Perceptions and experiences of medical confidentiality and privacy among healthcare workers and patients in Armenia: a qualitative research

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By

Ashkhen Grigoryan

Advising team

Tsovinar Harutyunyan, MPH, PhD

Lusine Musheghyan, MSW, MPH

Gerald and Patricia Turpanjian School of Public Health

American University of Armenia

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List of abbreviations

WHO World Health Organization

HIPPA Health Insurance Portability and Accountability Act

USA United States of America

HITECH Health Information Technology for Economic and Clinical Health Act

CDC Centers for Disease Control and Prevention

UK United Kingdom

UNESCO United Nations Educational, Scientific and Cultural Organization

TB tuberculosis

HIV human immunodeficiency virus

AIDS acquired immunodeficiency syndrome

STI sexually transmitted infection

EU European Union

MoH Ministry of Health

MoESCS Ministry of Education, Science, Culture and Sport

Abstract

Confidentiality and privacy are essential parts of healthcare system. According to the available literature, the concepts are valued by healthcare professionals and patients. It is also shown that perception of confidentiality affects patient behavior to seek care and utilize available healthcare resources. Maintenance of confidentiality is not only ethical but also a legal obligation, and there are available laws in a lot of countries to protect confidentiality of medical information. Yet, the laws are also available in Armenia, there are no studies to explore publics or healthcare professionals' perceptions and attitudes towards these concepts.

Thus, the qualitative study was conducted with the aim to explore patients' and physicians' perspectives of medical confidentiality and privacy in Armenia. The participants were recruited using purposive convenience sampling method, and the data was collected through in-depth interviews (IDIs) using self-developed semi-structured interview guides. The interview guides were developed based on the available literature and cultural context. The process was guided by the framework of responsiveness and confidentiality suggested by the World Health Organization (WHO). Six physicians and eleven patients were interviewed during the study.

The data was analyzed using inductive and deductive approaches.

The study findings have shown that confidentiality is valued and perceived as an important component of the healthcare system; however, a gap in knowledge of the concepts and laws was also identified. The study also identified a gap in medical education regarding confidentiality practices. According to the study findings, there are differences between current practices and expectations about access to healthcare information among participants. On the other hand, the importance of confidentiality was intensively stressed for sensitive and stigmatizing diseases. In contrast, the ideas about the importance of physical privacy were superficial, and it was not

emphasized during the interviews. The study also found a conservative approach and willingness to control the data available in electronic systems among patients, whereas physicians expressed that it is essential to access it fully. The unique finding of the study is participants' approach towards hiding the diagnosis from the patients, where the importance of patients' emotional status and readiness to listen to the diagnosis was highlighted by the majority of participants.

This was the first study exploring the topic in Armenia. The study findings have shown that there is a need to update the curriculum in medical universities. Also, it is important to create appropriate guidelines to make it easier for physicians to grasp the details of confidentiality and privacy concepts and laws. Simultaneously, there is a need to make patients aware of laws and their rights and provide appropriate information regarding confidentiality.

The study provides evidence-based information about confidentiality and privacy for all the stakeholders, including policy-makers, healthcare professionals, and researchers.

1. Introduction

1.1 Problem definition

Medical confidentiality is an ethical and legal obligation of doctors and a health care system to keep patients' information private. The importance of patient information security was highlighted in Hippocratic Oath² and has also been highlighted in modern times, including the 1996 "Health Insurance Portability and Accountability Act". Respect for confidentiality has been highlighted as one of the most important aspects of patients' interaction with health care systems by World Health Organization (WHO).4 It constitutes one of the eight domains of the health system's responsiveness – a concept that was proposed by WHO for the health system performance assessment in 2000. The WHO framework recognizes improved health, responsiveness, social and financial risk protection and improved efficiency" as the main outcomes of a health care system, along with quality and safety asssurance.⁵ Responsiveness has been defined as "aspects of care related to the way individuals are treated and the environment in which they are treated". 4 Medical confidentiality, as a domain of responsiveness, includes privacy of medical records, privacy of environment, and "privileged communication".⁴ Confidentiality was described both as keeping personal information from others and keeping environment safe, where information is being shared. 4 "Privileged communication" was mentioned as part of confidentiality as patients' perception of confidentiality is crucial to share all the information with healthcare professionals.⁴

While "privacy" is part of "confidentiality" in the healthcare responsiveness system framework suggested by WHO,⁴ and the terms have often been used interchangeably in the literature, other scholars note that these are distinct concepts.^{6,7} The concept of privacy indicates patients' rights to control all the aspects of personal data and space, including physical privacy, decision privacy,

associational privacy, and information privacy.⁸ Every individual's right to control their medical information and decide its use or disclosure is known as information privacy, and privacy rules regulate handling of personal information.⁹ Yet confidentiality is related to information privacy and defined as the doctors' legal obligation to keep the received information and not disclose it inappropriately.⁹

There is a number of factors that patients associate with privacy, including hearing others' personal information, personal information heard by others, being noticed by bystanders, the privacy of space, unintentional hearing of medical staff's conversation and their respect for privacy, and the higher ratings of privacy were a significant indicator of satisfaction. The absence of medical confidentiality might influence care-seeking behavior in individuals. Several studies have shown that a safe and confidential environment increases the utilization of healthcare services.

Despite the stressed importance of maintaining medical confidentiality, the studies have shown that breaches of it take place in health care settings and that the confidentiality rules are most frequently violated by physicians. A study conducted in 37 Clinical Management Units tertiary care by Beltran-Aroca and et al. had demonstrated that 54.6% of breaches had occurred when patient information was disclosed to the medical personnel who were not included in the clinical care of the patients or to the external people. The second and third most frequent breaches were related to custody of clinical records (34.4%), cases when clinical records or histories were not safeguarded properly, and infrastructure breaches (11.0%). The latter included situations when confidentiality was not maintained because of the poor infrastructure or organization, including disclosing personal information inwards, operating rooms, or waiting rooms. The authors characterized the breaches as severe when the disclosed information was related to stigmatized

or mental illness, sexual life, ethnic background, and disclosure of information to the third party not included in the patient care or intentional disclosure of medical information.¹⁷ The aforementioned breaches happened in 46.7% of cases.¹⁷ Physicians were involved in breaches in 51.4% of cases, followed by nurses (20.0%) and residents (18.8%).¹⁷

Some examples of the most frequent Health Insurance Portability and Accountability Act breaches reported in 2021 were examining healthcare records of friends, family members, and celebrities or inappropriate disclosure of patient information (disclosing information to patient's employer). Another type of breach is failure to ensure confidentiality, such as failure to limit access to electronic health records or failure to destroy non-required information. 18

1.2 Guidelines and recommendations for protecting medical confidentiality

In addition to regulations and laws, guidelines and recommendations for healthcare workers, including physicians, nurses, administrative staff, and managers, are available to ensure compliance with laws and regulations. New technologies and electronic systems have been introduced in the health care system, and the number of regulations and laws has increased to ensure confidentiality of information kept in these systems.

The Health Insurance Portability and Accountability Act (HIPPA) act¹⁹, originally developed in 1996 in the United States of America (USA), was amended several times, including the introduction of the Privacy Rule in 2000²⁰, the Security Rule in 2003²¹, the Health Information Technology for Economic and Clinical Health Act (HITECH) in 2009²², The Omnibus Final Rule in 2013²³. Similar acts exist in other countries, including The Personal Information Protection and Electronic Documents Act of 2001 in Canda²⁴, The Privacy Act of 1998²⁵ in Australia with the introduction of the Personally Controlled Electronic Health Records Act 2012.²⁶ To follow and understand all the rules is a challenging task for healthcare workers.

"HIPPA compliance guide" was developed for the administrative staff and managers, with all the steps and scenarios described to ensure HIPPA compliance in healthcare centers in the USA.²⁷ Royal Australian College of General Practitioners has published a similar guide to provide up-to-date information regarding privacy and health information management.²⁸

"Infection Control in Healthcare Personnel: Infrastructure and Routine Practices for Occupational Infection Prevention and Control Services", which has been released by the USA Centers for Disease Control and Prevention (CDC), has a separate chapter on the management of healthcare workers' medical records.²⁹

The Steering Committee of the European Network of Cancer Registries publishes and updates guidelines on confidentiality for cancer registration and related activities to explain and guide all the procedures pertaining to cancer registration not only within but also outside the European Union.³⁰

Similar guides have been designed not only for the healthcare sector but for patients as well. European patients forum has a guide for patient and patient organizations to help them to understand the legislation and protect patient privacy and right to access their health data.³¹

1.3 Confidentiality perceptions among patients in different countries

The perceptions of medical confidentiality vary from country to country as they are affected by cultural and social norms.^{32,33} The study conducted in the USA has shown that two-thirds of the USA adults had some concern about their health information security³⁴. Another study conducted in the United Kingdom (UK) has demonstrated that patients were unaware of the rules that have been implemented to guide who should have access to their medical records thinking that except doctors, no one has access to their records.³⁵ Most of the participants felt it was normal for

nurses and midwives to have access to their records; however, those who had concerns regarding this stuff justified it with the lack of training for nurses.³⁵ Most of the participants agreed that administrative staff should not have access to their information and some of them also mentioned that the doctors who are not involved in their care should not have access.³⁵ The study which was conducted among Japanese health care workers and patients to explore participants' reaction to using their medical information without their agreement, has shown different perspectives on this issue; however, the majority agreed that there is a need to take consent form from patients to access their records.³⁶

Several studies have explored the concerns regarding the security of electronic medical records.^{37–42} A mixed-methods study in the UK has shown that although the respondents had some concerns regarding the security of electronic health records, the benefits introduced by medical records outnumbered the risks in their opinion.³⁸ Study results conducted in the USA in 2011 have shown that only 22% of participants did not have any concerns regarding the security of medical records.³⁹ A study conducted in Myanmar identified challenges regarding implementing an electronic medical records system, one of which was a concern of medical confidentiality due to increased data accessibility, which could lead to data breaches.⁴⁰ The concern related to confidentiality of the data stored in electronic health records was identified only among 14.4% of the patients visiting primary care hospitals, and 66.7% stated that they feel comfortable in cases when their data was shared with another professional for a second opinion in Greece.⁴¹ Another study conducted in Greece in 2018 demonstrated that 48.8% of general populations and 53.1% of physicians worried about the security of electronic records, besides physicians expressed some concerns regarding the increased workload.⁴²

1.4 Confidentiality perceptions among healthcare providers

The study conducted in Jordan reported that physicians mentioned that they follow the rules and keep the information confidential in the majority of cases, however, the same study also reported that physicians valued the role of confidentiality more when dealing with sensitive diseases. Another study also reported that physicians valued the role of confidentiality, even in cases when working with adolescents. On the other hand, the literature shows a lack of knowledge of the concept and laws among physicians. Another study also reported that physicians valued the role of confidentiality, even in cases when working with adolescents.

One of the main medical confidentiality issues experienced by physicians across different cultural and social settings is sharing patient information with patient's relatives. In the modern era, influenced by western culture, the autonomy and freedom of patients are being valued, and physicians tend to disclose the information to patients directly.⁴⁶ However, the approach is different in the Eastern and Islamic parts of the world, where disclosing the diagnosis to relatives and withholding it from the patients is still widely accepted practice.^{47,48}

There are different laws and recommendations protecting patient privacy and confidentiality in different countries, notably US's HIPPA,⁴⁹ Australia's Privacy Act,²⁵ Taiwan's Personal Data Protection Act⁵⁰, UK's General Medical Council's guidance⁵¹ based on the existing laws, and Patient's Rights Chapter of Iran.⁵² Yet all the aforementioned laws and regulations share the common thread stating that disclosure of medical information to the third party, including relatives, without patient permission, is allowed only in case the patient cannot consent for disclosure or when the disclosure of information benefit for public outgrows the risks for the patient.

Nonetheless, this aspect of confidentiality brings some dilemmas even in well-developed countries, particularly because there is no consensus regarding how the genetic testing results

should be shared. Godard et al. identified multiple guidelines released by international or regional organizations (WHO, UNESCO, Council of Europe) or developed at the national level (Denmark, US, Italy, Japan, France, etc.); nevertheless, the recommendations vary, and there is no universal advice or regulation on how physicians should act.⁵³ Meanwhile, systematic review results have shown patients' and physicians' opinions vary; half of the patients mentioned that they would not like their doctors to disclose their information, whereas most doctors felt morally responsible for letting relatives know about the genetic risks they have.⁵⁴

1.5 Situation in Armenia

There are two laws in Armenia which have clauses about medical confidentiality. 55,56 Law On Protection of Personal Data is a general law on protection of personal information, including personal medical data. 55 The second one is the Law of the Republic of Armenia on Medical Assistance and Service to the Population, which defines what constitutes private information and how confidentiality should be maintained. 56 The revision of the latter law was proposed by the Ministry of Health, and the revised version was passed in 2020, with a separate article on confidentiality issues. 57 According to the Criminal Code, violation of the mentioned laws and sharing personal medical data with a third party will be punished with fines from 200.000 to 500,000 drams, arrest or revocation of medical license depending on the severity of the consequences of the disclosure of personal medical information. 58

The topic of medical confidentiality is not well-studied in Armenia. However, several studies on other components of health care have covered some aspects of medical ethics and confidentiality. The study which explored patient satisfaction with primary health care in two marzes in Armenia reported that 70% of respondents were sure that medical information shared with their doctors had been kept confidential.⁵⁹ Another study regarding patient satisfaction identified that medical

confidentiality as part of high-quality medical services was recognized by few participants; however, participants also reported cases when confidentiality was neglected. On the other hand, a recent study that explored the barriers to the utilization of adolescent health services in Armenia identified medical confidentiality as one of the barriers mentioned by participants. The study on tuberculosis (TB) treatment practices in primary healthcare settings in Armenia revealed doctors' willingness to maintain patients' health-related information; however, the study also showed that some of the patients were not aware of how their information confidentiality was assured. Concomitantly, the study identified physicians' lack of knowledge about existing laws and regulations regarding patient privacy and confidentiality protection. Almost all patients receiving tuberculosis treatment in inpatient centers were informed about how their medical data would be handled; however, some of the healthcare providers failed to protect all aspects of confidentiality of personal information, including handling sensitive information related to human immunodeficiency virus (HIV) or acquired immunodeficiency syndrome (AIDS) coinfection.

This study will explore the experiences and general perceptions of confidentiality and privacy among Armenian patients and health care providers and provide policymakers and healthcare system administrators with the evidence base to reform the corresponding aspects of the healthcare system and enhance the law on confidentiality.

2. Study aim and research question

This study will explore the perceptions and experiences of medical privacy and confidentiality among healthcare providers and patients in secondary and tertiary care hospitals.

The study will answer the following research questions:

- 1. What are the perceptions of medical privacy and confidentiality among healthcare providers and patients of the secondary and tertiary care hospitals?
- 2. What are the experiences of medical privacy and confidentiality issues among patients and health care providers of the secondary and tertiary care hospitals?

3. Methods

3.1. Design

The qualitative study design using in-depth interviews (IDIs) with semi-structured topic guides was utilized. To ensure the credibility of the study, triangulation of the data sources was done by interviewing both physicians and patients.⁶⁴ Given that the research on this topic in Armenia is scarce, this method allows exploring different views and experiences of the participants and understand the phenomena deeply by covering all dimensions of the issue.⁶⁵

3.2. Setting and study participants

To maintain the heterogeneity of participants and to be able to explore diverse experiences and opinions, the student investigator recruited participants from the secondary and tertiary care hospitals in Yerevan and marzes.

All the participants were recruited through purposive convenience sampling method⁶⁶ using the personal contacts of the student investigator. To explore participants' different experiences, they were recruited from different hospitals and different departments, which helped to explore different perceptions of confidentiality depending on the specialty or medical condition. The snowball technique was used to recruit more participants in both groups.

Medical background and experience in the field made the student-investigator an insider, which could possibly help during the interviews with medical staff. Self-reflecting techniques were

utilized to avoid interpretation of the gathered data from the personal point of view and to ensure the trustworthiness of the study. After recruiting the first participants, using the snowball technique, more contacts of doctors were obtained, and they were invited to take part in the study. Patients were recruited through different individuals who did not have any relation to the healthcare system, thus giving them an opportunity to share all the concerns and issues experienced in hospitals without any concerns that this information could be conveyed to their doctors. Both females and males and representatives of different age groups were invited to participate in the study. Only people hospitalized in the last five years were invited to participate in the study to share their recent experience and to avoid recall bias.

3.3. Data collection

The interviews were conducted using online methods (calls via Zoom, Viber, Skype) considering the COVID-19 pandemic.⁶⁸ After obtaining permission from the participants, the interview was audio recorded to ensure that all the information is saved for the analysis. In addition to recordings, the student-investigator took field notes during the interviews to record participants' nonverbal behavior (gestures, poses, emotions, any changes to the questions), to analyze and present contextual information.⁶⁹

3.4. Interview guide

The student investigator collected study data using self-developed semi-structured interview guides (Appendices 1-4). Two topic guides were developed for two participant categories. The development of the interview guides was based on the available literature on this topic and the knowledge of Armenian cultural context. The questions were mainly guided by the WHO responsiveness framework. An additional domain in the topic guides was included to explore

perceptions of electronic health system and its security. The domains of the topic guides are the following:

- knowledge about medical confidentiality and its role in healthcare system
- confidentiality of medical records
- environment and communication
- physical privacy
- confidentiality issues related to e-health

The topic guides for physicians and patients, comprised 17 and 22 open-ended questions, respectively. Socio-demographic characteristics of the participants were also collected prior to the interviews. Both topic guides were developed in English and then translated into Armenian.

3.5. Data management and analysis

Data analysis started after the completion of the first interviews. The simultaneous data collection and analysis allowed us to adjust the data collection and expand the sample size as necessary to explore the categories in detail.⁷⁰ The recruitment of participants continued until achieving saturation.

The interviews were transcribed in Armenian. The verbatim transcription method was utilized, and all the details of the interview process were recorded. The coding and analysis were done in Armenian to ensure there is no content change⁷¹; final themes developed during the analysis were translated to English. The data was analyzed in two stages using deductive and inductive approaches.

During the first stage of coding the initial 11 interviews were coded using value, descriptive, invivo and process inductive codes.⁷² The last 6 interviews were coded mainly using the

established codes. Additionally, new codes were used to code new ideas and phrases. During the second stage of coding the codes were grouped under the categories to describe certain patterns. The grouping of codes under the certain categories was mainly guided by the sections of topic guide, which was developed based on the WHO framework of responsiveness.⁴

Audit trails were implemented to describe all the stages and show the rigor of the completed study and demonstrate trustworthiness.⁷³ Peer debriefing was conducted during the fielding process.

3.5 Ethical considerations

Study protocol was approved by the Institutional Review Board of the American University of Armenia. All the study participants were informed about the study details including benefits and risks, and opportunity to stop the interview at any time. Oral consent was obtained before each interview (Appendices 5-8). The names and phone numbers of participants were not recorded. Recordings of the interviews were kept in the personal computer protected with a password and were destroyed after the analysis.

4. Results

4.1 Sociodemographic characteristics

Overall, 17 IDIs were conducted, out of which 6 were with physicians and 11 with patients. Considering Covid-19 pandemic, all interviews were conducted online using applications such as Viber, WhatsApp, Zoom, Skpye and Messenger. The interviews with physicians lasted 46-69 minutes, with an average of 56.3 minutes, while the interviews with patients took 23-65 minutes, with an average of 35.2 minutes. The mean age of physicians was 28.6 ranging from 26 to 35. The mean age of patients 36.0 years old, ranging from 20 to 51. All the participants were from

Yerevan, except one patient, who was hospitalized in marz, and one physician working both in marz and Yerevan. The specialists were working in the departments of internal medicine, radiology, gynecology, and endocrinology. All the participants agreed to record the interviews.

4.2. Knowledge of confidentiality and its role in healthcare

4.2.1 Defining confidentiality

The definitions of confidentiality given by all interviewed patients and physicians were quite similar. The patients mainly highlighted it as a way of data maintenance and keeping it away from the third party. The physicians defined it as securing the received information and not sharing it with the third party without patient permission.

"Medical confidentiality? I assume there is a formal definition, which I do not know, but I think that it is the maintenance of personal medical data, which should be kept secret and disclosed with the person's permission." (Patient 3)

"Medical confidentiality is that patient's relatives and other people should not know what has been discussed between the patient and the doctor." (Patient 5)

"I know that anything related to patients, starting from symptoms to ... all clinical and laboratory findings, and treatment, do not refer to anyone but the patient." (Physician 4) "Patients' all personal data along with diagnosis is considered confidential and should be accessible for the physician and the patient, and people approved by the patient." (Physician 5) Both physicians and patients valued medical confidentiality and perceived it as an important part of the medical system. It was valued as a necessary component of confidentiality in general and an indicator of the patient's quality of life. The leakage of confidential information was thought to lead to possible emotional issues.

"It is a quality of life indicator, people feel comfortable when only they know their information.

That is why confidentiality assurance in this era is very important." (Patient 2)

"Because it can cause... a violation of human rights, it is everyone's right to keep their personality confidential, and also, it could lead to conflicts, non-pleasant consequences, and emotional outbreaks." (Patient 3)

"It is the ethical component of the medical system. It is not directly associated with treatment, improves patient-physician collaboration, which is important for the further treatment of the disease." (Physician 1)

"Of course, it is. What is it, if not a part of the system? It is a tool which doctors should work with. Of course, it is part of the medical system, it is a skill that, by the way, a doctor should be competent in." (Physician 2)

4.2.2 Awareness of laws on medical confidentiality and privacy

While all the doctors knew about the concept of confidentiality and were aware of the existence of laws regulating this filed, none of them knew about the specific content of the laws and penalties set for violations.

"Oh, to be honest, no idea [about laws]. I know, there is such thing, I know that there are some restrictions, but I do not know any specific thing." (Physician 1)

"I just know I cannot violate [the laws], but to be honest, I do not know how they work, or what would happen if I violate those" (Physician 3)

As physicians, patients did not know much about the laws, and some even did not know about their existence. Most of the participants believed that keeping information confidential is first of all, a moral obligation for doctors and is as important as their legal responsibility.

"It is a moral obligation. Apparently if they took an oath, it means that it is their moral obligation." (Patient 1)

"There is no way without it, it is first of all moral, and then legal obligation." (Patient 4)

"In general, medical institution should force them [physicians], to keep the information confidential. On the other side it depends on what kind of person each particular physician is, how moral he is, and if he will share that information with others." (Patient 11)

4.2.3. Training on medical confidentiality and knowledge gaps

All physicians mentioned medical university as a primary source of knowledge on medical confidentiality issues. Most of them said that they never tried to read more about this topic or attend additional training. Moreover, the majority of them thought that the knowledge they received was not very useful for medical practice.

"In the university, we had bioethics [course], but I do not remember anything from it. Besides, we had law, medical law class...but I graduated without a good understanding." (Physician 2) "Yes, we had a law class, do not remember the year, 5th or 6th, maybe 6th...I remember I was listening with interest, but did not retain anything." (Physician 4)

"We had bioethics, which was a mandatory class on medical confidentiality, attitude, all the ethical rules related to medical confidentiality." (Physician 5)

Only one physician said she was interested in the topic and used a variety of sources to enhance his knowledge.

"I had an inner understanding of ethics and was interested in it. I did not violate it even before learning it. There was a book of ethical cases in English. And then I attended a workshop on this topic." (Physician 2)

4.3. Confidentiality of medical records

4.3.1. Access to medical records for physicians and nurses

The physician participants worked in different hospitals and departments, where medical information was kept both in paper and electronic format. Most of the doctors mentioned that the paper documents are more accessible in the department and even junior medical staff can access it. However, the overwhelming perception was that the leakage of information is not probable because of multiple factors, including medical language used in the documents or personnel's awareness and the attitude towards confidentiality in the department, which makes everyone to understand that medical information should remain within the staff.

When asked if they ever had any concerns regarding the security of medical documents, one physician said:

"All the text is written in medical language. If the junior medical staff could access it, they would still be unable to understand that information properly." (Physician 1)

"I cannot say that I have ever been concerned about that. Also, I would not say that everything is being kept very safe. But I have never been concerned, because that kind of incident never happened, and also there is an ethical approach to this in our department." (Physician 6) Most physicians said that only physicians involved in care should access confidential information.

"You know I looked at whether nurses should have access to medical histories from a legal perspective...I do not think they should access everything, except what they really need, such as prescription documents, name, surname of the patient, the status of hepatitis B, what else do they need? But in reality, they have access and can read medical histories." (Physician 2)

"Maybe nurses should access prescription documents, but not medical histories. Maybe the parts they need for their work...but some parts, personal information - I do not think there is a need for them to access this." (Physician 5)

Physicians' approaches varied, with some of them mentioning that there is no need for nurses to know all the details. Despite reporting never having confidentiality concerns, some of them also mentioned that nurses could possibly be a source of confidentiality breach. Nevertheless, most of them mentioned that in practice it is a challenging task to keep the documents accessible for doctors only, especially in secondary care, where nurses have a variety of responsibilities and also nightshifts.

"There can be information in medical histories which can lead to certain consequences [if disclosed]. They can have personal interest in ta particular case; that is why it is not welcomed."

(Physician 1)

"They [nurses] can open, read the address and say "this is my neighbor"... I do not know, there are things they should not know. But in reality, they have full access." (Physician 2)

Patients' expressed opinions very similar to those of physicians, saying that doctors involved in care are the ones who should access their information.

"Physicians, maybe, head of the department. For nurses, I do not think they should [have access]." (Patient 4)

"I do not know who can see it, but I would like only my doctor to see it, and in case I have any concern head of department or another specialist, can see access it, but they also should ask my permission. However, I think that now whoever wants to can open [the record] and look at it". (Patient 6)

"In my opinion, there should be a separate documentation, for example if there is written that at this or that hour these manipulations should be done, then they should have access to these documents only." (Patient 10)

Most of the patients' said that they do not think nurses understand medical information and it is not their job, so they should do their work and not read the details of the medical records.

"I think everyone should do their job. If they [nurses] understood it, they would work as physicians, not nurses. Maybe, now they can open [medical histories] for their interest, but I think it should not be accessible for them." (Patient 8)

"They [nurses] should not have an access to medical histories. Why do they need it? It is not their part of their work." (Patient 5)

In contrast to this, some participants did not think keeping the information secure was important and did not see any problem with keeping it open.

"I do not think there is a problem with this information, it can be open, and the type of information does not matter." (Patient 9)

4.3.2. Confidentiality related to stigmatized medical conditions

When talking about their concerns about medical confidentiality, most of the patients mentioned that they have never experienced it, as they did not have any stigmatized diseases. Such diseases most commonly mentioned by physicians and patients included sexually transmitted infections (STIs) and human immunodeficiency virus (HIV). Other diseases in this list were oncological and gynecological problems.

"In reality, I have never had concerns, because there was no hypersensitive information. But of course, if there was some information like that, it would concern me. If it is an orthopedic problem, I do not see an issue. Anyone can come and see that I have a leg fracture." (Patient 2)

"No, thank God, there has never been a case of a disease that would have to be kept secret."

(Patient 4)

"I have never had a sensitive disease, to think if they [doctors] would tell about it to anyone or not." (Patient 7)

This perspective was also validated by the physicians. Almost all of them mentioned that patients are more concerned or ask about confidentiality when they perceive the disease as serious or sensitive.

"It depends on the main disease usually ...some conditions can be a source of stigmatization; it would be a problem for them. But if it is Covid pneumonia, although I would say I feel kind of stigmatization regarding Covid pneumonia in Armenia...so I would say yes, it depends on the problem." (Physician 3)

"There was a case when a patient had HIV. He had lymphadenopathy, which had to be evaluated. And his parents approached and asked to keep that information [HIV] secret, and of course, everyone agreed to that." (Physician 4)

"My specialty is a bit specific, and there are a lot of personal aspects, that they would not like others to know. In my case it [confidentiality] is more important, and I do not think it is a case for other specialties, for example they would not say: "Oh, I have a fracture, I would not like others to know it"." (Physician 6)

4.4. Physical privacy

4.4.1. Getting patients' permission for starting physical examination

In general, patients did not seem to be interested in the topic of confidentiality of physical examinations. Most of them did not think that their approval or opinion should be asked before

starting the examination. Only few of the participants mentioned they would prefer to be notified about the physical exam. Similar opinions were dominant among physicians, who talked about not directly asking, but rather notifying about the start of the examination.

"No, no need to ask, physician should not ask that, but notify that I am going to examine chest, or abdomen." (Patient 7)

"Ask? Why should a physician ask about that? If you are in the hospital, then you are the one who wants the physician to examine you." (Patient 8)

"We preliminarily describe the process. We do not ask directly "May I start the exam?", no, it is assumed that they know what to expect." (Physician 3)

"We notify, that it [physical exam] is important, but we do not obtain permission like that ...if they came to us, it is assumed they gave their permission for examination." (Physician 5)

4.4.2. Presence of medical students and other people at physical examination

When asked about who they would prefer to be present during their physical exam, most of the patients mentioned that except their doctor, nobody else but nurse could be present, and only in case if there is a need for her to be in the room.

Different opinions were expressed on the topic of presence of medical students at the physical examination. The majority of respondents highlighted the importance of asking patients' permission; at the same time, most of them agreed that this is the only opportunity for the students to learn, so it was considered as normal practice. Some of the participants thought that there is no need to ask permission at all.

"There is no problem with them [students], they can be there [in the room], finally they should learn it somewhere." (Patient 1)

"Is the student guilty that she/he is studying in a medical university, and that he/she will be doing surgery in the future? Should they learn it somewhere or not? These people need to be present without asking any permission." (Patient 10)

In general, there was a positive attitude towards students' presence during physical exam among the study participants. Only one participant strongly opposed this practice.

"No, it is not pleasant for me, and I would not like students to be present...and it is doctors' obligation to ask my permission first before letting them be present." (Patient 6)

When asked about real experiences with the presence of students during physical examination, the participants who have been in such situation mentioned that their permission was asked before the students were allowed to be present.

"In all cases, when I was in hospital, my permission for students' attendance was asked...they should stay to learn, as they are future doctors." (Patient 8)

"Whenever I went to the hospital, they [physicians] asked all the time "Would you like them [students] to be present?"...and I felt that they [students] were looking for my reaction and I agreed, because they should learn, and I have very positive attitude towards them, very positive." (Patient 11)

One participant recalled being in a situation when permission was not asked in advance.

However, even in that case, the presence was not seen as a problem, but the huge number of the students in the room was.

"Patient's permission should be asked in advance...I have been in such situation; I asked the physician if the students could leave the room, because I did not feel comfortable with that many people. And then, only two girls out of ten stayed in the room." (Patient 4)

When asked about physical privacy assurance, most of the physicians mentioned using curtains or closing the doors, however there were also other ways to assure patients' physical privacy. "If I know that there is need for the patient to take off the cloths, I lock the door. And I have curtains in my room so even if someone opens the door, they will not see the patient." (Physician 1)

"The examination is conducted by one physician and it is behind the closed doors." (Physician 2)

"Every room in our department has a water closet and we usually perform physical exams there." (Physician 5)

4.5 Confidentiality issues related to e-Health

4.5.1. Security of electronic medical records versus paper-based records

The use of electronic medical systems was the topic discussed quite superficially as most of the patients did not know about the system in general and ARMED electronic health system in Armenia in particular. Similarly, most of the doctors did not use it and were not aware of how the system works in Armenia.

Electronic system of medical records was not seen as more secure compared to paper-based documentation, but rather the same. Some physicians thought it could be even more risky because of the possibility of hacking the system.

"If the [patients'] medical investigation result in the electronic system gets hacked, it can become accessible to seven billion people." (Physician 1)

"I think it is more difficult, it is more difficult to ensure its [electronic system] security. If papers are shared, it would be accessible for one or two people. No one would come and take all the

archived papers. But if it is electronic and is concentrated in one place, that information would be possible to disseminate with one click." (Physician 5)

Patients had similar opinions about the security of electronic systems. Most of them mentioned about hacking as a potential problem; however, they did not consider it as a very probable scenario.

4.5.2. Misuse of the system in Armenia and possible confidentiality breaches

Another aspect of the security of the system was its improper application in Armenia.

"As much as I know, our operator [person working in the electronic system] asked for permission to work from home, and he did work from home, and I think anyone could see it [records] there. People who work from home open these accounts in their personal phones. It is vulnerable [for hacking] because these people do not appreciate the importance of confidentiality." (Physician 2)

"I would say that yes, every doctor has their password, but there are physicians, for example department heads, who would download information, and let her/his nurse know the password. And there are physicians who would say, "I do not have time for it [to fill in the data], this is the password" [to residents in order to fill in the data] ... and not only physicians could access it, but also medical residents. Yes, maybe junior medical staff would not have access, but still, information would be accessible." (Physician 6)

4.5.3. Obtaining permission for using electronic patient record

Despite the mentioned challenges, most of the physicians stressed that electronic medical system could be useful for doctors, especially from the perspective of having all the medical information regarding a patient concentrated in one place. Moreover, they mentioned that in case of having

this kind of system, the available information, including sensitive information, should be accessible for the doctors and not depend on the patients' permission.

"Physician should know everything [about the patient], because it is important for diagnosis, for accurate treatment. If there is no trust towards that doctor, no need to approach that doctor at all." (Physician 1)

Notably, according to some of the physicians, having access to complete information about the patient might also help to protect medical staff in case of serious infectious diseases.

"I know the case when a patient with HIV was admitted to the hospital, and did not notify medical personnel, and blood sampling and other manipulations were conducted. In these cases they have to notify, and if they don't, they [patient] should be punished for possible complications." (Physician 3)

"From the medical personnel's perspective it [all the medical information] is the same. For example, [if someone has] HIV, even junior medical staff should be aware of it, because all the staff is at risk" (Physician 6)

As opposed to physicians, most patients suggested imposing some restrictions on the use of electronic records. None of them wanted this information to be accessible to all physicians even during their visit. Most of them would like to give permission for accessing their information.

Some thought that access should depend on physicians' specialty.

"I think it should be with permission, even for a doctor, they should ask and then see it [medical information]." (Patient 1)

"I think she/he should say that they have the information and ask if they can open and see it.

Maybe I do not want her/him to see it, because I went to this specialist for the second opinion,
and ...I do not want her/him to see what the previous one [doctor] wrote there." (Patient 7)

While the arguments brought by the study participants varied substantially, all of them were for having some kind of control over access to medical information stored in the system.

"If it is your doctor, then yes she/he can see it, but the patient should be aware about type of information available there, all the personal information and information related to treatment."

(Patient 5)

"I would say there is no problem of who can see it, but the problem of control...if I learn that some information was leaked, I would like to know the names or IDs of those doctors who accessed my information." (Patient 10)

4.6. Communication

4.6.1. Notification of risk

Another important topic discussed with physicians was their responsibility to share information with people at risk for certain diseases. None of the physicians perceived it as their obligation and brought a variety of reasons for their viewpoint as well as possible solutions for the issue. Two main questions discussed in this context were risk notification in case of sexually transmitted infections (STIs), HIV, and genetic risk. The most common suggested solution for this problem was encouraging a patient to share with their relatives, friends, or family members about the risk.

"I had a case when my patient was HIV positive. First, he refused to talk to his wife... I continued to encourage him, and finally he was able to talk to his wife, but imagine the enormous amount of time spent on it." (Physician 2)

"If they decided that they are not going to disclose...maybe they do not realize all the risks, because they are not informed of all the risks they carry... Maybe it is possible to talk to them and to explain all the consequences. Maybe this could change their decision, I hope so."
(Physician 3)

"I would never inform about it. If it is my patient, and she has an STI, then I see her as my patient, but her husband is not my patient. I would never take the phone and call him, even if it is HIV." (Physician 6)

4.6.2. Hiding the diagnosis

The most engaging and most discussed question was the issue of hiding the diagnosis from patients and the reasons for doing so. Diverse opinions were obtained regarding this topic from the participants.

The most common thought was that there is no right or wrong practice and the decision should be made on a case by case basis.

"It is not right [to hide the diagnosis], but on the other hand, it depends on the patient, their intellectual state. If they are not in an adequate state, it is preferable to tell [disclose the diagnosis] to other people, but if the patient is adequate, then, first of all, they should know the information." (Patient 2)

"I do not know, but if the patient would take it very bad and suffer, then it is right to keep it a secret. Maybe if you knew they would take it easy, information could be shared with them."

(Patient 5)

None of the participants thought that hiding the diagnosis is an absolutely right decision, but they provided justifications for that scenario.

"This is a very tricky question...but for me, it is right not to inform them, because if the person knows that they have one month to live, it becomes a countdown. If they do not know, they will live the last days of their life in joy. If the government could finance their treatment in another

country [not available in Armenia] then maybe you can inform the patient about the cancer diagnosis" (Patient 10)

Some physicians said that although it was probably not the right decision, they hid the diagnosis when asked by patients' relatives. All of them started their explanations with the statement that it is the patients' right to know his/her diagnosis, but brought a variety of arguments in favor of hiding the diagnosis. The argument most commonly mentioned by both physicians and patients was emotional burden for patients, which could worsen their mental and physical state. Other popular arguments were absence of certain treatment options in Armenia, not appropriate attitude towards the diagnosis of cancer, and not wanting friends or family members to suffer knowing about their incurable disease.

"I do not think it is right, but it depends on a patient...of course it is a difficult case for us, yes, for our [cultural]mindset it is a very difficult problem." (Physician 3)

"I think it is preferable to disclose all the results and diagnosis to the patient, but there are cases when patient's relatives know them better, their character and temperament...and knowing their diagnosis at this stage could threaten their life and worsen the process of treatment." (Physician 4)

"It depends on the patient. There are people who are lost, have no energy to fight the disease right after knowing the diagnosis, and there are people, who indeed want to fight their disease."

(Physician 6)

5. Discussion

This study was the first attempt to explore physicians' and patients' attitudes and experiences of medical confidentiality and privacy in Armenia. Our in-depth interiews revealed somewhat superficial understanding of the concept of medical confidentiality and privacy among patients.

Physicians had a better understanding of the importance and complexity of the discussed topics, yet many of their perceptions were similar to those of the patients.

Most of the participants were able to describe the confidentiality concept in their own words and

identify its essential components. Also, many physicians seemed to appreciate the importance of maintaining confidentiality for good treatment outcomes and better quality of life for patients. However, none of them had good knowledge of regulations in the field of medical confidentiality. These findings support the existing literature which shows that in many countries patients are aware of the meaning of medical confidentiality, yet their knowledge of laws and regulations is poor. Lack of knowledge of medical laws and regulations among physicians was also confirmed in the previous studies. ^{76–78}

The primary source of knowledge about medical confidentiality and privacy for physicians in Armenia was the course they took in the medical university. Most of them did not have any other training and have never been interested in further learning on this topic. In contrast to this, studies conducted in other countries have revealed multiple sources of training confidentiality and privacy concepts for physicians. The apparent gaps in the knowledge of confidentiality concepts and laws warrant some interventions in the area of medical education in Armenia. The effectiveness and need for postgraduate/residency courses of ethics in general and confidentiality, in particular, has been shown by multiple studies. To overcome the gap of knowledge of laws, many countries created guidelines for health care providers regarding the requirements of laws.

Most of the physicians and patients in our study believed that nurses and administrative staff should not have access to their medical records or it should be limited to the information essential for nurses to conduct their daily tasks. Armenian law does not regulate who can access

medical records but requires all medical staff to ensure the confidentiality of medical information available to them.⁵⁶ This practice is also accepted in other countries, such as the USA⁴⁹ or UK⁸² where the law refers to all healthcare providers and all of them are obligated to keep medical information confidential. The main argument against nurses having access to their records expressed by the participants was their concern that the nurse does not have appropriate knowledge and does not need to know the details. The physicians also stressed there is no need for nurses to obtain information they do not use in everyday practice and expressed a need to limit the number of people accessing detailed information, however they agreed that nurses should be informed about the conditions that impose certain risks for their health such as hepatitis B or HIV. Also, most of the participants had a negative attitude towards the nurse's presence during the physical exam unless doctors need their help. Studies exploring patients' perspectives of confidentiality reported a similar attitude towards administrative staff; however, most of the participants in these studies had a positive attitude towards nurses having access to their records. 35,83 It has also been reported that this acceptance might be guided by the belief that nurses are appropriately trained to keep the information confidential³⁵ which apparently was not true for Armenian participants. The study has shown that nurses' role is underestimated among both physicians and patients in Armenia, and it was guided by the belief that they do not need information as their responsibilities are limited. The finding is in line with another study conducted in Armenia, which reported that along with physicians and the public, even nurses did not perceive themselves as independent practitioners and did not think they play an important role in the healthcare system.⁸⁴

Compared to similar studies conducted in Greece and Italy, the awareness of electronic record systems was not very high in the present study. 42,85 The same studies have shown that the public

and physicians had a positive attitude towards the electronic system, whereas, in the current study, only physicians saw the integration of the system in the medical field as a beneficial reform.⁴² While in other countries, people seemed to be mostly concerned about the possibility of unauthorized access in Armenia, the possibility of hacking was the highest concern, albeit perceived as not very probable. 42 Patients in Armenia expressed a desire to control the access to their medical information, to be informed of the information in the system, and to see who opened their personal documents, which was also found in other studies, however it was not expressed by the majority of participants of previous studies. 86,87 As with paper-based records, most of the participants were open for their doctors to access their data and had some reservations regarding nurses, administrative staff, or other professionals from different departments not directly involved in care. This resembles the data obtained from the studies conducted in Greece and the UK, which explored patients' concerns and perceptions of electronic health systems, has also shown that patients expressed a willingness to limit access for nurses or administrative staff. 38,42 The perceptions of the safety and confidentiality of the electronic medical records were clearly influenced by the fact that the system has been implemented in Armenia only recently and has not been fully in force, and therefore patients had very vague and uninformed ideas about the system.

The participants' positive attitude towards students' presence during their consultation and physical exam was very similar to what was reported in previous studies conducted in different countries around the globe, ^{88–92} which probably means that this is an attitude shared across different cultures. Another study demonstrated that patients' positive attitude was mostly explained by their appreciation of the practical skills that students should get as part of their medical education, which was confirmed by this study findings as well. ⁹³

The "duty to warn" meaning physicians' obligation to warn patients' partners or relatives about their risk, is a challenging aspect of medical confidentiality and has been discussed in the literature from the moral and legal perspectives. The situations where the probability of risk is high, including the cases of infections and those with no certain likelihood, such as results of genetic testing were examined by several authors. 94,95 Both scenarios were discussed with the physicians in the current study, and it was found that physicians did not feel obliged to notify about the risk of infectious disease or about genetic predisposition to a certain disease. Instead, all the physicians suggested encouraging patients to notify their partners as the best way to inform people at risk. Similar findings have been reported in the study conducted among physicians providing STIs care in the US, where most physicians did not collect information about sexual partners and encouraged participants to talk to them and notify them about the risks. 96 Physicians' preference to keep medical confidentiality and not to disclose information about sexually transmitted diseases and HIV to the partners of their patients was also found in two different studies conducted in France. 97,98 The same pattern of not disclosing the risk was found in other studies showing that even health care professionals working in the genetic testing sphere are prone to not disclosing the genetic risk to relatives without patient consent. 99,100 In contrast to this, the study conducted by Daly et al. in Ireland has reported that most of the participants were for disclosing the information to people at risk. 101

The law in Armenia, however, requires medical centers and laboratories to refer HIV positive blood samples to the center of AIDS prevention for further investigation and patient management.¹⁰² Physicians included in the management and treatment of these patients are obliged to inform their patients to notify about the risks to appropriate people, but are not obligated to inform people at risk directly.¹⁰² According to Criminal Code, people who know

about their disease and fail to notify others are punished by imprisonment from 3 to 8 years in case of not informing about HIV, and by fines or imprisonment of 2 years, in case of STIs.⁵⁸ There is no standardized approach to risk notification in the US, where requirements vary from state to state. In some states, physicians are required to report contacts' names to the state health agency, in other states, it is up to physicians to decide if they want to report the names to agency or talk to contacts directly, whereas in some states, reporting to a state agency is optional. One of the states requiring doctors to report to the health agency also defined the penalties for doctors who failed to report HIV cases appropriately. 104 According to the European Center for Disease Prevention and Control (CDC), the laws vary in the European countries, where notification is mandatory either for doctors, either for patients or both of them, and there are countries where it is not compulsory for any of them. Out of 23 European Union (EU) countries and the UK, only in 9, healthcare providers are obliged to notify partners, and in 4 countries, patients are obliged to notify their partners of risk. 105 Only in 9 countries the law prosecutes people failing to notify their partners about the infection, however, the criminalization is based on the different laws available in these countries. 105 In Armenia, compared to this practice, physicians do not have any direct obligation to notify partners, and there are no penalties for them if they fail to inform partners. Interestingly, none of the participants referred to specific HIV law existing in Armenia and did not mention they will refer their patients to the HIV center, but their thoughts were very similar to the law, not feeling any direct responsibility to notify people at risk. Another aspect of confidentiality is hiding the diagnosis from the patient. World Medical

Another aspect of confidentiality is hiding the diagnosis from the patient. World Medical Association's declares that every patient has a right to make a free decision regarding her/his diagnosis and treatment. On the other hand, the USA's HIPPA act states that personal medical information can be shared with the third party in case of getting patient's permission, unless

he/she is unconscious, deceased, or with an effort of disaster relief. 107 Notably, the law 57 in Armenia also states that it is within every patient's right to get appropriate information about their diagnosis, and to make informed decision about their treatment, and that medical information can be shared with family members, only in cases when patient is unconscious. It has been postulated that hiding the diagnosis was an accepted approach in the last century, while openly discussing the diagnosis is more common at the present. 46 Also, disclosing the diagnosis is quite conventional in Western culture as opposed to other cultures. 46,108 A large study conducted among 800 participants in the United States showed that compared to Korean and Mexican Americans, European and African Americans believed it is right to inform the patient about their diagnosis. 109 Our study revealed that making such decisions is challenging for healthcare providers in Armenia as well, with almost all the study participants missing a definite approach to the issue and good understanding of the corresponding legal basis. Similar patterns have been observed among patients. A study comparing perspectives of Japanese and American physicians and patients revealed that the majority of participants from the USA agreed that patients should know about the diagnosis, whereas only 42% of patients and even fewer physicians from Japan preferred the patient to be informed about the diagnosis of cancer. 110 A qualitative study conducted among Iranian patients and physicians has shown that most of the physicians believed that the information should not be delivered directly; instead, patients should be informed about having some health issues. However, the authors reported that patients' preferred to be informed and engaged in the process of treatment. 111 The results of the present study are somewhat comparable to the aforementioned study in Iran, as most patients expressed willingness to know the diagnosis. Yet, the unique finding of our study is the importance that both providers and patients attributed to the context of disclosing the diagnosis

in each particular case. Attitude towards cancer and emotional burden imposed by the diagnosis were mentioned as factors most influencing the decision to disclose the diagnosis to the patient by physicians and were deemed valid by patients as well. Notably, several participants from both groups shared an idea that the lack of treatment options in Armenia and financial difficulties to get treatment in other countries might justify withholding the cancer diagnosis from certain patients.

Overall, misunderstandings and poor awareness about how medical information is being kept and communicated found throughout different groups of participants and various confidentiality domains indicate that both patients and physicians in Armenia should be better informed and prepared to deal with potential issues in case of confidentiality breaches. Implementation of a medical agreement or contract before the hospitalization could address the issue and make both sides aware of rights and responsibilities.

5.1 Study strengths and limitations

No studies have previously explored the perceptions and experiences of medical confidentiality in Armenia, and therefore our qualitative exploration could serve as an important evidence base for future researchers as well as policy-makers and administrators in the healthcare field. The study provided valuable insights into general perceptions of confidentiality and privacy among Armenian physicians and patients and highlighted the most important confidentiality issues and concerns which can be further explored through qualitative or quantitative investigations.

One of the strengths of the study is the triangulation of data sources as both physicians and patients were interviewed. This helped not only to validate and compare the experiences but also to identify the differences in expectations and perceptions of confidentiality. The detailed and comprehensive interview guide used in this study allowed exploring the breadth of issues related

to medical confidentiality and understand the full range of perceptions and experiences. The maintenance of the research diary by the student investigator ensured the reflexivity and trustworthiness of the study

The following study limitations should be highlighted. First of all, the online mode of interviews restricted the participants' recruitment opportunities, particularly among those from the marzes and older age groups, which could have affected the transferability of the study results.

5.2 Recommendations

The following recommendations are proposed based on the analysis of the study findings:

- 1. Implementation of a medical agreement or contract before the hospitalization could address the issue and make both sides aware of rights and responsibilities. The Ministry of Health (MoH) along with the heads of hospitals, should initiate and pilot the proposed mechanism to evaluate the gaps and barriers and fully implement it.
- 2. There is a need to update the curriculum and integrate the ethics/confidentiality course into residency program. The Ministry of Education, Science, Culture, and Sport (MoESCS) with medical universities of Armenia are the central responsible bodies to develop and update the suggested courses.
- 3. The lack of knowledge among doctors indicates that most probably there is a gap in nurses knowledge. Yet there is a need to explore it, our recommendation is to develop a course/training regarding confidentiality/ethics and integrate it into nurses' educational curriculum. The recommendation refers to MoH and the MoEDCS. The stakeholders and responsible bodies for successful implementation are the institutions providing nursing education in Armenia.
- 4. We recommend creating guidelines for healthcare providers. Considering the complexity of all laws and penalties, all the stakeholders including MoH, medical law department of medical

university, lawyers working in medical spheres, are recommended to develop a comprehensive guide about confidentiality and privacy, providing information about the concept and local laws and regulations.

- 5. In order to overcome the barriers of informing patients about their diagnosis, there is a need to create a committee in the oncological hospital and departments of oncology. The committee with experienced physicians and psychologists would help physicians to learn effective methods to provide information in an appropriate manner. Besides, the role of a committee could be expanded to have a discussion session with the public to increase awareness of cancer, its treatment and to overcome stigmatization of cancer.
- 6. The AIDS prevention center is the responsible body in Armenia for HIV testing, screening and treatment. We recommend the development of training for physicians working in the AIDS prevention center to improve the effectiveness of contact tracing and partner notification. We suggest reviewing the law to make it compulsory for physicians and create resources for them to get into active contact tracing. The latter recommendation refers to the MoH.
- 7. We recommend the development of training programs for healthcare professionals about electronic systems section discussing confidentiality of information. Simultaneously, there is a need to spread awareness regarding this system and its confidentiality among the general public. The recommendations refer to the MoH and e-Health operator in Armenia.
- 9. There is a need to conduct more studies to understand the main barriers to appropriate practice of confidentiality in Armenian hospitals and other healthcare settings, including policlinics.

 Additionally, there is a need to explore this topic among nurses and administrative staff who were not included in our study.

References

- 1. Department of Health. Confidentiality: NHS Code of Practice. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/200146/Confidentiality_-_NHS_Code_of_Practice.pdf. Published 2003. Accessed June 17, 2021.
- 2. Hippocrates. Greek Medicine The Hippocratic Oath. U.S. National Library of Medicine. https://www.nlm.nih.gov/hmd/greek/greek_oath.html. Published 2012. Accessed November 28, 2020.
- 3. Health Insurance Portability and Accountability Act of 1996 (HIPAA). Centers for Disease Control and Prevention website. https://www.cdc.gov/phlp/publications/topic/hipaa.html. Accessed June 17, 2021.
- 4. Valentine N, de Silva A, Kawabata K, et al. Health system responsiveness: concepts, domains, and operationalization. In: *Health System Performance Assessment*.; 2003:573-680. https://www.researchgate.net/publication/242475744_Health_System_Responsiveness_Concepts_Domains_and_Operationalization/citations. Accessed June 17, 2021.
- 5. World Health Organization. Everybody's business -- strengthening health systems to improve health outcomes: WHO's framework for action. https://apps.who.int/iris/handle/10665/43918. Published 2007. Accessed June 17, 2021.
- 6. Moskop JC, Marco CA, Larkin GL, Geiderman JM, Derse AR. From Hippocrates to HIPAA: Privacy and confidentiality in Emergency Medicine Part I: Conceptual, moral, and legal foundations. *Ann Emerg Med.* 2005;45(1):53-59. doi:10.1016/j.annemergmed.2004.08.008
- 7. Resnik DB. Protecting Privacy and Confidentiality in Environmental Health Research. *Ethics Biol Eng Med*. 2010;1(4):285. /pmc/articles/PMC3633517/. Accessed March 26, 2021.
- 8. Code of Medical Ethics: Privacy, confidentiality & medical records. American Medical Association. https://www.ama-assn.org/delivering-care/ethics/code-medical-ethics-privacy-confidentiality-medical-records. Accessed June 17, 2021.
- 9. U.S. Department of Health and Human Services. Recommendations on Privacy and Confidentiality, 2006-2008. https://www.cdc.gov/nchs/data/ncvhs/ncvhs06-08.pdf. Published 2009. Accessed June 17, 2021.
- 10. Lin YK, Lin CJ. Factors predicting patients' perception of privacy and satisfaction for emergency care. *Emerg Med J.* 2011;28(7):604-608. doi:10.1136/emj.2010.093807
- 11. Hartigan L, Cussen L, Meaney S, O'Donoghue K. Patients' perception of privacy and confidentiality in the emergency department of a busy obstetric unit. *BMC Health Serv Res.* 2018;18(1):978. doi:10.1186/s12913-018-3782-6
- 12. Nass SJ, Levit LA, Gostin LO, Institute of Medicine (US) Committee on Health Research and the Privacy of Health Information: The HIPAA Privacy Rule E. Beyond the HIPAA Privacy Rule: Enhancing Privacy, Improving Health Through Research. National

- Academies Press (US); 2009. https://www.ncbi.nlm.nih.gov/books/NBK9579/. Accessed June 17, 2021.
- 13. Andrasfay T. Reproductive Health-Care Utilization of Young Adults Insured as Dependents. *J Adolesc Heal*. 2018;62(5):570-576. doi:10.1016/j.jadohealth.2017.11.295
- 14. Garg A, Panda P, Neudecker M, Lee S. Barriers to the access and utilization of healthcare for trafficked youth: A systematic review. *Child Abus Negl.* 2020;100:104137. doi:10.1016/j.chiabu.2019.104137
- 15. Guille C, Speller H, Laff R, Epperson CN, Sen S. Utilization and Barriers to Mental Health Services Among Depressed Medical Interns: A Prospective Multisite Study. *J Grad Med Educ*. 2010;2(2):210-214. doi:10.4300/jgme-d-09-00086.1
- 16. Pellowski JA. Barriers to care for rural people living with HIV: A review of domestic research and health care models. *J Assoc Nurses AIDS Care*. 2013;24(5):422-437. doi:10.1016/j.jana.2012.08.007
- 17. Beltran-Aroca CM, Girela-Lopez E, Collazo-Chao E, Montero-Pérez-Barquero M, Muñoz-Villanueva MC. Confidentiality breaches in clinical practice: what happens in hospitals? *BMC Med Ethics*. 2016;17(1):52. doi:10.1186/s12910-016-0136-y
- 18. The Most Common HIPAA Violations You Should Be Aware Of. HIPPA Journal. https://www.hipaajournal.com/common-hipaa-violations/. Published 2019. Accessed March 31, 2021.
- 19. Health insurance portability and accountability act of 1996. OFFICE OF THE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION. https://aspe.hhs.gov/report/health-insurance-portability-and-accountability-act-1996. Accessed June 18, 2021.
- 20. The HIPAA Privacy Rule. U.S. Department of Health & Human Services. https://www.hhs.gov/hipaa/for-professionals/privacy/index.html. Published 2002. Accessed June 18, 2021.
- 21. The Security Rule. U.S. Department of Health & Human Services. https://www.hhs.gov/hipaa/for-professionals/security/index.html. Published 2017. Accessed April 4, 2021.
- 22. HITECH Act Enforcement Interim Final Rule. U.S. Department of Health and Human Services. https://www.hhs.gov/hipaa/for-professionals/special-topics/hitech-act-enforcement-interim-final-rule/index.html. Published 2017. Accessed April 4, 2021.
- 23. Omnibus HIPAA Rulemaking. U.S. Department of Health & Human Services. https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/combined-regulation-text/omnibus-hipaa-rulemaking/index.html. Published 2019. Accessed April 4, 2021.
- 24. The Personal Information Protection and Electronic Documents Act (PIPEDA). Office of the Privacy Commissioner of Canada. https://www.priv.gc.ca/en/privacy-topics/privacy-laws-in-canada/the-personal-information-protection-and-electronic-documents-act-pipeda/. Published 2021. Accessed April 4, 2021.

- 25. The Privacy Act. Office of the Australian Information Commissioner. https://www.oaic.gov.au/privacy/the-privacy-act/. Published 1988. Accessed April 4, 2021.
- 26. History of the Privacy Act. Office of the Australian Information Commissioner. https://www.oaic.gov.au/privacy/the-privacy-act/history-of-the-privacy-act/. Accessed April 4, 2021.
- 27. HIPAA Compliance Guide. The HIPAA Guide. https://www.hipaaguide.net/hipaacompliance-guide/. Accessed March 31, 2021.
- 28. The Royal Australian College of General Practicioners. Privacy and managing health information in general practice. https://www.racgp.org.au/getattachment/f15c7f47-9abb-48e7-9d31-082e7dd517fe/Privacy-and-managing-health-information-in-general-practice.aspx. Published 2017. Accessed June 18, 2021.
- 29. Infection Control in Healthcare Personnel. Centers for Disease Control and Prevention. https://www.cdc.gov/infectioncontrol/guidelines/healthcare-personnel/index.html. Published 2019. Accessed March 31, 2021.
- 30. European Network of Cancer Registries. Guidelines on Confidentiality and ethics for population-based cancer registration and linked activities in Europe. 2011;(May). https://www.encr.eu/sites/default/files/pdf/ENCR_Eurocouse_GuidelinesConfidentialityEthics.pdf. Accessed June 14, 2021.
- 31. European Patients Forum. The new EU Regulation on the protection of personal data: what does it mean for patients? :23. http://www.eu-patient.eu/globalassets/policy/data-protection/data-protection-guide-for-patients-organisations.pdf.
- 32. Parrott R, Burgoon JK, Burgoon M, LePoire BA. Privacy between physicians and patients: More than a matter of confidentiality. *Soc Sci Med.* 1989;29(12):1381-1385. doi:10.1016/0277-9536(89)90239-6
- 33. Nápoles-Springer AM, Santoyo J, Houston K, Pérez-Stable EJ, Stewart AL. Patients' perceptions of cultural factors affecting the quality of their medical encounters. *Heal Expect*. 2005;8(1):4-17. doi:10.1111/j.1369-7625.2004.00298.x
- 34. Agaku IT, Adisa AO, Ayo-Yusuf OA, Connolly GN. Concern about security and privacy, and perceived control over collection and use of health information are related to withholding of health information from healthcare providers. *J Am Med Informatics Assoc.* 2014;21(2):374-378. doi:10.1136/amiajnl-2013-002079
- 35. Carman D, Britten N. Confidentiality of medical records: The patient's perspective. *Br J Gen Pract*. 1995;45(398):485-488. /pmc/articles/PMC1239373/?report=abstract. Accessed November 30, 2020.
- 36. Asai A, Ohnishi M, Nishigaki E, Sekimoto M, Fukuhara S, Fukui T. Attitudes of the Japanese public and doctors towards use of archivedinformation and samples without informed consent: Preliminary findings basedonfocus group interviews. *BMC Med Ethics*. 2002;3:1-10. doi:10.1186/1472-6939-3-1
- 37. Palojoki S, Pajunen T, Saranto K, Lehtonen L. Electronic health record-related safety

- concerns: A cross-sectional survey of electronic health record users. *JMIR Med Informatics*. 2016;4(2). doi:10.2196/medinform.5238
- 38. Papoutsi C, Reed JE, Marston C, Lewis R, Majeed A, Bell D. Patient and public views about the security and privacy of Electronic Health Records (EHRs) in the UK: results from a mixed methods study. *BMC Med Inform Decis Mak*. 2015;15(1):86. doi:10.1186/s12911-015-0202-2
- 39. Gaylin DS, Moiduddin A, Mohamoud S, Lundeen K, Kelly JA. Public attitudes about health information technology, and its relationship to health care quality, costs, and privacy. *Health Serv Res.* 2011;46(3):920-938. doi:10.1111/j.1475-6773.2010.01233.x
- 40. Thit WM, Kaewkungwal J, Soonthornworasiri N, et al. Electronic Medical Records in Myanmar: User Perceptions At Marie St. *Southeast Asian J Trop Med Public Health*. 2016;47(4):799-809.
- 41. Chronaki C, Kontoyiannis V, Mytaras M, et al. Evaluation of shared EHR services in primary healthcare centers and their rural community offices: the twister story. *Conf Proc IEEE Eng Med Biol Soc.* 2007:6422-6425.
- 42. Entzeridou E, Markopoulou E, Mollaki V. Public and physician's expectations and ethical concerns about electronic health record: Benefits outweigh risks except for information security. *Int J Med Inform.* 2018;110:98-107. doi:10.1016/j.ijmedinf.2017.12.004
- 43. Karasneh R, Al-Mistarehi AH, Al-Azzam S, et al. Physicians' knowledge, perceptions, and attitudes related to patient confidentiality and data sharing. *Int J Gen Med*. 2021;14:721-731. doi:10.2147/IJGM.S301800
- 44. Riley M, Ahmed S, Reed BD, Quint EH. Physician Knowledge and Attitudes around Confidential Care for Minor Patients. *J Pediatr Adolesc Gynecol*. 2015;28(4):234-239. doi:10.1016/j.jpag.2014.08.008
- 45. Elger BS. Violations of medical confidentiality: Opinions of primary care physicians. *Br J Gen Pract*. 2009;59(567):754-760. doi:10.3399/bjgp09X472647
- 46. Gold M. Is honesty always the best policy? Ethical aspects of truth telling. *Intern Med J.* 2004;34(9-10):578-580. doi:10.1111/j.1445-5994.2004.00673.x
- 47. De Pentheny O'Kelly C, Urch C, Brown EA. The impact of culture and religion on truth telling at the end of life. *Nephrol Dial Transplant*. 2011;26(12):3838-3842. doi:10.1093/ndt/gfr630
- 48. Montazeri A, Tavoli A, Mohagheghi MA, Roshan R, Tavoli Z. Disclosure of cancer diagnosis and quality of life in cancer patients: Should it be the same everywhere? *BMC Cancer*. 2009;9:39. doi:10.1186/1471-2407-9-39
- 49. Summary of the HIPAA Privacy Rule. U.S. Department of Health & Human Services. https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html. Accessed March 30, 2021.
- 50. Personal Data Protection Act. Laws and Regulations Database of The Republic of China. https://law.moj.gov.tw/ENG/LawClass/LawAll.aspx?pcode=I0050021. Accessed April 6,

2021.

- 51. General Medical Council. Good medical practice. https://www.gmc-uk.org/-/media/documents/good-medical-practice---english-20200128_pdf-51527435.pdf?la=en&hash=DA1263358CCA88F298785FE2BD7610EB4EE9A530. Published 2015. Accessed June 18, 2021.
- 52. Parsapoor A, Bagheri A, Larijani B. Patient's Rights Charter in Iran. *Acta Med Iran*. 2014;52(1):24-28. https://acta.tums.ac.ir/index.php/acta/article/view/4746. Accessed April 6, 2021.
- 53. Godard B, Hurlimann T, Letendre M, Égalité N. Guidelines for disclosing genetic information to family members: From development to use. *Fam Cancer*. 2006;5(1):103-116. doi:10.1007/s10689-005-2581-5
- 54. Dheensa S, Fenwick A, Shkedi-Rafid S, Crawford G, Lucassen A. Health-care professionals' responsibility to patients' relatives in genetic medicine: A systematic review and synthesis of empirical research. *Genet Med.* 2016;18(4):290-301. doi:10.1038/gim.2015.72
- 55. Հ ԱՅ ԱՍՏ ԱՆԻ Հ ԱՆՐԱՊԵՏ ՈՒԹՅ Ա ՕՐԵՆՔԸ ԱՆՁՆԱԿԱՆ Տ ՎՅ ԱԼ ՆԵՐԻ ՊԱՇՏ ՊԱՆՈՒԹՅ ԱՆ ՄԱՍԻՆ. Armenian Legal Information System (ARLIS). https://www.arlis.am/documentview.aspx?docid=98338. Published 2015. Accessed March 22, 2021.
- 56. Հ ԱՅ ԱՍՏ ԱՆԻ Հ ԱՆՐ ԱՊԵՏ ՈՒԹՅ ԱՆ ՕՐԵՆՔԸ ԲՆԱԿՉ ՈՒԹՅ ԱՆ ԲԺՇԿԱԿԱՆ ՕԳՆՈՒԹՅ ԱՆ ԵՎ ՍՊԱՍԱՐԿՄԱՆ ՄԱՍԻՆ. Armenian Legal Information System (ARLIS). https://www.arlis.am/documentView.aspx?docID=104958. Published 1996. Accessed March 22, 2021.
- 57. Հ ԱՅ ԱՍՏ ԱՆԻ Հ ԱՆՐԱՊԵՏ ՈՒԹՅ ԱՆ ՕՐԵՆՔԸ «ԲՆԱԿՉ ՈՒԹՅ ԱՆ ԲԺՇԿԱԿԱՆ ՕԳՆՈՒԹՅ ԱՆ ԵՎ ՍՊԱՍԱՐԿՄԱՆ ՄԱՍԻՆ» ՕՐԵՆՔՈՒՄ ՓՈՓՈԽՈՒԹՅ ՈՒՆ ԿԱՏ ԱՐԵԼ ՈՒ ՄԱՍԻՆ. Armenian Legal Information System (ARLIS). https://www.arlis.am/documentView.aspx?docid=142602. Published 2020. Accessed March 22, 2021.
- 58. Հ ԱՅ ԱՍՏ ԱՆԻ Հ ԱՆՐԱՊԵՏ ՈՒԹՅ ԱՆ ՔՐԵԱԿԱՆ ՕՐԵՆՍԳԻՐՔ. Armenian Legal Information System (ARLIS). https://www.arlis.am/documentview.aspx?docid=69646. Published 2003. Accessed March 22, 2021.
- 59. Harutyunyan T, Demirchyan A, Thompson ME, Petrosyan V. Patient satisfaction with primary care in Armenia: Good rating of bad services? *Heal Serv Manag Res*. 2010;23(1):12-17. doi:10.1258/hsmr.2009.009012
- 60. Grigoryan R. Investigating Reasons for High Patient Satisfaction Given Low Utilization of Health Care Services, Armenia, 2007: Qualitative Research. [Master's thesis]. American University of Armenia. 2007. https://law.aua.am/chsr/PDF/MPH/2007/GrigoryanRuzanna.pdf. Accessed November 29, 2020.

- 61. Hayrumyan V, Grigoryan Z, Sargsyan Z, Sahakyan S, Aslanyan L, Harutyunyan A. Barriers to utilization of adolescent friendly health services in primary healthcare facilities in Armenia: a qualitative study. *Int J Public Health*. 2020;65(8):1247-1255. doi:10.1007/s00038-020-01499-9
- 62. Truzyan N, Musheghyan L, Grigoryan Z, Aslanyan L, Khachadourian V, Petrosyan V. Institutionalization of Patient-Centered Tuberculosis (TB) Treatment in Armenia Result Area 1: Strategy for improved quality and safety of TB service delivery at PHC level endorsed by stakeholders. https://chsr.aua.am/files/2020/10/Institutionalization-of-Patient-Centered-Tuberculosis-TB-Treatment-in-Armenia-2019.pdf. Published 2019. Accessed June 18, 2021.
- 63. Truzyan N, Musheghyan L, Grigoryan Z, Petrosyan V HA. In-patient Tuberculosis (TB) Treatment in Armenia: Establishment of a Continuous Quality Improvement System A Needs Assessment. https://chsr.aua.am/files/2016/02/NTCC-Inpatient-Services-Assessment-Report_Dec-2016-reporting.pdf. Published 2016. Accessed June 18, 2021.
- 64. Carter N, Bryant-Lukosius D, Dicenso A, Blythe J, Neville AJ. The use of triangulation in qualitative research. *Oncol Nurs Forum*. 2014;41(5):545-547. doi:10.1188/14.ONF.545-547
- 65. Pope C, Mays N. Qualitative Research: Reaching The parts other methods cannot reach: An introduction to qualitative methods in health and health services research. *BMJ*. 1995;311(6996):42. doi:10.1136/bmj.311.6996.42
- 66. Moser A, Korstjens I. Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis. *Eur J Gen Pract*. 2018;24(1):9-18. doi:10.1080/13814788.2017.1375091
- 67. Berger R. Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qual Res.* 2015;15(2):219-234. doi:10.1177/1468794112468475
- 68. Advice for the Public Sector. World Health Organization. https://www.who.int/emergencies/diseases/novel-coronavirus-2019/advice-for-public. Accessed November 28, 2020.
- 69. Phillippi J, Lauderdale J. A Guide to Field Notes for Qualitative Research: Context and Conversation. *Qual Health Res.* 2018;28(3):381-388. doi:10.1177/1049732317697102
- 70. Bradley EH, Curry LA, Devers KJ. Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. *Health Serv Res*. 2007;42(4):1758-1772. doi:10.1111/j.1475-6773.2006.00684.x
- 71. van Nes F, Abma T, Jonsson H, Deeg D. Language differences in qualitative research: Is meaning lost in translation? *Eur J Ageing*. 2010;7(4):313-316. doi:10.1007/s10433-010-0168-y
- 72. Saldaña J. *The Coding Manual for Qualitative Researchers*. 3rd ed. SAGE Publications Ltd; 2015. https://us.sagepub.com/en-us/nam/the-coding-manual-for-qualitative-researchers/book243616. Accessed June 12, 2021.
- 73. Wolf ZR. Exploring the audit trail for qualitative investigations. *Nurse Educ*.

- 2003;28(4):175-178. doi:10.1097/00006223-200307000-00008
- 74. Schmid D, Appelbaum PS, Roth LH, Lidz C. Confidentiality in psychiatry: A study of the patient's view. *Educ Heal*. 21(2):69. doi:10.1176/ps.34.4.353
- 75. Mohammadi M, Larijani B, Razavi HE, et al. Do patients know that physicians should be confidential? a study on patients' awareness of privacy and confidentiality. *J Med Ethics Hist Med*. 2018;11:1. /pmc/articles/PMC6150920/. Accessed June 5, 2021.
- 76. Singh S, Sharma P, Bhandari B, Kaur R. Knowledge, awareness and practice of ethics among doctors in tertiary care hospital. *Indian J Pharmacol*. 2016;48(7):S89-S93. doi:10.4103/0253-7613.193320
- 77. Shrier I, Green S, Solin J, et al. Knowledge of and attitude toward patient confidentiality within three family medicine teaching units. *Acad Med.* 1998;73(6):710-712. doi:10.1097/00001888-199806000-00021
- 78. Hariharan S, Jonnalagadda R, Walrond E, Moseley H. Knowledge, attitudes and practice of healthcare ethics and law among doctors and nurses in Barbados. *BMC Med Ethics*. 2006;7:7. doi:10.1186/1472-6939-7-7
- 79. Roberts LW, Warner TD, Hammond KAG, Geppert CMA, Heinrich T. Becoming a good doctor: Perceived need for ethics training focused on practical and professional development topics. *Acad Psychiatry*. 2005;29(3):301-309. doi:10.1176/appi.ap.29.3.301
- 80. Vertrees SM, Shuman AG, Fins JJ. Learning by doing: Effectively incorporating ethics education into residency training. *J Gen Intern Med*. 2013;28(4):578-582. doi:10.1007/s11606-012-2277-0
- 81. Ramalingam S, Bhuvaneswari S, Sankaran R. Ethics workshops- Are they effective in improving the competencies of faculty and postgraduates? *J Clin Diagnostic Res*. 2014;8(7):XC01. doi:10.7860/JCDR/2014/8825.4561
- 82. Nursing & Midwifery Council. The Code: Professional standards of practice and behaviour for nurses, midwives and nursing associates. https://www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/nmc-code.pdf. Published 2015. Accessed June 10, 2021.
- 83. Shaw M, Tomlinson D, Higginson I. Survey of HIV patients' views on confidentiality and non-discrimination policies in general practice. *Br Med J*. 1996;312(7044):1463-1464. doi:10.1136/bmj.312.7044.1463
- 84. Sahakyan S, Akopyan K, Petrosyan V. Nurses role, importance and status in Armenia: A mixed method study. *J Nurs Manag.* 2020;28(7):1561-1569. doi:10.1111/jonm.13109
- 85. Comandé G, Nocco L, Peigné V. An empirical study of healthcare providers and patients' perceptions of electronic health records. *Comput Biol Med*. 2015;59:194-201. doi:10.1016/j.compbiomed.2014.01.011
- 86. Campos-Castillo C, Anthony DL. The double-edged sword of electronic health records: Implications for patient disclosure. *J Am Med Informatics Assoc*. 2014;22(e1):e130-e140. doi:10.1136/amiajnl-2014-002804

- 87. Schwartz PH, Caine K, Alpert SA, Meslin EM, Carroll AE, Tierney WM. Patient Preferences in Controlling Access to Their Electronic Health Records: a Prospective Cohort Study in Primary Care. *J Gen Intern Med*. 2015;30(1):25-30. doi:10.1007/s11606-014-3054-z
- 88. Prislin MD, Morrison E, Giglio M, Truong P, Radecki S. Patients' perceptions of medical students in a longitudinal family medicine clerkship. *Fam Med.* 2001;33(3):187-191. https://escholarship.org/uc/item/3tf298dn. Accessed June 13, 2021.
- 89. Passaperuma K, Higgins J, Power S, Taylor T. Do patients' comfort levels and attitudes regarding medical student involvement vary across specialties? *Med Teach*. 2008;30(1):48-54. doi:10.1080/01421590701753443
- 90. Choudhury TR, Moosa AA, Cushing A, Bestwick J. Patients' attitudes towards the presence of medical students during consultations. *Med Teach*. 2006;28(7). doi:10.1080/01421590600834336
- 91. Abdulghani HM, Al-Rukban MO, Ahmad SS. Patient attitudes towards medical students in Riyadh, Saudi Arabia. *Educ Heal*. 2008;21(2):69. https://pubmed.ncbi.nlm.nih.gov/19039740/. Accessed June 9, 2021.
- 92. Sayed-Hassan RM, Bashour HN, Koudsi AY. Patient attitudes towards medical students at Damascus University teaching hospitals. *BMC Med Educ*. 2012;12(1):13. doi:10.1186/1472-6920-12-13
- 93. Vaughn JL, Rickborn LR, Davis JA. Patients' Attitudes Toward Medical Student Participation Across Specialties: A Systematic Review. *Teach Learn Med*. 2015;27(3):245-253. doi:10.1080/10401334.2015.1044750
- 94. Offit K, Groeger E, Turner S, Wadsworth EA, Weiser MA. The "duty to warn" a patient's family members about hereditary disease risks. *J Am Med Assoc*. 2004;292(12):1469-1473. doi:10.1001/jama.292.12.1469
- 95. Lucassen A, Gilbar R. Alerting relatives about heritable risks: the limits of confidentiality. *BMJ*. 2018;361:k1409. doi:10.1136/bmj.k1409
- 96. St. Lawrence JS, Montaño DE, Kasprzyk D, Phillips WR, Armstrong K, Leichliter JS. STD screening, testing, case reporting, and clinical and partner notification practices: A national survey of US physicians. *Am J Public Health*. 2002;92(11):1784-1788. doi:10.2105/AJPH.92.11.1784
- 97. Moatti JP, Souville M, Obadia Y, et al. Ethical dilemmas in care for HIV infection among French general practitioners. *Health Policy (New York)*. 1995;31(3):197-210. doi:10.1016/0168-8510(94)00698-E
- 98. Guedj M, Muñoz Sastre MT, Mullet E, Sorum PC. Do French lay people and health professionals find it acceptable to breach confidentiality to protect a patient's wife from a sexually transmitted disease? *J Med Ethics*. 2006;32(7):414-419. doi:10.1136/jme.2005.012195
- 99. Perry TJ, Patton SI, Farmer MB, Hurst CB, McGwin G, Robin NH. The duty to warn atrisk relatives—The experience of genetic counselors and medical geneticists. *Am J Med*

- Genet Part A. 2020;182(2):314-321. doi:10.1002/ajmg.a.61425
- 100. Dheensa S, Fenwick A, Lucassen A. Approaching confidentiality at a familial level in genomic medicine: A focus group study with healthcare professionals. *BMJ Open*. 2017;7(2). doi:10.1136/bmjopen-2016-012443
- 101. Daly M, Hevey D, Regan C. The role of perceived risk in general practitioners' decisions to inform partners of HIV-infected patients. *Br J Health Psychol*. 2011;16(2):273-287. doi:10.1348/135910710X498714
- 102. Հ ԱՅ ԱՍՏ ԱՆԻ Հ ԱՆՐԱՊԵՏ ՈՒԹՅ ԱՆ ՕՐԵՆՔԸ ՄԱՐԴՈՒ ԻՄՈՒՆԱՅ ԻՆ ԱՆԲԱՎԱՐԱՐՈՒԹՅ ԱՆ ՎԻՐՈՒՍԻՑ ԱՌԱՋԱՑ ԱԾ Հ ԻՎԱՆԴՈՒԹՅ ԱՆ ԿԱՆԽԱՐԳԵԼ ՄԱՆ ՄԱՍԻՆ. Armenian Legal Information System (ARLIS). https://www.arlis.am/DocumentView.aspx?DocID=78616. Published 1997. Accessed June 13, 2021.
- 103. Lin L, Liang BA. HIV and health law: Striking the balance between legal mandates and medical ethics. *Virtual Mentor*. 2005;7(10):687-692. doi:10.1001/virtualmentor.2005.7.10.hlaw1-0510
- 104. HIV Reporting and Partner Notification Questions and Answers. New York State Department of Health.

 https://www.health.ny.gov/diseases/aids/providers/regulations/reporting_and_notification/question_answer.htm#fiftyfive. Accessed June 13, 2021.
- 105. Low N, Martin-Hilber A, Röllin A, et al. Public health benefits of partner notification for sexually transmitted infections and HIV. European Centre for Disease Prevention and Control. https://www.ecdc.europa.eu/sites/default/files/media/en/publications/Publications/Partner-notification-for-HIV-STI-June-2013.pdf. Published 2013.
- 106. WMA DECLARATION OF LISBON ON THE RIGHTS OF THE PATIENT. World Medical Association. https://www.wma.net/policies-post/wma-declaration-of-lisbon-on-the-rights-of-the-patient/. Published 2005.
- 107. 45 CFR § 164.508 Uses and disclosures for which an authorization is required. Cornell Law School. https://www.law.cornell.edu/cfr/text/45/164.510. Published 2019. Accessed June 16, 2021.
- 108. Kazdaglis GA, Arnaoutoglou C, Karypidis D, Memekidou G, Spanos G, Papadopoulos O. Disclosing the truth to terminal cancer patients: a discussion of ethical and cultural issues. *East Mediterr Heal J.* 2010;16(4):442-447. doi:10.26719/2010.16.4.442
- 109. Blackhall LJ, Frank G, Murphy ST, Michel V, Palmer JM, Azen SP. Ethnicity and attitudes towards life sustaining technology. *Soc Sci Med.* 1999;48(12):1779-1789. doi:10.1016/S0277-9536(99)00077-5
- 110. Ruhnke GW, Wilson SR, Akamatsu T, et al. Ethical decision making and patient autonomy: A comparison of physicians and patients in Japan and the United States. *Chest*. 2000;118(4):1172-1182. doi:10.1378/chest.118.4.1172
- 111. Beyraghi N, Mottaghipour Y, Mehraban A, Eslamian E, Esfahani F. Disclosure of cancer

information in Iran: A perspective of patients, family members, and health professionals. *Iran J Cancer Prev.* 2011;4(3):131-135. /pmc/articles/PMC4551296/. Accessed June 7, 2021.

Appendix 1

In-depth interview guide for patients

Start time of interview...

Ice-breaker questions.

Thank you for agreeing to participate in this study.

Let's start our interview by talking about how you understand medical confidentiality.

Knowledge about medical confidentiality and its role in healthcare system

- 1. Please describe what do you think medical confidentiality means? *Probe: Could you describe any real/possible medical confidentiality issues that you are aware of? Do you think it is a moral or legal obligation*? Do you remember if you thought about this when you were hospitalized? Have you had any issues related to this when you were hospitalized? What were the issues? How were they solved?
- 2. What do you know about laws and regulations ensuring medical confidentiality? *Probe:* What is your opinion about the protection of your personal information in Armenia?
- 3. Why do you think medical confidentiality is important?

Now let's discuss what medical information is and how it should be kept.

Confidentiality of medical records

- 4. What kind of information was being recorded during your last stay in the hospital? If you were hospitalized before, what kind of differences did you notice between past and present practice related to this? What is the purpose of the documentation of the information? Do you know what is being done with this information after your visit?
- 5. To your knowledge, who has access to your medical data in your polyclinic/hospitals?

 Probe: Do you think your doctor has access to it? What about other doctors or nurses?

 What about administrative or secretarial staff?
- 6. And who should have access to your medical records? Why do you think so?

- Probe: Other doctors of the hospital, nurses, administrative and secretarial staff?
- 7. In your opinion, what kind of personal information should be kept on the medical records? Why? Do you think all medical information should be treated in the same way, or are there specific topics that need special attention? *Probe: What do you think about confidentiality-sensitive topics such as HIV or mental illness?*
- 8. In your opinion, is there any type of information that does need to be kept confidential? What kind of information is that?
- 9. Have you ever been concerned about your personal/medical data that was recorded in your medical cards? *Probe: Did you have any concerns that the information could be shared with your family/relatives/friends without your permission? Did you have any concerns regarding information disclosure to your employers? If yes, why?*

Now let's discuss the importance of confidentiality for patients.

Environment and communication

- 10. What could you say about the difficulties disclosing health information related to your health to doctors who treated you during your stay in the hospital? What kind of difficulties were those? Was this because of confidentiality concerns?
- 11. How the environment of the department affected your willingness to share your medical information with your doctor? What would you say about difficulties sharing this information with other doctors/staff of the department? What was the reason for that?
- 12. How did your doctor tell you that your medical information will be kept confidential? How she/he explained what confidential means? Did you ask any questions to her/him regarding this?
- 13. How do you choose which clinic to attend in case of need? *Probe: Do you ever check about the hospital's reputation as a place where your personal information will be recorded?*
- 14. What do you think about the situation when the diagnosis is being disclosed to relatives or friends without disclosing it to the patient?

Physical privacy

- 15. What do you think about the importance of asking your permission before conducting physical exam? *Probe: For example: to perform lung or hurt auscultation or abdominal palpation.*
- 16. Who do you think should be present in the room during the physical exam? *Probe:* Should other doctors than your doctor be there? What about a nurse?
- 17. What do you think about the situation when another individual enters the room during your exam? Have you experienced it? If yes, what were your thoughts about that situation? What have you done in that situation?
- 18. What do you think about how your physical privacy should be ensured? *Probe: Do you think the doors should be locked during an examination? Why if yes/no? What else should be taken into account during the physical exam?*

Now let's talk about electronic systems and technologies in the medical field.

Confidentiality issues related to e-health

19. Please tell me what you know about the electronic health system (this is a computed system, where health information is stored in digital format). What do you know about the ARMED system in Armenia? Do you know how to access your medical information through this system (using social card number register in the ARMED system and have access to medical data)? Have you ever used it? If yes, do you find it helpful? If not, why?

- 20. What do you think about the safety of medical data that is being kept in the system/electronically? What do you think about other people's access to it? What do you think about the possibility that the system can be hacked (unauthorized access or control of system, which could make all the information accessible to public)
- 21. Do you think your doctor should have access to your electronic information without your permission? Why yes/no? *Probe: What do you think about accessing sensitive topics* (HIV, mental illnesses, etc.)
- 22. Is there anything that I did not ask but you would like to add?

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- Age
- Gender

Thank you!	
Notes	

End time of interview...

Appendix 2

Խորացված հարցազրույցի ուղեցույց պացիեն տն երի համար Հարցազրույցը սկսելու ժամը . . .

Ներած ական հարցեր

Շնորհակալ եմ,որ համաձայնեցիք մասնակցել հետագոտությանը։

Եկենք սկսենք հարցազրույցը`բժշկական գաղտնիքի մասին Ձեր պատկերացումների մասին խոսելով։

Բժշկական գաղտնիքի ընկալումը և դրա դերը առողջապահական համակարգում

- 1. Խնդրում եմ նկարագրեք թե ինչ է բժշկական գաղտնիքն T
 ըստ Ձեզ։ Հուշում։ Կարո՞ղ եք նկարագրել բժշկական
 գաղտնիքի հետ կապված որ և է իր ական կամ հնարավոր խնդիր,
 որի մասին Դուք տեղյակեք։ Կարծու՞մ եք այն օրինակա՞ն,
 թե՞ բարոյական պարտավորություն է։ Հիշու՞մ եք, որ այս
 մասին Ձեզ տեղեկացրած լինեք հիվանդանոցում գտնվելու
 ժամանակ։ Սրա հետ կապված որ և է խնդիր ունեցե՞լ եք, երբ
 հիվանդանոցում էիք։ Որ ո՞նք էին այդ խնդիրները։ Դրանք
- 2. Ի՞ նչ գիտեք այն օրենքների կամ կարգավորումների մասին, որոնք ապահովում են բժշկական տվյալների գաղտնիությունը։ Հուշում։ Ի՞նչ կարծիք ունեք Հայաստանում Ձեր անձնական տվյալների պաշտպանության մասին։
- 3. Ինչու՞ եք կարծում,որ բժշկական տվյալների գաղտնիությունը կարևոր է։

Այ ժմ եկեք քննարկենք թե ինչ է բժշկական տեղեկատվությունը և ինչ պես պետք է այն պահպանվի։

Բժշկական տեղեկատվության պահպանումը

- 4. Ձեզ վերաբերող ինչ պիսի տեղեկատվություն է փաստաթղթավորվել /պահպանվել հիվանդանոցում վերջին անգամ լինելու ժամանակ։ Եթե նախկինում էլի հոսպիտալացված եք եղել սրա հետ կապված ինչ պիսի տարբերություններ եք նկատել նախկին և վերջին հոսպիտալացումների/հիվանդանոցում լինելու միջև։ Ո՞րն է այս տեղեկությունը փաստաթղթավորելու իմաստը։ Ձեր կարծիքով ի՞նչ է կատարվում այս տեղեկատվության հետ Ձեր այցից հետո։
- 5. Ինչ եք կարծում ու՞մ են հասանելի Ձեր բժշկական տվյալները պոլիկլինիկայում/հիվանդանոցում։

 Հուշում։ Կարծու՞մ եք Ձեր բժշկին հասանելի են։ Ինչ
 կասե՞ք այլ բժիշկների կամ բուժքույրների մասին։ Ի՞սկ
 ղեկավար կամ սպասարկման բաժնի աշխատակիցների մասին։
- 6. Իսկի՞նչ եք կարծում ով պետք է հասանելիություն ունենա այս տեղեկատվությանը։ Ինչու՞ եք այդպես կարծում։ Հուշում. Այլ բժիշկներ, բուժքույրներ, ղեկավար կամ սպասարկման բաժնի աշխատակիցներ։
- 7. Ձեր կարծիքով անձնական ինչ պիսի՞ տեղեկատվություն պետք է պահպանվի բժշկական փաստաթղթերում։ Ինչու՞։ Ի՞նչ եք կարծում բոլոր տեսակի տեղեկատվությունը պետք է պահվի նույն կերպ,թե՞ կա այն պիսի տեղեկատվություն, որը հատուկ ուշադրության կարիք ունի։ Հուշում. Ի՞նչ եք կարծում այն պիսի զգայուն տեղեկատվության գաղտնիության մասին ինչ պիսիք են օրինակ ՄԻԱՎ-ը կամ հոգեկան առոողջության հետ կապված խնդիրները։

- 8. Ձեր կարծօքով կա՞այ նպիսի տեղեկատվություն,որը գաղտնի պահելու անհրաժեշտություն չկա։ Ինչպիսի՞ տեղեկատվությունն է դա։
- 9. Ի՞նչ կասեք երբևէ ունեցած Ձեր անհանգստությունների մասին՝ կապված Ձեր բժշկական փաստաթղթերում պահպանվող տեղեկատվության հետ։ Հուշում։ Երբևէ անհանգստացե՞լ եք, որ այս տեղեկատվությունը առանց Ձեր թույլ տվության կարող է տրամադրվել Ձեր ընտանիքի անդամներին/հարազատներին/ընկերներին։ Իսկ երբևէ անհանգստացե՞լ եք, որ այն կարող է տրամադրվել Ձեր զործատուին։ Եթե այո՝ ինչու՞։

Այժմ եկեք քննարկենք այցելուների համար գաղտնիության պահպանման կարևորությունը

Միջավայրը և շփումը

- 10. Ի՞նչ կասեք հիվանդանոցում բուժման ընթացքում Ձեր բժշկին որևէ անձնական տեղեկատվություն հայ տնելու դժվարությունների մասին։ Ինչպիսի՞ դժվարություններ էին դրանք։ Պատձառը գաղտնիության պահպանման վերաբերյալ անհանգստություններն էի՞ն։
- 11. Բաժան մու ն ք ի մ իջ ավ այ րը ի ն չ պե՞ս է ր ազդու մ Ձե ր
 բժշ կ ակ ան տեղեկ ատվությունը հաղորդելու
 պատրաս տակամության վրա։ Ի՞ն չ կ աս ե ք
 տեղեկատվությունը բաժան մու ն ք ի այ լ
 բժիշ կներին/բուժքույրներին հայտնելու հետ կապված
 դժվարությունների մասին։ Ի՞ն չն էր դրա պատ մատ ը։
- 12. Ինչ պե՞ս են Ձեզ տեղեկացրել, որ Ձեր բժշկական տվյալները գաղտնի են պահվելու։ Ինչ պե՞ս են բացատրել

- թե ինչ է նշանակում գաղտնի։ Դուք որևէ հարց տվե՞լ եք դրա վերաբերյալ։
- 13. Ան հրաժեշտության դեպքում ինչ պե՞ս եք ընտրում, թե որ բժշկական հաստատություն այցելեք։ Հուշում. Արդյո՞ք ստուգում եք հաստատության հեղինակությունը, որպես վայր որտեղ պահպանվելու է Ձեզ վերաբերվող անձնական տեղեկատվությունը։
- 14. Ի՞նչ եք կարծում այն իրավիմակների մասին,երբ ախտորոշումը հայ տնում են ընտանիքին կամ ընկերներին, բայց թաքցնում են հիվանդից։

Ֆիզիկական (տվյալների) անվտանգություն/գաղտնիություն

- 15. Ի՞նչ եք կարծում մինչ և ֆիզիկական զննում կատարելը Ձեզ դրա մասին հարցնելու կարևորության մասին։ Հուշում։ Օրինակ՝ մինչ թոքերը լսելը կամ որովայնի շոշափումը։
- 16. Ի՞նչ եք կարծում ֆիզիկական զննում իրականցնելիս ով կարող է ներկա գտնվել սենյ ակում։ Հուշում։ Բացի Ձեզ բուժող բժշկից այլ բժիշկներ պետք է՞ներկա լինեն։ Իսկ ի՞նչ կասեք բուժքույրների մասին։
- 17. Ի՞նչ եք կարծում այն իրավիձակի մասին,երբ Ձեզ հետազոտելու ընթացքում այլ մարդ է մտնում սենյ ակ։ Դուք երբևէ այդպիսի իրավիձակում եղե՞լ եք։ Եթե այո՝ ի՞նչ էիք մտածում այդ պահին։ Ինչ պե՞ս վարվեցիք այդ պահին։
- 18. Ի՞նչ եք կարծում Ձեր ֆիզիկական զննման գաղտնիությունը ինչ պես պետք է ապահովվի։ Հուշում։ Կարծու՞մ եք սենյակի դուոր պետք է փակել զննման ժամանակ։ Եթե այո/ոչ՝ ինչու՞։ Բացի սրանից, էլ ի՞նչ պետք է հաշվի առնել ֆիզիկական հետազոտության ժամանակ։

Այ ժմ եկեք խոսենք բժշկական ոլ որտում նորարարական տեխնոլոգիաների և էլ եկտրոնային համակարգերի կիրառության մասին։

Էլ եկտրոն այ ին առողջ ապահության համակարգի հետ կապված գաղտնիության խնդիրներ

- 19. Խնդրում եմ ասեք թե ինչ գիտեք էլ եկտրոնայ ին ատողջության համակարգի մասին։ (սրանք համակարգերն են, որտեղ Ձեր ատողջական տեղեկատվությունը պահպանվում է էլ եկտրոնայ ին/թվայ ին տարբերակով): Ի՞նչ գիտեք Հայ աստանում գործող ԱՐՄԵԴ համակարգի մասին։ Գիտե՞ք թե ինչ պես կարող եք այս համակարգի միջոցով տեսնել Ձեզ վերաբերող բժշկական տեղեկատվությունը (գրանցվել համակարգում սոցիալ ական քարտի համարի միջոցով և տեսնել անձնական բժշկական տեղեկատվությունը՝ տեղեկատվությունը։ Երբևիցե՞ օգտվել եք դրանից։ Ի՞նչ կասեք դրա օգտակարության մասին։
- 20. Ի՞նչ եք կարծում այն տեղեկատվության անվտանգության մասին, որը պահպանվում է այս համակարգում/էլ եկտրոնային տարբերակով։ Ի՞նչ եք կարծում այն մասին, որ այլ մարդիկ ևս հասանել իություն ունեն դրան։ Ի՞նչ եք կարծում այս համակարգի հարձակման ենթարկվելու հավանականության մասին (սրանք այն իրավիձակներն են, երբ համակարգի աշխատանքը խափանվում է այլ մարդկանց կողմից և տեղեկատվությունը բաց և հասանելի է դառնում բոլորի համար):
- 21. Ի՞ նչ եք կարծում Ձեր բժիշկը պետք է հասանել իություն ունենա Ձեր անձնական տեղեկատվությանը առանց Ձեր թույլտվության։ Հուշում. Ի՞նչ կասեք զգայուն

թեմաներին վերաբերող տեղեկատվության մասին (ՄԻԱՎ, հոգեկան առողջության խնդիրներ)։

22. Կա այ ն պիս ի բ ան, որ ես չ հարցրի, բ այ ց Դու ք կցան կ ան այ ի ք ավել ացնել։

Ծողովրդագրական տվյալներ

- Տարիք
- Uե n

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Շնորհակալություն։
Նշումներ...
Հարցազրույցը ավարտելու ժամը...
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Appendix 3

In-depth interview guide for doctors

Start time of interview ...

Ice-breaker questions.

Thank you for aggreging to participate in this study

Let's start our interview by talking about how you understand medical confidentiality.

Knowledge about medical confidentiality and its role in healthcare system

- 1. Please describe what confidentiality is. *Probe: could you describe any real/possible medical confidentiality issues that you are aware of?* How did you learn about it? *Probe: Medical school, hospital, colleagues?* Did you have any training on the topic of medical confidentiality? Do you think it is a part of the medical system? If yes, why? If no, why?
- 2. Have you had any issues related to this? What were the issues? How were they solved?
- 3. Please describe what you know about the legislation on medical confidentiality? If no information, have you ever been interested in it? How is personal information protected in Armenia?
- 4. What kind of ethical difficulties did you experience in your practice regarding medical confidentiality? What kind of situation do you consider ethically problematic? Please, describe how did/would you resolve this kind of situation? Whom do you approach in case of a dilemma? *Probe: colleague, patients' relatives, hospital management team?*

Now let's discuss what medical information is and how it should be kept.

Confidentiality of medical records

5. In your opinion, who should have access to medical information in your department? Probe: Other doctors or nurses of the department? Administrative staff? Why do you think so? How do you ensure that medical records are being kept safe in your department? Have you ever had any concerns that this information could be accessible to non-authorized people? Probe: could you describe such instances?

- 6. In your opinion, should all medical information be kept in the same way, or are there specific topics that need special attention? *Probe: What do you think about confidentiality-sensitive topics such as HIV or mental illness?*
- 7. What do you think how you should act in situations when patients' disease status could also affect others' health (for example, infections, HIV, genetic testing results)? What are your thoughts about sharing it with a third party without patient permission?
- 8. What do you think about hiding the diagnosis from the patient and disclosing it to the patient's relatives/friends? What is your opinion about sharing it with relatives/friends without asking patients' permission?

Now let's discuss the importance of confidentiality for patients.

Environment and communication with patients

- 9. How do patients perceive medical confidentiality/ What do you think about their perspectives on this issue?
- 10. How do you ensure that patients are sharing all the needed information with you? *Probe:*What is your opinion about highlighting that the confidentiality of the information will be kept safe? How this can change patients' attitude regarding sharing more information with you? How do you tell your patients that their medical information will be kept confidential?
- 11. As all doctors can access the medical information shared in ARMED, what do you think about the availability of sensitive information? *Probe: Should it be available for all doctors?* Do you think patients' permission is necessary to access their medical records? Why yes/why not?

Physical privacy

- 12. Please describe the measures you use to ensure your patients' physical privacy. For example, do you ensure that doors are closed while you are conducting physical exam? Do you ask other people to leave the room before starting physical exam?
- 13. Do you ask the patient's permission before conducting physical exam? What do you think about asking patients' permission to conduct the exam?

Now let's talk about electronic systems and technologies in the medical field.

Confidentiality issues related to e-health

14. What do you think about using electronic medical records (this is a computed system,

where health information is stored in digital format)? What do you think about the safety

of electronic systems? What do you think about the possibility that this system could be

hacked (unauthorized access or control of system, which could make all the information

accessible to public)?

15. Please describe the safety measures implemented in your practice to ensure the safety of

electronic medical records? Probe: Do you close the system every time before leaving a

room?

16. What are the main barriers to using electronic health systems? Probe: Do you think there

are security issues?

17. Is there anything that I did not ask but you would like to add?

Sociodemographic characteristics

• Age

Gender

Specialty

• Hospital and department

Thank you!

Notes...

End time of interview...

Appendix 4

Խորացված հարցազրույցի ուղեցույց բժիշկների համար Հարցազրույցը սկսելու ժամը . . .

Ներած ական հարցեր

Շնորհակալ եմ,որ համաձայնեցիք մասնակցել հետագոտությանը։

Եկենք սկսենք հարցազրույցը`բժշկական գաղտնիքի մասին Ձեր պատկերացումների մասին խոսելով։

Բժշկական գաղտնիքի ընկալումը և դրա դերը առողջ ապահական համակարգում

- 1. Խնդրում եմ նկարագրեք ինչ է բժշկական գաղտնիքը ըստ Ձեզ։ Հուշում։ Կարո՞ղ եք նկարագրել բժշկական գաղտնիքի հետկապված որևէ իրական կամ հնարավոր խնդիր, որի մասին Դուք տեղյակ եք։ Ինչ պե՞ս եք Դուք իմացել դրա մասին։ Հուշում. Բժշկական համալսարանու՞մ, հիվանդանոցու՞մ, գործընկերների՞ց։ Այս թեմայով որևէ վեր ապատրաստման/դասընթացի մասնակցե՞լ եք։ Կարծու՞մ եք, որ այն բժշկական համակարգի մասն է։ Եթե այո, ապա ինչու՞։ Եթե ոչ, ապա ինչու՞։
- 2. Այս թեմայի հետ կապված որև է խնդիր ու նեցե՞լ եք։ Որո՞նք են եղել այդ խնդիրները։ Ինչ պե՞ս են դրանք լուծվել։
- 3. Խնդրում եմ նկարագրեք թե ինչ գիտեք բժշկական գաղտնիքի օրինական կարգավորման մասին։ Եթե ոչինչ չգիտեք՝ երբևէ հետաքրքրվե՞լ եք այդ մասին։ Ինչպե՞ս է անձնական տեղեկատվությունը պահպանվում Հայաստանում։
- 4. Բժշկական գաղտնիքի հետ կապված ինչ պիսի՞ էթիկական խնդիրներ եք ունեցել Ձեր գործունեության ժամանակ։

Ինչ պիսի ՝ իրավիձակներն եք համարում բարդ։ Խնդրում եմ նկարագրեք ինչ պե՝ ս եք հաղթահարել /կհաղթահարեիք այսպիսի խնդիրները։ Ու ՝ մ կդիմեիք եթե լինեիք բժշկական տեսանկյունից երկընտրանքի առաջ։ Հուշում. Գործընկերներին, պացիենտի բարեկամներին, հիվանդանոցի ղեկավարությանը։

Այ ժմ եկեք քննարկենք թե ինչ է բժշկական տեղեկատվությունը և ինպես պետք է այն պահպանվի։

Բժշկական տեղեկատվության պահպանումը

- 5. Ձեր կարծիքով ո՞վ պետք է հասանել իություն ունենա բժշկական տեղեկատվությանը Ձեր բաժանմունքում։ Հուշում. Բաժանմունքի այլ բժիշկները՞, բուժքույրները՞։ Ղեկավարող/սպասարկման բաժնի աշխատակիցները՞։ Ինչու՞ եք այդպես կարծում։ Ձեր բաժանմունքում ինչ պե՞ս եք ապահովում բժշկական տեղեկատվության անվտանգությունը։ Երբևիցե որևէ անհանգստություն ունեցե՞լ եք այդ կապակցությամբ։ Երբևէ որևէ անհանգստություն ունեցե՞լ եք,որ այս տեղեկատվությունը կարող է հասանելի դառնալչլիազորված անձանց համար։ Հուշում։ Կարո՞ղ եք այդպիսիս դեպքեր նկարագրել։
- 6. Ձեր կարծիքով ամբողջ տեղեկատվությունը պետք է պահվի նույն կերպ,թե՞ կա այն պիսի տեղեկատվություն,որը հատուկ ուշադրության կարիք ունի։ Հուշում. Ի՞նչ եք կարծում այն պիսի զգայուն տեղեկատվության գաղտնիության մասին ինչ պիսիք են օրինակ ՄԻԱՎ-ը կամ հոգեկան առողջության հետ կապված խնդիրները։

- 7. Ի՞նչ եք կարծում ինչ պես պետք է վարվեք այն պիսի իրավիձակներում,երբ պացիենտի առողջական վիձակը կարող է ազդել այլ մարդկնաց առողջության վրա (օրինակ՝ վարակիչ հիվանդությունների, ՄԻԱՎ-ի, գենետիկ հիվանդությունների դեպքում): Ի՞նչ եք կարծում առանց պացիենտի թույլտվությունը ստանալու դրա մասին երրորդ անձանց տեղեկացնելու մասին։
- 8. Ի՞նչ կարծիք ունեք այն մասին,երբ ախտորոշումը թաքցվում է պացիենտից,սակայն դրա մասին տեղեկացվում են ընտանիքի անդամները/ընկերները։ Ի՞նչ եք կարծում այս տեղեկատվությունը առանց պացիենտի թույլտվության հարզազտներին/ընկերներին հայտնելու մասին։

Այժմ եկեք քննարկենք պացիենտի համար գաղտնիության պահպանման կարևորությունը։

Միջավայրը և պացիենտների հետ շփումը

- 9. Ինչ պե՞ս են պացիեն տները ընկալում բժշկական գաղտնիքը։ Ի՞նչ եք կարծում այս խնդրի վերաբերյալ նրանց պատկերացումների մասին։ Կարծու՞մ եք բժշկական տեղեկատվության գաղտնիությունը կարևոր է՞ պացիեն տների համար։ Եթե՝ այո, ինչու՞։ Եթե՝ ոչ, ինչու՞։
- 10. Ի՞ նչ պես եք ապահովում, որպեսզի պացիեն տները Ձեզ ներկայ ացնեն բժշկական տեղեկատվությունը ամբողջությամբ։ Հուշում. Ի՞նչ եք կարծում այն մասին, որ կարող եք նշել, որ ստացված ամբողջ տեղեկատվության գաղտնիությունը կապահովվի։ Եղե՞լ են այն պիսի դեպքեր, երբ կարիք է եղել շեշ տել, որ ամբողջ տեղեկատվությունը պահպանվում է անվտանգ։ Ինչ պե՞ս կարող է սա ազդել

- ավելի շատ տեղեկատվություն տրամադրելու պացիեն տների պատրաստակամության վրա։ Ինչ պե՞ս եք Ձեր պացիեն տներին տեղեկացնում,որ նրաբժշկական տվյալները գաղտնի են պահվելու։
- 11. Քանի որ բոլորը բժիշկները հասանելիություն ունեն ԱՐՄԵԴ համակարգին, ի՞նչ եք կարծում այնտեղ զգայուն տեղեկատվության հասանելիության մասին։ Հուշում.

 Դե՞տք է այն հասանելի լինի բոլոր բժիշկների համար։
 Ի՞նչ եք կարծում պացիենտների թույլտվությունը ան հրաժեշտ է նրանց բժշկական տեղեկատվությանը հասանելիություն ունենալու համա՞ր։ Ինչու՞ այո/ինչու՞ ոչ։

 \mathfrak{S} ի զի կ ակ ան (տվ յ ալ ն երի) ան վ տան գությ ան /գ աղ տն իությ ու ն

- 12. Խնդրում եմ նկարագրեք այն միջոցառումները, որոնք Դուք կիրառում եք պացիենտի ֆիզիկական (տվյալների) գաղտնիությունը ապահովելու համար։ Օրինակ՝ ապահովու՞մ եք, որպեսզի ֆիզիկական զննման ժամանակսենյակի դուռը փակլինի։ Ֆիզիկական զննում իրականացնելուց առաջ խնդրու՞մ եք, որ այլ մարդիկ դուրս գան սենյակից։
- 13. Ֆիզիկական զննումը սկսելուց առաջ հարցնու՞մ եք պացիենտի թույլտվությունը։ Ի՞նչ եք կարծում զննումից առաջ պացիենտի թույլտվությունը հարցնելու մասին։

Այ ժմ եկեք խոսենք բժշկական ոլ որտում նորարարական տեխնոլոգիաների և էլ եկտրոնային համակարգերի կիրառության մասին Էլ եկտրոն այ ին ատողջ ապահության համակարգի հետ կապված գաղտնիության խնդիրներ

- 14. Ի՞նչ եք կարծում էլ եկտրոանային ատողջապահության համակարգերի կիրատման մասին (սրանք համակարգերն են, որտեղ ատողջական տեղեկատվությունը պահպանվում է էլ եկտրոնային/թվային տարբերակով)։ Ի՞նչ եք կարծում էլ եկտրոնային համակարգերի անվտանգության մասին։ Ի՞նչ եք կարծում այս համակարգի հարձակման ենթարկվելու հավանականության մասին (սրանք այն իրավիձակներն են,երբ համակարգի աշխատանքը խափանվում է այլ մարդկանց կողմից և տեղեկատվությունը բաց և հասանելի է դատնում բոլորի համար)։
- 15. Խնդրում եմ նկարագրեք այն միջոցառումները, որոնք Դուք կիրառում եք Ձեր առօրյա գործունեության ընթացքում էլեկտրոն ային բժշկական տեղեկատվության անվտանգությունն ապահովելու համար։ Հուշում։ Ամեն անգամ սենյակից դուրս գալիս փակու՞մ եք համակարգը։
- 16. Որ ո՞ն ք են համակարգը կիրառել ու հիմնական խոչ ընդոտները անվտանգության տեսանկյունից։
- 17. Կա այ ն պիս ի բ ան, որ ես չ հարցրի, բ այ ց Դու ք կցան կան այ ի ք ավել ացնել։

Ժողովրդագրական տվյալներ

- Տարիք
- Uե n
- Մաս ն ագ ի տաց ո ւ մ
- Հիվանդանոց և բաժան մու նք

Շնորհակալություն

Նշումներ...

Հարցազրույցը ավարտելու ժամը...

Appendix 5

American University of Armenia

Turpanjian School of Public Health

Institutional Review Board # 1

Oral consent form for patients

Principal investigator: Tsovinar Harutyunyan, MPH, PhD

Co-investigator: Lusine Musheghyan, MA, MPH

Student-investigator: Ashkhen Grigoryan, MD

Project title: Perceptions and experiences of medical confidentiality and privacy among healthcare workers and patients in Armenia: a qualitative research

Hello, I am Ashkhen Grigoryan. I am a second-year student of Masters of Public Health at the American University of Armenia. As part of my thesis project under my advisors' supervision, I am conducting a research study. The topic of my research is medical confidentiality. This study aims to find out the perception of medical confidentiality in Armenia among physicians and patients.

You are one of the several participants that have been invited participate in this study. You are invited to participate in this study as a patient who has been hospitalized in the secondary care hospital in Armenia. In order to find out your perceptions of medical confidentiality, I would like to conduct an interview with you, which may last 30-60 minutes. I will ask questions regarding medical confidentiality and its role in the healthcare system, confidentiality of medical records, environment and communication with patients, physical privacy, and confidentiality issues related to electronic health systems. Your participation in this study is limited to just that interview. Your participation is completely voluntary. You can stop the interview any time you want. You can also skip answering the questions that you do not want to answer. Refusing to answer any question or stopping the interview does not have any consequences for you.

Though you will not have any personal benefits from this interview, this study could be possibly helpful for future reform of laws and regulations regarding personal information protection in Armenia.

With your permission, I would like to audio or video record our conversation to remember all the details of our discussion. You are free to refuse to record our conversation or any part of it. I will ensure the confidentiality of information that you provide. The recordings will be kept on my personal computer protected by password. I will not attach any personal information to the recordings. I will destroy the recordings as soon as the data are analyzed.

The study results can be published, and I would use some of your words in the paper; however, there will not be your name or any other personal information that will help identify your personality.

Before we start, I would like to make sure that I clearly explained all the points. Please let me know if you have any questions. If you have any questions in the future, you can contact my supervisor Tsovinar Harutyunyan at 374 60 612592.

If you think you have been hurt by joining the study or have not been treated fairly, you can contact Varduhi Hayrumyan, the Human Protections Administrator of the American University of Armenia at (060) 61 25 61.

Do you agree to participate?

Do you agree to audio or video record our discussion? If not, I will take notes during the interview.

Thank you.

Can we start?

Appendix 6

Հայ աստանի ամերիկյան համալսարան
Թրպան ձեան Հանրային առողջապահության ֆակուլտետ
Գիտահետազոտական էթիկայի թիվ 1 հանձնաժողով
Իրազեկ համաձայնության ձև պացիենտների համար
Հետազոտության ղեկավար՝ Ծովինար Հարությունյան
Հետազոտական թիմի անդամ՝ Լուսինե Մուշեղյան
Ուսանող՝ Աշխեն Գրիգորյան

Թեմա՝ Բժիշկների և պացիեն տների պատկերացումները և փորձառությունը բժշկական գաղտնիքի վերաբերյալ։ Որակական հետագոտություն

Ողջույն, իմ անունը Աշխեն Գրիգորյան է. ես Հայաստանի ամերիկյան համալսարանի Թրփան ձեան Հանրային առողջապահության ֆակուլտետի մագիստրոսական ծրագրի երկրորդ կուրսի ուսանող եմ։ Իմ ավարտական թեզի շրջանակներում իմ ղեկավարների հետ միասին ես իրականացնում եմ բժշկական գաղտնիքի վերաբերյալ հետազոտություն։ Իմ հետազոտության թեման բժշկական գաղտնիքն է։ Այս հետազոտության նպատակը Հայաստանում բժիշկների և պացիենտների շրջանում բժշկական գաղտնիքի վերաբերյալ պատկերացումների ուսումնասիրումն է։

Դուք հետազոտությանը մասնակցելու հրավիրված մասնակիցներից մեկն եք։ Ձեզ հրավիրում եմ մասնակցելու այս հետազոտությանը, որպեսո պացիենտ, ով Հայաստանում հիվանդանողային օղակի հաստատությունում բուժվելու փորձառություն է ունեցել։ Բժշկական գաղտնիքի վերաբերյալ Ձեր կարծիքն իմանալու համար՝ ես կցանկանայի Ձեզ հետ հարցազրույց անցկացնել, որը կտևի 30-60 րոպե։ Այդ ընթացքում կտամ հարցեր բժշկական գաղտնիքի և ատողջապահական համակարգում դրա դերի, բժշկական տեղեկատվության պահպանման, բժշկական տեղեկատվության և հիվանդանոցի միջավայրի միջև կապի, ֆիզիկական անվտանգության, ինչպես նաև էլեկտրոնային համակարգերում ատողջական տվյալների պահպանման անվտանգության վերաբերյալ։ Ձեր մասնակցությունը այս հետազոտությանը սահմանափակվում է այս հարցազրույցով։ Այս հետազոտությանը Ձեր մասնակցությունը լրիովին կամավոր է։ Դուք կարող եք ընդհատել հարցազրույցը ցանկացած պահի։ Նաև կարող եք չպատասխանել այն հարցերին, որոնց չեք ցանկանում պատասախանել։ Հարցազրույցի ընդհատումը կամ որևէ հարցի պատասխանելուց հրաժարվելը որևէ հետևանք չի ունենա Ձեզ համար։

Այս հետազոտությանը մասնակցելով Դուք չեք ունենա որև է ան միջ ական օգուտ, սակայն այն կարող է օգտակար լինել Հայաստանում անձնական տվյալների պաշտպանությանը վերաբերող օրենքները և կարգավորումները բարեփոխելու համար։

Ձեր թույլտվությամբ, ես կցանկանայի ձայնագրել կամ տեսաձայնագրել մեր զրույցը, որպեսզի վստահ լինեմ, որ որևէ կարևոր տվյալ բացչեմ թողել։ Դուք կարող եք մերժել հարցազրույցի կամ դրացանկացած մասի ձայնագրումը։ Ես երաշ խավորում եմ Ձեր տրամադրած տեղեկատվության գաղտնիությունը։ Ձայնագրությունները կպահվեն իմ անձնական համակարգչում, որը պաշտպնված է ծածկագրով։ Ձեր անձնական տվյալները կցված չեն լինի այս ձայնագրություններին։ Տվյալների վերլուծությունից հետո ձայնագրությունները կոչնչացվեն։

Հետազոտության արդյունքները կարող են տպագրվել գիտական ամսագրերում՝ օգտագործելով մասնակիցների խոսքերից մեջբերումներ։ Այնոուամենայնիվ որևէ անուն կամ անձր նույնականացնող տվյալ չի օգտագործվի։

Մինչ սկսելը, ես կցանկանայի վստահ լինել, որ ես բացատրեցի բոլոր կետերը։ Եթե որևէ հարցունեք՝ խնդրեմ։ Եթե հետագայում հետազոտության հետ կապված որևէ հարցունենաք, կարող եք կապհաստատել հետազոտության ղեկավար Ծովինար Հարությունյանի հետ՝ 374 60 61 25 92 հեռախոսահամարով։

Եթե կարծում եք, որ այս հետազոտությանը մասնակցելով Ձեզ հետ Ճիշտ չեն վարվել կամ Ձեզ վիրավորել են, կարող եք կապ հաստատել Հայաստանի ամերիկյան համալսարանի գիտական Էթիկայի հանձնաժողովի համակարգող Վարդուհի Հայրումյանի հետ՝ 060 61 25 61 հեռախոսահամարով։

Համաձայն ե՞ք եք մասնակցել հետազոտությանը։

Համաձայն ե՞ք,որ հարցազրույցը ձայն ագրվի կամ տեսաձայն ագրվի։ Եթե ոչ,ես զրույցի ընթացքում որոշ նշումներ կանեմ։

Շնորհակալություն։

Կարո՞ դենք սկսել։

American University of Armenia

Turpanjian School of Public Health

Institutional Review Board # 1

English version of the oral consent form for physicians

Principal investigator: Tsovinar Harutyunyan, MPH, PhD

Co-investigator: Lusine Musheghyan, MA, MPH

Student-investigator: Ashkhen Grigoryan, MD

Project title: Perceptions and experiences of medical confidentiality and privacy among healthcare workers and patients in Armenia: a qualitative research

Hello, I am Ashkhen Grigoryan. I am a second-year student of Masters of Public Health at the American University of Armenia. As part of my thesis project under my advisors' supervision, I am conducting a research study. The topic of my research is medical confidentiality. This study aims to find out the perception of medical confidentiality in Armenia among physicians and patients.

You are one of the several participants that have been invited to participate in this study. You are invited to participate in this study as a physician who works in secondary care hospital in Armenia. In order to find out your perceptions of medical confidentiality, I would like to conduct an interview with you, which may last 30-60 minutes. I will ask questions regarding medical confidentiality and its role in the healthcare system, confidentiality of medical records, environment and communication with patients, physical privacy, and confidentiality issues related to electronic health systems. Your participation in this study is limited to just this interview. Your participation is completely voluntary. You can stop the interview any time you want. You can also skip answering the questions that you do not want to answer. Refusing to answer any question or stopping the interview does not have any consequences for you.

Though you will not have any personal benefits from this interview, this study could possibly be helpful for future reform of laws and regulations regarding personal information protection in Armenia.

With your permission, I would like to audio or video record our conversation to remember all the details of our discussion. You are free to refuse to record our conversation or any part of it. I will ensure the confidentiality of information that you provide. The recordings will be kept on my personal computer protected by password. I will not attach any personal information to the recordings. I will destroy the recordings as soon as the data are analyzed.

The study results can be published, and I would use some of your words in the paper; however, there will not be your name or any other personal information that will help identify your personality.

Before we start, I would like to make sure that I clearly explained all the points. Please let me know if you have any questions. If you have any questions in the future, you can contact my supervisor Tsovinar Harutyunyan at 374 60 612592.

If you think you have been hurt by joining the study or have not been treated fairly, you can contact Varduhi Hayrumyan, the Human Protections Administrator of the American University of Armenia at (060) 61 25 61.

Do you agree to participate?

Do you agree to audio or video record our discussion? If not, I will take notes during the interview.

Thank you.

Can we start?

Appendix 8

Հայ աստանի ամերիկյան համալսարան
Թրպան ձեան Հանրային առողջապահության ֆակուլտետ
Գիտահետազոտական էթիկայի թիվ 1 հանձնաժողով
Իրազեկ համաձայնության ձև բժիշկների համար
Հետազոտության ղեկավար՝ Ծովինար Հարությունյան
Հետազոտական թիմի անդամ՝ Լուսինե Մուշեղյան
Ուսանող՝ Աշխեն Գրիգորյան

Թեմա՝ Բժիշկների և պացիեն տների պատկերացումները և փորձառությունը բժշկական գաղտնիքի վերաբերյալ։ Որակական հետագոտություն

Ողջույն, իմ անունը Աշխեն Գրիգորյան է. ես Հայաստանի ամերիկյան համալսարանի Թրփան ձեան Հանրային առողջապահության ֆակուլտետի մագիստրոսական ծրագրիերկրորդ կուրսի ուսանող եմ։ Իմ ավարտական թեզի շրջանակներում իմ ղեկավարների հետ միասին ես իրականացնում եմ բժշկական գաղտնիքի վերաբերյալ հետազոտություն։ Այս հետազոտության նպատակը Հայաստանում բժիշկների և պացիենտների շրջանում բժշկական գաղտնիքի վերաբերյալ պատկերացումների ուսումնասիրումն

Դուք հետազոտությանը մասնակցելու հրավիրված մասնակիցներից մեկն եք։ : Ձեզ հրավիրում եմ մասնակցելուայս հետազոտությանը որպես բժիշկ,ով աշխատում է Հայաստանում՝ հիվանդանոցային օղակի բժշկական հաստատությունում։ Բժշկական գաղտնիքի վերաբերյալ Ձեր կարծիքն իմանալու համար ես կցանկանայի Ձեզ հետ հարցազրույց անցկացնել,որը կտևի 30-60 րոպե։ Այդ ընթացքում կտամ հարցեր բժշկական գաղտնիքի և ատողջապահական համակարգում դրա դերի, բժշկական տեղեկատվության պահպանման, բժշկական տեղեկատվության և հիվանդանոցի միջավայրի միջև կապի, ֆիզիկական անվտանգության, ինչպես նաև էլեկտրոնային համակարգերում ատողջական տվյալների պահպանման անվտանգության վերաբերյալ։ Ձեր մասնակցությունն այս հետազոտությանը սահմանափակվում է այս հարցազրույցով։ Այս հետազոտությանը Ձեր մասնակցությունը լրիովին կամավոր է։ Դուք կարող եք ընդհատել հարցազրույցը ցանկացած պահի։ Նաև կարող եք չպատասխանել այն հարցերին, որոնց չեք ցանկանում պատասախանել։ Հարցազրույցի ընդհատումը կամ որևէ հարցի պատասխանելուց հրաժարվելը որևէ հետևանք չի ունենա Ձեզ համար։

Այս հետազոտությանը մասնակցելով Դուք չեք ունենա որև է ան միջ ական օգուտ, սակայն այն կարող է օգտակար լինել Հայաստանում անձնական տվյալների պաշտպանությանը վերաբերող օրենքները և կարգավորումները բարեփոխելու համար։

Ձեր թույլտվությամբ, ես կցանկանայի ձայնագրել կամ տեսաձայնագրել մեր զրույցը, որպեսզի վստահ լինեմ, որ որևէ կարևոր տվյալ բացչեմ թողել։ Դուք կարող եք մերժել հարցազրույցի կամ դրացանկացած մասի ձայնագրումը։ Ես երաշ խավորում եմ Ձեր տրամադրած տեղեկատվության գաղտնիությունը։ Ձայնագրությունները կպահվեն իմ անձնական համակարգչում, որը պաշտպնված է ծածկագրով։ Ձեր անձնական տվյալները կցված չեն լինի այս ձայնագրություններին։ Տվյալների վերլուծությունից հետո ձայնագրությունները կոչնչացվեն։

Հետազոտության արդյունքները կարող են տպագրվել գիտական ամսագրերում՝ օգտագործելով մասնակիցների խոսքերից մեջբերումներ։ Այնոուամենայնիվ որևէ անուն կամ անձր նույնականացնող տվյալ չի օգտագործվի։

Մինչ սկսելը, ես կցանկանայի վստահ լինել, որես բացատրեցի բոլոր կետերը։ Եթե որևէ հարցունեք՝ խնդրեմ։ Եթե հետագայում հետազոտության հետ կապված որևէ հարցունենաք, կարող եք կապ հաստատել հետազոտության ղեկավար Ծովինար Հարությունյանի հետ՝ 37460612592 հեռախոսահամարով։

Եթե կարծում եք, որ այս հետազոտությանը մասնակցելով Ձեզ հետ Ճիշտ չեն վարվել կամ Ձեզ վիրավորել են, կարող եք կապ հաստատել Հայաստանի ամերիկյան համալսարանի գիտական Էթիկայի հանձնաժողովի համակարգող Վարդուհի Հայրումյանի հետ՝ 060 61 25 61 հեռախոսահամարով։

Համաձա՞յն եք մասնակցել հետազոտությանը։

Համաձա՞յն եք,որ հարցազրույցը ձայ նագրվի կամ տեսաձայ նագրվի։ Եթե ոչ,ես զրույցի ընթացքում որոշ նշումներ կանեմ։

Կարո՞ղ ենք սկսել։