American University of Armenia

Gerald and Patricia Turpanjian School of Public Health

Evaluation of Patient-Reported Experiences among cancer survivors in two public hospitals in Yerevan, Armenia, before and after changes in reimbursement policy.

Program Evaluation Framework

by

Meri Sahakyan, DDS, MPH Candidate

Advisors Lusine Abrahamyan, MD, MPH, PhD

Michael E. Thompson, DrPH, MS

Yeva Sahakyan MD, MPH, MSc

Gerald and Patricia Turpanjian School of Public Health

American University of Armenia

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List of Abbreviations

PREM	Patient-reported experience measure
PROM	Patient-reported outcome measure
CAHPS	Consumer Assessment of Healthcare Providers and Systems
AUA	American University or Armenia
CHSR	Center for Health Services Research and Development
IRB	Institutional Review Board
RQ	Research Question

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I would like to devote my work to Dr. Gohar Panajyan, my internship preceptor, and a good friend, who passed away in May 2020, being diagnosed with cancer.

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Executive Summary

Introduction: Cancer is the second leading cause of death all over the world, but the number of cancer survivors is also increasing. On average, 18.1 million people are diagnosed with cancer in the world annually. Being one of the costliest diseases to treat, cancer patients often face financial difficulties. The cost of the treatment can be a decisive factor in initiating treatment. Cancer survivors must first endure a long, emotionally, and physically stressful treatment period. The quality of provided health care services can have an impact on both treatment processes and outcomes. Patient-Reported Experience Measures (PREMs) is one of the accepted tools to measure patient experiences in hospitals and provide the patients' view on the quality of care.

At the beginning of 2019, the Armenian government implemented a new program that provided financial support to all Armenian citizens newly diagnosed with cancer. The program covers the full cost of surgical treatment for all types of newly diagnosed cancers and provides partial reimbursement for radiotherapy.

Aim: The study aims to assess the difference in the PREMs before and after the program implementation, identify the predictors of PREMs, investigate the effect of the program on the patients' financial burden as well as understand how it affected the time from the first diagnosis to the treatment.

Methods: The proposed evaluation will utilize a pre-post independent group design. Cancer survivors (n=348), who received the surgical treatment in 2 hospitals in Yerevan Armenia between 1 April and 30 September, 2019, will be interviewed via phone survey. Oral consent will be acquired from all study participants before starting the interview. PREMs will be measured via 9 different domains of the Consumer Assessment of Healthcare Providers and Systems Hospital Survey questionnaire. Additional questions will help to measure financial burden and the time between the diagnosis to treatment initiation. The Institutional Review Board 1 (IRB) of the American University of Armenia approved the study protocol. The study will be completed within two months.

Analysis: Descriptive analysis will be conducted to compare patient characteristics using the Chi-square test and Student-t-test for categorical and continuous variables, respectively. I will use scatter plots to assess the trends of PREMs and independent t-test to compare PREMs before and after the implantation of the program.

Significance:
The study can serve as a baseline evaluation of PREMs under the new governmental program. Moreover, the collected data will help to evaluate the quality of provided cancer care in Yerevan Armenia. The developed questionnaire can be further used as a national cancer PREMs survey tool.

1. Introduction

On average, 18.1 million people are diagnosed with cancer in the world annually.[1] The incidence of cancer is on the rise, becoming a global pandemic. In 2018 over half of all cancer cases were diagnosed in Asia, which is explained by population density. Approximately 23% of new cases were registered in European countries, probably associated with the increasing average age of Europeans.[2] Cancer incidence is higher in high-income countries than in low and middle-income countries.[1] For example, in 2018 the age-standardized cancer incidence in high-income countries such as Australia and the USA were 468 and 352.2 per 100,000 population respectively.[3,4] Whereas in the Central African Republic, which is considered as one of the poorest countries, it was 92.4 per 100,000 population.[5] In Armenia, which is a middle-income country, the age-standardized incidence of cancer was 194.8 per 100,000 population in 2018.[6] In 2012, more than 40% of all new cases were diagnosed in countries that had high human development index (HDI) and only 7% in countries that had low HDI.[7]

The ten most commonly diagnosed types of cancers are responsible for over 65% of newly diagnosed cases including the lung, female breast, prostate, stomach, liver, oesophagus, cervix uteri, thyroid, bladder and colorectal cancers.[1] Lung cancer is the most common cancer among male population followed by prostate, colorectal and liver cancer, whereas females are more commonly diagnosed with breast, lung, colorectal, and cervical cancer. [2]

The 5-year prevalence of cancer is approximately 43.8 million people in the world.[8] This number is increasing due to the early diagnosis of cancer and improved survival over the years. Despite the scientific efforts to create new and more effective treatment guidelines,

cancer continues to be the second leading cause of mortality worldwide after cardiovascular diseases. In 2018, 9.6 million people died from cancer in the world.[8] Only one type of cancer – lung cancer – was the most common cause of death in 93 different countries and was responsible for 1.8 million deaths in the world during the same year (or 18.4% of cancer deaths).[1,2]

The incidence of cancer is increasing in Armenia as well. In 2017, 8,389 people were diagnosed with neoplasms in Armenia, which is 14% higher than in 2008 and 63% higher than in 1998.[9,10] Leading types of cancer among the male population were neoplasms of the respiratory system (lungs, broncs and larynges), stomach, bladder, and prostate and among females were breast, cervical, and colon cancers.[10]

1.1 Quality of provided health care services in cancer treatment

Cancer is an unforeseen event that can happen to every human being. Life after cancer diagnosis changes unexpectedly both for patients and family members who need to adapt to new psychological and physical norms.[11] The quality of provided health care can have a significant impact on the processes and outcomes of treatment as well as on the emotional well-being of patients.[12] A person who has just became a cancer patient may have many questions about the effectiveness of treatment, the severity of side effects and new life after the recovery.[11]

High-quality health care is an aggregate of human efforts, technologies and management to provide the best available treatment and support to patients.[13] Quality of provided cancer care can be perceived from two potentially different, physician and patient perspectives. While physicians could be more concerned about the availability of equipment, adequacy of

facilities and nurse shortage, patients are more focused on the processes of care, for instance communication with doctors, painfulness of treatment, and active decision making. [12,14] Two main measurement domains capture patient perspectives on provided care. The first, patient-reported outcome measures (PROMs), reflect different aspects of patient well-being, such as quality of life, and physical and mental health.[15,16] PROMs are widely used in cancer clinical trials to assess cancer treatment effectiveness and side-effects.[16] The second, patient reported experience measures (PREMs), are commonly used in determining the quality of care from the perspective of health care consumers. PREMs are considered as an objective measure of provided health care services as it eliminates the subjectivity associated with the reported patient satisfaction.[12] In comparison to PROMs, PREMs do not refer to the outcome of the treatment but reflect the process of it.[12] They are used as indirect indicators of the quality of the provided health services.

1.2 Financial toxicity and cancer outcomes

Cancer is one of the costliest diseases to treat,[17] and the cost of treatment is continuously increasing .[18,19] Per cycle costs of newly approved cancer drugs vary from around $10,000 to 100,000 in the USA.[20] Being only 2% of prescriptions made by US doctors, cancer drugs accounted for about 30% of overall spending for medications by insurance companies.[20] In Australia, the average cost of prescribed cancer drugs are approximately 2.5 times higher than the average cost of therapeutic medications during the last decade. [21] The price of the same drug can be different based on the field of usage. For instance, in the USA the cost of medicines that contain monoclonal antibodies is much higher when used in oncology than when used in immunology, allergology, cardiology, and endocrinology.[21]

The financial burden can influence patients' decisions about the initiation or continuation of cancer care.[18] Patients and their families appear in the vicious circle of financial problems. Having cancer leads to a decrease in working capacity, which directly reduces the income of the family. Thus, financial toxicity or burden can lead to catastrophic expenditures, which occur when one spends a relatively significant part of household income on medical services.[22]

Cancer outcomes can vary by patients' socio-economic status, race and type of insurance. These differences can be explained by inequities in access to treatments as well as differences in lifestyles.[19,23] Low social economic status was correlated with late-stage diagnosis among patients with prostate and breast cancer.[23] Introduction of health insurance is one of the effective ways to improve access to cancer treatment.[24,25]

1.3 Oncological services in Armenia

As a part of the national program against cancer, at the beginning of 2019, the Government of the Republic of Armenia changed the financing mechanism for the cancer treatment. The three main cancer treatment modalities include surgery, radiotherapy and chemotherapy. Previously, a 2011 order of the Minister of Health, established a co-payment scheme for surgical treatment.[26,27] The surgery techniques were classified into different categories, and for each category a fixed reimbursement established. This approach was not a traditional co-payment mechanism as patients were supposed to pay more than 50% of the cost, whereas originally co-payments were created as a good method to control the moral hazard. According to the new national program, introduced in 2019, surgical treatment for all types of cancer for Armenian citizens are fully reimbursed by the Armenian Government. For the chemotherapeutic treatment for each patient 150,000 AMD is allocated each year which was

paid with restrictions, with no more than 30,000 AMD paid for each course of treatment. If the patients are included in a vulnerable group (i.e., disabled population, WWII veterans, orphans, or children <18 years old without parental care and those related to them, children <18 years old in families with disabled members, children <18 years old in families with four or more children, <18 years old disabled children, children in orphanages and adults in nursing homes) the amount of reimbursement for the chemotherapeutic treatment is doubled.[28] The new national program does not include any changes in compensation for chemotherapeutic treatment. The payment for the radiotherapy was changed to differentiate services by the specific type of radiotherapeutic appliance used, such as linear accelerators which have power 15 Megavoltage and higher. Previously, the reimbursement for the single procedure was set as 26,500 AMD and after the changes it was almost doubled, reaching 46,500 AMD.[29]

1.4 Study rationale

In Armenia, no prior study examined patient-reported experiences among patients who received surgical treatment for cancer, neither before the implementation of the new national program nor after. In addition, it is not a common practice to evaluate PREMs in any types of patients. Therefore, it is important to collect information about the experience of patients regarding provided oncological services and evaluate the quality of provided cancer care. Such study can serve as a baseline evaluation of PREMs under the new governmental program and can be monitored continuously thereafter. The developed questionnaire can be further used as a national cancer PREMs survey tool.

2. Aim and study objectives

The study aims to evaluate patient-reported experiences of care among patients with cancer in Armenia. The primary objective of the study is to compare patient-reported experience measures among cancer survivors who received the surgical treatment before and after the implementation of the new government program in Yerevan, Armenia, 2019 and assess for meaningful differences.

The secondary objectives are to:

- assess the effect of the program on time between first diagnosis to treatment initiation;
- investigate the effect of the program on the patients' financial burden.
- identify the determinants of patient-reported experiences among cancer survivors in Armenia;

3. Conceptual framework

Several concetual frameworks attempt to measure the quality of the services provided in health care settings. The Hierarchical Model of Health Service Quality Scale served as a base for the Agency for Healthcare Research and Quality in the process of creation the HCAPHS hospital service questionnaire *(Figure 1)*.[30,31] The framework was created by Dagger et all and has four constructs that explore different aspects of the patient experience including interpersonal quality, technical quality, environment quality and administrative quality.[30] The authors of the framework emphasized the quality of interpersonal communication inside the hospital such as respect and dignity towards the patients.[30] Technical quality of provided care such as pain management, involvement of patients in the process of decision making about the treatment as well as physical environment of the hospital affect the attitude toward

the care process.[30] And finally, the administrative aspects of the treatment can form the perception of the quality of provided care.[30]

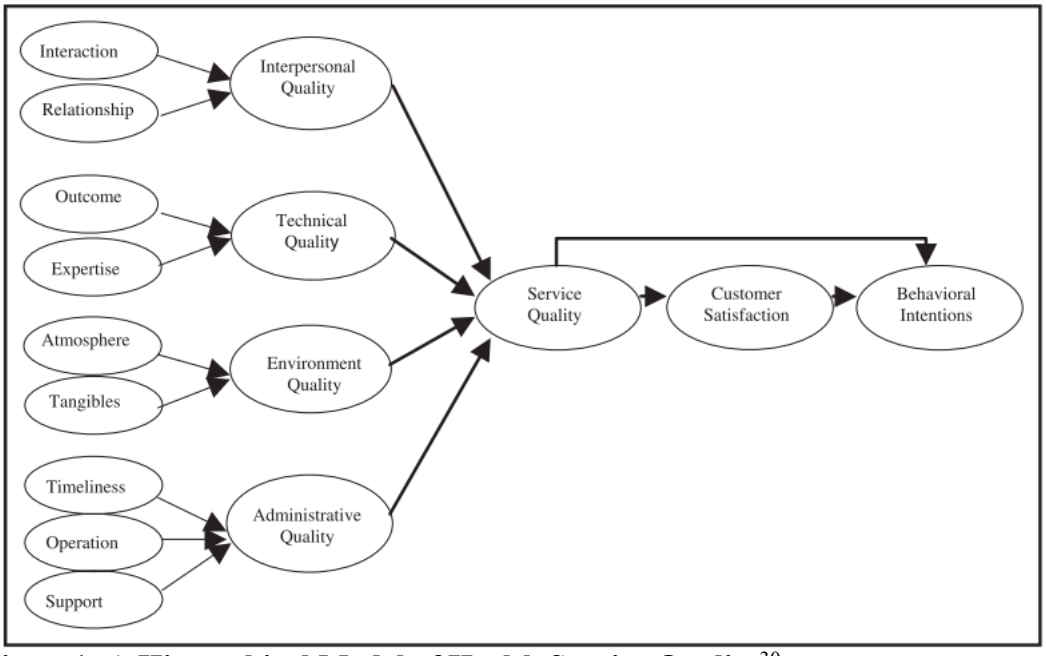

Figure1: A Hierarchical Model of Health Service Quality[30]

4. Literature review

One of the most important aspects of patent experience is communication with patients. Poor communication between healthcare providers and patients can influence the psychological health of patients leading to a denial of the disease,[32] depression and anxiety.[33] Relationships between cancer patients and doctors should be formed on active listening, informed decision making, personal needs of patients.A large gap exists between the needs of patients and what doctors think they need.[34] Thus, the literature emphasizes the importance of patient involvement in the decision-making process.[14,35] In a systematic review, Beck et al presented evidence of favorable health outcomes being associated with verbal communication.[36] Patients have higher satisfaction and increased compliance with their treatment when doctors provide emotional support as well as discuss their feelings.[37] Moreover, the treatment process benefits if doctors use less technical words so patients have no difficulties understanding the

disease or the treatment. Additionally, younger patients usually are more interested in receiving detailed information.[38] Misunderstandings can occur between doctors and patients, when patients bring up detailed information about feelings, thinking that it could be important, whereas doctors do not emphasize the emotional aspect of treatment.[37] Additionally, it is important to involve family members in the decision-making process.

Family is the primary supporting institution for cancer patients both emotionally, physically, and financially. Interestingly, the role of family members can vary in different cultures.[39] In western countries, information about the diagnosis is delivered directly to the patient.[40] Whereas in eastern countries such as Japan, doctors initially will consult with family members and then after with the patients.[41] No studies conducted in Armenia have explored this aspect of cancer care, although the cultural aspect of treatment is similar to eastern countries. Considering these cultural differences, doctors should be prepared to deliver the information about the diagnosis and prognosis of the treatment to both family and patient.[37] Involvement of patients and their family members in treatment process can improve the experience during the treatment and impact the positive outcomes.[42] "Patient involvement in the treatment process" includes the clear explanation of treatment stages, effects of prescribed drugs as well as detailed information about possible side effects of both treatment and drugs.[42,43] Only having complete information patients can become active decision makers, which is associated with better patient-reported experience.[44]

Physical comfort also can influence patient experience during the treatment. Cancer treatment often is associated with severe pain, which can significantly affect the quality of life of patients.[45,46] Additionally, patients might require assistance with daily activities during the treatment, which directly influence the psychological perception of treatment from patients'

point of view.[24] And finally, the environment in hospitals needs to be adapted to the patients' needs as well as be clean and calm to have a positive impact on the process of treatment.[35]

After treatment in hospitals, cancer survivors usually require special care at home such as management of specific symptoms, fatigue, and pain.[47] They demand proper nutrition and emotional support.[47] Both family members and patients must be prepared and taught how to deal with difficulties that occur after discharge.[35] The plan of the care should be adapted to the needs and available conditions of patients.[24] Cancer patients might need assistance after the release from the hospitals. Therefore, accessibility to medical personnel after office hours is essential. [24,35]

By setting standard procedures to measure PREMs, hospitals can increase the effectiveness of their treatment, improve the quality of treatment, and address the true expectations of patients.[48] PREMs can be classified into two groups, relational and functional. Relational PREMs are used to explore the relationships of medical personal, support staff and patients.[12] Functional PREMs are utilized to identify practical issues such as access to treatment.[12]

Since 2008 in the USA, the Consumer Assessment of Healthcare Providers and Systems (CAHPS) program has been launched with an overarching aim to increase scientific knowledge based on the consumers' point of view. It provides patients with an opportunity to share their experiences related to treatment plans, health care providers and organization of facilities.[49] Every patient who receives care in hospitals has a chance to participate in the assessment. Participants are selected randomly, and around 300 patients are surveyed annually from each hospital.[49] Data are collected by the hospitals and reported to the CAHPS Project Team quarterly, which analyzes and reports results back to the hospitals. Since April

2015, the collected information has been used for publicly reported hospital rating, which makes easier for patients and family members to select hospitals. The summary results of CAHPS Star Ratings are freely available on the CAPHS official website.[49] Other countries have embraced regular PREMs reporting. Based on CAHPS, for example, the Canadian Patient Experiences Survey was created, which is a standardized tool that collects data about PREMs in Canada.[50] PREMs are being extensively utilized as the indicators of quality of care in the UK and Netherlands as well.[12]

4.1 Factors influencing PREMs

PREMs can be influenced not only by the quality of provided care but also by patient characteristics.[48] These factors are interrelated, and it is hard to assess the effect of a specific element on patient-reported experience accurately. Experiences of cancer survivors can be different depending on age, gender, cancer type and stage, residential status, education level and financial status, the financial burden of treatment and other factors.[51] The literature demonstrates that one of the main factors influencing patient experience is the education level. Studies reported on the negative association between education level and reported patient experience score.[51,52] Previous studies showed that older survivors are more likely to provide higher scores for overall experience in comparison with younger patients[12] since they usually demonstrate better psychological adaptation to the new reality and cancer compared with younger patients.[53] However, the impact of age on patient-reported outcomes varies. Avis et al. reported that age could also be negatively associated with PREMs, given the prescribed treatment;younger patients, who are usually healthier, might receive more aggressive treatment which could negatively impact the experience of care.[54]At the same time, older patients with impaired physical health are more likely to develop complications during the treatment, which could also negatively affect the PREMs.[55]

Literature suggests a strong positive correlation between self-reported health status and PREMs.[56] Additionally, mental health or emotional well-being can positively impact the experience of cancer survivors.[56] Cancer type and stage can also affect the patient-reported experience. [51,56] In a study by Halperna et al. patients diagnosed with lung cancer were more likely to have lower PREMs in comparison with breast, colorectal and prostate cancer survivors.[56] PREMs can be influenced by the amount of out-of-pocket expenditures.[56] The financial burden of cancer treatment can harm the experience of patients while receiving services.[56]

5. Methods and Materials

5.1 Study design

I will conduct a phone survey and use a separate sample (independent) pre-post design to evaluate the PREMs of cancer survivors before and after the implementation of the national cancer program. The pre-program time period will include patients who received cancer surgery between 1 April and 6 July 2019. The post-program period will include patients who received cancer surgery between 8 July and 30 September 2019. Patients will be recruited from the two hospitals that provided cancer surgery services both before and after the implantation of the program. The selected study design will provide the opportunity to answer the research questions and will be feasible given the study time frame. While it may be subject to recall bias since data will be collected more than one year after receiving the care in the hospitals, I can use these findings to establish a basis at this time of policy transition and the need for a more rigorous prospective study.

5.2 Sample size calculation

The sample size was calculated based on the formula for independent group pre-post design and then inflated by design effect to account for the clustering.[57] The primary outcome is the PREM before and after the intervention. The sample size was calculated based on one of the nine domains in the CAHPS questionnaire, based on a single question asking patients to provide the "Overall rating of the hospital" on a scale from 0 to 10. The literature does not establish clinically meaningful difference for this scale. Considering that the scale for the outcome variable has an increment of 1, I assumed the effect size of 1 to be a meaningful difference in the scope of this study. I considered the standard deviation of 2.01 from the survey conducted to compare patient experience in two hospitals during the CAHPS Hospital Survey questionnaire validation process.[31] The sample size was calculated with α=0.05 and power=0.80. First, the formula for two sample means comparison was applied

$n_1 = 2\sigma^2 \frac{(Z_{\alpha/2}+Z_\beta)^2}{d^2}$, where σ^2 is variance of the outcome variable and d is the meaningful difference, n_1 is the sample size per group required under the assumption of independent samples,

$n_1 = 2 * 2.01^2 \frac{(1.96+0.842)^2}{1^2} = 64$

Considering the fact that patients received the treatment in the same hospitals both in pre and post-observation period, responses are likely correlated. Therefore, I inflated the computed sample size by design effect and estimated the final sample using the following formula:

$n_c = \frac{n_1 [1-\rho]}{\mathrm{k}-n_1\rho}$

where n_c is the sample size per cluster, ρ is the correlation within the cluster, and k is the number of clusters.

As there are no similar studies that measure the correlation in the quality of provided services score reported by patients that were treated in the same hospital, I assumed the largest correlation of 0.02 that provides the meaningful sample size given the limited number of available clusters (k=2).

$n_c = \frac{64_{[1-0.02]}}{2-64*0.02}$=87 per each cluster

Hence, the required sample is 87 before and 87 after the implementation of intervention per each hospital, with the total target sample size (accounting for two hospitals) of 348 patients.

6. Study setting and population

6.1 Study centers

The largest center that provides surgical and non-surgical treatment to the patients diagnosed with cancer is the National Center of Oncology named after V.A. Fanarjyan in Yerevan, Armenia. Cancer treatment services (although not in full spectrum) are also provided in other urban hospitals such as Nairi Medical Center, Shengavit Medical Center, Erebuni Medical Center, Medline Clinique, ArtMed Medical Center and Surb Grigor Lusavorich Medical Center and others.

I included the only two hospitals in Yerevan, Armenia that provided surgical treatment for cancer before implementation of the new program: the V.A. Fanarjyan National Oncology

Center and the Surb Grigor Lusavorich Medical Center. The National Oncology Center had the biggest share of the reallocated money after the implementation of the program.

6.2 Study population

The study target population is the patients who received the surgical treatment for cancer in Armenia before and after the implementation of the new national cancer program. The study population includes patients who received cancer surgery at the National Oncology Center or at the Surb Grigor Lusavorich Medical Center, Yerevan, Armenia. Cancer survivors who underwent cancer surgery during the defined pre- and post-program implementation periods in these two hospitals will be included in the sample population. The main focus of the study are patients who underwent surgical treatment as chemotherapeutic treatment did not change under the new program.

6.3 Study eligibility criteria

Patients will be eligible to the study if they were 18 years old at the time of diagnosis and received surgical treatment during the six months (April - September 2019) in the selected study hospitals. Patients with all stages of cancer and types will be included in the study. Participants should be fluent in Armenian or English and be Armenian citizens. If the patient had more than one surgery during these months, he/she will be surveyed only regarding the experiences around the first surgery.

6.4 Sampling strategy

Each hospital is considered a cluster as it most likely serves similar types of patients. Simple random sampling will be applied within each cluster (i.e., hospital) to identify 87 patients in the pre-implementation and post-implementation groups, respectively. E-health data collected

in hospitals for claims purposes submitted to State Health Agency in Armenia will be used as a sampling frame. The database also captures the ICD-10 diagnostic codes for cancers and patient contact information. Each claimant in the database who had a cancer surgery between April - September 2019 will be assigned a sequential number after which I will randomly select study participants using the "RANDBETWEEN" function in Excel. Thus, I will have 174 patients who receive the treatment before and after the initiation of the program, respectively.

7. Sources of data

7.1 Study variables

I will summarize the following variables/domains of interest to describe patient reported experiences in the study (Table 1): care from nurses, care from doctors, hospital environment, experience in the hospital, overall rating of the hospital, care after the discharge, care from medical center and contacting surgery team which are continuous variables and pain during the treatment which is a dichotomous variable. Time between diagnosis and surgical treatment is a continuous variable which indicates an average waiting length in months. Financial burden is a continuous variable, describing the hardship of the patient and family members during the treatment and will be assessed based on the scale from 0-10. Informal payment is a binary variable with yes/no responses. Additionally, the study participants will have an option to specify the amount of payment if they selected "yes" in a previous variable. The main independent variable of the study is the implementation of the intervention defined by study pre-implementation and post-implementation group designation variable. Other important covariates of interest are age, gender, education level, self-reported mental health,

self-reported physical health, residential status and monthly expenditures as an indicator of the financial status.

Table 1: Independent and dependent variables

	cc	Type	Range
Dependent	***9 Domains of PREMs****		
	Care form nurses	Continuous	1-4
	Care form doctors	Continuous	1-4
	Hospital environment	Continuous	1-4
	Experiences in the hospital	Continuous	1-4
	Care after the discharge	Continuous	1-4
	Care from medical center	Continuous	1-4
	Pain during the treatment	Binary	Yes/No
	Overall rating of the hospital	Continuous	0-10
	Contacting surgery team	Continuous	1-3
	Secondary outcome variables		
	Financial burden	Continuous	0-10
	Informal payment	Binary	Yes/No
	Informal payment amount (AMD)	Continuous	
	Time to treatment	Continuous	Months
Independent	*Age*	Continuous	Years
	Gender	Binary	Male/Female
	Residential status	Binary	Yerevan/non-Yerevan
	Education level	Ordinal	School (< 10 yrs); School (10 yrs); Professional technical education (10-13 yrs); University; Postgraduate
	Self-reported physical health,	Ordinal	Excellent; Very good; Good; Fair; Poor
	Self-reported mental health	Ordinal	Excellent; Very good; Good; Fair; Poor
	Monthly expenditures (AMD)	Ordinal	<50,000; 50,001 - 100,000; 100,001 - 200,000; 200,001 - 300, 000; > 300,001
	Inclusion in the program	Binary	Yes/No

**Each of nine domains of PREMs is composed of 1 to 5 items (Appendix 2). The composite score for each domain is calculated as an average score of the items within the domain.*

7.2 Data collection

Two trained interviewers will do data collection. Interviewers will participate in two-day trainings based on the interviewer manual. (Appendix 1) Data will be collected via phone surveys and simultaneously entered in an electronic database in SPSS software. The data collection process will require two months. Paper-based questionnaires will be kept in a safe place, and only student investigator and research assistants will have access to the data. I will conduct data cleaning procedures such as double data entry and range check to minimize errors. Each questionnaire will have an ID number in order to correct the inaccuracies that will be found as a result of data cleaning. After the data cleaning, missing values will be assessed. Data analysis will be done after the data cleaning using STATA software.

7.3 Survey procedure

After assessing for eligibility, the interviewers will contact the potential participant using the phone number in the e-record. They will inform about the ongoing study, read the consent form and ask about the willingness to participate in the survey. If the participant agreed to participate, the interviewer will administer the survey. The interview can be conducted when the phone call was made or later, at the agreed time convenient for the patient. If the phone number belongs to a person other than the patient, interviewers will present the study, and the contact number of the patients will be asked from the owner of the given number. If the patient deceased, the interviewers will apologize for the disturbance and politely complete the conversation.

7.4 Study instrument

The CAHPS Hospital Survey instrument was selected as the study instrument as it is coherent with the research question and conceptual framework. The validated questionnaire measures

seven different dimensions of patient experiences including communication with nurses, communication with doctors, hospital environment, experience in the hospital, discharge information, overall rating of the hospital and care transition.[49] The Spearman-Brown reliability ranges from 0.80 to 0.93 for different domains of the questionnaire. Cronbach's alpha, which tests the internal consistency, Cronbach Alfa of the various domains of the instrument was found to be between 0.51 -0.86 [49]. The tool has also been shown to have high criterion validity. [49]

The original CAPHS Hospital Survey instrument has the following domains: "Care from nurses" (4 items), "Care from doctors" (3 items), "Hospital environment" (2 items), "Experiences in the hospital" (5 items), "Overall rating of hospital" (1 items), Understanding the care when you left the hospital" (3 items). Additionally, three more domains from the cancer specific HCAPHS questionnaire such as "Your care from this cancer center" (3 items), "Contacting your cancer surgery team" (3 items) and "Pain management" (2 items), were also added to the questionnaire. The questions about the demographic characteristics (education level, monthly expenditures, self-reported mental and physical health) were developed based on the same CAPHS Hospital Survey tool and questions from the existing Armenian instruments published by CHSR.[58] Additional questions about the time of diagnosis and type of treatment were added to this section. Three questions about the National Program was created. The utilization of the CAHPS Cancer Care questionnaire was omitted, considering that the diagnosis of cancer is not always disclosed to patients in Armenia and patients might not be aware of their cancer. The used questionnaire was changed in a way, that if a person is not aware of their disease, will not be able to guess it from the study. For the same reason, the word "cancer" was excluded from the questionnaire and referred as 'the condition for which you had a surgery'.

The final questionnaire has an overall 37 items, measuring 9 different domains as described. “Care from nurses”, “Care from doctors”, “Hospital Environment”, “Experiences in the hospital” and “Your care from this cancer center" are measured in the 4-item scale from “Always, Sometimes, Usually, Never”. "Overall rating of the hospital" has two items which will be measured form the scales from 0 to 10. And finally, two domains “Contacting your cancer surgery team" and “Understanding your care when you left the hospital" will be measured with the following options: "Strongly disagree, Disagree, Agree, Strongly agree”.

The final version of the questionnaire was developed in English and adapted to the local context, considering the fact that in Armenia, many patients could be not aware of their final diagnosis. The questionnaire was translated into Armenian by two separate translators. Afterwards, the final version of the Armenian questionnaire was created and translated back into English by a bilingual native speaker. The translated English version was compared with the original questionnaire in order to assess the quality of translation. Final version of the instrument both in Armenian and English is attached in *Appendix 2* and *Appendix 3* respectively.

8. Statistical analysis

Descriptive analysis will be conducted to characterize patients in pre- and post-implementation periods. Categorical and ordinal variables such as gender, education level, residential status, self-reported mental and physical health and monthly expenditures will be summarized as frequencies and percentages and compared using Chi-square test and continuous variable-age will be described as mean value and standard deviations (or as

median and interquartile ranges if non-normally distributed variables) and compared using Student-t-test as applicable.*(Table 1).*

Descriptive analysis followed by hypothesis testing will be conducted to evaluate each outcome outlined in research questions:

Primary objective. Differences in patient-reported experiences between cancer survivors who received surgical treatment before and after the implementation of the program will be evaluated through individual domains of PREMs. Pain during treatment, a binary variable, will be presented as counts and percentages and the values before and after implementation the program will be compared using Chi-square test. Care from doctors, care from nurses, experience in the hospital, overall rating of the hospital, care after the discharge, care from medical center and contacting surgery team which are continuous variables will be described as mean/median and standard deviations/interquartile ranges and compared using Student –t-test or two-sample Mann–Whitney U Test respectively.

Secondary Objectives. Time between the first diagnosis and treatment initiation (***Objective 2***) and financial burden (***Objective 3***) before and after implementation of the program, both continuous variables, will be analyzed similarly. Additionally, the number of patients who gave informal payments as well as the amount of it will be compared before and after the program using Chi-square test and Student –t-test or two-sample Mann–Whitney U Test respectively.

In the literature, the overall rating of the hospital is often used as an indicator of overall PREMs. Thus, for the purpose of this study, scores on overall hospital rating will represent the overall patient experience with hospital services. To identify determinants of patient overall experience, I will conduct unadjusted and adjusted linear regression analyses (***Objective 4***). A univariable regression will be performed to estimate the effect of age, gender, education level, self-reported mental health, self-reported physical health, residential status and monthly expenditures on overall hospital rating. Variables with $p< 0.25$ will be further included in multivariable regression analysis. I will use step-wise backward elimination procedure for model selection. A final model will be selected based on Akaike information criterion. [59] Statistical significance will be considered at $p <0.05$ for all tests. Analysis will be completed using STATA software.

9. Logistic considerations

The study will take two months to complete, starting from July 6, 2020 *(Table 3).* Two trained interviewers will complete the data collection for three weeks. Double data entry will be done simultaneously with data collection. The study coordinator will do spot checks for two interviews per day on the same day of the interview. Data cleaning and analysis will require tree weeks starting from August 3, 2020. The study investigators will analyze data and prepare the final report.

Table 2. Timelines of the study

Procedure	**Date of initiation**	**Duration**
Data collection	July 6, 2020	3 weeks
Data Entry	July 7, 2020	4 weeks
Data cleaning	August 3, 2020	1 week
Data analysis	August 10, 2020	2 weeks
Final report to present the results	August 24, 2020	2 weeks

9.1 Study personnel

The study personnel will include a coordinator, two interviewers who will also complete the data entry and a statistician. The study coordinator will be responsible for (1) the coordination of the study in compliance with the study protocol and timelines, (2) training of the interviewers, (3) ensuring implementation of proper procedures to maintain confidentiality (4) quality control of data collection (e.g., spot checks) and data entry and (5) drafting the final report under the guidance of study investigators.

9.2 Study budget

The financial resources of the proposed research will be allocated between the salaries for hired personnel and operational cost of the study. Two hired interviewers and two data enterers will be paid on hourly bases, whereas the study coordinator and statistician will have a fixed salary. Staff costs are calculated based on average operating salaries in non-governmental research organizations in Armenia (Table 4). The operational costs will include phone bills as well as costs of printing materials. The office rent was calculated based on the average cost of the small office in Yerevan and can be revised if the funding organization provides the operating office. The overall budget of the proposed study is 667,500AMD including 557,600 AMD in total for personnel costs and 109,900 AMD for operational costs *(Table 4).*

Table 3. Budget allocation

Service	***Unit type***	***Number of units***	***Cost per unit in AMD***	***Final Cost***
Personnel				
Study coordinator	Monthly salary	2	80,000	160,000
Interviewer	Hours	118	1,200	115,000
Data entry clerk	Hours	48	1,200	57,600
Statistician	Monthly salary	1	225,000	225,000
			Total cost for personnel	557,600

Operational costs				
Printing cost: Questionnaire	6 pages/ Double sided	370	8	17,760
Printing cost: Journal Forms and training materials	Single sided	42	12	500
Stationary (Pen, pencils, notebooks)		1	8,000	8,000
Phone bill	Cost per minute	5,576*	15	83,640
			Total operational cost	109,900
			Total budget	667,500

**Total number of minutes were calculated based on 15 minutes/call for 354 calls and 5 % for the spot checks and additional calls.*

10. Ethical considerations

The Institutional Review Board 1 (IRB) of the American University of Armenia approved this study protocol (PROTOCOL #: AUA-2020-003) (Appendix 4). I conducted the pretest of the questionnaire among ten cancer survivors after the approval.

Oral consent will be acquired from all study participants before starting the interview *(Appendix 5, Appendix 6).* The information obtained from the study participants will be confidential and will be used only for study purposes. The phone numbers of participants will be obtained from the e-health database in an electronic version. Phone numbers will not be printed but kept in an electronic password protected file. All selected participants will be given an ID, which will be linked to phone numbers. Study database that will capture survey responses will only have patient IDs (no phone numbers, names or any other identifiers). Patients who refuse to participate will be accounted for in the journal form and reasons for refusal recorded (*Appendix 7).* Any study-related hard copy documents (journal forms, questionnaires if paper forms are used) will be stored in a locked cabinet at CHSR, AUA. The electronic study databases will be password protected and kept in a password protected

computer. Only the research team, which includes student investigator and co-investigators, will have access to data.

11. Significance

Quality of provided care and financial burden of care can have a direct influence on treatment outcomes. Thus, to assess the quality of care from a patient's perspective, I propose to measure patient-reported experiences among cancer survivors who underwent the treatment before and after the implementation of the nationwide financial program which aimed to relieve the financial burden among Armenian citizens diagnosed with neoplasms. The findings of the study will provide baseline evaluation for the national program and potentially create foundation for continuous reporting of consumers' perspectives on provided cancer care in Armenia. The results of the survey will help to identify the areas for improvement as well as emphasize the stronger aspects of care. The adapted instrument can be further used for the annual nationwide surveys to evaluate PREMs among cancer survivors.

References

1. Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, Jemal A. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin*. 2018;68(6):394-424. doi:10.3322/caac.21492
2. Thomas A. International Agency of Research on Cancer (France). *J Med Soc Toho Univ*. 2018;50(1):106-107.
3. International Agency for Research on Cancer, Global Cancer Observatory. Report Globocan in United States of America. 2018;087:3. https://gco.iarc.fr/today/data/factsheets/populations/840-united-states-of-america-fact-sheets.pdf.
4. International Agency for Research on, Observatory GC. Report Globocan in Australia. 2018;558:2018-2019. https://gco.iarc.fr/today/data/factsheets/populations/36-australia-fact-sheets.
5. International Agency for Research on Cancer. Report Globocan in Central African Republic. 2018;537:2018-2019. http://gco.iarc.fr/today/data/factsheets/populations/140-central-african-republic-fact-sheets.
6. World HealthOrganisation. Armenia. Factsheet of cancer. 2019;375:2018-2019.
7. International Agency for Research on Cancer, Observatory GC. Report Globocan in World cancer. 2014. www.cruk.org/cancerstats.
8. American Cancer Society. Estimated Number of New Cancer Cases by World Area, 2018. 2018. doi:10.1787/health_glance_eur-2018-graph47-en
9. The Republic of Armenia Ministry of Health. *Statistical Yearbook of Armenia, PUBLIC HEALTH*.; 2019.
10. D.Andreasyan, A Bazarchyann S. S et al. *Health and Healthcare Statistical Year Book 2017, National Institute of Health Named after Academician S. Avdalbekyan*. Yerevan; 2017.
11. Canadian Partnership Against Cancer. Living with Cancer: A Report on the Patient Experience. 2018;(January):52. https://content.cancerview.ca/download/cv/quality_and_planning/system_performance/documents/living_with_cancer_patient_experience_report_enpdf?attachment=0.
12. Baumhauer JF, Bozic KJ, Wright JG, et al. A Guide to Patient Reported Measures – Theory , Landscape and Uses A Guide to Patient Reported Measures A Guide to Patient Reported Measures – Theory , Landscape and Uses. *Cureus*. 2017;9(1):315-317. doi:10.7759/cureus.1046
13. Donabedian A. Quality assessment and assurance: unity of purpose, diversity of means. *Inquiry*. 1988;25(1):173-192.
14. Robert G, Cornwell J, Locock L, Purushotham A, Sturmey G, Gager M. Patients and staff as codesigners of healthcare services. *BMJ*. 2015;350(February):1DUMMUY. doi:10.1136/bmj.g7714
15. Bouazza Y Ben, Chiairi I, El Kharbouchi O, et al. Patient-reported outcome measures (PROMs) in the management of lung cancer: A systematic review. *Lung Cancer*. 2017;113:140-151. doi:10.1016/j.lungcan.2017.09.011
16. Fitzpatrick R, Davey C, Buxton MJ, Jones DR. Evaluating patient-based outcome measures for use in clinical trials. *Health Technol Assess (Rockv)*. 1998;2(14). doi:10.3310/hta2140
17. Chi M. The Hidden Cost of Cancer: Helping Clients Cope with Financial Toxicity. *Clin Soc Work J*. 2019;47(3):249-257. doi:10.1007/s10615-017-0640-7

18. Zafar SY, Abernethy AP. Financial toxicity, Part I: a new name for a growing problem. *Oncology (Williston Park)*. 2013;27(2):2-6.
19. Ramsey S, Shankaran V. Managing the Financial Impact of Cancer Treatment : The Role of Clinical Practice Guidelines Journal of the National Comprehensive Cancer Network The Last Word Managing the Financial Impact of Cancer Treatment : The Role of Clinical Practice Guidelines Th. *J Natl Compr Can Netw*. 2012;10(8):1037-1042.
20. Light DW, Kantarjian H. Market spiral pricing of cancer drugs. *Cancer*. 2013;119(22):3900-3902. doi:10.1002/cncr.28321
21. World Health Organization. *Pricing of Cancer Medicines and Its Impacts*.; 2018.
22. Xu K, Evans DB, Carrin G, Aguilar-Rivera Ana Mylena. *DESIGNING HEALTH FINANCING SYSTEMS TO REDUCE CATASTROPHIC HEALTH EXPENDITURE*.; 2005.
23. Clegg LX, Reichman ME, Miller B a, et al. Impact of socioeconomic status on cancer incidence and stage and end results: National Longitudinal Mortality Study. *Cancer Causes Control*. 2009;20(4):417-435. doi:10.1007/s10552-008-9256-0.Impact
24. Levit L, Balogh E, Nass S, Ganz PA. *Delivering High-Quality Cancer Care : Charting a New Course for a System in Crisis Challenges of an Aging Population ; Board on Health Care Services ;*; 2013.
25. Timbie JW, Bogart A, Damberg CL, et al. Medicare Advantage and Fee-for-Service Performance on Clinical Quality and Patient Experience Measures: Comparisons from Three Large States. *Health Serv Res*. 2017;52(6):2038-2060. doi:10.1111/1475-6773.12787
26. ՀԱՅԱՍՏԱՆԻ ՀԱՆՐԱՊԵՏՈՒԹՅԱՆ ԿԱՌԱՎԱՐՈՒԹՅՈՒՆ. ՀԱՅԱՍՏԱՆԻ ՀԱՆՐԱՊԵՏՈՒԹՅԱՆ ԿԱՌԱՎԱՐՈՒԹՅԱՆ 2004 ԹՎԱԿԱՆԻ ՄԱՐՏԻ 4-Ի N 318-Ն ՈՐՈՇՄԱՆ ՄԵՋ ՓՈՓՈԽՈՒԹՅՈՒՆՆԵՐ ԵՎ ԼՐԱՑՈՒՄ ԿԱՏԱՐԵԼՈՒ ՄԱՍԻՆ. 2015.
27. Հայաստանի Հանրապետության կառավարության. Ո Ր Ո Շ ՈՒ Մ Պետության կողմից երաշխավորված անվճար բժշկական օգնության և սպասարկման մասին. 2004;318 որոշու.
28. Dorothee Chen. Universal Health Coverage Study Series No . 36. *World Bank*. 2018;(36):1-36. doi:10.1145/958491.958516
29. Հայաստանի Հանրապետության Առողջապահության Նախարարի Հրաման. Պետության կողմից երաշխավորված բժշկական օգնության և սպասարկման " Ուռուցքաբանական և արյունաբանական հիվանդությունների բժշկական օգնության ծառայություններ" ծրագրի շրջանակներում 15 և ավելի MEV հզորություն ունեցող բժշկական գծային արագացուցիչով ճառագայթային բուժո. In: Vol հունվար 19. ; 2020:257.
30. Dagger TS, Sweeney JC, Johnson LW. A hierarchical model of health service quality: Scale development and investigation of an integrated model. *J Serv Res*. 2007;10(2):123-142. doi:10.1177/1094670507309594
31. Westbrook KW, Babakus E, Grant CC. Measuring Patient-Perceived Hospital Service Quality: Validity and Managerial Usefulness of HCAHPS Scales. *Health Mark Q*. 2014;31(2):97-114. doi:10.1080/07359683.2014.907114
32. Maguire P, Faulkner A. Communication with cancer patients: 1 Handling bad news and difficult questions. *Br Med J*. 1988;297(6653):907-909. doi:10.1136/bmj.297.6653.907
33. Fallowfield LJ, Hall A, Maguire GP, Baum M. Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. *Br Med J*.

1990;301(6752):575-580. doi:10.1136/bmj.301.6752.575
34. Lee CN, Hultman CS, Sepucha K. Do patients and providers agree about the most important facts and goals for breast reconstruction decisions? *Ann Plast Surg*. 2010;64(5):563-566. doi:10.1097/SAP.0b013e3181c01279
35. NQB NQB. NHS Patient Experience Framework. *Dep Heal*. 2011;(17273):17273. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215159/dh_132788.pdf.
36. Beck RS, Daughtridge R, Sloane PD. Physician-patient communication in the primary care office: A systematic review. *J Am Board Fam Pract*. 2002;15(1):25-38.
37. Baile WF, Aaron J. Patient-physician communication in oncology: Past, present, and future. *Curr Opin Oncol*. 2005;17(4):331-335. doi:10.1097/01.cco.0000167738.49325.2c
38. Jenkins V, Fallowfield L, Saul J. Information needs of patients with cancer: Results from a large study in UK cancer centres. *Br J Cancer*. 2001;84(1):48-51. doi:10.1054/bjoc.2000.1573
39. Al-Bahri A, Al-Moundhri M, Al-Azri M. The role of patients' families in cancer treatment decision-making: Perspectives among eastern and western families. *Sultan Qaboos Univ Med J*. 2017;17(4):e383-e385. doi:10.18295/squmj.2017.17.04.001
40. Pardon K, Deschepper R, Stichele R Vander, et al. Preferences of patients with advanced lung cancer regarding the involvement of family and others in medical decision-making. *J Palliat Med*. 2010;13(10):1199-1203. doi:10.1089/jpm.2010.0100
41. Sekimoto M, Asai A, Ohnishi M, et al. Patients' preferences for involvement in treatment decision making in Japan. *BMC Fam Pract*. 2004;5:1-10. doi:10.1186/1471-2296-5-1
42. Vahdat S, Hamzehgardeshi L, Hessam S, Hamzehgardeshi Z. Patient involvement in health care decision making: A review. *Iran Red Crescent Med J*. 2014;16(1):1-7. doi:10.5812/ircmj.12454
43. Hawley ST, Lantz PM, Janz NK, et al. Factors Associated with Patient Involvement in Surgical Treatment Decision Making for Breast Cancer. *Bone*. 2008;23(1):1-7. doi:10.1038/jid.2014.371
44. Arnetz JE, Almin I, Bergström K, Franzén Y, Nilsson H. Active patient involvement in the establishment of physical therapy goals: Effects on treatment outcome and quality of care. *Adv Physiother*. 2004;6(2):50-69. doi:10.1080/14038190310017147
45. Pergolizzi J V., Gharibo C, Ho KY. Treatment Considerations for Cancer Pain: A Global Perspective. *Pain Pract*. 2015;15(8):778-792. doi:10.1111/papr.12253
46. Niv D, Kreitler S. Pain and Quality of Life. *Pain Pract*. 2001;1(2):150-161. doi:10.1046/j.1533-2500.2001.01016.x
47. Hendrix CC, Bailey Jr DE, Steinhauser KE, et al. Effects of Enhanced Caregiver Training Program on Cancer Caregiver's Self-Efficacy, Preparedness, and Psychological Well-Being. *Physiol Behav*. 2017;176(1):139-148. doi:10.1016/j.physbeh.2017.03.040
48. Kingsley C, Patel S. Patient-reported outcome measures and patient-reported experience measures. *BJA Educ*. 2017;17(4):137-144. doi:10.1093/bjaed/mkw060
49. HCAHPS. HCAHPS Fact Sheet. *Centers Medicare Medicaid Serv*. 2017;(June):1-4. http://www.hcahpsonline.org/Files/HCAHPS_Fact_Sheet_June_2015.pdf.
50. Canadian Institute for Health Information. Canadian Patient Experiences Survey, Inpatient Care Procedure Manual. 2019.
51. Tremblay D, Roberge D, Berbiche D. Determinants of patient-reported experience of cancer services responsiveness. *BMC Health Serv Res*. 2015;15(1):1-10.

doi:10.1186/s12913-015-1104-9
52. Holzer BM, Minder CE. A simple approach to fairer hospital benchmarking using patient experience data. *Int J Qual Heal Care*. 2011;23(5):524-530. doi:10.1093/intqhc/mzr047
53. Avis NE, Smith KW, McGraw S, Smith RG, Petronis VM, Carver CS. Assessing Quality of Life in Adult Cancer Survivors (QLACS). *Qual Life Res*. 2005;39(1):1007-1023. doi:10.1007/sI 1136-004-2147-2
54. Avis NE, Deimling GT. Cancer survivorship and aging. *Cancer*. 2008;113(12 SUPPL.):3519-3529. doi:10.1002/cncr.23941
55. Kenzik K, Morey MC, Cohen HJ, et al. Intervention Study of Older Cancer Survivors. 2016;6(6):424-432. doi:10.1016/j.jgo.2015.08.004.Symptoms
56. Halperna MT, Uratoa MP, Linesa LM, Cohena JB, Neeraj A, Erin EK. Healthcare Experience among Older Cancer Survivors: Analysis of the SEER-CAHPS Dataset Michael. *Am Fam Physician*. 2018;38(1). doi:10.1016/j.jgo.2017.11.005.
57. Donner A, Birkett N, Buck C. Randomization by cluster: sample size requirements and analysis. *Nurs Res*. 1991;40(6):356-358. doi:10.1097/00006199-199111000-00007
58. Demirchyan A, Harutyunyan T, Petrosyan V TM. Household Health Survey: Baseline Evaluation. 2008:90-91. http://aua.am/chsr/UserFiles/File/1_HHS2006_FINAL.pdf.
59. Awad AM. Properties of the akaike information criterion. *Microelectron Reliab*. 1996;36(4):457-464. doi:10.1016/0026-2714(95)00143-3

Appendix 1. Interviewer guide (Armenian version)

ՈՒՂԵՑՈՒՅՑ ՀԱՐՑԱԶՐՈՒՑԱՎԱՐՆԵՐԻ ՀԱՄԱՐ

Քաղցկեղով հիվնադների շրջանում բուժառուների փորձառության փոփոխության գնահատում ֆինանսավորման վերաբերյալ օրենքի ներդրման արդյունքում երկու հանրային հիվանդանոցներում, Երևան, Հայաստան:

Ծանոթություն ծրագրին

Այս հետազոտության նպատակն է ուսումնասիրել և համեմատել քաղցկեղով հիվանդերի շրջանում բուժառուների փորձառությունը, որոնք բուժում են ստացել 2018 հոկտեմբերից մինչև 2019 թվականի մարտ ամիսը ընկած ժամանակահատվածում Վ. Ա. Ֆանարջյանի անվան Ուռուցքաբանության Ազգային Կենտրոնում կամ Սուրբ Գրիգոր Լուսավորիչ բժշկական կենտրոնում: Այդ նպատակով կատարվելու է հետազոտություն հեռախոսազանգերի միջոցով:

Հարցմանը ենթակա բնակչությունը

Հետազոտությանը մասնակցելու են Հայաստանի Հանրապետության այն քաղաքացիները, որոնք ստացել են վիրահատական բուժում կա՛մ Վ. Ա. Ֆանարջյանի անվան Ուռուցքաբանության Ազգային Կենտրոնում, կա՛մ Սուրբ Գրիգոր Լուսավորիչ բժշկական կենտրոնում: Մասնակիցները բաժանվել են երկու խմբի՝ կախված բուժումը ստանալու ժամանակահատվածից:

Հարցազրուցավարների նախապատրաստում

Հետազոտությանը մասնակցելու համար ընտրված հարցազրուցավարները պետք է մասնակցեն երկժամյա ուսուցմանը: Ուսուցման ընթացքում նրանք կծանոթանան հետազոտության նպատակին, իրենց գործողությունների կարգին և հերթականությանը: Դասընթացի ընթացքում հարցազրուցավարները հնարավորություն կունենան կարդալ հարցաթերթիկը և փորձարկել հարցազրույցի ընթացքը միմյանց հետ:

Հետազոտության ընթացքում հարցազրուցավարին կտրամադրվեն հարցաթերթիկներ և հարցման մատյանի ձև, որոնք պետք է լրացվեն յուրաքյանչյուր հեռախոսազանգի ժամանակ: Մեկ հեռախոսազրույցի տևողությունն է 10-15 րոպե:

Հարցազրուցավարների պարտականությունները

Հետոզոտության համակարգողը կտրամադրի հարցազրուցավարներին բուժառուների աննունները և հեռախոսահամարները: Հարցերի դեպքում հարցազրուցավարը պետք է կապ հաստատի հետազոտության համակարգողի հետ և չկայացնի ինքնուրույն որոշումներ:
Հարցազրույցը տեղի կունենա Ամերիկյան Համալսարանի Հանրային Առողջության Ֆակուլտետի Սոխիկյան գրադարանում:

Ներածություն հարցազրուցավարի համար

Բարև Ձեզ: Իմ անունը Մերի է: Ես Հայաստանի Ամերիկյան Համալսարանի Թրփանճեան Հանրային առողջապահության ֆակուլտետի ավարտական կուրսի ուսանող եմ և այժմ աշխատում եմ իմ մագիստրոսական թեզի վրա, որի նպատակն է գնահատել բուժառուների փորձառությունը Քանաքեռի հիվանդանոցում / Սուրբ Գրիգոր Լուսավորիչ ԲԿ-ում բուժում ստանալիս: Ձեր հեռախոսահամարը տրամադրվել է Առողջապահության Նախարարության կողմից: Ձեր կողմից տրամադրված ինֆորմացիան կմնա գաղտնի:

(Հարցազրուցավարի համար)Ես Հայաստանի Ամերիկյան Համալսարանի Առողջապահական ծառայությունների հետազոտման և զարգացման կենտրոնից եմ: Իմ անունն է ____: Այժմ իրականացվում է մի հետազոտություն, որի նպատակն է գնահատել բուժառուների փորձառությունը Քանաքեռի հիվանդանոցում / Սուրբ Գրիգոր Լուսավորիչ ԲԿ-ում բուժում ստանալիս: Ձեր հեռախոսահամարը տրամադրվել է Առողջապահության Նախարարության կողմից: Ձեր կողմից տրամադրված ինֆորմացիան կմնա գաղտնի:

<u>ԿԱՍԿԱԾԻ</u> դեպքում

Հարցումը անանուն է, իսկ հեռախոսահամարները կոչնչացվեն անմիջապես հետազոտության ավարտից հետո: Տրամադրված տվյալները կօգնեն բարելավել հիվանդանոցային ծառայությունների որակը: Հետազոտության տվյալները չեն վնասելու ո՛չ բժիշկներին, ո՛չ բուժքույրերին, ո՛չ բուժանձնակազմի այլ անդամներին:

- **<u>ՄԵՐԺՄԱՆ</u>** դեպքում

Շնորհակալություն հայտնել մասնակցին տրամադրած ժամանակի համար և պարզել մերժման պատճառը:

- **<u>ՀԱՄԱՁԱՅՆՎԵԼՈՒ</u>** դեպքում

Շնորհակալություն հայտնել և ստուգել մասնակցի համապատասխանությունը:

Արդյոք դուք ստացել եք բուժում Քանաքեռի հիվանդանոցում/ Սուրբ Գրիգոր Լուսավորիչ Բժշկական կենտրոնում 2018 հոկտեմբերից մինչև 2019 մարտ ընկած ժամանակահատվածում:

- Եթե մասնակիցը **<u>ՀԱՄԱՊԱՏԱՍԽԱՆՈՒՄ Է</u>** հետազոտության չափանիշներին կարող եք շարունակել հարցազրույցը և անցնել բանավոր համաձայնության ձևին:

- Եթե մասնակիցը **<u>ՉԻ ՀԱՄԱՊԱՏԱՍԽԱՆՈՒՄ</u>**

1. կարող եք խնդրել, եթե հանարավոր է տրամադրել բուժառուի կոնտակտային տվյալները
2. եթե բուժառուն այլևս կենդանի չէ, ասել որ ցավում եք կորստի համար, ներողություն խնդրել անհանգստացնելու համար և ավարտել հարցազրույցը

Ավարտելիս շնորհակալություն հայտնել մասնակցության համար:

Appendix 2. Questionnaire (English version)

Questionnaire to measure patient reported experience among cancer survivors in Yerevan Armenia.

Participant ID _____

Interviewer ID _____

Date (_ _ / _ _ /2020)

Start time __ : __ End time __: __ (24 hour format)

Type of cancer _____

FURTHER QUESTIONS RELATE TO THE CARE RECEIVED FROM NURSES		
1.	During this hospital stay, how often did nurses treat you with courtesy and respect?	1☐ Never 2☐ Sometimes 3☐ Usually 4☐ Always
2.	During this hospital stay, how often did nurses listen carefully to you?	1☐ Never 2☐ Sometimes 3☐ Usually 4☐ Always
3.	During this hospital stay, how often did nurses explain things in a way you could understand?	1☐ Never 2☐ Sometimes 3☐ Usually 4☐ Always
4.	During this hospital stay, when you needed a help from nurses, how often did you get help as soon as you wanted it?	1☐ Never 2☐ Sometimes 3☐ Usually 4☐ Always
FURTHER QUESTIONS RELATE TO THE CARE RECEIVED FROM DOCTORS		

5.	During this hospital stay, how often did doctors treat you with courtesy and respect?	1☐ Never 2☐ Sometimes 3☐ Usually 4☐ Always
6.	During this hospital stay, how often did doctors listen carefully to you?	1☐ Never 2☐ Sometimes 3☐ Usually 4☐ Always
7.	During this hospital stay, how often did doctors explain things in a way you could understand?	1☐ Never 2☐ Sometimes 3☐ Usually 4☐ Always
	Further questions relate to the hospital environment	
8.	During this hospital stay, how often were your room and bathroom kept clean?	1☐ Never 2☐ Sometimes 3☐ Usually 4☐ Always
9.	During this hospital stay, how often was the area around your room quiet at night?	1☐ Never 2☐ Sometimes 3☐ Usually 4☐ Always
FURTHER QUESTIONS RELATE TO THE EXPERIENCES IN THE HOSPITAL		
10.	During this hospital stay, did you need help from nurses or other hospital staff in getting to the bathroom or in using a bedpan?	1☐ Yes 2☐ No ➔ If No, Go to Question 12
11.	How often did you get help in getting to the bathroom or in using a bedpan as soon as you wanted?	1☐ Never 2☐ Sometimes 3☐ Usually 4☐ Always

		5☐ I did not approach
12.	During this hospital stay, were you given any medicine that you had not taken before?	1☐ Yes 2☐No ➔If No, Go to Question 15
13.	Before giving you any new medicine, how often did hospital staff tell you what the medicine was for?	1☐ Never 2☐ Sometimes 3☐ Usually 4☐ Always
14.	Before giving you any new medicine, how often did hospital staff describe possible side effects in a way you could understand?	1☐ Never 2☐ Sometimes 3☐ Usually 4☐ Always
FURTHER QUESTIONS IS ABOUT PAIN DURING THE HOSPITAL STAY		
15.	During the time spend in the hospital were you bothered by pain from your disease or surgery?	1☐Yes 2☐No
16.	Did your treating team help you deal with this pain?	1☐Yes 2☐No
FURTHER QUESTION RELATES TO THE OVERALL RATING OF HOSPITAL		
17.	Considering all your care at this center, using any number from 0 to 10, where 0 is the worst overall care experience possible and 10 is the best overall care experience possible, what number would you use to rate your overall hospital services?	0 ☐ Worse possible 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10☐ Excellent
FURTHER QUESTIONS RELATE TO UNDERSTANDING YOUR CARE WHEN YOU LEFT THE HOSPITAL		
18.	When I left the hospital, I had a good understanding of the things I was responsible for in managing my health.	1☐Strongly disagree 2☐ Disagree 3☐ Agree 4☐Strongly agree
19.	When I left the hospital, I clearly understood the purpose for taking each	1☐Strongly disagree

	of my medications.	2☐ Disagree 3☐ Agree 4☐Strongly agree 5☐I was not given any medication when I left the hospital
FURTHER QUESTIONS RELATE TO THE PROCESS OF CONTACTING YOUR SURGERY TEAM		
20.	Since it was decided that you would have surgery, did your treating team encourage you to contact them with questions between visits?	1☐Yes, definitely 2☐Yes, somewhat 3☐No
21.	Since it was decided that you would have the surgery, did your treating team tell you to call them immediately if you have specific symptoms or side effects?	1☐Yes, definitely 2☐Yes, somewhat 3☐No
22.	Since it was decided that you would have the surgery, did your treating team give you clear instructions about how to contact them after regular office hours?	1☐Yes, definitely 2☐Yes, somewhat 3☐No
FURTHER QUESTIONS RELATE TO THE YOUR CARE FROM THIS MEDICAL CENTER		
23.	When you contacted this hospital to get an appointment for care you needed right away, how often did you get an appointment as soon as you needed?	1☐ Never 2☐ Sometimes 3☐ Usually 4☐ Always
24.	Starting from the first referral to the hospital, did you make any appointments for a check-up or routine care at this hospital?	1☐ Yes 2☐ No → If No, go to Question 26
25.	Starting from the first referral to the hospital, when you made an appointment for a check-up or routine care at this hospital, how often did you get an appointment as soon as you	1☐ Never 2☐ Sometimes 3☐ Usually

	needed?		4☐ Always	
FURTHER QUESTIONS RELATE TO THE NATIONAL PROGRAM				
26.	Did hospital staff give you information about how to get financial help?		1☐ Yes 2☐No, but I would have liked information 3☐It was not necessary 4☐ Don't know	
27.	Did you make any payments during your surgical treatment (including "thank you" payments and gifts)?		1☐Yes, please specify the amount _____ 2☐No	
28.	To what degree surgical treatment caused financial problems for you and your family? Where 0 means no difficulties and 10 for severe difficulties.		0 ☐ Do not caused difficulties 1 ☐ 2 ☐ 3 ☐ 4 ☐	5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10☐ Caused severe difficulties
DEMOGRAPHIC DATA				
29.	How old are you?		_____	
30.	Please indicate your gender? (Do not read the question)		1☐ Male 2☐ Female	
31.	From which part of Armenia are you?	1 ☐ Yerevan 2 ☐ Aragatsotn 3 ☐ Ararat 4 ☐ Armavir	5 ☐ Gegharkunik 6 ☐ Kotayk 7 ☐ Lori 8 ☐ Shirak	9 ☐ Syunik 10 ☐ Tavush 11 ☐ Vayots Dzor
32.	What is the highest grade or level of school that you have obtained? *Choose*		1 ☐ School (less than 10 years)	

	only one	2 ☐School (10 years) 3 ☐Professional technical education (10-13 years) 4☐University/Institute (14-16 years) 5☐ Postgraduate
33.	In general, how would you rate your overall mental or emotional health? *Choose only one*	1☐Excellent 2☐Very good 3☐Good 4☐Fair 5☐Poor
34.	In general, how would you rate your overall health? *Choose only one*	1☐Excellent 2☐Very good 3☐Good 4☐Fair 5☐Poor
35.	How many months before the initiation of the treatment you were diagnosed with the condition for what you underwent the surgery in the XX hospital?	_____ (months)
36.	Besides the surgery, have you ever received any other types of treatments or services from this hospital related to the condition for which you underwent the surgery?	1☐Yes 2☐No
37.	Indicate the average monthly expenditures of your household in Armenian drams.	1☐ Up to 50,000 AMD 2☐ 50,001 - 100,000 AMD 3☐ 100,001 - 200,000 AMD 4☐ 200,001 - 300, 000 AMD 5☐ Above 300,001 AMD 6☐ I do not want to mention

Appendix 3. Questionnaire (Armenian version)

Հարցաշար - Քաղցկեղի հիվանդների շրջանում բուժառուների փորձառության գնահատում

Հարցազրուցավար ID _____

Ամսաթիվ (_ _ / _ _ /2020)

Սկիզբ __ : __ Ավարտ __: __ (24 hour format)

Մասնակցի ID _____

Քաղցկեղի տեսակ _____

ՀԱՋՈՐԴՈՂ ՀԱՐՑԵՐԸ ՎԵՐԱԲԵՐՎՈՒՄ ԵՆ ԲՈՒԺՔՈՒՅՐԵՐԻ ԿՈՂՄԻՑ ՄԱՏՈՒՑՎԱԾ ԾԱՌԱՅՈՒԹՅՈՒՆՆԵՐԻՆ		
1	Հիվանդանոցում գտնվելիս ինչքա՞ն հաճախ է բուժքույրի վերաբերմունքը եղել սիրալիր և հարգալից:	1☐ Երբեք 2☐ Հազվադեպ 3☐ Սովորաբար 4☐ Միշտ
2	Հիվանդանոցում գտնվելիս ինչքա՞ն հաճախ են բուժքույրերը ուշադրությամբ լսել Ձեզ:	1☐ Երբեք 2☐ Երբեմն 3☐ Սովորաբար 4☐ Միշտ
3	Հիվանդանոցում գտնվելիս ինչքա՞ն հաճախ են բուժքույրերը բացատրել Ձեզ տարբեր խնդիրներ այնպես, որ Դուք լիարժեք հասկանաք:	1☐ Երբեք 2☐ Հազվադեպ 3☐ Սովորաբար 4☐ Միշտ
4	Հիվանդանոցում գտնվելիս ինչքա՞ն հաճախ եք օգնություն ստացել բուժքույրերից օգնություն խնդրելուց անմիջապես հետո:	1☐ Երբեք 2☐ Հազվադեպ 3☐ Սովորաբար 4☐ Միշտ

ՀԱՋՈՐԴՈՂ ՀԱՐՑԵՐԸ ՎԵՐԱԲԵՐՎՈՒՄ ԵՆ ԲԺԻՇԿՆԵՐԻ ԿՈՂՄԻՑ ՄԱՏՈՒՑՎԱԾ ԾԱՌԱՅՈՒԹՅՈՒՆՆԵՐ		
5	Հիվանդանոցում գտնվելու ժամանակ ինչքա՞ն հաճախ են բժիշկները Ձեզ վերաբերվել սիրալիր և հարգալից:	1☐ Երբեք 2☐ Հազվադեպ 3☐ Սովորաբար 4☐ Միշտ
6	Հիվանդանոցում գտնվելու ժամանակ ինչքա՞ն հաճախ են բժիշկները ուշադրությամբ լսել Ձեզ:	1☐ Երբեք 2☐ Հազվադեպ 3☐ Սովորաբար 4☐ Միշտ
7	Հիվանդանոցում գտնվելու ժամանակ ինչքա՞ն հաճախ են բժիշկները բացատրել Ձեզ տարբեր խնդիրներ այնպես, որ Դուք լիարժեք հասկանաք:	1☐ Երբեք 2☐ Հազվադեպ 3☐ Սովորաբար 4☐ Միշտ
ՀԱՋՈՐԴՈՂ ՀԱՐՑԵՐԸ ՎԵՐԱԲԵՐՎՈՒՄ ԵՆ ՀԻՎԱՆԴԱՆՈՑԱՅԻՆ ՄԻՋԱՎԱՅՐ		
8	Հիվանդանոցում գտնվելու ժամանակ ի՞նքան հաճախ է սենյակը և լոգարանը մաքուր եղել:	1☐ Երբեք 2☐ Հազվադեպ 3☐ Սովորաբար 4☐ Միշտ
9	Հիվանդանոցում գտնվելու ժամանակ գիշերային ժամերին ինչքա՞ն հաճախ է սենյակի մոտակայքը աղմկոտ եղել :	1☐ Երբեք 2☐ Երբեմն 3☐ Սովորաբար 4☐ Միշտ
ՀԱՋՈՐԴՈՂ ՀԱՐՑԵՐԸ ՎԵՐԱԲԵՐՎՈՒՄ ԵՆ ՓՈՐՁԱՌԱԹՅՈՒՆԸ ՀԻՎԱՆԴԱՆՈՑՈՒՄ		
10	Հիվանդանոցում գտնվելու ժամանակ արդյո՞ք կարիք եք ունեցել, որ Ձեզ օժանդակեն զուգարան գնալիս կամ միզանոթ օգտագործելիս:	1☐ Այո 2☐ Ոչ➔ եթե Ոչ անցնել հարց 12
11	Ի՞նչ հաճախականությամբ եք ստացել օգնություն զուգարան գնալիս կամ միզանոթ օգտագործելիս անմիջապես բուժանձնակազմին դիմելուց հետո:	1☐ Երբեք 2☐ Հազվադեպ

		3☐ Սովորաբար 4☐ Միշտ 5☐ Չեմ դիմել
12	Հիվանդանոցում գտնվելիս, արդյո՞ք ստացել եք Ձեր համար անծանոթ դեղամիջոցներ:	1☐ Այո 2☐ Ոչ➔ եթե Ոչ անցնել հարց 15
13	Ցանկացած տեսակի նոր դեղամիջոց ստանալուց առաջ, ի՞նչ հաճախականությամբ է բուժող թիմը ասել, թե ինչի համար է նախատեսված դեղամիջոցը:	1☐ Երբեք 2☐ Հազվադեպ 3☐ Սովորաբար 4☐ Միշտ
14	Ցանկացած տեսակի նոր դեղամիջոց ստանալուց առաջ, ի՞նչ հաճախականությամբ է բուժող թիմը զգուշացրել Ձեզ հնարավոր կողմնակի ազդեցությունների մասին:	1☐ Երբեք 2☐ Հազվադեպ 3☐ Սովորաբար 4☐ Միշտ
ՀԱՋՈՐԴՈՂ ՀԱՐՑԵՐԸ ՎԵՐԱԲԵՐՎՈՒՄ ԵՆ ՀԱՐՑԵՐ ՑԱՎԻ ՄԱՍԻՆ		
15	Հիվանդանոցում գտնվելիս ունեցե՞լ եք ցավեր կապված Ձեր հիվանդության կամ վիրահատության հետ:	1☐Այո 2☐Ոչ
16	Արդյո՞ք Ձեզ բուժող թիմը օգնել է հաղթահարել ցավը:	1☐Այո 2☐Ոչ
ՀԱՋՈՐԴՈՂ ՀԱՐՑԵՐԸ ՎԵՐԱԲԵՐՎՈՒՄ ԵՆ ԸՆԴՀԱՆՈՒՐ ՀԻՎԱՆԴԱՆՈՑԻ ԳՆԱՀԱՏՈՒՄ		
17	Գնահատեք Ձեզ **տրամադրված հիվանդանոցային ծառայությունների որակը**, որտեղ 0-ն հնարավոր ամենավատ, իսկ 10-ը հնարավոր ամենալավ գնահատականն է:	0 ☐ Հնարավոր ամենավատ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10☐ Հնարավոր ամենալավ
ՀԱՋՈՐԴՈՂ ՀԱՐՑԵՐԸ ՎԵՐԱԲԵՐՎՈՒՄ ԵՆ ԽՆԱՄՔ ՀԻՎԱՆԴԱՆՈՑԸ ԼՔԵԼՈՒՑ ՀԵՏՈ **Կխնդրեմ պատասխանել լիովին համաձայն չեմ, համաձայն չեմ, համաձայն եմ, լիովին համաձայն եմ**		

18	Հիվանդանոցը լքելիս, Դուք հստակ պատկերացրել եք այն գործողությունները որոնք անհրաժեշտ են Ձեր առողջությունը պահպանելու համար:	1☐Ընդհանրապես համաձայն չեմ 2☐ Համաձայն չեմ 3☐ Համաձայն եմ 4☐ Լիովին համաձայն եմ
19	Հիվանդանոցր լքելիս, Դուք հստակ հասկացել եք յուրաքանչյուր դեղամիջոց ընդունելու նպատակը:	1☐Ընդհանրապես համաձայն չեմ 2☐ Համաձայն չեմ 3☐ Համաձայն եմ 4☐ Լիովին համաձայն եմ 5☐ Ինձ չեն նշանակել դեղորայք դուրսգումից հետո
ՀԱՋՈՐԴՈՂ ՀԱՐՑԵՐԸ ՎԵՐԱԲԵՐՎՈՒՄ ԵՆ ԲՈՒԺՈՂ ԹԻՄԻՆ ԴԻՄԵԼԻՈՒԹՅԱՆ ՄԱՍԻՆ ՀԱՐՑԵՐ		
20	Արդյո՞ք Ձեզ բուժող թիմը խրախուսել է հարցեր ունենալու պարագայում կապ հաստատել իրենց հետ մինչ հաջորդ այցելությունը:	1☐Այո, իհարկե 2☐ Այո, մասամբ 3☐Ոչ
21	Արդյո՞ք բուժող թիմը զգուշացրել է Ձեզ անմիջապես զանգահարել, եթե ունեք բնորոշ սիմպտոմներ կամ կողմնակի ազդեցություններ:	1☐Այո, իհարկե 2☐ Այո, մասամբ 3☐Ոչ
22	Արդյո՞ք Ձեզ բուժող թիմը տվել է Ձեզ հստակ ցուցումներ, ինչպես կապնվել իրենց հետ աշխատանքային ժամերից դուրս:	1☐Այո, իհարկե 2☐ Այո, մասամբ 3☐Ոչ
ՀԱՋՈՐԴՈՂ ՀԱՐՑԵՐԸ ՎԵՐԱԲԵՐՎՈՒՄ ԵՆ ՀԱՐՑԵՐ ԲՈՒԺՄԱՆ ԸՆԹԱՑՔԻ ՎԵՐԱԲԵՐՅԱԼ		
23	Երբ Դուք կապնվել եք հիվանդանոցի հետ վիրահատության գրանցվելու նպատակով, ի՞նչ հաճախականությամբ եք ստացել այդ այցելությունը այնքան արագ, որքան ցանկանում էիք:	1☐ Երբեք 2☐ Հազվադեպ 3☐ Սովորաբար 4☐ Միշտ
24	Վիրահատությունից հետո, արդյո՞ք ունեցել եք այցելություններ նույն հիվանդանոցում հերթական ստուգումներ կատարելու	1☐Այո 2☐Ոչ →եթե Ոչ անցնել հարց 26

	նպատակով:	
25	Հերթական ստուգումներ անցնելիս, ի՞նչ հաճախականությամբ եք ստացել այդ այցելությունը այնքան արագ որքան ցանկանում էիք:	1☐ Երբեք 2☐ Հազվադեպ 3☐ Սովորաբար 4☐ Միշտ
ՀԱՋՈՐԴՈՂ ՀԱՐՑԵՐԸ ՎԵՐԱԲԵՐՎՈՒՄ ԵՆ ՀԱՐՑԵՐ ԱՋԳԱՅԻՆ ԾՐԱԳՐԻ ՎԵՐԱԲԵՐՅԱԼ		
26	Արդյո՞ք հիվանդանոցի անձնակազմը տրամադրել է Ձեզ ինֆորմացիա, թե ինչպես ստանալ ֆինանսական աջակցություն:	1☐ Այո 2☐Ոչ, բայց ես կցանկանայի ունենալ 3☐Կարիք չկար 4☐ Չգիտեմ
27	Դուք կատարել եք որևէ վճարում վիրահատական բուժման ընթացքում (ներառյալ մագարիչ կամ նվեր):	1☐Այո, խնդրում եմ մանրամասնեք ինչքան գումար եք վճարել _____ 2☐Ոչ
28	Ինչքանո՞վ է բուժումը առաջացրել ֆինանսական խնդիրներ Ձեր և Ձեր ընտանիքի համար, որտեղ 0 ընդհանրապես չի առաջացրել ֆինանսական բարդություն, իսկ 10 առաջացրել է ծանր ֆինանսական խնդիրներ:	0 ☐ Ընդհանրապես չի առաջացրել 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10☐ Առաջացրել է ծանր ֆինանսական խնդիրներ

ԴԵՄՈԳՐԱՖԻԿ ՏՎՅԱԼՆԵՐ			
29	Ձեր տարի՞քը		_____ տարեկան
30	Ձեր սեռը (Չկարդալ հարցը)		1☐ Արական 2☐ Իգական
31	Հայաստանի ո՞ր տարածաշրջանից եք:	1 ☐ Երևան 2 ☐ Արագածոտն 3 ☐ Արարատ	5 ☐ Գեղարքունիք 6 ☐ Կոտայք 7 ☐Լոռի	9 ☐ Սյունիք 10 ☐ Տավուշ 11 ☐ Վայոց

		4 ☐ Արմավիր 8 ☐ Ճիրակ Զոր	
32	Նշեք Ձեր ստացած կրթության ամենաբարձր աստիճանը: Ընտրեք միայն մեկը:		1☐ Դպրոց (մինչև 10 տարի) 2☐Դպրոց (10 տարի և ավելի) 3☐ Միջին մասնագիտական կրթություն (10-13 տարի) 4☐Ինստիտուտ/համալսարան (14-16 տարի) 5☐Հետբուհական
33	Ինչպե՞ս կգնահատեք Ձեր ընդհանուր հոգեբանական վիճակը վիրահատությունից հետո: Ընտրեք միայն մեկը:		1☐ Ճատ լավ 2☐ Լավ 3☐Բավարար 4☐Վատ 5☐Ճատ վատ
34	Ինչպե՞ս ներկայումս կգնահատեք Ձեր ընդհանուր առողջական վիճակը: Ընտրեք միայն մեկը:		1☐ Ճատ լավ 2☐ Լավ 3☐Բավարար 4☐Վատ 5☐Ճատ վատ
35	Բուժումը սկսելուց քանի՞ ամիս առաջ են հայտնաբերել այն հիվանդությունը, որի համար վիրահատվել եք:		_____ (ամիս)
36	Բացի վիրահատությունից, ստացել ե՞ք այլ տեսակի բուժում նույն հիվանդանոցում:		1☐Այո 2☐Ոչ
37	Խնդրում ենք նշել Ձեր ընտանիքի միջին ամսական ծախսերը (դրամ):		1☐ Մինչեւ 50,000 դրամ 2☐ 50,001 - 100,000 դրամ 3☐ 100,001 - 200,000 դրամ 4☐ 200,001 - 300,000 դրամ 5☐ 300,001 դրամից բարձր 6☐ Չեմ ցանկանում պատասխանել

Appendix 4. Letter of IRB approval from the Institutional Review Board of American University of Armenia

AUA American University of Armenia

February 19, 2020

PRINCIPAL INVESTIGATOR: Lusine Abrahamyan, MD, MPH, PhD
CO-INVESTIGATOR(S): Michael E. Thompson, DrPH, MS; Yeva Sahakyan MD, MPH, MSc
STUDENT INVESTIGATOR(S): Meri Sahakyan, DMD

TITLE: Evaluation of Patient Reported Experiences among cancer survivors in two public hospitals before and after the changes in reimbursement policy in Yerevan, Armenia.

PROTOCOL #: AUA-2020-003

Via Email: labrahamyan@aua.am ; meri_sahakyan@edu.aua.am

Dear Dr. Abrahamyan and Ms. Sahakyan,

The above referenced protocol was reviewed and approved by the Chair of the Institutional Review Board of the American University of Armenia using the expedited procedure set forth in 45 CFR 46.110, category 6,7, on February 19, 2020. This study will be due for continuing review on or before February 19, 2021. Annual continuing reviews will be required for this proposal. The proposed study can proceed as it is approved by the AUA IRB. However, please note, the IRB must be kept apprised of any and all changes in the research that may have an impact on the level and type of IRB review needed for a specific proposal. You are required to notify the AUA IRB if any changes are proposed in the study that might alter its IRB status and consent procedures. New procedures that may have an impact on the risk-to-benefit ratio cannot be initiated until IRB approval has been given. Please retain this letter as documentation of the IRB's determination regarding your proposal. Please contact me, at vkhachadourian@aua.am with a copy to auairb@aua.am, should you have any questions about the information in this letter. Thank you.

Sincerely,

Vahe Khachadourian, MD, MPH, PhD
Chair, AUA IRB
Assistant Professor, Turpanjian School of Public Health, AUA

40 Marshal Baghramyan Ave.,
Yerevan, 0019, RA
Phone: (+374 60) 61 25 92
(+374 60) 61 40 40
Fax: (+374 60) 61 25 12
E-mail: info@aua.am

U.S. Office
300 Lakeside Drive, Suite 700
Oakland, California 94612
Phone: +1(510) 987-9452
Fax: +1(510) 280-3576

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Appendix 5. Oral consent form (English version)

American University of Armenia

Turpanjian School of Public Health

Institutional Review Board # 1

Oral consent form

Hi. My name is Meri. I am a graduate student at the Turpanjian School of Public Health at the American University of Armenia. In collaboration with the Ministry of Health I am conducting a study in the scope of my thesis project, to investigate the patient experience related to treatment received in the Qanaqer hospital (National Oncological Center) / St Grigor Lusavorich Medical center.

(For the interviewer) I am from the American University of Armenia. My name is _____. In collaboration with the Ministry of Health a research is being carried out, which aims to investigate the patient experience related to treatment received in the Qanaqer hospital (National Oncological Center) / St Grigor Lusavorich Medical center.

The research is conducted among 348 patients who received treatment in the period from October 2018 to March 2019. You are invited to participate in this study, as you received the surgical treatment at Qanaqer hospital (National Oncological Center)/ St Grigor Lusavorich Medical center in 2019. The contact information was provided by the Ministry of Health. Your participation in this study will involve only the current telephone interview that will last 10-15 minutes and help to identify different aspects of your experience in the hospital . I would like to ask you to participate in this study to share some additional details about your experience.

Your participation is voluntary, and your decision to participate or refuse to participate will not have any undesirable consequences. You may skip any question you prefer not to answer and you may stop the interview any time without any undesirable consequences for you. Participation in the study will not have a negative impact on you.

Your participation is important for the study. There is no direct benefit for the participation, but the information provided by you and obtained from you contribute to the improvement of health services provided in the hospitals. The collected information will not harm either doctors, nurses or other medical staff.

The information received from you is fully confidential and will be used only for study purposes. No identifiable information will appear on the questionnaire and the final report. Your contact information will be destroyed immediately after completing the data collection.

If you have any questions regarding this study, you can contact the Assistant Professor of the Gerald and Patricia Turpanjian School of Public Health, Vahe Khachadouryan at (060) 612570. If you think you have been hurt by participating in the study or feel you have not been treated fairly you can contact the American University of Armenia Human Protections Administrator, Varduhi Hayrumyan at (060) 61 25 61.

Do you agree to participate?

Thank you.

Appendix 6. Oral consent form (Armenian version)

Հայաստանի ամերիկյան համալսարան

Թրփանճեան Հանրային առողջապահության ֆակուլտետ

Գիտահետազոտական էթիկայի թիվ 1 հանձնաժողով

Իրազեկ համաձայնության ձև

Բարև Ձեզ: Իմ անունը Մերի է: Ես Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության ֆակուլտետի ավարտական կուրսի ուսանող եմ: Մենք Առողջապահության Նախարարության հետ համատեղ իմ թեզի շրջանակներում իրականացնում ենք հարցում, որի նպատակն է գնահատել պացիենտների փորձառությունը Քանաքեռի հիվանդանոցում (Ազգային Օնկոկոլոգիական Կենտրոն) / Սուրբ Գրիգոր Լուսավորիչ հիվանդանոցում բուժծառայություններ ստանալիս:

(Հարցազրուցավարի համար) Ես Հայաստանի ամերիկյան համալսարանի Առողջապահական ծառայությունների հետազոտման և զարգացման կենտրոնից եմ: Իմ անունն ____ է: Մենք Առողջապահության Նախարարության հետ համատեղ իրականացնում ենք հարցում, որի նպատակն է գնահատել բուժառուների փորձառությունը Քանաքեռի հիվանդանոցում / Սուրբ Գրիգոր Լուսավորիչ հիվանդանոցում բուժծառայություններ ստանալիս:

Հետազոտությունը իրականացվում է այն 348 պացիենտների շրջանում, ովքեր բուժում են ստացել վերոնշյալ բժշկական կենտրոնում 2018 հոկտեմբերից մինչև 2019 թվականի մարտ ամիսը:

Դուք հրավիրված եք մասնակցել այս հետազոտությանը, քանի որ բուժում եք ստացել Քանաքեռի հիվանդանոցում/ Սուրբ Գրիգոր Լուսավորիչ հիվանդանոցում: Ձեր հեռախոսահամարը տրամադրել է Առողջապահության Նախարարությունը: Ձեր մասնակցությունը այս հարցմանը սահմանափակվում է միայն այս հեռախոսային հարցազրույցով, որը կտևի 10-15 րոպե: Ես կխնդրեի Ձեզ մասնակցել այս հարցմանը և ավելի մանրամասն պատմել Ձեր փորձառության մասին:

Հարցմանը մասնակցությունը կամավոր է և Ձեր մասնակցությունը կամ դրանից հրաժարվելու որոշումը չի ունենա որևէ անցանկալի հետևանքներ: Դուք կարող եք բաց թողնել ցանկացած հարց, որին գերադասում եք չպատասխանել և դադարեցնել հարցազրույցը ցանկացած պահի առանց որևէ անցանկալի հետևանքների: Հարցմանը մասնակցելը բացասական հետևանք չի ունենա Ձեզ համար:

Ձեր մասնակցությունը կարևոր է հետազոտության համար: Ձեր մասնակցությունը չի ենթադրում անմիջական շահ Ձեզ համար, բայց Ձեր տրամադրած տվյալները կօգնեն բարելավել հիվանդանոցներում տրամադրվող

ծառայությունների որակը: Հավաքագրված ինֆորմացիան չի օգտագործվելու ի վնաս բժիշկների, բուժքույրերի և այլ բժշկական անձնակազմի:

Ձեր կողմից տրամադրված տվյալները ամբողջովին գաղտնի են պահվելու և օգտագործվելու են միայն հետազոտության նպատակով: Ձեր անձը բացահայտող որևէ ինֆորմացիա չի նշվելու հարցաթերթիկում և վերջնական զեկույցում: Ձեր կոնտակտային տվյալները կոչնչացվեն անմիջապես տվյալների հավաքագրումից հետո:

Այս հետազոտության վերաբերյալ հարցեր ունենալու դեպքում կարող եք կապ հաստատել Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության ֆակուլտետի դոցենտ՝ Վահե Խաչադուրյանի հետ, հետևյալ հեռախոսահամարով ՝ (060) 612570: Եթե Դուք կարծում եք, որ հետազոտությանը Ձեր մասնակցությունը Ձեզ վնաս է պատճառել կամ Ձեզ լավ չեն վերաբերվել, կարող եք կապ հաստատել Հայաստանի ամերիկյան համալսարանի էթիկայի հանձնաժողովի համակարգող, Վարդուհի Հայրումյանի հետ, հետևյալ հեռախոսահամարով՝ (060) 61 25 61.

Համաձա՞յն եք մասնակցել:

Շնորհակալություն:

Appendix 7. Journal Form

Interviewer ID_____
Date __/__/___

Patient ID	Attempt 1	Attempt 2	Attempt 3

1. Complete response (Interviewee completed the interview)
2. Not complete response (Interviewee did not completed the interview)
3. Do not agreed to participate in the interview (reason specify _____)
4. Dis not answered to the phone call
5. Busy number
6. Call later
7. Not eligible (number is wrong, or other reason specify_____)
8. Patient is not alive anymore.