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Research Article

Banking on You? The Level of Public Awareness of Biobanks in Malta

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Abstract. This paper explores the level of awareness of the Maltese general public in relation to the existence and use of biobanks as resources for biomedical and genomic research. Using a quantitative research design, a four question survey was administered face-to-face to a random stratified quota sample ($n = 387$) of the Maltese population. The survey assessed whether the general public understands what a biobank is, and what the people believe/ think a biobank might be. Results show that the overwhelming majority of the public is not aware of the term 'biobank', and when asked to think about what a biobank could be, the majority of these failed to give an accurate answer, with a financial institution being the most frequent suggestion. This said, 26.5% of those who initially claimed that they did not know what a biobank is (or claimed they were not sure) went on to give a legitimate response when asked to speculate about what a biobank could be. Most of these respondents mentioned biobanks which store gametes and/or embryos and biobanks which store blood and organs for the purpose of donation. Whilst gender does not seem to be a significant factor in the outcome as an independant variable, educational achievement did have an influence on the accuracy of the responses. The key finding is that only 2.3% of the Maltese population promptly associated the term 'biobank' with a facility for storing tissue for the purpose of biomedical research, while the vast majority believed it referred to a financial institution.

Keywords: Biobanks, biomedical research, participants, knowledge, perceptions

1 Introduction

A biobank can be defined as a "bank that collects, stores and distributes biological samples" (Schmilden, 2016). Understood in its broadest form, a biobank stores biological matter ranging from human blood and/or other tissue, to tissue of animals and/ or plants (de Souza & Greenspan, 2013). It is, however, the awareness of biobanking related to biomedical and genomic research that is the key focus of this paper.

Large-scale biobanks have become important in this context as they serve as a resource for stored samples and their accompanying data, and a potential hub for sharing and reuse of these samples rooted within stringent ethical proceedures (Holub et al., 2018; Colledge, Elger & Howard, 2013). Using established networks of biobanks as a collaborative infrastructure for resources becomes even more pertinent when dealing with rare genetic diseases where participants are normally sparsley distributed geographically. Biobanking protocols allow researchers to share samples and data, consequently facilitating the research process (Schmilden, 2016). Within the backdrop of the recent key role of genetic studies in understanding the aetiology and development of human diseases, there has been a rise in the number of biobanks around the globe over the past decades (Chen & Pang, 2015).

Malta is no exception to this trend. The Malta Biobank was established in 1989 and forms part of the Centre for Molecular Medicine and Biobanking, University of Malta. It is a founder member of the Biobanking and BioMolecular Resources Research Infrastructure, European Research Infrastructure Consortium (BBMRI-ERIC), aimed at facilitating sample and data sharing (Mayrhofer, Holub, Wutte & Litton, 2016).

The biobank currently holds approximately 26,000 samples of human biological samples in its clinical and population based banks. One of its major collections is the Globin Bank which includes abnormal haemoglobin and thalassemia in the Mediterranean. There are also collections related to research into type 2 dia-

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betes melitis, muscular dystrophy, cystic fibrosis, ALS and colorectal cancer (see also University of Malta, n.d.-a). The Malta Human Genome Project is also based at the Malta Biobank where a Maltese reference draft genome has been drawn up through sequencing a random collection of 400 (i.e. 0.1% of the population) Maltese DNA samples (Borg, 2018, September). The team is now in the process of recruiting participants to build a collection of samples from 1% of the Maltese population. This project is aimed at discovering new DNA variants that cause disease in Malta. Once completed, it will have the potential to positively impact medical practice in Malta, by creating the possibility for clinicians to provide personalised treatments for their patients (University of Malta, n.d.-b).

Clearly, all research depends on the active engagement of participants who provide their tissues/blood and permission to link their biological sample to personal health data. To date, there are no studies assessing the awareness of biobanking activity in Malta, and the perception and understanding of the general public in this respect. Findings from a Europe based study, however, indicate a very low level of awareness. The authors of one particular study raised concerns in their conclusions where they stated that "[t]wo-thirds of Europeans recently surveyed have never heard of biobanks. [...] most Europeans haven't heard of their nation's repositories of human blood and tissue samples. Promote them, or they could fail" (Gaskell & Gottweis, 2011).

The success of a biobank is entirely dependent on active participants who are motivated to participate by donating their biospecimen for research purposes (Gaskell & Gottweis, 2011). This motivation is intrinsically related to issues of transparancy and trustworthiness of biobanking proceedures, clear and unambiguous consenting protocol, and robust ethical governance of data and samples (Locock & Boylan, 2016). Even more fundamental, however, is nurturing frank understanding of the purpose of research oriented biobanks and their potential to improve the health of future generations (Goisauf & Durnová, 2018). On a local level, the 'Connecting for Health' project which is currently ongoing at the Centre for Molecular Medicine and Biobanking within the University of Malta, is building an IT portal to facilitate public engagement. It will act as a communication interface between the research community at the Malta biobank and the general public, with the aim of encouraging members of the public to become research partners by donating their sample for genomic research.

The data presented here are from a preliminary survey related to this project which will contribute to contextualising subsequent phases of planned qualitative research into beliefs and perceptions of biobanking and genomic research in Malta.

2 Methods

A quantitative research design was used to collect statistically generalizable data about the level of awareness and accuracy of understanding of the Maltese general public in relation to biobanks.

The research questions driving the design were:

- Does the Maltese general public know what a biobank is?
- How aware is the Maltese general public of the existence of biobanks?
- What first comes to the mind of the Maltese general public when they hear the word 'biobank'?

2.1 Sample

National statistics office (NSO) data on the Maltese population (450,000 in 2017) were used to set the quotas on a random sample stratified for gender and education. A sample size of 387 participants was used which allows for a ±5% margin of error and a confidence interval of 95%. Quotas were set to stratify the sample for gender, and for education as detailed in Table 1.

2.2 Research Tool

A simple four-point survey was designed to gather data as follows:

Q1: Do you know what a biobank is? **(Skip to Q4 if answer is NO. Continue if answer is YES.)**
Q2: What is a biobank?
Q3: How did you learn about biobanks? **(Stop here)**
Q4: What do you think a biobank is?

Table 1: Sample stratified by education.

SAMPLE		
59.8% of 387 participants	**231 participants**	People who completed primary and/or secondary education - this includes persons who never attended an educational institution.
22.4% of 387 participants	**87 participants**	People who completed post-secondary education.
17.8% of 387 participants	**69 participants**	People who graduated from tertiary education.
100% of 387 participants	**387 participants**	**TOTAL**

2.3 Data Collection

Data were gathered between the 6th of April 2018 and the 26th of April 2018 by inviting individuals to participate at strategic points of public access (Valletta Bus Terminus, Valletta Republic street, Ċirkewwa terminal and University campus canteen and quadrangle). Participants were recruited according to the sample stratification strategy as described above.

The survey was conducted in the language of preference (Maltese or English) of the respondent, with Maltese being the dominant choice. These responses were translated at source and data recorded in English. The word 'Biobank' was used in both languages. No suggestions or prompts were given as possible answers to the survey questions, and all data were spontaneous responses from interviewees.

2.4 Ethics

The study was carried out with approval from the University of Malta Research Ethics Committee. All participants were given a verbal explanation of the aims of the study, and the ways in which the data will be used, emphasising the fact that all data will be fully anonymous. No personal data were collected. All participants were given a printed information sheet about the research project.

3 Results

3.1 General Understanding of the Term 'Biobank'

When asked the initial question of the survey questionnaire (Q1: 'Do you know what a biobank is?'), a significant 87.1% (337) claimed 'no' and another 5.4% (21) said 'not sure'. Only 7.5% (29) of the sample ($n = 387$) claimed that 'yes' they do know what a biobank is (see Fig. 1).

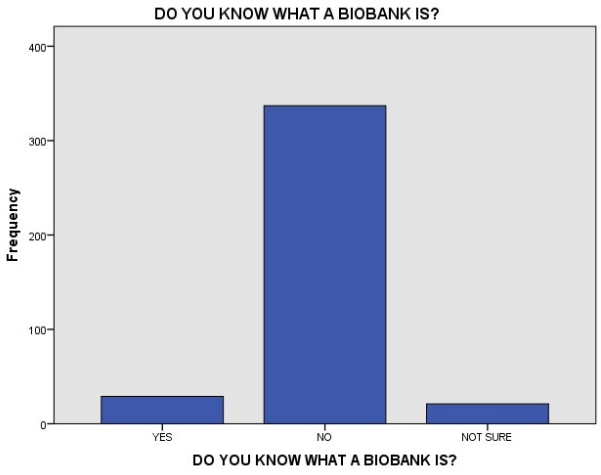

Figure 1: Do you know what a biobank is? ($n = 387$)

It is interesting to note, as will be discussed in more detail below, that not all who claimed 'yes' gave a valid answer when asked to explain what a biobank is, in fact 27.6% of those who answered 'yes' when initially asked 'Do you know what a biobank is?', gave an invalid response when asked to specify (see Fig. 3). Hence, when compared to the number of respondents who claimed to know what a biobank is, the number of respondents actually knowing what a biobank is, and mentioning one type of biobank, dropped to 5.4% from the original 7.5%, as of the 29 respondents who claimed to know what a biobank is, 8 respondents gave an invalid explanation.

3.2 Speculation About Possible Meaning of the Word 'biobank'

Those respondents who declared that that they did not know what a biobank is were then invited to speculate about the meaning of the word. Fig. 2 illustrates in a categorical manner the responses of these 358 participants (92.5%) when asked to speculate about what a biobank might be after responding with 'no' or 'not sure' when asked if they knew what a biobank is. The most frequent response by far is that it was some form of bank for money.

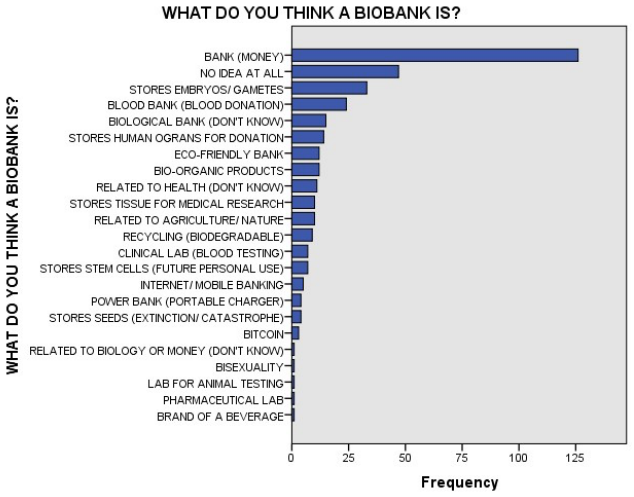

Figure 2: Responses to Q4: What do you think a biobank is? ($n = 358$)

It is clear that the suffix 'bank' in 'biobank' is dominant in forming perceptions in the Maltese public, with 40% of those who were invited to speculate on the meaning of 'biobank' assuming it referred to a financial institution (126 respondents mentioned 'bank (money)', 12 respondents mentioned 'eco-friendly bank' and another 5 respondents mentioned 'mobile banking').

The prefix 'Bio' in 'biobank' proved to be influential in some responses, with 6.7% suggesting it may be linked to some eco-friendly (12 mentions) or 'organic' (12 mentions) institution/product. Another 4.2% (15 respondents) assumed that a 'biobank' is a biological bank, however failed to reason out what the function of such a bank might be. Some responses were interesting in virtue of their originality, with 'powerbank charger' (4 mentions), 'bitcoin' (3 mentions) and 'brand of beverage' (one mention) being the most notable.

It is interesting to note that 3.1% said that they believed that a biobank is something which relates to health, but had no idea of its use; and another 2.6% of the respondents mentioned types of scientific labs; namely 'a clinical lab' (2%), 'a pharmaceutical lab' (0.3%) and 'a lab for animal testing' (0.3%).

13.4% of the respondents claimed that they could not think of anything that a biobank could represent and did not want to try and guess, claiming that they had "no idea at all".

A notable 25.4% (91 respondents) of those who initially claimed that they did not know what a biobank is or claimed they were not sure ($n = 358$) then gave a legitimate response and mentioned a type of biobank when asked to think about what a biobank could be, with the storage of embryos and gametes being the most frequent association in this respect. The percentage breakdown of these data is as follows:

- 9.2% of these mentioned embryo freezing and/or gamete freezing;
- 6.7% mentioned blood banks with the purpose of blood transfusion/ donation;
- 3.9% mentioned biobanks which store organs for donation;
- 2.8% mentioned biobanks which store tissue for the purpose of biomedical research;
- 1.7% mentioned stem cells to be used for future self;
- 1.1% mentioned the storing of seeds to be used in case of extinction/ catastrophe.

When analysing these data in association with level of education, 38.5% of the respondents had completed their education at either primary or secondary level. 29.7% were individuals who had completed post-secondary education, and 31.9% were respondents who completed tertiary education. It is important to note that the vast majority of those who stopped at Primary or Secondary level most commonly mentioned *'embryo freezing and/or gamete freezing'* and *'blood banks with the purpose of blood transfusion/ donation'*. Whereas those with a post-secondary or tertiary level of education were more likely to mention the other types of biobanks.

Table 2 shows the demographics of gender of the 91 respondents who initially claimed they did not know what a biobank is, and later gave a valid answer to the question, *'What do you think a biobank is?'*. Male gender is seen to have a marginal association with valid answers.

Table 2: Valid answer to Q4 by gender.

Q4 'What do you think a Biobank is?': Valid answers by gender.

		Frequency	Percentage out of 91	Percentage out of 387
Gender	Male	54	59.3	13.9
	Female	37	40.7	9.6
	Total	91	100.0	23.5

As mentioned previously, 27.6% (8 participants) of those who answered 'yes' when initially asked 'Do you know what a biobank is?', went on to give an invalid answer when asked the question 'What is a biobank?'. Here again, the suffix 'bank' is dominant as most of these assumed, and seemed to be sure, that a biobank had to do with finance.

However, it can be observed the majority of those who answered the first question (**Q1**: Do you know what a biobank is?) with a yes, had a valid answer to the follow up question (**Q2**: What is a biobank?). Out of these valid responses 9 respondents mentioned biobanks which store tissue for the purpose of medical research. Another 7 participants mentioned biobanks which store gametes or frozen embryos, 4 participants mentioned biobanks which store organs for the purpose of organ donation. One participant mentioned private stem cell stores.

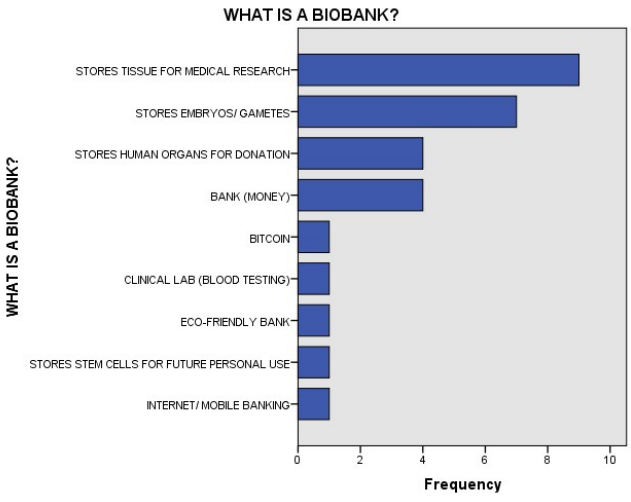

Figure 3: Responses to Q2 'What is a biobank?' by individuals who claimed they knew ($n = 29$).

3.3 Mentioning Biomedical Research as the Function of a 'Biobank'

Other than evaluating the level of comprehension of the term 'biobank' in general, the specific link of biobanking activity with biomedical and genomic research was also examined. Data show that this level of understanding is minimal with only 2.3% (9 participants) of the whole sample initially stating that 'yes' they know what a biobank is, and then mentioning biobanks which 'store tissue for biomedical research'. A significant majority of 77.7% (of the 9 participants) consisted of individuals who have completed tertiary education, and 6 of these were male.

There were also 10 respondents (2.6% of the whole sample) who had initially stated that they did not know what a biobank is, who then also went on to suggest that it might be a place which stores tissue for the purpose of medical research. As expected, the level of educational attainment is also a significant variable here. None (0%) of those with a primary/secondary level of education, who stated that they did not know what a biobank is, mentioned the storing of tissue for biomedical research when asked the follow up question. 60% of those who did mention biobank which store tissue for medical research were tertiary education graduates, and 40% were respondents who have continued their studies to post-secondary education.

3.4 Sources of Information About Biobanks Used for Research Purposes

All those who mentioned biobanks which 'store tissue for medical research' ($n = 19$), after being asked the follow-up question, **Q2**: *"What is a biobank?"*, were asked a third question, **Q3**: *"How did you learn about biobanks?"*. This includes both those who answered the first question (Do you know what a biobank is?) with a 'yes' and those who answered with a 'no/ not sure' answer, but ultimately mentioned the *'storing of tissue for biomedical research'*.

The bar chart Fig. 4 illustrates how each of the 19 respondents who mentioned biobanks which 'store tissue for biomedical research' learnt about the function of a biobank.

Seven respondents were students who are currently enrolled in a course related to pharmacy, medicine or health science.

Six respondents were people who were not involved in pharmaceuticals or medicine but stay updated through independent reading.

Five respondents said that they learnt about biobanks for the purpose of medical research through their work in the pharmaceutical/ medical sector.

One respondent claimed that they learnt about biobanks after being asked to donate their own DNA sample for medical research.

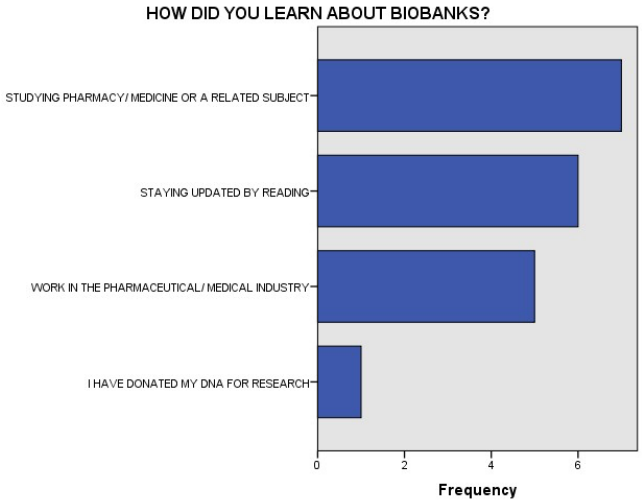

Figure 4: Responses to Q3: 'How did you learn about biobanks?' ($n = 19$)

Clearly, the majority of respondents attributed their knowledge about the use of biobanks for research purposes to their career, career prospects and/or interest in the process. There is no mention of knowledge drawn from local public information campaigns or recruitment drives.

3.5 A Breakdown of Numbers Indicating the Level of Biobank Awareness Amongst the Maltese Population

Table 3 is a simplified illustration of the numbers which unveil the level of awareness of biobanks amongst the general public. The first row indicates the distribution of responses to the first question of the survey questionnaire (Q1: "Do you know what a biobank is?"). The second row highlights the validity of the responses when the research participants were asked the follow-up question to elaborate about the purpose of a biobank (Q2: "What is a biobank?" & Q4: "What do you think a biobank is?").[1]

Table 3: Breakdown of responses to Q1, Q2 & Q4.

Yes, know what is a biobank is: **29**		No, don't know what a biobank is (includes those who claimed 'don't know'): **358**	
Legitimate answer to Q2: **21**	Non-legitimate answer to Q2: **8**	Legitimate answer to Q4: **91**	Non-legitimate answer to Q4: **267**

[1] Q2 was asked to those who initially claimed that they know what a biobank is, whereas Q4 was asked to those who initially claimed that they don't know what a biobank is and to those who claimed that they are not sure whether or not they know what a biobank is.

4 Discussion

The dominant finding is that the overwhelming majority of the population does not know what a biobank is. Looking at the respondents who instantly claimed that they do not know what a biobank is ($n = 358$), when pressed to speculate about what it might be, a significant proportion of these (48.6%) gave an invalid answer and went on to mention something completely unrelated to biology and/or science. Another 12.6% linked the term to health and/or science but went completely off-track and did not mention anything related to biobanks when asked to explain further. 13.4% claimed that they had "no idea at all". The remaining 25.4% gave a valid answer when asked to think about what a biobank might be, however only a marginal 2.8% mentioned biobanks which store blood and/or tissue for the purpose of biomedical research.

To those who have no knowledge about its meaning, the word 'biobank' has strong associations with 'money', indeed the suffix 'bank' in 'biobank' is dominant in forming perceptions in the Maltese public, with 40% of those who were invited to speculate on the meaning of 'biobank' assuming it referred to a financial institution. Three respondents seem to have taken this to its most cutting-edge, by speculating that the word might mean a form of bitcoin currency. The prefix 'Bio' also proved to be influential, though much less so, with respondents who were asked to speculate about the meaning of the word 'biobank' suggesting it was some eco-friendly or 'organic' institution/product.

The dominant misconception, by far, is that a 'biobank' is some form of financial institution. This said, a noteworthy number of respondents did make the link between the term 'biobank' and medicine, biology, science and/or nature, with 28.9% (112 respondents) of the whole sample mentioning a valid type of biobank. The most common response in this respect was a biobank which stores gametes and/or embryos for the process of IVF. It is highly likely that the frequency of this response is due to the fact that during the time when the field research was conducted, the Maltese parliament and media were actively debating the matter of IVF, gamete donation and embryo freezing, and the debate was predominant in public discourse in the everyday social environment. When analysing the gender of the respondents who initially claimed they did not know what a biobank was, and then went on to suggest an appropriate response when asked to speculate, male gender was seen to have a marginal association with valid answers.

Results highlight the fact that the Maltese general public's awareness of biobanks used for the purpose of biomedical research is minimal, and that when the term 'biobank' is associated with science, then there is a stronger association with gametes and sperm collection/storage for IVF than with molecular medicine/genomic research. Indeed, only a total of 19 respondents (4.9% of the whole sample) mentioned biobanks which store tissue for the purpose of biomedical research. Ten of these participants had initially stated that they did not know what a biobank was, and only mentioned this type of biobank after thinking further about what the term 'biobank' could mean. It is noteworthy that only 2.3% (9 participants) of the whole sample were prompt to claim that they know what a biobank is and mentioned biomedical research when asked to explain further. This indicates that the awareness of the research process in molecular medicine is higher than the awareness of the term 'biobank', despite noting that awareness about both is significantly low.

Clearly the level of education of the research participants is significant when analysing all those who mentioned biobanks which store tissue for the purpose of medical research, with a significant positive correlation between tertiary educational achievement and mentioning such type of biobanks. Within this caveat, and flagging this with caution as the numbers involved here are small, gender becomes a significant variable when associated with education and career choice as 63.2% (12 respondents) of those who mentioned biobanks for biomedical research are either studying or working in the pharmaceutical or medical sectors, and the significant majority of those were male.

5 Conclusion

It is clear from the data presented herein, that the vast majority of the Maltese general public does not know what the term 'biobank' means, and does not associate the term with biomedical or genomic research. The suffix 'bank' is the most influential in forming the general public's assessment of what it might be, with the vast majority mentioning a financial institution as a possibility. The prefix 'bio' also has an interesting impact on public perception of what a biobank might be, with a small proportion suggesting it may be linked to some eco-friendly or 'organic' institution/product. Results indicate that there is great scope for increasing science communication in relation to research linked biobanking in order to enhance the process of biomedical and genomic research in Malta.

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