



Attitudes toward medical and genetic confidentiality in the Saudi research biobank: An exploratory survey



Ghiath Alahmad^{a,b,*}, Tamer Hifnawy^{c,d}, Badaruddin Abbasi^e, Kris Dierickx^f

^a King Abdullah International Medical Research Center (KAIMRC), King Abdulaziz Medical City, Riyadh, Saudi Arabia

^b Center of Bioethics, Harvard Medical School, Boston, MA, USA

^c Department of Public Health and Community Medicine, College of Dentistry, Taibah University, Medina, Saudi Arabia

^d Faculty of Medicine, Beni Suef University, Beni Suef, Egypt

^e Deanship of Scientific Research, Dammam University, Dammam, Saudi Arabia

^f Centre for Biomedical Ethics and Law, Katholieke Universiteit Leuven, Leuven, Belgium

ARTICLE INFO

Article history:

Received 3 February 2015

Received in revised form 5 December 2015

Accepted 21 December 2015

Keywords:

Confidentiality

Survey

Ethics

Biobank

Genetic research

ABSTRACT

Achieving a balance between giving access to information and respecting donors' confidentiality is a crucial issue for any biobank, with its large number of samples and associated information. Despite the existence of much empirical literature on confidentiality, there are too few surveys in the Middle East about the topic, particularly in the Saudi context. A survey was conducted of 200 respondents at King Abdulaziz Medical City in Riyadh, Saudi Arabia, among 5 groups of equal size, comprised of researchers, physicians, medical students, donors and laypersons, respectively. The majority of participants agreed that confidentiality is an important issue and that it is well protected in the Saudi biobank. All 5 groups showed different attitudes toward disclosing information to various third parties. They were in favor of allowing treating physicians, and to a certain extent family members, to have access to medical and genetic results from research. No significant differences were found between views on medical and genetic confidentiality. The majority of respondents agreed that confidentiality might be breached in cases with specific justified reasons. Even considering differences in religion, culture and other factors, the results of the study were consistent with those reported in the literature and research conducted in other countries. We therefore place emphasis on the importance of protecting and promoting patient/donor confidentiality and privacy.

© 2016 Published by Elsevier Ireland Ltd.

1. Introduction

Medical research on stored samples is very important for discovering the mechanisms and pathology of diseases, and for developing appropriate treatments [1]. Establishing research biobanks with huge numbers of samples and personal and genetic data will contribute to advances in medical research. The computerization of medical records will enable easy and safe access to the data required for empirical research [1,2]. Although having access to medical information is necessary for conducting medical research, unintended leakage of information may produce very dangerous consequences for individuals [3]. Therefore, research biobanks employ a number of precautions to maintain medical confidentiality including coding and access security systems. Medical

confidentiality is crucial in all human relationships and safeguarding the confidentiality of medical information is an ethical duty of all medical healthcare personnel and researchers [4]. Medical confidentiality is built on the concept of trust, which is considered necessary to conduct research; it enables conditions where research participants will give correct and accurate information [3,5]. Genetic information holds a special importance because it is related to sensitive issues that may be attached not only to the person themselves but also to their relatives. It is essential to strike a balance between the necessity of giving access to information for research purposes on the one hand and the obligation of respecting medical confidentiality on the other. Any disclosure of medical information in clinical research or practice can only be made if informed consent is given by the participants that permits researchers to access or disclose any information related to them [6,7]. However, in some situations disclosing medical information without consent may be justified in order to avoid greater harm, or in clear cases of individual or societal benefits e.g. the notification of infectious diseases [8]. Confidentiality is not limited to the information provided by

* Corresponding author at: King Abdullah International Medical Research Center (KAIMRC), King Abdulaziz Medical City, Riyadh, Saudi Arabia.

E-mail address: ghiathalahmad@hotmail.com (G. Alahmad).

Table 1
Socio-demographic characteristics of the study groups.

	Researchers	Physicians	Students	Donors	Laypersons	Totals
18–25 years	(3) 7.5%	(2) 5%	(31) 77.5%	(15) 37.5%	(7) 17.5%	(58) 29%
26–40 years	(34) 85%	(30) 75%	(9) 22.5%	(23) 57.5%	(23) 57.5%	(119) 59.5%
14–55 years	(3) 7.5%	(7) 17.5%	(0) 0%	(1) 2.5%	(8) 20%	(19) 9.5%
>55 years	(0) 0%	(0) 0%	(0) 0%	(1) 2.5%	(1) 2.5%	(2) 1%
$\chi^2 = 80.865, P < 0.001$						
Male	(11) 27.5%	(25) 62.5%	(30) 75%	(6) 15%	(16) 40%	(88) 44%
Female	(29) 72.5%	(15) 37.5%	(10) 25%	(34) 85%	(25) 60%	(112) 56%
$\chi^2 = 39.489, P < 0.001$						
None/primary	(0) 0%	(0) 0%	(0) 0%	(4) 10%	(7) 17.5%	(11) 2.8%
Secondary school/diploma	(8) 20%	(0) 0%	(18) 45%	(12) 30%	(12) 30%	(50) 25.1%
Bachelor	(10) 25%	(1) 2.6%	(15) 37.5%	(20) 50%	(14) 35%	(70) 35.2%
Postgraduate	(12) 30%	(38) 97.4%	(7) 17.5%	(4) 10%	(7) 17.5%	(68) 34.2%
$\chi^2 = 107.533, P < 0.001$						

research participants or taken from their samples or data, but also extends to the research results [9,10].

Because of the importance of medical and genetic confidentiality, and the lack of surveys in the Middle East about this subject, particularly in the Saudi context, research in the field is necessary and timely.

2. Methods

The study was designed to investigate the views of a random sample of employees and visitors to the King Abdulaziz Medical City, Riyadh, Saudi Arabia. The topic was confidentiality of medical and genetic research data, specifically that stored in the research biobank of Saudi Arabia, which has recently been established. The study comprised 5 different groups comprised of 40 participants namely, medical students, physicians, researchers (employees), donors and laypersons (visitors). The researchers were working in the King Abdul International Medical Research Center (KAIMRC), the physicians in the King Fahad Hospital, National Guard, and the medical students attended the University of King Saud bin Abdulaziz University for Health Sciences. The members of the donor group consisted of individuals who had previously donated clinical samples for the purposes of research. The laypersons group included individuals who visited the hospital or were companions of patients. The total number of respondents was 200.

Several specialists from different medical specialties, such as researchers, healthcare quality management and general practitioners reviewed the questions in order to establish their suitability, effectiveness, reliability and content validity. Cronbach's alpha was used and test–retest reliability was ensured in a pilot study of 5 subjects before starting data collection for the main study.

Survey questions were written in English and then translated into Arabic, and the content of the Arabic copy validated. The English version was used to elicit the views of groups of physicians, researchers and medical students, while the Arabic version was used to elicit the views of donors and the general public. Two trained research coordinators and one medical student collected the questionnaires. All respondents completed the questionnaires by themselves, except for lay people when interview-based questionnaires were used.

The questionnaires were divided into several sections. The first questions inquired about participants' personal information. Questions in the second section measured attitudes towards the importance of confidentiality in medical research as well as the actual respect of confidentiality in the research center. The third section assessed participants' views on the accessibility of medical and genetic information by different people. The fourth section assessed participants' views about providing research results to others. Finally, in the fifth section, participants' views about jus-

tified reasons to disclose confidential medical information to third parties were explored.

The Institutional Ethics Committee of the King Abdullah International Medical Research Center granted approval to conduct this research. We obtained approval from all participants and informed them about the research and its goals, before gathering any information from them. We assured participants about the issue of respect for privacy and confidentiality at all stages of the research. Participants were also given the right to withdraw at any time without any negative consequences. Females were interviewed in the presence of a female nurse; there was no need for the presence of a father, husband or brother during the interview.

All questionnaires were coded and entered into a password-protected computer under the direct supervision of the principal investigator.

The data were collected and analyzed using the program SPSS, ver. 19. All items were measured on a 5-point Likert scale, which were then converted to a 3-point Likert scale, which lowers the number of comparison groups to conduct statistical analysis and estimate the standard deviation.

The study used chi-square and ANOVA tests to evaluate between group differences and considered $P < 0.05$ to be significant.

3. Results

3.1. Personal characteristics

The study cohort comprised 200 respondents from 5 different groups, who differed significantly in age, sex and education ($P < 0.001$). More women were involved and the majority of respondents were between 26 and 40 years of age. The majority of participating physicians had a postgraduate degree, while postgraduate diploma holders were fewer among donors, students and laypersons (Table 1).

3.2. Confidentiality in theory and practice

With regard to considering medical information as confidential and that data confidentiality was well protected in the Saudi biobank, the majority of respondents agreed; however, a significant difference was found, with more than 90% agreed on the first issue and only about two thirds on the second (*vide supra*).

Donors indicated the lowest degree of agreement regarding the necessity of keeping medical information confidential ($P < 0.001$), but both donors and laypersons agreed less than others that data confidentiality was well protected in the Saudi biobank.

It was unequivocally established that laypersons and donors knew and fully appreciated the type of information being requested before they answered survey questions. When comparing two

Download English Version:

<https://daneshyari.com/en/article/516709>

Download Persian Version:

<https://daneshyari.com/article/516709>

[Daneshyari.com](https://daneshyari.com)