

# Biobanks for aging research - perceptions and choices among rheumatology outpatients

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ACTA REUMATOL PORT. 2021;46:218-229

## ABSTRACT

**Objective:** Biobanks for research (BBR) have enormous value for research, including those specifically oriented to chronic diseases. Knowing public attitudes and perceptions is key to design and implement patient-centered BBR. We assessed patient awareness, perception and choices among rheumatology outpatients regarding aging biobanking activities.

**Methods:** We conducted a cross-sectional survey of patients, aged 50 or older, attending an outpatient rheumatology tertiary department. Demographic data and perceptions about biobanking were collected and statistical analysis was performed.

**Results:** 132 valid questionnaires were obtained (mean age: 63.4; 68.2% female; mean education years: 8.35). 61.7% of respondents did not know the specific term “biobank”, 57.7% knew they could donate biological material for BBR, 89.9% agreed with these infrastructures and 88.3% would consider participation. Those participants with more years of education were more knowledgeable and prone to biobank participation. Willingness to participate in BBR was mainly related (86.4%) to the advancement of scientific knowledge and not individual gain. Scientific research institutes were indicated as the most adequate institutions to manage BBR. Informed consent, anonymity and confidentiality ranked as top requisites for biobank participation. 61.3% of respondents expressed their agree-

ment with aging biobanks, considering these as a sign of respect for specific problems of people of older ages such as higher disease burdens.

**Conclusion:** Knowledge of biobanks was found to be limited. Participants were positive toward the setting up of biobanks in general and patient-centered aging biobanks in particular. Knowledge about biobanks and acceptance were higher among participants with higher education years.

**Keywords:** Biobank; Aging; Ethics; Patient awareness.

## INTRODUCTION

Biobanks for research (BBR) consist in organized repositories of biological samples with associated data for research purposes<sup>1</sup>. Such collections can be representative of a population or a subset of a population<sup>2</sup>. Samples stored in BBR, including those of human origin, can consist in organs, tissues, biofluids (e.g. blood, urine) and genetic materials (e.g. DNA)<sup>3,4</sup>. Human biological samples may be obtained from a variety of sources: from healthy volunteers, patients or retrieved post-mortem<sup>5</sup>. Furthermore, sample collections can be population-based or disease-specific, originating from individuals with different demographics, health, behaviours and lifestyles<sup>4</sup>. Classification of human sample-related BBR varies<sup>6</sup>. Nonetheless, three major types can be identified: (i) population-based biobanks whose primary goal is to obtain biomarkers of population identity and susceptibility (typically from the DNA of large numbers of healthy donors), representative of a country/region/ethnic cohort; (ii) disease-oriented biobanks for epidemiology studies and (iii) disease-oriented general biobanks<sup>7-9</sup>. In terms of ownership, BBR can be public, private or result from partnerships across different sectors and be held by hospitals, research institutes, pharmaceutical companies and patient organizations<sup>4</sup>. BBR governance models also vary substantially<sup>10</sup>.

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Growing numbers of BBR have been created throughout Europe in the last decades<sup>11-15</sup>. The implementation of a vast range of BBR in Europe and elsewhere, coupled with the large number of shared samples have been widely considered as a fundamental resource for scientific research, potentiating the collective capacity to understand human biology and medicine while contributing to fight disease and improve quality of life.

In parallel, as a result of relevant developmental efforts, Portuguese BBR have also been created and implemented<sup>16</sup>. Subsequently, a national biobank consortium (Biobanco.pt) has been set up to inventory national infrastructures, catalogue samples, harmonise procedures and promote national and international research<sup>17</sup>.

In parallel and in line with their relevant role for healthcare, BBR participation and BBR inclusion in patient-centered health systems has been studied and debated<sup>5,7,18</sup>.

To design and develop patient-centered biobanks, public awareness, perceptions and choices regarding these fundamental infrastructures must be evaluated and understood<sup>19</sup>. More than acting as mere sample donors, members of the public can, and perhaps should, act as partners or collaborators as their perspective is a valuable resource for the biobank<sup>20</sup>. Previous studies have shown that citizens express a variable willingness to participate in medical research<sup>21-28</sup>. However, their answer is generally positive when they were specifically questioned about donating samples to BBR<sup>24,29-36</sup>.

Despite these largely positive attitudes towards participation, BBR, particularly those of national and international scope, face significant challenges<sup>37</sup>. In particular, ethical, legal and social issues (ELSI) of BBR deserve particular attention<sup>15,38</sup>.

Relevant ELSI of BBR include (but are not exclusive to): i) the protection of the rights to autonomy, confidentiality and privacy of participants while also respecting the public interest of scientific research; ii) selecting the method, scope, level of detail, and periodicity of informed consent for BBR; iii) security measures that should be adopted; iv) balancing non-commercial use of human biological material for scientific research purposes and the development of commercial products directly arising from stored and shared samples; v) promoting public trust and inclusion; vi) incentives for donor participation; vii) ownership, governance and management issues; viii) access to research results; ix) ensuring maximum quality of sample preservation and management, while facilitat-

ing sample access and sharing<sup>7,8,29,33,39-44</sup>.

In particular, the European Commission 2010 Eurobarometer report on European citizens attitudes towards biotechnology has provided relevant insights into the level of awareness towards biobanking activities in Europe<sup>45</sup>. In Portugal, less than one in five respondents (19%) had heard of biobanks prior to the survey (EU average – 34%)<sup>45</sup>. Moreover, it was found that for EU citizens consent is fundamental for BBR (*ibid.*, p.142) and medical doctors were preferred to protect the public interest, with researchers being the second most preferred group. The intensity of this preference was most pronounced in Portugal (60%) (*ibid.*, p.147). Willingness to provide personal information to biobanks was mixed (*ibid.*, p.144) despite concerns regarding the collection of personal information in biobanks (*ibid.*, p.149). Additionally, EU citizens were generally in favour of data and materials being exchanged across biobanks in different Member States, with opinions varying significantly between countries on this specific matter (*ibid.*, p.151)<sup>45</sup>.

A decade has passed since this seminal European report. Nevertheless, doubts about ELSI continue to influence patient acceptability to tissue banking programs and transparency remains key to foster acceptance of the ways a biobank is developed and used<sup>7</sup>.

In the last decade, biobanks have gained significant relevance and momentum<sup>46</sup>. In particular, public perceptions about BBR, and specifically those oriented to chronic diseases populations, have gathered heightened attention<sup>3,24,29,30,33-35,47</sup>. Furthermore, even more recently, the importance of BBR for the understanding of prevalent conditions and multimorbidity of middle-aged and older adults has been stressed<sup>48</sup>. Epidemiological findings resulting from biobanks for aging have also been published in crucial areas such as prostate cancer and the relation between statin use and cancer development<sup>49-51</sup>.

These advances have led to the development of biobanks dedicated to aging research<sup>7,52</sup>. Some of these BBR focus on the collection of samples from middle age or elderly participants and due to this fact elicit new ELSI or exacerbate general ones<sup>53-58</sup>.

However, despite the established need for public acceptance and involvement and the increasing attention to aging research biobanks and healthy aging research in general, to the best of our knowledge no study has evaluated the public's perceptions of a BBR dedicated to aging, in particular in a rheumatology context.

Hence, while generally aiming to fill that gap, the

present study specifically aims to:

1. identify rheumatology patients' awareness, perceptions, concerns and preferences regarding BBR and their willingness to donate human biological samples for biomedical research;
2. understand the individual perception of rheumatology patients regarding relevant BBR ELSI;
3. investigate rheumatology patient's opinion and acceptance regarding BBR especially dedicated to the study of aging and aging populations.

## MATERIAL AND METHODS

### STUDY DESIGN, METHODS AND PROCEDURES

We designed a cross-sectional study in a random sample of tertiary rheumatology outpatients from the Rheumatology Unit of the Egas Moniz University Hospital, in Lisbon, Portugal. Data was collected through the application of a self-administered questionnaire. Questionnaire quality and adequacy was guaranteed by a cyclical process of revision, update and improvement, involving experts (researchers and physicians). The final questionnaire consisted in 20 closed-ended and semi-closed-ended questions, divided in four parts: the first and second parts (questions 1-10) assessed the respondents' opinions about "General awareness and perception of biobanking activities" and "Patient perceptions regarding biobank participation in BBR"; the third part (questions 11 and 12) focused exclusively on "Perceptions about biobanks dedicated to the study of aging"; the fourth part, including 8 questions (A-H) assessed respondents demographic characteristics. In some questions, the respondents were given the opportunity to write comments to complete their answer.

The questionnaires were provided to the participants by a researcher not involved in providing patient care or working in biobank management. Participants received the questionnaire in a rheumatology clinic waiting room setting and prior to participation received complete written information about the study context, objectives, research team, data anonymity and future research results communication.

**Inclusion criteria:** adult rheumatology outpatients aged 50 years or older who were able to read and understand the provided study information. Exclusion criteria: place of residence outside Portugal.

The questionnaire was applied to a random sample of one hundred and fifty-three subjects between March-

-October 2016. The final response rate was 86.3% (n = 132). Twenty-one questionnaires were excluded according to the following criteria: (i) blank questionnaires: 3; (ii) questionnaires where the socio-demographic section was more than 25% incomplete (two or more answers) or which included no indication of respondents age: 15; (iii) individuals under 50 years old: 4; (iv) more than one questionnaire filled with the same handwriting: 1. Inconsistent or contradictory answers to questions 3-4 and 11-12 were not considered.

**Ethics:** The procedures followed were in accordance with the Helsinki Declaration of 1975/83, the International Ethical Guidelines for Epidemiological Studies (2009) and the standards of the responsible local committee. The study protocol, information to the participant and questionnaire were submitted for review to the competent institutional review board (Ethics Committee, Egas Moniz University Hospital, Lisbon, Portugal), with subsequent approval (approval number 20170700050).

**Statistics:** frequency distribution tables with counts and percentages were used to describe categorical variables as well as mean and standard deviation for numerical variables. Variables were crossed and tested for statistical associations with chi-square test/Fisher exact test. All hypothesis tests were two-sided for 5% significance level. All data was coded and analysed using SPSS Statistics 23® software.

## RESULTS

### DEMOGRAPHIC CHARACTERIZATION OF THE STUDY POPULATION

Demographic characteristics of the surveyed population are presented in Table I. Survey respondents were mostly women (sex ratio 2.1:1, female: male, n=90 and 42, respectively) with a mean age of 63.98 years old. Middle school was the most prevalent education level (mean of 8.35 education years) and the majority of respondents were already retired (53.8%).

### GENERAL AWARENESS AND PERCEPTION OF BIOBANKS FOR RESEARCH

The first objective of our study was to evaluate the general understanding of rheumatology patients regarding biobanks for research. To achieve this goal, we first asked respondents whether they were aware of the possibility of storing biological material for scientific research purposes (Question - Q1). As a result, we

**TABLE I. SOCIO-DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS**

Socio-demographic variables	Results
Age [mean (min-max)]	63.98 (50-93)
Sex ratio M/F (%)	31.8%/68.2%
Education years mean (min-max)	8.35 (2-18)
Working status (%)	
Active	29.2%
Retired	53.8%
Unemployed	12.3%
No activity/stay-at-home	4.6%

min - minimum, max - maximum; M - masculine, F - feminine

observed that more than half of the respondents (57.7%) were informed about this possibility (Table II). However, when asked whether they knew what a biobank is (Q2), only 38.0% of those inquired responded affirmatively (Table II).

Importantly, knowledge about the term biobank correlated with education years in a statistically significant manner, as those with 10 or more years of education (secondary school level in Portugal) exhibited higher knowledge (51.9%) in comparison to those with 0 to 9 years education years (28.9%) (Table III).

Knowledge about what a biobank is might also correlate with age (45.6% of respondents between 50 and 64 years of age said they knew what a biobank is while only 30.0% responded yes to the same question in the 65 years old or older group), suggesting this might be a variable of interest for future studies in higher samples (in our study these differences were below statistical significance,  $p=0,101$ ). Knowledge about the term biobank did not depend on the gender of the respondent.

We also set out to evaluate overall perceptions regarding biobanking activities. In order to achieve this objective, we asked respondents whether they agreed with the existence of organized repositories of biological samples and associated clinical data for research purposes (Q3). Unambiguously, 89.9% of the respondents stated their agreement with the existence of such research infrastructures (Table II). Agreement seemed to diminish with age and increase with education years, but these correlations were below statistical significance ( $p=0,100$  and  $p=0,111$ , respectively). Again, the gender of the respondent did not seem to affect answers to this question (Table III).

In probing the basis for agreement or disagreement with BBR, we found a mixture of altruistic and individualistic reasons (Q4). Largely, respondents said their agreement was based on the contribution of BBR to the advancement of scientific knowledge, even though that advancement might not benefit them directly (86.4%) (Table II). Nonetheless, 66.1% of those inquired expressed that they agreed with the existence of BBR because the quality of care available to them in the future could be improved. On the contrary, the majority of those who declared not to agree with BBR stated as reasons for their disagreement the preference for animal studies or *in vitro* models (61.5%). A fraction of the same population (46.2%) also declared that they thought that biobanks should only be used for medical purposes and not research (Table II).

Lastly, in order to complete our characterization of the general public perception of biobanks we asked which entities or organisations are adequate to manage BBR (Q5). The vast majority of those inquired (89.1%) responded that scientific research institutes (which in Portugal are autonomous and not equivalent to research buildings of universities) were adequate organisations to manage biobanks, followed by hospitals (42.9%), universities (28.6%), biotechnology or pharmaceutical companies (12.6%), community health centers (4.2%), other governmental entities (1.7%) and patient associations (0.8%) (Table II).

#### **PATIENT REQUIREMENTS REGARDING BIOBANK PARTICIPATION AND PUBLIC TRUST IN BIOBANKS**

Globally, 88.3% of the patients surveyed considered participating in a biobank (Table IV). Willingness to participate correlated with education years in a statistically significant manner, as those with 10 or more years of education (secondary school level in Portugal) are more willing to participate (97.8%) in comparison to those with 0 to 9 years education years (80.7%) (Table V).

Participation might also correlate with younger age (93.0% of respondents between 50 and 64 years of age versus 82.6% in the 65 years old or older group), but in our study this difference was below statistical significance ( $p=0,129$ ). As was the case with other variables, willingness to participate in biobanks did not depend on the gender of the respondent (Table VI).

In terms of requisites for participation, 72.0% of patients identified explicit authorization/informed consent, 52.5% prefer to participate in a study relevant for their individual health and 50.0% stated that they would require no negative health effects resulting from

**TABLE II. GENERAL AWARENESS AND PERCEPTION OF BBR**

	Valid answers (n)	Yes (n)	No (n)	Indifferent (n)
Q1. Did you know that biological materials (blood, urine or others) could be stored and used for research purposes?	130	57.7% (75)	42.3% (55)	–
Q2. Do you know what a biobank is?	128	38.3% (49)	61.7% (79)	–
Q3. A biobank for scientific research consists in an organized repository of biological materials and associated clinical information, for sharing between scientific researchers to improve their studies. Do you agree with such projects?	119	89.9% (107)	0.8%(1)	9.2%(11)
Q4. In accordance with the previous answer, please indicate the reasons for your choice (Please select all valid options)	118			
<b>Agreement with the existence of BBR</b>				
It can improve the healthcare I might receive in the future		66.1% (78)	–	–
It might advance scientific knowledge even if I do not benefit directly		86.4% (102)	–	–
Other (state which)		4.2% (5)	–	–
<b>Disagreement with the existence of BBR</b>	13			
Biological materials are part of a person's body and should only be used for disease diagnostics and treatments and should be destroyed immediately after		46.2% (6)	–	–
Scientific studies should be performed using solely animal or in vitro models		61.5% (8)	–	–
Other (state which)		0% (0)	–	–
Q5. Please indicated which organizations you think are adequate to manage a BBR	119			–
Scientific research institutes		89.1% (106)	–	–
Hospitals		42.9% (51)	–	–
Universities		28.6% (34)	–	–
Biotechnology or pharmaceutical companies		12.6% (15)	–	–
Community health centers		4.2% (5)	–	–
Other governmental entities		1.7% (2)	–	–
Patient associations		0.8% (1)	–	–
Other (state which)		0% (0)	–	–

their participation (Table IV). 39.0% of patients expressed they would only participate in BBR in case of benefits for their individual treatment, 29.7% highlighted the possibility of sample destruction in case they change their mind, 21.2% value the absence of extra harvest of biological samples for research purposes, 16.9% demand keeping property rights over the samples, 7.6% would only participate if they had the right to profit from the research results only 4.2% required remuneration or equivalent benefits in retribution for BBR participation (Table IV).

In terms of management as a requisite for participation (Q8), 43.3% of respondents required a public biobank, 32.5% expressed that they would donate to a biobank that was run by a physician or a researcher they knew, 27.5% required a biobank that is governed by an entity of their trust, while only 4.2% stated their requirement of a private biobank. Indifference toward the different management options was expressed by 45.8% of those inquired (Table IV).

Regarding the security measures as a requisite for BBR participation (Q9), confidentiality/anonymity

**TABLE III. GENERAL AWARENESS AND PERCEPTION OF BBR ACCORDING TO SEX, AGE AND EDUCATION YEARS**

	Valid answers (n)	Yes (n)	No (n)	Indifferent (n)
<b>Q2. Do you know what a biobank is?</b>	128	38.3% (49)	61.7% (79)	–
Female	87	37.9% (33)	62.1% (54)	–
Male (p = 0,999)	41	39.0% (16)	61.0% (25)	–
50-64 years old	68	45.6% (31)	54.4% (37)	–
65 years old or older (p = 0,999)	60	30.0% (18)	70.0% (42)	–
0 to 9 years education	76	28.9% (22)	71.1% (54)	–
10 years education or more (p = 0,009)	52	51.9% (27)	48.1% (25)	–
<b>Q3. A biobank for scientific research consists in an organized repository of biological materials and associated clinical information, for sharing between scientific researchers to improve their studies. Do you agree with such projects?</b>	119	89.9% (107)	0.8% (1)	9.2% (11)
Female	82	89.0% (73)	1.2% (1)	9.8% (8)
Male (p = 0,760)	37	91.9% (34)	0.0% (0)	8.1% (3)
50-64 years old	66	93.9% (62)	1.5% (1)	4.5% (3)
65 years old or older (p = 0,100)	53	84.9% (45)	0.0% (0)	15.1% (8)
0 to 9 years education	67	86.6% (58)	0.0% (0)	13.4% (9)
10 years education or more (p = 0,111)	52	94.2% (49)	1.9% (1)	3.8% (2)

about participation and confidentiality about individual clinical data were selected as top priorities (by 65.3% and 58.5% of respondents, respectively) (Table III). Moreover, 35.6% said they valued the impossibility to share their donated samples for studies for which they did not consent (which implies a denial of open consent models that have been largely debated and supported in the biobanking discourse (59–61). 22.9% of surveyed patients stated their requirement for re-consent in case of publication of research results. Only 14.4% of respondents stated they viewed direct security measures (such as alarms, locks or passwords) as necessary for participation, and 11.0% accentuated the impossibility of sample sharing with different researchers as a required protection arrangement.

Notably, in terms of public trust, an overwhelming majority of respondents (94.2%) stated they would publicize the existence of a specific biobank so that other people could participate (Table IV).

#### **PATIENT PERCEPTIONS ABOUT BIOBANKS DEDICATED TO THE STUDY OF AGING**

In order to assess patient perceptions about biobanks for aging research we asked respondents their opinion about a biobank dedicated to the study of aging, which

only collected samples from people of older ages (Q11). Most respondents (61.3%) expressed their agreement with such research infrastructure and research practice, while only 9.4% stated their disagreement (Table VI).

Agreement seemed to increase with education years, but this correlation was below statistical significance ( $p=0,125$ ). Both age and gender of the respondent did not seem to affect answers to this question (Table VI)

Subsequently, we went on to probe further the reasons for agreement and disagreement with aging biobanks (Q12). The majority of those who agree (76.3%) indicated that people of older ages have higher disease burdens, which specially justifies their study (Table IV). Importantly, 51.5% also responded that such research infrastructures and practices were a sign of respect for the particular problems of people of older ages, while 6.3% selected other reasons of their own creation (Table VI). For those who disagree, 53.5% considered that the elderly should not be differentiated from those of any other age. In parallel, 25.6% of those who disagree adopted a more paternalistic approach stating that people of older age are more vulnerable and unable to make free and informed decisions. Also, 16.3% of those who disagree stated that people of older age have higher disease burdens and

**TABLE IV. PATIENT REQUIREMENTS REGARDING BIOBANK PARTICIPATION AND PUBLIC TRUST IN BIOBANKS**

	Valid answers (n)	Yes (n)	No (n)
Q6. Would you consider participating in a biobank by donating biological material (blood, urine, other) for scientific research purposes?	103	88.3% (91)	11.7% (12)
Q7. Please indicate the essential requisites for your participation in a biobank. (Please select all valid options)	118		
Explicit authorization/informed consent		72.0% (85)	–
The study of a disease or condition that affects me		52.5% (62)	–
Absence of negative health effects resulting from my participation		50.0% (59)	–
Benefits for my individual treatment		39.0% (46)	–
Possibility of sample destruction in case I change my mind		29.7% (35)	–
No extra sample collection procedures required (using samples collected for diagnostic purposes)		21.2% (25)	–
Keeping property rights over the samples		16.9% (20)	–
Right to profit from the results of the research		7.6% (9)	–
Remuneration or other equivalent benefit		4.2% (5)	–
Q8. In your opinion how should a biobank be managed for you to consider donating your samples? (Please select all valid answers)	120		
Public biobank		43.3% (52)	–
Indifferent, I would donate my samples independently of biobank management		40.0% (48)	–
Biobank managed by a physician or researcher that I know		32.5% (39)	–
Biobank managed by an entity that I trust		27.5% (33)	–
Indifferent, I would never donate my samples to a biobank		5.8% (7)	–
Private biobank		4.2% (5)	–
Q9. In your opinion, which would be the required security measures for you to consider donating your samples? (Please select all valid answers)	118		
Confidentiality about my participation or anonymity		65.3% (77)	–
Confidentiality about my clinical data		58.5% (69)	–
Impossibility to share donated samples for studies for which I did not consent		35.6% (42)	–
Need to reconsult for publication of research results using the samples I donated		22.9% (27)	–
Existence of direct security measures for the protection of my samples (e.g. alarms, locks or passwords)		14.4% (17)	–
Impossibility of sample sharing with different researchers		11.0% (13)	–
Q10. Would you accept to publicize the existence of a specific biobank so that other people could participate?	103	94.2%(97)	5.8%(6)

therefore focus should be on treatment and not research. Finally, 9.3% indicated that their disagreement was based on other reasons (Table VI).

**DISCUSSION**

Biobanks have become much more prevalent in the last

years. More recently, biobanks dedicated to aging research have been developed, which begs the question of whether chronic patients, in particular rheumatology patients support these infrastructures. Hence, the purpose of this study was to identify participants' perceptions and concerns as participants in BBR and willingness to donate human biological samples for biomedical research, while exploring preferences regarding BBR

**TABLE V. PATIENT REQUIREMENTS REGARDING BIOBANK PARTICIPATION AND PUBLIC TRUST IN BIOBANKS ACCORDING TO SEX, AGE AND EDUCATION YEARS**

	Valid answers (n)	Yes (n)	No (n)
<b>Q6. Would you consider participating in a biobank by donating biological material (blood, urine, other) for scientific research purposes?</b>	103	88.3% (91)	11.7% (12)
Female	70	88.6% (62)	11.4% (8)
Male (p = 0,999)	33	87.9% (29)	12.1% (4)
50-64 years old	57	93.0% (53)	7.0% (4)
65 years old or older (p = 0,129)	46	82.6% (38)	17.4% (8)
0 to 9 years education	57	80.7% (46)	19.3% (11)
10 years education or more (p = 0,011)	46	97.8% (45)	2.2% (1)

ownership and management. We also set out to understand rheumatology patients' support and perceptions regarding BBR exclusively dedicated to aging.

In terms of the general understanding of rheumatology hospital outpatients regarding biobanking activities we observed that more than half of the respondents were informed about the possibility to store biological material for scientific research purposes but only 38.3% was aware of the term biobank. Notwithstanding, knowledge about this term increased significantly (to 51.9%) among those with secondary school studies. These results demonstrate that despite its growing application in research, clinical, academic and commercial settings, the term "biobank" remains largely unknown. In order to address this challenge and raise BBR awareness, scientists, researchers and biobank professionals should consider active strategies to inform the public about the existence, relevance and potential of these infrastructures. Particularly, local, regional and national public information campaigns as well as participatory policies and citizen science programs should be considered<sup>62,63</sup>.

We also found that willingness to contribute to BBR is high: 88.3% agreed potentially to provide biological materials for the constitution of a BBR. These rates are in the higher range in comparison with studies from other countries about biobanking participation and are extraordinarily high among those with secondary school studies (97.8%)<sup>3,19,29,30,32-36,47</sup>. Notably, the vast majority of our respondents agreed to advertise a biobank so that others could participate (94.2%). Taken together these results indicate that the overall trust in biobanks for research purposes is very high amongst the rheumatology outpatients we surveyed.

The average age of the rheumatology patients we surveyed may also justify the high predisposition to participation rate, since it has been shown that both the likelihood of donating a biospecimen and clinical health information to a BBR are reportedly higher for middle and older ages<sup>24,31,32,64</sup>. This fact might be explained by Erikson's theory of generativity, i.e. an increasing concern with age for guiding and caring for the next generation<sup>24</sup>. Curiously, we found a tendency (not statistically significant) for a higher willingness to participate among the younger respondents of the study group (50-64 years old). Future studies in higher samples should clarify the issue of age-dependent willingness to participate in BBR.

In line with previous studies, it was evident in our study that the decision to donate samples to a BBR is primarily based on altruistic reasons<sup>24</sup>. Nonetheless, the fact that the large majority of rheumatology patients we surveyed (88.2%) do not expect remuneration or economic gain from participation in BBR does not mean that they do not have an expectation of getting something in return. The study of a disease or condition that affects them and benefit for their individual treatment were indicated as essential requisites for participation for 52.5% and 39.0% of respondents, respectively.

Positive attitudes toward BBR and trust in biobank owners are vital for the future of biobanking research<sup>65,66</sup>. The same can be concluded from our study as 60.0% of the rheumatology outpatients we surveyed indicated that they preferred to donate samples when that element of trust is present (be it a known researcher or a physician or a trusted entity). Also, we found that rheumatology outpatients largely trust re-



**TABLE VI. PATIENT PERCEPTIONS ABOUT BIOBANKS DEDICATED TO THE STUDY OF AGING**

	Valid answers (n)	Yes (n)	No (n)	Indifferent (n)
<b>Q11. What do you think about a biobank which only collected samples from people of older ages for aging research purposes?</b>	106	61.3% (65)	9.4% (10)	29.2% (31)
Female	73	60.3% (44)	11.0% (8)	28.8% (21)
Male (p = 0,727)	33	63.6% (21)	6.1% (2)	30.3% (10)
50-64 years old	61	62.3% (38)	8.2% (5)	29.5% (18)
65 years old or older (p = 0,879)	45	60.0% (27)	11.1% (5)	28.9% (13)
0 to 9 years education	59	54.2% (32)	8.5% (5)	37.3% (22)
10 years education or more (p = 0,125)	47	70.2% (33)	10.6% (5)	19.1%(9)
<b>Q12. In accordance with the previous answer, please indicate the reasons for your choice (Please select all valid options)</b>				
Agreement with the existence of aging BBR	97			
As they age people have higher disease burdens, which specially justifies their study		76.3% (74)	–	–
It is a sign of respect for the issues of people of more advanced age		51.5% (50)	–	–
Other (state which): “the possibility to prevent diseases in people of younger ages and the improvement of the quality of life of the elderly”		6.3% (6)	–	–
Disagreement with the existence of aging BBR	43			
People of older age usually have higher disease burdens and therefore should only be treated, there is no reason for them to be studied		16.3% (7)	–	–
People of older ages are the exactly the same as those of any other age and therefore deserve no different treatment		53.5% (23)	–	–
People of older age are sometimes more vulnerable and do not have the conditions to make free and informed decisions		25.6% (11)	–	–
Other (state which): “diseases at old age are many times the result of unsolved or unfound problems at young ages or that the focus should be on prevention to avoid problems of older ages not on the study of the latter”		9.3% (4)	–	–

search institutes and hospitals to manage BBR, which is in line with other research results in the past<sup>67</sup>. Although 45.8% of our respondents willing to donate samples were indifferent to the nature of BBR management, those who expressed preference for donating samples to a private biobank were very few (4.2%) in comparison to those who preferred donating to a public biobank (43.3%), which is in line with other studies elsewhere<sup>68</sup> and the 2010 EU Eurobarometer<sup>45</sup>.

Evaluating motivations and attitudes toward BBR is important but understanding barriers and facilitators of public participation is also fundamental. Notably, pre-

vious studies have shown that informed consent is one of the most relevant and discussed elements for balanced and participatory constitution of biobanks<sup>25,28,43,69,70</sup>.

Unsurprisingly, explicit informed consent was the essential requisite for participation most selected by our respondents. Moreover, informed consent for sample sharing within specific research studies was also significantly identified by rheumatology patients as being essential. This observation implies a tendency towards denial of open consent models that have been largely debated with some degree of support in the

biobanking discourse<sup>29,43,59</sup>. It is also noteworthy that a non-negligible proportion of our respondents (22.9%) indicated the need for re-consent in case of publication of research results, suggesting that clarification of this possibility when recruiting participants for BBR is paramount. Also, in line with previous studies, confidentiality and data protection measures (both regarding participation and clinical data) were referred in our study as relevant guarantees for BBR participation<sup>65,68,71</sup>.

Finally, we also aimed to evaluate the level of support for biobanks dedicated to aging research, in particular those who collect samples from people of an older age. Such research infrastructures have gathered pace recently and may prove important for chronic disease research, and rheumatology research in particular<sup>53,54,56</sup>. Our results are encouraging on that front as they indicate that the population of rheumatology outpatients surveyed favour and value the existence of aging biobanks that collect samples from people of older ages. Such acceptance was mainly justified by higher disease burdens in this population but more than 50% interprets this idea as a sign of respect. Significant concerns remain, however, in particular in relation to the protection of those who are most vulnerable and their potential discrimination. As this study only surveyed patients attending a Rheumatology outpatient clinic in only one tertiary hospital it would be interesting to investigate possible discrepancies amongst the attitudes of patients depending on different disorders and residence areas in the future.

## CONCLUSIONS

In conclusion, our study constitutes a comprehensive analysis of public perceptions and patient choices regarding general biobanks and biobanks for aging research purposes among rheumatology outpatients. To the best of our knowledge this is the first study where these variables were assessed in this population. Although awareness is still suboptimal, BBR are highly regarded health infrastructures with enormous potential for further patient-centered development. Taken together, our results indicate that the population of hospital outpatients surveyed favour and value the existence of biobanks in general and aging biobanks in particular. Addressing concerns, their motives and advancing public education in these areas will enhance participation and engagement, which are critical to the future foundation and design of aging BBR. More than

acting as mere donors, patients can and should be involved in structured and harmonised national and international biobanking activities<sup>72,73</sup> as their voice and perspective can be a valuable resource for the biobank. We believe our study contributes to highlight the importance of patient centered biobanks, particularly for aging and chronic disease research.

## FUNDING

This study was partially funded by Project PEst-OE/SADG/UI4067/2014 - CESNOVA/FCT Fundacao para a Ciencia e Tecnologia, Portugal. <https://www.fct.pt/index.phtml.en>. Awarded to JVC

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## REFERENCES

1. Parodi B. Biobanks: A Definition. *Int Libr ethics, law Technol.* Vol 14. 2015;14:1–277.
2. OECD. *Creation and Governance of Human Genetic Research Databases.* OECD Publishing. 2006. pp 35–45, 105–118, 131–137. Available from: [https://www.oecd-ilibrary.org/science-and-technology/creation-and-governance-of-human-genetic-research-databases\\_9789264028531-en](https://www.oecd-ilibrary.org/science-and-technology/creation-and-governance-of-human-genetic-research-databases_9789264028531-en).
3. 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; 3:1–11.
4. Kinkorová J. Biobanks in the era of personalized medicine: Objectives, challenges, and innovation. *EPMA J.* 2016;7: 1–12.
5. De Souza YG, Greenspan JS. Biobanking past, present and future: Responsibilities and benefits. *Aids.* 2013;27: 303–12.
6. Watson PH, Barnes RO. A proposed schema for classifying human research biobanks. *Biopreserv Biobank.* 2011;9: 327–33.
7. Mitchell D, Geissler J, Parry-Jones A, Keulen H, Schmitt DC, Vavassori R, et al. Biobanking from the patient perspective. *Res Involv Engagem.* 2015;1 :4.
8. Riegman PHJ, Morente MM, Betsou F, de Blasio P, Geary P. Biobanking for better healthcare. *Mol Oncol.* 2008;2: 213–22.
9. Symmons DPM. Epidemiology research in rheumatology - Progress and pitfalls. *Nat Rev Rheumatol.* 2015;11: 631–8.
10. Gottweis H, Lauss G. Biobank governance: Heterogeneous modes of ordering and democratization. *J Community Genet.* 2012;3: 61–72.
11. Yuille M, van ommen GJ, Bréchet C, Cambon-Thomsen A, Dagher G, Landegren U, et al. Biobanking for Europe. *Brief Bioinform.* 2008;9: 14–24.
12. Wichmann HE, Kuhn KA, Waldenberger M, Schmelcher D, Schuffenhauer S, Meitinger T, et al. Comprehensive catalog of European biobanks. *Nat Biotechnol.* 2011;29: 795–7.
13. Arampatzis A, Papagiouvanni I, Anastakis D, Tsolaki M. A Classification and Comparative Study of European Biobanks: an Analysis of Biobanking Activity and its Contribution to Scientific Progress. *Arch Med.* 2016;8: 1–10.
14. Kinkorová J, Topol an O. Biobanks in Horizon 2020: sustainability and attractive perspectives. *EPMA J.* 2018;9: 345–53.
15. Hirtzlin I, Dubreuil C, Préaubert N, Duchier J, Jansen BJ, Si-

- mon J, et al. An empirical survey on biobanking of human genetic material and data in six EU countries. *Eur J Hum Genet.* 2003;11: 475–88.
16. Afonso Â, Pereira JP, Dias S. Biobanco-IMM, lisbon academic medical centre. *Biopreserv Biobank.* 2014;12: 433–4.
  17. Biobanco.pt. p. www.biobanco.pt. Accessed in February 3rd 2021.
  18. Coors ME, Westfall N, Zittleman L, Taylor M, Westfall JM. Translating Biobank Science into Patient-Centered Language. *Biopreserv Biobank.* 2018;16: 59–63.
  19. L'Heureux J, Murray JC, Newbury E, Shinkunas L, Simon CM. Public perspectives on biospecimen procurement: what biorepositories should consider. *Biopreserv Biobank.* 2013;11: 137–143.
  20. Burgess MM. From “trust us” to participatory governance: Deliberative publics and science policy. *Public Underst Sci.* 2014;23: 48–52.
  21. Jones CW, Braz VA, McBride SM, Roberts BW, Platts-Mills TF. Cross-sectional assessment of patient attitudes towards participation in clinical trials: Does making results publicly available matter? *BMJ Open.* 2016;6: 1–6.
  22. Sood A, Prasad K, Chhatwani L, Shinozaki E, Cha SS, Loehrer LL, et al. Patients' attitudes and preferences about participation and recruitment strategies in clinical trials. *Mayo Clin Proc.* 2009;84: 243–247.
  23. Tohid H, Choudhury SM, Agouba S, Aden A, Ahmed LHM, Omar O, et al. Perceptions and attitudes to clinical research participation in Qatar. *Contemp Clin Trials Commun.* 2017;8: 241–247.
  24. Kettis-Lindblad Å, Ring L, Viberth E, Hansson MG. Genetic research and donation of tissue samples to biobanks. What do potential sample donors in the Swedish general public think? *Eur J Public Health.* 2006;16: 433–440.
  25. Cambon-Thomsen A, Rial-Sebbag E, Knoppers BM. Trends in ethical and legal frameworks for the use of human biobanks. *Eur Respir J.* 2007;30: 373–382.
  26. Madsen SM, Holm S, Riis P. Attitudes towards clinical research among cancer trial participants and non-participants: An interview study using a grounded theory approach. *J Med Ethics.* 2007;33: 234–240.
  27. Comis RL, Miller JD, Aldigé CR, Krebs L, Stoval E. Public attitudes toward participation in cancer clinical trials. *J Clin Oncol.* 2003;21: 830–835.
  28. Donald J Willison, Karim Keshavjee, Kalpana Nair, Charlie Goldsmith AMH. Patient consent preferences for research uses of information in electronic medical records: interview and survey data. *Bmj.* 2003;326: 373–373.
  29. Tupasela A, Snell K, Sihvo S, Hemminki E, Jallinoja pa, Aro AR. Attitudes towards biomedical use of tissue sample collections, consent, and biobanks among Finns. *Scand J Public Health.* 2010;38:46–52.
  30. Gayet-Ageron A, Rudaz S, Perneger T. Biobank attributes associated with higher patient participation: A randomized study. *Eur J Hum Genet.* 2016;25: 31–36.
  31. Malone T, Catalano PJ, O'Dwyer PJ, Giantonio B. High rate of consent to bank biologic samples for future research: The Eastern Cooperative Oncology Group experience. *J Natl Cancer Inst.* 2002;94: 769–771.
  32. Mcdonald JA, Vadaparampil S, Bowen D, Magwood G, Obeid JS, Jefferson M, et al. Intentions to donate to a biobank in a national sample of African Americans. *Public Health Genomics.* 2014;17: 173–182.
  33. Bryant J, Sanson-Fisher R, Fradgley E, Regan T, Hobden B, Ackland SP. Oncology patients overwhelmingly support tissue banking. *BMC Cancer.* 2015;15: 1–8.
  34. Long MD, Cadigan RJ, Cook SF, Kuczynski K, Sandler RS, Martin F, et al. Perceptions of Patients with Inflammatory Bowel Diseases on Biobanking. *Inflamm Bowel Dis.* 2015;21: 132–138.
  35. Porter C, Pasqualetti P, Togni E, Parker M. Public's attitudes on participation in a biobank for research: An Italian survey. *BMC Med Ethics.* 2014;15: 1–10.
  36. Johnsson L, Helgesson G, Rafnar T, Halldorsdottir I, Chia KS, Eriksson S, et al. Hypothetical and factual willingness to participate in biobank research. *Eur J Hum Genet.* 2010;18: 1261–1264.
  37. Budin-Ljøne I, Harris JR, Kaye J, Knoppers BM, Tassé AM, Bravo E, et al. ELSI challenges and strategies of national biobank infrastructures. *Nor Epidemiol.* 2012;21: 155–160.
  38. Bledsoe MJ. Ethical Legal and Social Issues of Biobanking: Past, Present, and Future. *Biopreserv Biobank.* 2017;15: 142–147.
  39. Smith, Maureen E. SA. Biobanking: The Melding of Research with Clinical Care Maureen. *Curr Genet Med Rep.* 1: 122–8.
  40. Bledsoe MJ. Ethical Legal and Social Issues of Biobanking: Past, Present, and Future. *Biopreserv Biobank.* 2017;15: 142–147.
  41. De Vries RG, Tomlinson T, Kim HM, Krenz C, Haggerty D, Ryan KA, et al. Understanding the public's reservations about broad consent and study-by-study consent for donations to a biobank: Results of a national survey. *PLoS One.* 2016;11: 1–11.
  42. Caulfield T, Murdoch B. Genes, cells, and biobanks: Yes, there's still a consent problem. *PLoS Biol.* 2017;15: 1–9.
  43. Hofmann B, Solbakk JH, Holm S. Consent to Biobank Research: One Size Fits All? In: Solbakk JH, Holm S, Hofmann B, editors. *The Ethics of Research Biobanking. The Ethics of Research Biobanking.* Springer, Boston, MA; 2009. pp. 3–4.
  44. Faria PL De. Ownership Rights in Research Biobanks: Do We Need a New Kind of ‘Biological Property’? In: Solbakk JH, Holm S, Hofmann B, editors. *The Ethics of Research Biobanking.* Springer, Boston, MA; 2009. pp. 263–264.
  45. Special Eurobarometer 341: Biotechnology. *Biotechnology.* 2010. Available from: [https://ec.europa.eu/commfrontoffice/publicopinion/archives/ebs/ebs\\_341\\_en.pdf](https://ec.europa.eu/commfrontoffice/publicopinion/archives/ebs/ebs_341_en.pdf)
  46. De Clercq E, Kaye J, Wolf SM, Koenig BA, Elger BS. Returning Results in Biobank Research: Global Trends and Solutions. *Genet Test Mol Biomarkers.* 2017;21: 128–131.
  47. Gornick MC, Ryan KA, Kim SYH. Impact of non-welfare interests on willingness to donate to biobanks: An experimental survey. *J Empir Res Hum Res Ethics.* 2014;9: 22–33.
  48. Zemedikun DT, Gray LJ, Khunti K, Davies MJ, Dhalwani NN. Patterns of Multimorbidity in Middle-Aged and Older Adults: An Analysis of the UK Biobank Data. *Mayo Clin Proc.* 2018;93: 857–866.
  49. Ukawa S, Nakamura K, Okada E, Hirata M, Nagai A, Yamagata Z, et al. Clinical and histopathological characteristics of patients with prostate cancer in the BioBank Japan project. *J Epidemiol.* 2017;27: S65–70.
  50. Yokomichi H, Nagai A, Hirata M, Tamakoshi A, Kiyohara Y, Kamatani Y, et al. Statin use and all-cause and cancer mortality: BioBank Japan cohort. *J Epidemiol.* 2017;27: S84–91.
  51. Suri P, Palmer MR, Tsepilov YA, Freidin MB, Boer CG, Yau MS, et al. Genome-wide meta-analysis of 158,000 individuals of European ancestry identifies three loci associated with chronic back pain. 2018 Sep 27;14(9):e1007601. doi: 10.1371/jour-

- nal.pgen.1007601.
52. Berr C, Gabelle A, Fievet N, Goldberg M, Zins M, Carriere I. How to optimize the use of biobanks from population-based cohorts in aging research. *Biogerontology*. 2016;17: 221–227.
  53. Avlund K, Osler M, Mortensen EL, Christensen U, Bruunsgaard H, Holm-Pedersen P, et al. Copenhagen Aging and Midlife Biobank (CAMB): An introduction. *J Aging Health*. 2014;26: 5–20.
  54. Lund R, Mortensen EL, Christensen U, Bruunsgaard H, Holm-Pedersen P, Fiehn NE, et al. Cohort profile: The Copenhagen aging and midlife Biobank (Camb). *Int J Epidemiol*. 2016;45: 1044–1053.
  55. 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;17(1):1–18.
  56. AgingResearchBiobank. 2020. pp. 1–2. Available from: <https://agingresearchbiobank.nia.nih.gov/about/>
  57. ASPIrin in Reducing Events in the Elderly The ASPREE Healthy Ageing Biobank The ASPREE Healthy Ageing Biobank. 2020. pp. 1–4. Available from: <https://aspree.org/aus/sub-studies/ive-been-everywhere-the-aspree-biobus-story/>.
  58. Seppet E, Pääsuke M, Conte M, Capri M, Franceschi C. Ethical aspects of aging research. *Biogerontology*. 2011;12: 491–502.
  59. 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.
  60. Master Z, Campo-Engelstein L, Caulfield T. Scientists’ perspectives on consent in the context of biobanking research. *Eur J Hum Genet*. 2015;23: 569–574.
  61. Master Z, Nelson E, Murdoch B, Caulfield T. Biobanks, consent and claims of consensus. *Nat Methods*. 2012;9: 885–888.
  62. Lacerda EM, Kingdon CC, Bowman EW, Nacul L. HHS Public Access. 2019; 6: 1–4.
  63. Buyx A, Del Savio L, Prainsack B, Völzke H. Every participant is a PI. Citizen science and participatory governance in population studies. *Int J Epidemiol*. 2017;46: 377–384.
  64. Cunningham J, Dunbar T. Consent for long-term storage of blood samples by Indigenous Australian research participants: The DRUID Study experience. *Epidemiol Perspect Innov*. 2007;4: 1–11.
  65. Budimir D, Polašek O, Maruši A, Kol i I, Zemunik T, Boraska V, et al. Ethical aspects of human biobanks: A systematic review. *Croat Med J*. 2011;52: 262–279.
  66. Platt J, Kardia S. Public trust in health information sharing: Implications for biobanking and electronic health record systems. *J Pers Med*. 2015;5: 3–21.
  67. Master Z, Claudio JO, Rachul C, Wang JCY, Minden MD, Caulfield T. Cancer patient perceptions on the ethical and legal issues related to biobanking. *BMC Med Genomics*. 2013;6: 2–11.
  68. 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 Jun 21;16(12):2209. doi: 10.3390/ijerph16122209.
  69. Braun KL, Tsark JU, Powers A, Croom K, Kim R, Gachupin FC, et al. Cancer patient perceptions about biobanking and preferred timing of consent. *Biopreserv Biobank*. 2014;12: 106–12.
  70. Cordeiro J V. Ethical and legal challenges of personalized medicine: Paradigmatic examples of research, prevention, diagnosis and treatment. *Rev Port Saude Publica*. 2014;32: 164–180.
  71. Faria PL De, Cordeiro JV. Health data privacy and confidentiality rights: Crisis or redemption? *Rev Port Saude Publica*. 2014;32: 123–133.
  72. Boeckhout M, Reuzel R, Zielhuis G. The donor as partner: how to involve patients and the public in the governance of biobanks and registries. 2014. Available from: [https://www.bbMRI.nl/sites/bbMRI/files/guidelineeng\\_def\\_0.pdf](https://www.bbMRI.nl/sites/bbMRI/files/guidelineeng_def_0.pdf).
  73. Langhof H, Kahrass H, Illig T, Jahns R, Strech D. Current practices for access, compensation, and prioritization in biobanks. Results from an interview study. *Eur J Hum Genet*. 2018;26: 1572–1581.