sharef Y. Assessment of medical students' knowledge and attitude towards biobanks and biospecimens donation. *J Med Res Inst.* 2017;38:1–9.
12. Tsvetkova LA, Eritsyanyan KY, Antonova NA. Russian students' awareness of and attitudes toward donating to biobanks. *Psychol Russ State Art.* 2016;9:30–8.
13. Tozzo P, Fassina A, Caenazzo L. Young people's awareness on biobanking and DNA profiling: results of a questionnaire administered to Italian university students. *Life Sci Soc Policy.* 2017;13:9.
14. Garrison NA, Sathe NA, Antommaria AHM, Holm IA, Sanderson SC, Smith ME, et al. A systematic literature review of individuals' perspectives on broad consent and data sharing in the United States. *Genet Med.* 2016;18:663–71.
15. Domaradzki J, Pawlikowski J. Public attitudes toward biobanking of human biological material for research purposes: A literature review. *Int J Environ Res Public Health.* 2019;16:220.
16. Caixeiro NJ, Byun HL, Descallar J, Levesque J V., De Souza P, Soon Lee C. Health professionals' opinions on supporting a cancer biobank: Identification of barriers to combat biobanking pitfalls. *Eur J Hum Genet.* 2016;24:626–32.
17. Abdelhafiz AS, Sultan EA, Ziady HH, Ahmed E, Khairy WA, Sayed DM, et al. What Egyptians think. Knowledge, attitude, and opinions of Egyptian patients towards biobanking issues. *BMC Med Ethics.* 2019;20:57.
18. Lewis C, Clotworthy M, Hilton S, Magee C, Robertson MJ, Stubbins LJ, et al. Public views on the donation and use of human biological samples in biomedical research: A mixed methods study. *BMJ Open.* 2013;3:e003056.
19. Vaz M, Vaz M, Srinivasan K. Listening to the voices of the general public in India on biomedical research—an exploratory study. *Indian J Med Ethics.* 2015;12:68–77.
20. Ahram M, Othman A, Shahrouri M. Public support and consent preference for biomedical research and biobanking in Jordan. *Eur J Hum Genet.* 2013;21:567–70.
21. Ahram M, Zaza R, Ibayyan L, Dahbour S, Bahou Y, El-Omar A, et al. Towards establishing a multiple sclerosis biobank in Jordan. *Int J Neurosci.* 2014;124:812–7.
22. Platt T, Platt J, Thiel DB, Fisher N, Kardina SLR. 'Cool! and creepy': engaging with college student stakeholders in Michigan's biobank. *J Community Genet.* 2014;5:349–62.
23. Ahram M, Othman A, Shahrouri M, Mustafa E. Factors influencing public participation in biobanking. *Eur J Hum Genet.* 2014;22:445–51.

## Figures

Figure 1

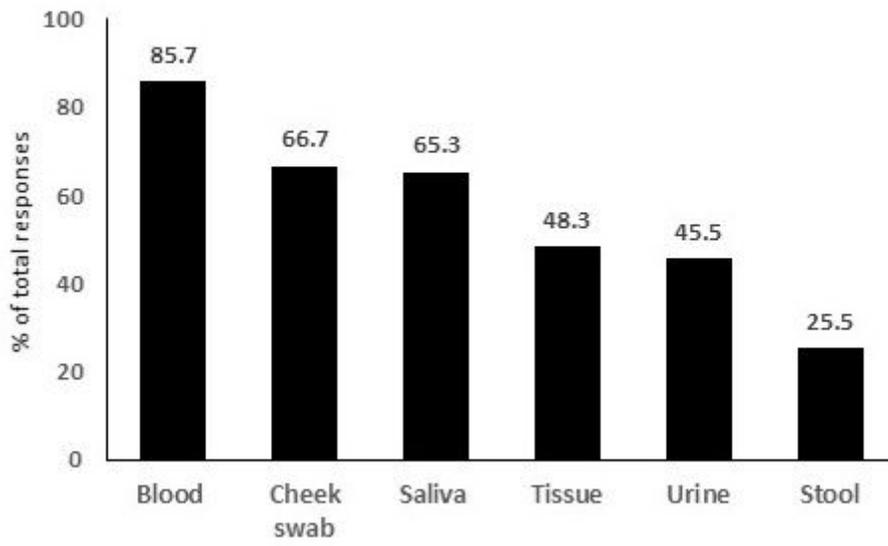


Figure 1

Preferences of biospecimens donated for research.