



# The demand for preventive medicine and the 7k Medicine model as a possibility for public primary care

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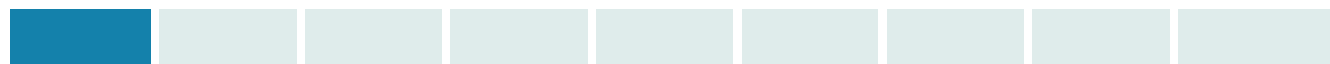
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# 1. Summary

The 7k Medicine model from the Gentest Institute in Turkey (see box 1) is a personalized medicine service that shows promising opportunities to prevent complex or chronic diseases (Ackermann, 2020; Garton, 2020). Adapting this program into a public healthcare setting in Turkey or in other countries, could signify a shift between illness centered medicine to a health management approach that focuses on early prevention and overall wellbeing and optimization according to each user's needs. Thus, this shift represents a significative turn from the usual focus in healthcare systems on curing illness to a perspective of maintaining and enhancing health. To be able to build a future pilot adaptable to public settings at national and international levels, this research focused first on the need to understand the current demands for the 7K Medicine model: the needs that this program meets in terms of the users' perceptions and values around prevention (what kind of information and sources ultimately build these needs). Therefore, this project aimed to understand this demand in current international users of the 7k Medicine model, learning from their international perspective and their interest on a preventive service outside of their current healthcare systems. The mixed methodology of this research included interviews with these international users, originally from Turkey but based internationally, but it also included a focus group with expats from different countries to compare results and asses the demand from different cultural and socioeconomic perspectives. Finally, a statistical analysis using open data from the OECD database explored some of the findings of the qualitative phase, identifying correlations between perceived quality of care (specifically related to patient-provider interaction), perceived health status, educational levels and out of pocket spending. The analysis of perspectives and expectations was developed through a health literacy and action framework, triangulating the qualitative information with the quantitative phase to give recommendations for the future of the program. Therefore, the results showed that users' perceptions around preventive medicine are linked to rehabilitation activities for the elderly and the sick, along with wellness activities that are sometimes perceived as discredited and non-scientific. Nevertheless, users did not perceived 7k Medicine as a preventive medicine service, despite having some preventive concerns as motivation to join the program. Mainly, the reason to choose 7k Medicine is the reassurance of the scientific background it offers, particularly because of the genetic profiling which convince them of the efficacy of these tools to achieve their goals (like weight loss or age delaying measures). However, what makes users adhere to the program is the personable care and the feeling of empowerment they have,

increasing their own health literacy and getting tools to oversee their own health. Although these factors are difficult to translate in public and international settings, the recommendations aim to articulate efforts with community actors and organizations, explore technological tools to expand access to monitoring and tracking personalized results and ultimately empower users on their own health management. Also, it is recommended to have more online presence and promotion strategies for the program, and the need for further research to be able to build the first pilots to expand it.

In the early 2000s the development of Gentest was commenced by the GENAR Institute for Public Health and Genomics Research in Ankara, and it aims at utilizing individual's health information, lifestyle factors, biomarkers and ones' genotype to prevent and detect chronic and complex diseases early in a targeted way (Cesuroglu et al., 2009). Gentest was founded as a private business in 2010 (Ackermann, 2020) and has been led since its creation by Dr. Serdar Savas who is a physician by education and has international and national experience with policy design and healthcare system reforms as he worked for the WHO regional office for Europe and the MoH of Turkey. The practice model is composed by several disciplines including biotechnology, genetics, nutrigenetics, personalized medicine and pharmacogenetics, and serves the purpose of changing behaviour and managing the health of individuals according to their priorities (Cesuroglu et al., 2009). The model has been identified as best practice model for public health genomics in Europe by the Public Health Genomics European Network (Cesuroglu, 2016). The practice model is determined by the 7K Medicine approach which is built on 7 criteria each beginning with a 'K' in Turkish and when translated are as follows: personalized, predicative, preventative, comprehensive, precise, participatory and evidence-based (Gentest, 2021; Cesuroglu et al., 2016). Thus, the knowledge, guidance and care that is provided through Gentest aim to incorporate these dimensions.

Following the innovative approach adopted by Gentest, it remains a service yet to be implemented into healthcare systems. Therefore, current consultees are those of a niche population; with a high motivation to engage in healthy practices and usually of higher socio-economical class due to the associated expenses and out of pocket payments that the institute currently relies on. Gentest therefore aims to implement its personalized and preventative approach to combating complex chronic diseases into primary care systems of various countries, including Turkey (Gentest, 2021). Gentest has served more than 2,000 individuals and in 2020 the Gentest staff included the head physician, attending nurse, five trained dietitian counsellors, the IT specialist, three staff scientist and the administrative secretary (Ackermann, 2020). However, due to the COVID-19 outbreak both the inflow of new consultees as the staff has sized down. In 2021 so far only five individuals have joined the program and currently the head physician, a dietitian and the IT specialist are still working at Gentest (Gentest, 2021).

\*This description is used across several parallel research studies for Gentest practice

### Box 1. Gentest Institute and background



## 2. Introduction

Non-Communicable Diseases (NCDs) account for approximately two third of all deaths worldwide (Bloom et al. 2011). These illnesses emerge from the complex interaction of genetics and lifestyle/environmental factors and can be drastically reduced by behavioral changes. Consequently, addressing NCDs is an urgent global health priority to avoid the impact on quality of life, burden, and financing crisis on healthcare systems in high, middle, and low-income countries (Cesuroglu, T. 2016: 173).

Therefore, most efforts are directed towards diagnostic and curative approaches, prevailing an illness-centered approach among health providers (Stewart et al., 2014). Moreover, the focus is often on the population level with little consideration for individual differences (Ryll, B. 2021). The prioritization of curative and diagnostic approaches often reflects attitudes to medical care as only to be sought in the case of illness and not deserving investment while in good health (Knox, M. 2018; Yong Kang, C. 2012). Thus, these attitudes focus on the consequences of the problem, when addressing the underlying issues would be a more effective approach for which preventive and personalized medicine show promising advances (Haque, et al., 2020).

At the same time, there is increasing investment in health and wellness strategies, including supplements, gym memberships, diet plans, among other activities aimed for prevention but mostly provided outside of the healthcare system (GWI, n.d; Pilzer, P. Z., 2002). These measures sometimes are taken even after health issues already affected the user, so prevention instead becomes entwined with the idea of rehabilitation. Therefore, the cultural shift to value preventive and personalized medicine both within users and healthcare professionals is a difficult challenge to overcome.

To achieve this, there is a need to change from an illness to a patient centered approach (Stewart et al., 2014), emphasizing on a more holistic view of health and including more efforts on preventive measures. Framed within this paradigm shift, innovation through personalized medicine based on genetic profiles and behavioral change has been proposed in the last decade aiming to detect early signs of chronic illnesses and provide users a tailored approach that could bring better results (Harper, C. 2009; Krist et al., 2017). Although personalized medicine is not necessarily preventive, some innovations do have a preventive focus. Moreover, these approaches allow for a more empowered and engaged process of the users in their own healthcare, making them part of the decision-making course and accountable for their own success (Prainsack, 2021). Thus, although preventive and personalized medicine show promising results to tackle NCDs (Grech, Grossman, 2015), current challenges and concerns need to be addressed to enhance its uptake and funding to benefit patients at a public and global level.

Personalized and preventive medicine models, such as 7k Medicine in Turkey (see box 2), provide a valuable opportunity to assess the impact of this type of approach, identify opportunities to implement it in other countries and even include it into primary healthcare in the future. Currently, this model is applied in GENTEST (Istanbul) as a private service, with clients both inside the country and the Turkish diaspora living around the world. The name 7k refers to *personalized, predictive, preventive, comprehensive, precise, evidence-based, and participatory* medicine (words that all begin with 'K' in Turkish) (Cesuroglu, T., Savas, S. 2021).

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The 7Ks constituting the 7K medicine model will be explained more extensively in this box to ensure a clear understanding of their meaning and operationalization. The explanations are taken and shortened if appropriate from a drafted article by Savaş & Cesuroğlu (2020):

- 1st K: Personalized (“kişiye özel”): Medicine needs to move from a ‘one size fits all’ approach towards a ‘personalized’ one. Biological, lifestyle and other determinants of health for individuals, covering a wide spectrum of inputs from genomics and others, as well as lifestyle and phenotypic data are needed.
- 2nd K: Predictive (“kestirimci”): Prevention efforts need to be targeted to the personal risk profile of the individual. This requires assessments enabling a prediction the risk of development of high burden chronic diseases.
- 3rd K: Preventive (“koruyucu”): Once the risk profile of the individual is determined, personalized preventive measures should be developed. These must include, among others, nutrition, and all other lifestyle factors, and, if necessary, medications.
- 4th K: Comprehensive (“kapsamlı”): A human being is a holistic system with its macro and microbiota. Medicine needs to approach human beings with all their dimensions in a comprehensive and holistic way.
- 5th K: Precise (“keskin”): With the advancement of technologies, increasing number of biomarkers at more granular levels can be analyzed in the laboratories with improved accuracy. When these are supported with other personal information, they allow the assessments and interventions to be more precise.
- 6th K: Evidence based (“kanıta dayalı”): Unlike the current use of the term ‘evidence based’ to cover development of ‘diagnostic and treatment guidelines and protocols’ (with heavy influence of the big pharma), the 7K approach conceptualizes evidence based as that all assessments and interventions on an individual should be based on the findings, thus the ‘evidence’, on that specific individual.
- 7th K: Participatory (“katılımcı”): Currently the patients are assumed to be in a passive role and does what the health providers tells him/her to do because of the information asymmetry. Chronic diseases need an approach that covers long years to monitor and prevent their progression development, diagnosis, and treatment. A key aspect of this approach is that the individual/patient becomes an active member of the whole process from the beginning by taking control of their health with the guidance and support of health professionals.

\*This description is used across several parallel research studies for Gentest practice

## Box2. The 7ks explained

7K Medicine uses different biomarkers, anthropometric measures, user's habits and genetic profiling to design an optimum lifestyle plan, including nutrition, supplements, exercise, stress management, smoking cessation, and sleep improvement (see box 3). This program is developed in a clinical setting by a team of physicians, dieticians, sports trainers, and psychologists. The program aims to change behavior according to individual's needs and priorities to prevent chronic diseases, prolong life, slow aging, and improve overall physical and mental performance (Cesuroglu, T., Savaş, S. 2020; Cesuroglu et al., 2009).



Implementation stages of Gentest practice model as according to Cesuroglu et al. (2016) and supplemented with information gathered from private conversations with Gentest employees.

### 1. Data & Information collection stage

The most suitable package is chosen in consultation with the physician during the intake based on the individual's personal characteristics and requirements. At the end, the individual signed a consent form for DNA analysis after clarity is given to all topics of concern that the individual and the issues that the counsellor felt like he/she needed to address. Once the individual joins the Gentest program he/she will be referred to as consultee.

### 2. Assessments stage

During a second appointment different inputs of data are collected by various assessments. These include personal information, health information, living and working conditions, lifestyle information, anthropometric and bio-impedance measurements, biomarkers and genotype information. To acquire this information blood and urine samples are taken, scales and tape measures are used for anthropometric measurements, and bioelectrical impedance; blood pressure and pulse are measured. The consultees are taken through a questionnaire addressing topics as nutrient intake, physical activity status and causes of smoking. The insight into food consumption and nutritional composition of diet in combination with age, gender, current diseases, genetic information and other lifestyle information is used to establish recommendations on maximum and minimum intake levels of macro-and micro-nutrients.

Furthermore, the recommended intake levels are based on algorithms incorporating international, national guidelines and literature on nutrition and nutrigenomics research. Physical activity and exercise status is assessed by analysing different areas of physical fitness: cardiorespiratory fitness, muscle strength, bone strength, muscle endurance, flexibility, balance, insulin sensitivity and body composition. The assessment entails a focus on type, intensity, duration and frequency of the exercises. The recommended levels are determined according to disease risks, genetic predispositions and personal preferences. The genetic analysis is executed by a partnering laboratory and includes common polymorphisms related to complex diseases and conditions. The number of polymorphisms analysed ranges from 35 to 65 in the different packages. The biochemical markers analysis is carried out by external clinical laboratories. The data from all these assessments are analysed by the GENAR Center for Personalized Medicine and Pharmacogenetics in order to produce the report of the individuals. This report includes the risks of the most common chronic complex diseases for the consultees. These cover myocardial infarction, stroke, Type 2 diabetes, osteoporosis and the five most prevalent cancers (lung, breast, prostate, colon and stomach). The risk assessments algorithms are established from risk factors disclosed in various epidemiological studies and risk assessment models. Three types of risks are presented: the estimated risk using the consultee's current data, the average risk for a peer (based on sex and age) of the consultee and the estimated risk when following recommended optimum lifestyle and medical follow-up plan. Graphics of these risks are presented to the consultees to provide insight into what outcomes are targeted for when following the plans over time and creating personal vulnerability and individual risk perception to enhance the motivation to change lifestyle. This lifestyle plan is an optimum program scheme for achieving (and maintaining) the personal goals of consultees and encompass personal nutrition and supplements plans, food exchange lists and exercise plans. Recommendations on smoking cessation are decided in relation to the personal causes of smoking.

### 3. Counselling & Follow-up

The report is presented to the consultees after approximately 4-8 weeks during a meeting with the head physician and a dietitian. The dietitian explains the nutritional program in detail. The report concludes with recommendations for medical follow-up with personalized screening plans. These recommendations are subject to change depending on e.g. progress of the consultee, consultee's concerns or occurrence of unknown/unexpected medical problems. If the consultee is interested in assistance in changing their lifestyle then the follow-up program is started. After the report interpretation, consultees can participate actively in the program by taking up follow-up meetings and engaging in one-to-one support via WhatsApp, telephone calling or other types of information communication techniques.

\*This description is used across several parallel research studies for Gentest practice

## Box 3. Stages of service

The model has registered positive outcomes and perceptions among users (Ackermann, 2020; Garton, 2020), and given its potential to address NCDs, Gentest is exploring the possibility to expand towards primary care in Turkey and eventually in other countries. To be able to propose the 7k Medicine model as a global and public healthcare strategy against NCDs, we first need to understand what drives current 7k Medicine users towards preventive healthcare, identifying how this program becomes appealing despite general acceptance of medicalized and curative discourses. Understanding these motivations, not only allows to maintain the adherence of users of the program, but also to assess whether these reasons are present elsewhere. If so, these will provide insights for the construction of a future pilot on 7k Medicine that can be adapted to other scenarios within the primary healthcare setting in Turkey and on a global scale. Learning about the needs of people and their perception of the value of prevention, will allow for the promotion of the 7k Medicine model to potential users, health system planners and stakeholders. Moreover, identifying factors that drive international users towards services outside of their current healthcare system will give insights on how this demand for the program is shaped.

Therefore, this project focused on the "Turkish diaspora" using the program to allow for a more international perspective on the demand for prevention and the 7k medicine model. Moreover, the project complemented this information with the perspectives of several expats not familiarized to the program, to contrast the findings and explore their impression on the model and possible demand of this kind of services. Finally, based on the main factors identified with the qualitative data, a quantitative analysis using international open databases was run to explore possible correlations within these concepts and have a wider view on what might influence demand for preventive and personalized medicine in different contexts.

Research question	What are the reasons behind the demand for preventive medicine outside of the healthcare system among 7k Medicine international users?
General objective	To identify possible factors related to the demand for preventive and personalized services within transnational users of healthcare systems.
Specific objectives	<ul style="list-style-type: none"><li>- Understand factors that shape the users' imaginaries<sup>1</sup>, values and expectations regarding preventive medicine</li><li>- Understand international users' motivation to choose a model outside of their healthcare system</li><li>- Identify reasons to continue or abandon the program</li><li>- Identify contextual socio-cultural factors that might influence their demand for the program</li><li>- Identify successful factors and points of improvement of the program to become an adaptable pilot to be implemented in public health in Turkey and other contexts</li><li>- Identify important relationships between motivating factors that can influence opportunities to attract potential users in different countries.</li></ul>

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<sup>1</sup> Imaginary is a concept widely used in anthropology to refer to a set of values, institutions, and symbols through which people build and imagine their social conception of different topics



### 3. Conceptual framework

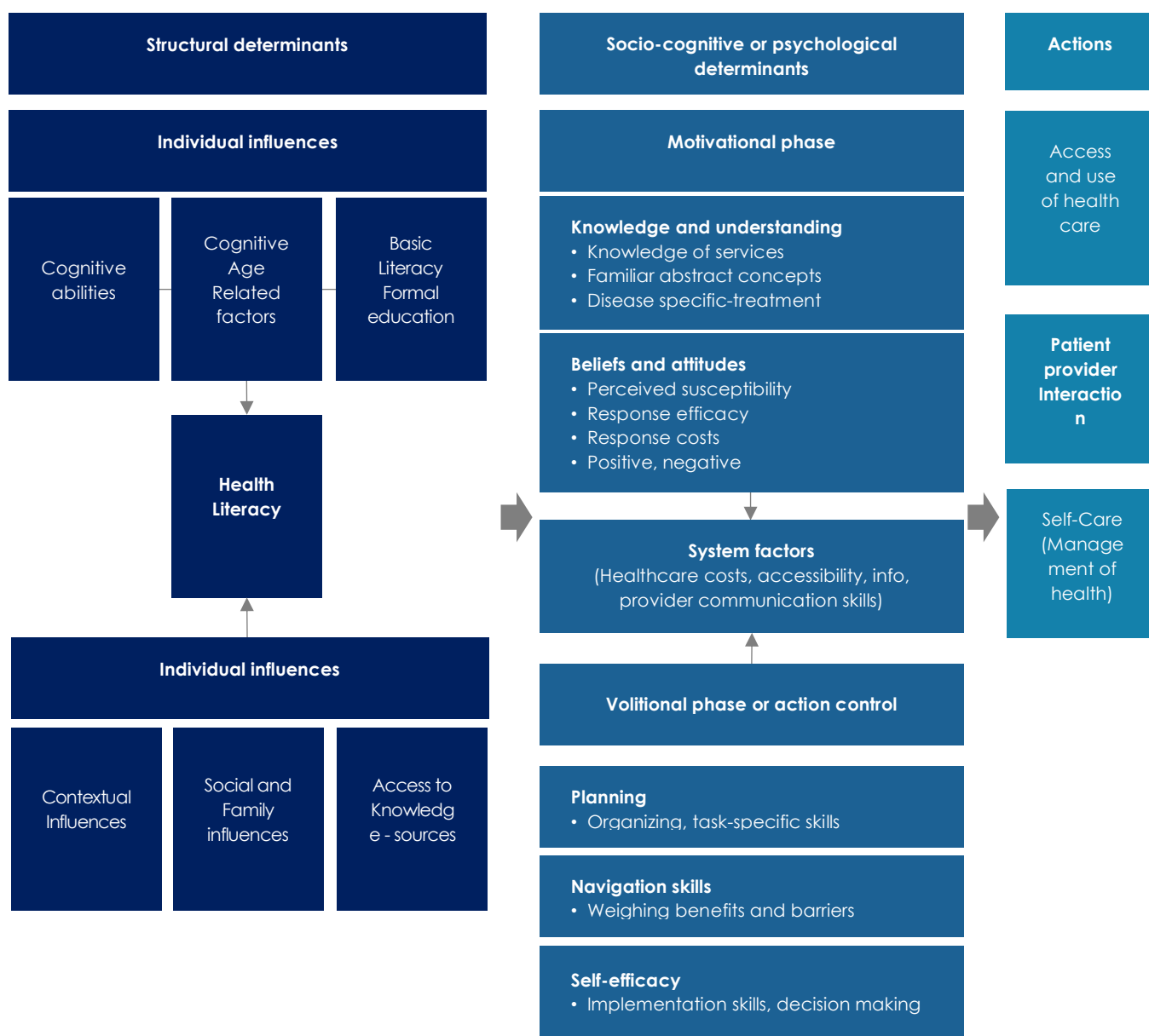
The demand for preventive and personalized measures can be seen as part of a global movement for “wellness”. This term has gained increased visibility since the 1960s (Dunn, H. 1961), evolving into mainstream healthy living, self-help, self-care, fitness, nutrition, diet, and spirituality practices. Although often confused with health, wellbeing, and happiness, wellness does not refer to a state of being (i.e., being happy, in good health) but rather to an active process of awareness and choices towards optimal health and wellbeing. The Global Wellness Institute (2019) defines wellness as “the active pursuit of activities, choices, and lifestyles that lead to a state of holistic health”. Thus, personalized medicine, along with other health related services, is seen as part of the “Wellness industry” (GWI, 2019).

Thus, this research needed to adapt a model to understand the demand for prevention within the globalized wellness concept inside and outside of healthcare services and beyond illness prevention. Thus, the main model chosen for this purpose is the “Framework of Health Literacy and Health Action” (HLHA) (Wagner et al., 2009), adapted using two similar models: The Extended Information–Motivation–Behavioral skills model (EIMB)<sup>2</sup> (Hu et al., 2020) and the Conceptual Framework of Preventive Health Model (PHM)<sup>3</sup> (Salimzadeh et al., 2013).

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<sup>2</sup> The Extended Information–Motivation–Behavioral skills model (EIMB) is based on the assumption that information and motivation are the fundamental determinants of preventive behavior or behavioral change (Hu et al., 2020).

<sup>3</sup> The Preventive Health Model (PHM) proposes that background factors (e.g., age, gender, medical history), cognitive and psychosocial constructs, and pro-program factors (e.g., interventions by health providers) are all predictors of the intention to take a preventive action (Salimzadeh et al., 2013).



**Figure 1.** Extended Framework of Health Literacy and Health Action (EHLHA) based on the Framework of Health Literacy and Health Action (Wagner et al., 2009).

Social cognition models of health actions, such as the health belief model or theory of planned behavior (which inspired the basis of these models) acknowledge that motivation alone is not the sole predictor of taking a health action (Hu et al. 2020). The adapted HLHA model distinguishes three different types of health actions that can be a result of the user's health literacy during the decision-making process: access to and utilization of health care, patient–

provider interaction, and self-care. Each of these domains is defined not only by the user's individual factors (cognitive skills, literacy, and numeracy capabilities) but also by external factors such as education, context, social and family influences.

First, the model addresses the structural determinants involved in the user's construction of health literacy. The individual influences refer to three factors that allow the individual to be able to comprehend and use knowledge in health to make decisions: cognitive abilities, age related cognitive factors and basic literacy or formal education. On the other hand, the external influences address the contextual factors that might be involved (socioeconomical, gender, geographical, among others), social and family influences (indicating references and interests based in friends and relative's opinions and attitudes regarding health), and access to knowledge (referring to selection of sources in health knowledge).

The framework places health literacy within the context of the external and individual variables that influence the user's ability to integrate, synthesize and analyze information to make decisions around their health. Health literacy has traditionally been associated with actions relating to management of illness rather than health, and has only recently been extended to health actions with the aim of managing health in everyday life (e.g., healthy eating, exercise), where its role is less well understood (Wagner et al., 2009: 864). Thus, this framework will include this latter understanding of health literacy.

Following the sociocognitive or psychological determinants, the model indicates the motivational phase and the volitional or implementation phase, which are mediated also by different system factors. Motivation can emerge due to individual attitudes towards a health action or from perceptions of a specific illness, so this phase refers to a wide variety of constructs including knowledge of opportunities for prevention and treatment and the person's perception of their own risk; ultimately resulting in a decision to attempt or not to perform a health action (Wagner et al., 2009: 865). Thus, factors are divided in the categories of "knowledge and understanding" and "beliefs and attitudes". The first category refers to the knowledge and understanding of health services, concepts, and relevant facts that drives the

user to eventually take health actions. The second category refers to beliefs and attitudes regarding health, which can be positive, negative, or associated with emotional or analytical information processes. This category was complemented by the concepts of response efficacy, perceived susceptibility, and response costs from the EIMB and the PHM models. Response efficacy addresses the benefits, referring to a belief that adopting a behavior will be effective, while perceived susceptibility refers to the individual's assessment of their own risk (Salimzadeh et al., 2013: 9). The response costs allude to costs that may hinder the occurrence or maintenance of preventive behavior (barriers, socioeconomic losses or unfavorable consequences) (Hu et al., 2020: 5).

On the other hand, the volitional phase or action control refers to the regulation of motivation and emotion during difficult or tedious tasks, contributing to adherence to plans and goal achievement. Health literacy plays an important part in a person's perceived and actual ability to participate in preventive processes, since it can influence the person's ability to navigate the process and implement the necessary tasks. This phase includes implementation skills (planning, organizing, task-specific skills), navigation skills (weighing benefits and barriers, decision making) and self-efficacy (ability to follow and implement the necessary steps to enact their intentions). Also, the proposed framework locates "system factors" between motivational and volitional phases as influences for both, recognizing possible healthcare costs, accessibility to health information, and the provider's communication skills.

Finally, the framework proposes three principal types of health action involved in the ability to seek and manage health as well as actions outside the health system: access and utilization of healthcare (beginning of use of health services), patient-provider interactions (trust, sharing decision making) and self-care (management of health and illness, following plans and recommendations, adherence).



## 4. Methodology

This research used a mixed methodology, allowing for the emergence of new themes and associations in the data (Cresswell, J., 2013). It followed a sequential explanatory design, starting with the collection and analysis of qualitative data, followed by the selection and analysis of quantitative data and finally the interpretation of the entire scheme. The focus was on the qualitative component, which allowed for the emergence of main themes that guided the quantitative research. Therefore, the aim of the qualitative part was to understand perceptions and values related to the demand for preventive medicine among international 7K medicine users. Then, based on these results, the quantitative phase focused on specific indicators related to wellness and prevention globally, using open data from the OECD database. This design provided a description of the current 7k international users' motivations, along with a general idea on how potential users might be interested on these services to get some insights and recommendations for the future of the program on an international scale.

### 4.1 Qualitative data collection

#### Interviews

The qualitative line of this research focused on the Turkish diaspora. From a total of 51 international users of the program (most of them from the Turkish diaspora), seven current 7k users were interviewed (6 men and 1 woman), located in Germany, USA, Malta, and Switzerland. The interviews were semi-structured, using an interview guide (see attachment 1) based on the conceptual framework, to gather data regarding the user's knowledge and perceptions about preventive medicine and assessing what needs are being met (or not) with the model. The semi-structured interviews permitted to collect views and opinions while



allowing respondents to expand on their answers (Gray, D., 2013: 217) which was desirable in this research since it was oriented to explore subjective meanings ascribed to concepts or events.

Thus, with help from the Gentest staff, the available users were contacted in advance to ask for their consent to participate in this research and be contacted later by the main researcher, to schedule the final videocall for the interview and send the informed consent. The sample did not aim for representativeness but instead focused on achieving saturation of the defined codes for the analysis (Kvale, 2007).

### Virtual Focus group

Subsequently, to complement the interview data, there was a virtual focus group with “expats”: people from different nationalities living outside of their home country. The activity was developed through a videocall with Zoom, and the topics were meant to expand some views regarding the personalized, personable, and preventive motivations found during interviews to understand how the reasons behind the demand for preventive medicine of current international 7k Medicine users compare to the ones of potential users from different cultural backgrounds. Also, the 7k Medicine model was presented and discussed with them during the focus group to assess their perceptions and interest in this program. The focus group had six participants, two men, three women and a non-binary person from different countries (Colombia, Australia, Chile, Brazil, Denmark, Russia) living in The Netherlands (4), United States (1) and France (1), mostly young professionals between 25 and 35 years old. They were recruited and asked for consent by the main researcher after a brief presentation of the project (see attachment 2), using a convenience sampling model (Lincoln & Denzin, 2000; Faugier & Sargeant, 1997).

### Digital ethnography

Since the beginning of this research, some opportunities to observe the process in Gentest through videocalls have been available. digital ethnography describes the process and methodology of doing ethnographic research in a digital space (Cyborg Anthropology, n.d).

Therefore, as a complementary part of the qualitative line of this project, fieldwork notes were developed to address the interactions of current 7k Medicine users and the Gentest staff during report reading consultations and follow up appointments (three in total). This information contributed to the understanding of the model, the development of trust and general interaction within users and providers.

## 4.2 Quantitative approach

After collecting qualitative data, the quantitative phase was fed with the main findings to find relationships between aspects that make the 7k model attractive, to strengthen success factors and find opportunities for the expansion of the program in different countries. Therefore, based on the findings around the importance of the interaction between user-provider and the empowerment of users as a crucial advantage of the program, the quantitative phase explored the indicators of “quality of health-patient experience” (enough time of consultation, enough opportunity to ask questions, and easy to understand indications) and “perceived health status”. Also, given that the level of education was one of the main factors related to the current users’ profile, the indicators of “adult level of education” and “out of pocket spending” were used to account for potential demand according to educational levels. All data belongs to the OECD database, and 28 countries were selected.

In the case of the patient experience and perceived health status indicators, all available countries were selected due to the limited amount of recent data (using 2016, the most recent year with the most data, 2016). On the other hand, in the case of educational levels and OOPS, data from 2019 was selected from 20 countries with the highest rate of “people living with 2 or more chronic diseases” published by OECD (2019). Finally, because in Low-Income Countries the rate of NCDs, the structural reasons behind them and the motivation and capabilities for the demand of preventive medicine are determined by different factors as the ones explored by this research, the countries considered in the quantitative phase are Middle and High-Income Countries.

Methodology and research objectives			
Method	Participants	Type	Objective
Interviews	7 Turkish Diaspora 7k Medicine users	Qualitative	<ul style="list-style-type: none"> <li>* Understand factors that shape international users' imaginaries, values and expectations regarding preventive medicine</li> <li>* Understand international users' motivation to choose a model outside of their healthcare system</li> <li>* Identify reasons to continue or abandon the program</li> <li>* Identify contextual socio-cultural factors that might influence their demand for the program</li> <li>* Identify successful factors and points of improvement of the program to become an adaptable pilot to be implemented in public health in Turkey and other contexts</li> </ul>
Focus Group	6 Expats from different countries	Qualitative	<ul style="list-style-type: none"> <li>* Understand factors that shape international users' imaginaries, values and expectations regarding preventive medicine</li> <li>* Understand international users' motivation to choose a model outside of their healthcare system</li> <li>* Identify reasons to continue or abandon the program</li> <li>* Identify contextual socio-cultural factors that might influence their demand for the program</li> <li>* Identify successful factors and points of improvement of the program to become an adaptable pilot to be implemented in public health in Turkey and other contexts</li> </ul>
Digital Ethnography	Observation of 3 online consultations	Qualitative	<ul style="list-style-type: none"> <li>* Identify contextual socio-cultural factors that might influence their demand for the program</li> <li>* Identify successful factors and points of improvement of the program to become an adaptable pilot to be implemented in public health in Turkey and other contexts</li> </ul>
OECD database analysis	Open Data from 28 countries	Quantitative	<ul style="list-style-type: none"> <li>* Identify successful factors and points of improvement of the program to become an adaptable pilot to be implemented in public health in Turkey and other contexts</li> <li>* Identify important relationships between motivating factors that can influence opportunities to attract potential users in different countries</li> </ul>

**Table 1.** Methodology and research objectives

### 4.3 Data Analysis and Coding

All qualitative data was coded and analyzed in NVivo11. The analysis followed a theory-informed approach (Charmaz, k., 2006) that integrated the theoretical frameworks and the collected data. Coding included all transcriptions of fieldnotes, focus group and interviews. The coding and analysis process followed the same coding strategies and structure: i) codebook generated based on semi-structured interview guide, theories and themes addressed (see attachment 3) ; ii) import codebook into NVivo11; iii) first cycle open coding

based on codebook structure and emerging themes (Charmaz, k., 2006; Saldaña, J., 2015) iv) second cycle axial coding organizing data around central themes (Saldaña, J., 2015) v) integration with theory in memo writing; vi) writing of final report.

For the quantitative data, the analysis was done developing a correlation matrix with the main selected variables, creating scatterplots to visualize the findings. Consequently, running a linear regression with the most relevant results to assess dependency and provide some insights about preventive and personalized medicine's demand on an international level. All data was analyzed using StataSE16.

Finally, data triangulation (primary and secondary sources) was done cross-referencing and comparing during the analysis to identify points of convergence and conclusions (Decrop, 1999). After second cycle coding, all transcriptions, notes, and quantitative data were integrated to answer each objective. Findings were integrated in axial codes that respond and expand questions on the relationship between wellness, health literacy and demand for preventive medicine.

## 4.4 Ethical considerations

Ethical approval for this research was obtained from the Askadar University Ethics Committee on March 10<sup>th</sup> of 2020 and was updated in March 2021 before the start of the data collection of this research. Drafts of the instruments were submitted for review and ethical approval. The ethical considerations approved for the general research from GENTEST which covers this project, follows the principles of the World Medical Association Declaration of Helsinki per Üsküdar University Policy, concerned in two primary areas: the ethical involvement of Gentest employee participants and the responsible use of protected health information (Ackermann, 2020; Garton, 2020). Likewise, the suggested self-check ethical review of the Faculty of Science at Vrije Universiteit "BETCHIE" was done before the start of the data collection (see attachment 4). Finally, as the analysis of this data will be conducted in the Netherlands, this study will comply with the General Data Protection Regulation (GDPR). All interviews and Focus groups had a signed informed consent, and all information was managed according to the data management protocols established for this research (see attachment 5). Users' privacy was

protected during all times, assigning codes for data anonymization, and the Gentest team did not have access to this data as stated on ethical commitments above.



## 5. Results

### 5.1 Qualitative results

#### Turkish diaspora: Interviews and fieldwork

The following points emerge as a result of the coding of the interviews and fieldwork notes:

#### **Users' relationships:**

This aspect refers to the users' social circle, such as relatives, acquaintances, and friends, with whom the user shared health concerns and received advice and recommendations. This aspect is mentioned in the framework as part of the external influences of health literacy, and is the most mentioned influence on the users' health literacy. During interviews, this influence can be seen in many ways, such as accessing Gentest for the first time. This first introduction is usually the result of a relative/friend suggestion. Also, many users reported having friends, relatives and acquaintances that are doctors or work in health-related fields, whom they usually rely on to ask health information. Also, for the youngest users, their parents' insistence and concerns about chronic illnesses influenced their access to the program, although they committed and valued the program as they started to see results.

#### **Knowledge sources:**

Regarding sources of health information, also part of the external influences of health literacy in the framework, users mostly reported using the internet to search for health data and services but preferred to do it directly with their GP or the staff at Gentest. In fact, after using the 7k Medicine model for a while, users report that Gentest became their main knowledge source,

asking questions about their health and lifestyle frequently because they trust that they will have quick and accurate answers. Age influences the choice of different knowledge sources, as it is more common for young users to rely on internet research, and for older users to ask their social circle or directly to their GP (television was only mentioned by the oldest user interviewed).



U: INTERNET IS MY MAIN SOURCE. I USE WIKIPEDIA A LOT. OBVIOUSLY NOT FOR DIAGNOSIS, BUT JUST TO UNDERSTAND HOW IT WORKS BIOLOGICALLY. OTHER THAN THAT, IF I HAVE TO LOOK FURTHER, I HAVE SOME FRIENDS WHO STUDY MEDICINE, I CAN ASK THEM.

(USER 23M0605)

## Prevention

There is very little understanding about preventive medicine. It seems that most users seek the program to optimize health or to solve a specific issue (like weight loss), but prevention is seemed like an additional gain they learn to appreciate during the process. Thus, the understanding of the term prevention had two main meanings for the interviewees. First, Prevention was linked to the ill or the elderly, prevailing the idea of prevention linked to rehabilitation (something to get when old or sick, but not when healthy and young). This perception was specially seen by younger users, who admitted having changed their mind once they progressed with the program and saw it as a lifestyle to optimize health and wellbeing.

Second, the term prevention was linked to wellness, but with a negative association. Activities related to the wellness industry are usually perceived as non-scientific and negatively associated. Most respondents did not associate Gentest to wellness, but they do see the concept of prevention as something associated to wellness (sometimes actively denying that they seek any preventive measures or care).



**I: WHAT WAS APPEALING FOR YOU ABOUT THE PROGRAM, WHAT CONVINCED YOU?**

U: THE ANCESTRY, THE GENETIC TESTING WAS MY MAIN PURPOSE TO JOIN THE PROGRAM. NOT PREVENTIVE MEDICINE. PREVENTIVE DIGESTION YES, BUT MEDICINE NO. NOW I'M APPLYING PREVENTIVE DIGESTION, BUT IT WAS NOT MY FIRST PURPOSE OR MY FIRST GOAL.

**I: AND WHAT WAS YOUR FIRST GOAL?**

U: TO HAVE AN IDEA ABOUT OUR CHRONIC ILLNESSES. IF WE HAVE ANY IN THE FAMILY, BECAUSE I HAD A SMALL HEART PROBLEM. AND MY FATHER HAD A SIMILAR PROBLEM. (USER 57M1705)

### Supplements:

The use of supplements was an emergent subcode, part of the main code of "wellness". It was one of the most mentioned by users because it tends to be the only measure about which they have doubts. There are two reasons why they deem the use of supplements problematic. First, because of the quantity of supplements they must take. Even if supplements are not comparable to medications, the idea of ingesting a large number of pills on daily basis is seen by the users as a practice for "old or sick" people.

This seem especially troublesome for younger users, who reported feeling a bit of shame at first when disclosing to others that they were in the program. However, after some time following the model, they felt that their health literacy expanded and realized the benefits of taking care of their health from early ages and following the guidelines (including the use of supplements), even recommending the program to friends their own age.



U: AT FIRST, I THOUGHT TO MYSELF, WHAT OTHER 21-YEAR-OLD WOULD DO THIS? WHAT ARE MY FRIENDS GOING TO SAY? I'M GOING TO TELL THEM I'M DOING THIS, AND THEY'RE GOING TO BE LIKE, WHAT? I HAD THIS CONCERN FOR SOME TIME, BUT THEN I THOUGHT IT DOESN'T MATTER, THIS IS FOR ME. (USER 23M2904)

Second, the recommendation to use supplements by Gentest is frequently contested by the users' GP advice. Regular doctors and even social circle of the 7k model users have in many cases discourage them to use supplements, considering them non effective, excessive, or even harmful. In some cases, the costs of the supplements were also mentioned, along with the difficulties of accessing some of them in certain countries (although Gentest usually provides alternatives in these situations). Nevertheless, they feel that they can afford them and that the benefits surpass the doubts and difficulties.

### **Formal education**

Formal education, part of the individual influences mentioned on the framework, is one of the most decisive factors for users when choosing a service like the 7k Medicine model. Some of the highest educated users expressed that their formal knowledge is one of the reasons why they follow a program like Gentest. They trust the model because of the scientific background (particularly, the use of genetic testing) which makes them perceive it as accurate and legitimate. They also feel that they are in an exclusive position because of their academic background that allows them to understand the program. The scientific background reassures them that the efficacy of the measures is unquestionable, and that they have definitive tools to achieve their goals.

### **Patient-provider interaction: personable care, user involvement and communication skills**

Adherence to the program is highly related to the personable and close attention users receive, particularly from Dr. Serdar Savaş. Because of his background as a highly recognized medical and public figure in Turkey, his medical authority reassures users about the program. Moreover, users reported that his personality and communication skills play a very important role in their perceptions of quality of care and trust. Charisma, close communication and follow up of the progress, are very appreciated factors by 7k medicine users.





U: HE IS ONE OF THE BEST. HE NEVER LEAVES LIKE, YOU KNOW, “MY TEAM CAN ANSWER THAT”. NO, HE IS ALWAYS THERE. HE IS READY TO ANSWER YOUR QUESTIONS OR HELP. YOU FEEL YOURSELF LIKE YOU ARE IN GOOD HANDS.

(USER 58F1705)

Users feel heard and included in the decision making of their process. They feel that Gentest considers their worries, goals, and perceived susceptibilities, giving sense to their illness or health status. Some users contrasted this to what they usually find from other health providers (particularly in primary and public healthcare services, where user-provider interaction is limited). This is one of the main reasons reported by users to acquire the service as an OOPS outside of their current healthcare system. They like feeling cared for by Dr. Serdar and the team, perceiving them as “familiar” (for many reasons, like cultural resemblance, trustworthiness, and how they relate on a personal level). Dr. Serdar’s medical authority and closeness reassures the users’ demand for an expert figure, but also a very approachable personality.

It is also important to note that users were also very pleased with the flexibility and accessibility of the program. Gentest has always adapted the service and guidelines to make the service accessible to all users (i.e., looking for solutions during COVID, home testing, adapting to the availability of supplements in each country, etc.).

### **Users’ empowerment: increased health literacy**

One of the most important gains reported by users beyond the health goals they reach, is the ability of understanding their bodies and health issues in an individualized level. Knowing specific data about their individual characteristics through the genetic profile and tests interpretation by Gentest, gives them a clear explanation to their illnesses and/or particular needs, feeling more in control even if they have not had big physical changes yet. This is “unquestionable” information: the genetic factor gives them confidence on the scientific background and, therefore, the legitimacy of the program. Thus, users continue in the program

also because of the increase in their health literacy, they value the understanding of what they have and what they can do about it. Knowing is seen already as a success, making users feel empowered.

### **Perceived self-efficacy and response efficacy**

Interviewees reported reasons for not following guidelines, mostly related to the decrease of motivation or time availability issues (travelling mostly, since expats tend to have busy schedules and difficulty to follow or adapt their routine “on the go”). Users have complete trust in the program's effectiveness (response efficacy), recognizing the issues on their own discipline or capacities (self-efficacy).

### **Distrust in healthcare systems:**

There is a feeling of disappointment or distrust in the current public healthcare system the 7k diaspora users have. Disenchantment with medicine in public health settings is common in many countries (Brown, 2004; Uribe, 2008; Martínez-Apráez, 2017), particularly because of the lack of time or interest of providers, perceived sometimes by users.



U: I DON'T TRUST THE MALTESE SYSTEM. I DON'T MEAN THE DOCTORS, BUT GENERALLY IT'S JUST TOO SLOW. IN TURKEY THERE'S A MILLION PROBLEMS, BUT IF YOU ARE TALKING ABOUT HEALTH, HEALTHCARE IS MUCH, MUCH BETTER.

**(USER 39M3004)**

Short times of consultation, waiting times for appointments and lack of integral care are some of the factors associated to this perception. Hence, interviewees reported barriers such as knowledge on how to access, gatekeeping limits to access specialized care, but mostly a general perception of lack of quality or even higher costs in their host healthcare systems. These are all common problems encountered by migrants in many scenarios. However, users also

acknowledge that they accessed Gentest in opportunistic visits in Turkey (holidays, for example) and they preferred to take this service because of the recommendations they had of people that know the program.

### **Costs of the program**

Costs are not usually an issue. Users realize that the program might be expensive, but worth it. They are in a wealthy position that allows them to cover the expenses of the program (diet, supplements, and tests costs). Therefore, it is important to note that current international 7k users belong to a high socioeconomic status and are well educated, and that influences their demand for the program.

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**Figure 2.** Word frequency cloud generated with Nvivo with coded interviews to 7k users.

### International users: Focus group

The focus group intended to complement the information found during the initial data collection and compare it in a wider cultural context to expand findings beyond the Turkish background of the interviewees. The Focus Group participants were young expats living in different countries (mostly in the Netherlands), professionals with high literacy (in some cases, involved also in healthcare).

All participants claimed to be very interested in preventive medicine and had a very clear understanding of the concept, in contrast with the interviews. They were interested in wellness activities, actively participating in some of them and relate them to healthier lifestyles and preventive measures. Most of the participants stated that they have relatives with chronic illnesses and that it makes them concerned about the possibility to develop them in the future and are also aware of certain behaviors that they can adopt to avoid them.

A very important finding was that all participants go back to their home country for healthcare, particularly for preventive care (general checkups). They complain that in their current countries they cannot access general checkups and that the providers' approach tends to be curative and medicalized, not giving them any chance to choose between alternatives or to access preventive screenings. Also, they deemed quality and cost better in their home countries for certain services.



“IN BRAZIL WE HAVE CHECKUPS EVERY YEAR. FOR ME, IT'S A BIT WEIRD THAT IN THE NETHERLANDS THEY DON'T DO CHECKUPS, IT CONCERNS ME”.

(WOMAN, FROM BRAZIL LIVING IN NL)

Furthermore, they identified a lack of personable and culturally sensitive care from health providers in their current countries, which they attribute to the focus on efficacy and the short time of consultation. They also feel that the focus is more on a business model than in wellbeing of users, and they do not feel heard or involved. Unable to know their medical history or results, they even feel disempowered and that they are treated differently because of their origins. Thus, to deal with these barriers, they develop strategies to navigate the system like exaggerating symptoms and report certain complains to match protocols and avoid gatekeeping strategies.



“LIKE, IF I HAVE ANY SYMPTOMS, I TRY TO MAKE IT WORSE BECAUSE OTHERWISE I WILL NOT BE ABLE TO SEE A SPECIALIST, AND I KNOW THAT THE GP WILL JUST GIVE ME PARACETAMOL AND CHECK AFTER TWO WEEKS. IT SEEMS LIKE YOU NEED TO ACT AND BE DRAMATIC TO GET SOMETHING HERE.”

(NONBINARY PERSON, FROM CHILE LIVING IN NL)

To demand accurate preventive care, alternative treatments, screenings, access to healthier lifestyles, or even to navigate the system with all barriers it has for foreign individuals, there is a need for a high health literacy. Therefore, accessing preventive healthcare in most context seems to be a privilege, still far out of reach for a big part of the population.



“IT IS SO COMMON IN THE US FOR PEOPLE TO NEGLECT THEIR HEALTH, BECAUSE THEY'RE LIKE “I DON'T HAVE THE MONEY TO BE SPENDING RIGHT NOW ON MY ANNUAL CHECKUP”. AND, IF YOU DON'T KNOW HOW TO CHECK YOURSELF FOR YOUR BREAST TISSUE FOR BREAST CANCER... THEN IT'S UP TO YOU.”

” (WOMAN, FROM RUSSIA LIVED IN USA)

Finally, after learning about the 7k Model, all participants seemed very interested and willing to access this service, recognizing that this would fulfill many of the needs they demand (both in and outside their countries of origin). The only concerns were about the possible cost of the program.

## 5.2 Quantitative results

According to the design of the research, the quantitative part was guided by the qualitative results around the demand for the 7k Medicine model. Therefore, the chosen variables responded to the main factors identified on interviews, particularly around patient-provider

interaction (including the patient on decision making, clarity and availability to answer questions and provider communication skills).

Thus, to explore similar international indicators to assess the importance of these factors in the global demand for personalized and preventive care, the OECD (2021) indicators of Quality of Care-Patient experience were selected, to see if they had any correlation with the Perceived Health Status by patients (perception of own health as good/very good). The selected indicators of the Quality of Care/Patient perceptions are<sup>4</sup>:

- Doctor spending enough time in consultations (positive perception of patients of having enough time during consultation)
- Easy to understand explanations (positive perception of patients on clarity of information given by physician)
- Doctor giving opportunity to ask questions (positive perception of patients of having enough opportunity to ask questions during consultation)

The idea behind this analysis was to explore possible relationships between these factors, such as that the influence of the quality of care perceived by patients on their perception of their health.

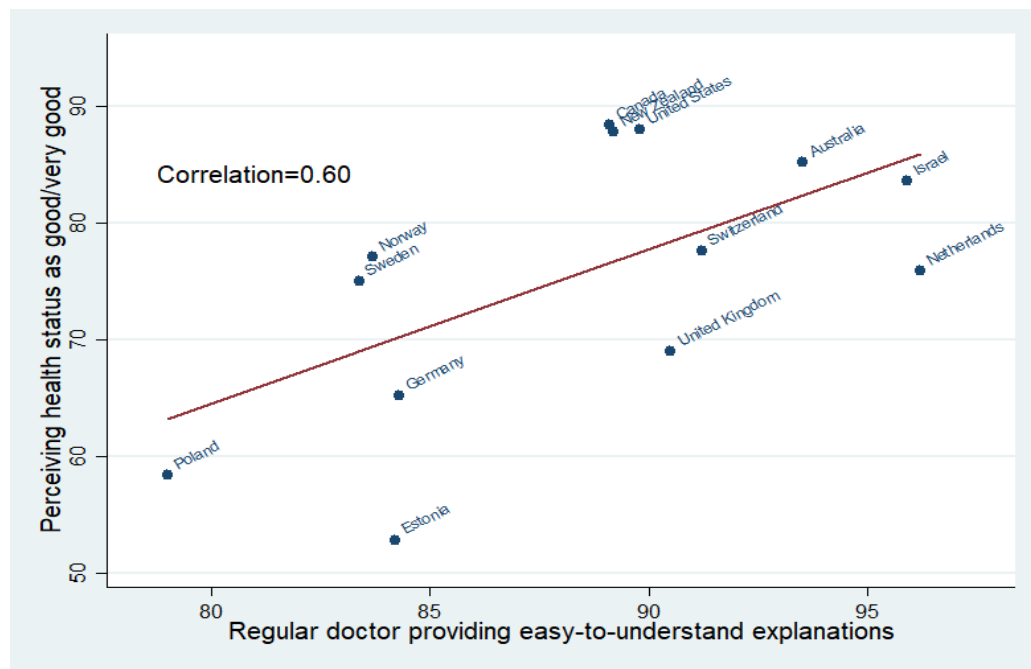
First, pairwise correlations were done to assess possible relations between these factors.

- Perceived health status/ Dr. giving opportunity to ask questions 0.67 (only 5 countries)
- Perceived health status/ Dr. giving enough time consultation: 0.34 (14 countries)
- Perceived health status/Dr. giving easy to understand explanations: 0.60 (14 countries)

In this first analysis, all available countries were selected due to the limited amount of recent data (using 14 countries with info from 2016, the most recent year with the most data, 2016). Although all correlations between quality-of-care factors and perceived health status were positive, they have very little power due to the very small number of observations available.

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<sup>4</sup> Values belong to 2016 (most recent year available). All available countries were used (very few were updated in the database).



**Figure 3.** Example of the correlations between quality-of-care factors and perceived health status

Unfortunately, although the patient experience-quality of health OECD indicators are the ones that can best contribute to the main topics identified during the qualitative phase, the database has a lot of missing information for recent years. Therefore, the results of this analysis do not have sufficient power due to the low number of available observations.

However, with the purpose to give some insights on these relationships with the available data on the topic, a multivariate regression was done to explore all the variables of quality of care in function of the perceived health status:



VARIABLES	(1) Perceived Health Status (good/very good)
Dr. enough time during consultation	-2.665* (0.216)
Dr. giving opportunity to ask questions	0.445 (0.434)
Dr. easy to understand explanations	4.319 (0.856)
Constant	-125.6 (43.80)
Observations	5
R-squared	0.951

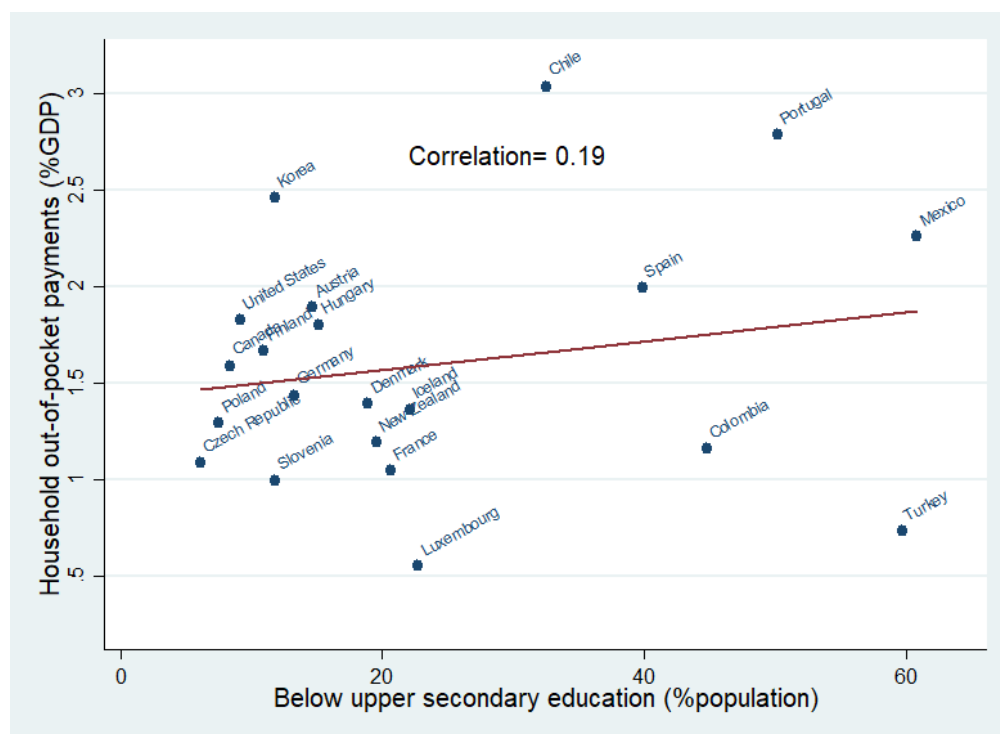
Robust standard errors in parentheses  
\*\*\* p<0.01, \*\* p<0.05, \* p<0.1

**Table 2.** Multivariate regression with quality-of-care factors and perceived health status.

It is important to acknowledge that the assumption of conditional independence for this regression is not fully met. Therefore, establishing a causal relationship with greater certainty would require more nuanced methods that exceed the means of this project.

On the other hand, to explore the impact of educational levels (as seen on the qualitative phase) on the patients' investment in health services outside of the healthcare system (as OOPS), data also from the OECD (2021) database was used. The indicators of "Household Out of Pocket Payments in health" and "Adult education level (% of 25–64-year-olds Below upper secondary)<sup>5</sup> were analyzed to seek for a possible correlation, using data from 2019 of 20 countries with the highest rate of "people living with 2 or more chronic diseases" published by OECD (2019). Nevertheless, the correlation was not significant.

<sup>5</sup> Data corresponds to 2019, using a selection of the top middle and high income with the highest rate of "people living with 2 or more chronic diseases" published by OECD (2019).



**Figure 4.** Scatterplot correlation between "Household out-of-pocket payments in health" and "Adult education level (Below upper secondary education)"

This analysis was intended to explore the possibility that the most educated people (such as current 7k medicine users) would spend more in out-of-pocket on healthcare costs. However, the correlation show that it might be the people with the lowest educational level who invests more in health out of their pocket.

The power of each analysis was not significant to be able to make strong statements about these relationships. However, the aim of the quantitative phase of this project was exploratory, pointing out some possible topics, the need for further research, as well as the lack of quantitative data on preventive health, motivation, and quality of care.



## 6. Discussion

To find the reasons behind the demand for preventive medicine of current 7k international users, it was necessary to understand how their ideas about prevention are shaped. Also, it was essential to identify socio-cultural factors that can influence the demand for healthcare when using systems outside their countries of origin. To summarize, this research found that the current international 7k users are attracted by the legitimacy of the scientific background of the model, but ultimately continue the program and value it because of the personable care, involvement on the decision making of their process and the individualized information which empowers them.

Likewise, users of the model tend to have higher educational levels and socioeconomic status, which also influences their demand and capabilities to access this service. Results of the interviews matched the ones of the focus group, which could mean that these factors might be common among different cultural backgrounds. Also, the results of the focus group emphasized that expats seek healthcare in their countries of origin, particularly demanding preventive screenings (general check-ups) which they cannot access easily in their current countries. Finally, the quantitative analysis explored indicators related to perceived quality of care with perceived health status, along with educational levels with out-of-pocket spending in health. Even though the quantitative results were not conclusive, they show some clues on the importance of these factors in global health and the need for more updated and available data on the topic.

### **The misconception of prevention**

The 7k medicine “Turkish diaspora” comes to GENTEST with specific goals, such as delaying the aging process or tackling weight loss. These reasons are linked to preventive measures, but

consultees do not necessarily perceive them in this way. Thus, 7k medicine is not perceived by users as prevention but optimizing health. The confusion around the term “preventive medicine” relates on one side to the misunderstanding of prevention as rehabilitation for the elderly and the sick. This perception might be a result from mainstream curative systems, an illness-centered and not patient-centered culture in which users value healthcare as medicalized and curative.

On the other hand, there is an attitude of discredit towards wellness and wellbeing practices (associated to many new age practices and non-scientific approaches) that somehow includes the concept of prevention. However, some users did not associate 7k to prevention at all, even though their motivation could have been linked to preventive goals it is not perceived as such because of the scientific reassurance the program has. This is linked to an idea of personalized medicine (specially related to genetic testing) as a rational act, a motivation of highly educated users.

The case of the use of supplements and the clashes between regular GP and Gentest guidelines is a good example of this contradiction. Supplements are seen as part of the wellness industry, and thus perceived negatively by some physicians and people close to the users, fearing ineffectiveness or even harmful secondary results. Thus, the use of supplements is in the middle of this dispute between scientifically proven personalized medicine and measures and activities related to the wellness industry.

### **Prevention, wellness, and privilege**

Despite this reluctance among 7k users to be involved in wellness activities, highly educated and wealthy people tend to be the main consumers of this industry (Mendelson, 1998). Participants of the focus group did not have such strong reluctance to wellness activities and had clearer concept of preventive medicine and measures. Thus, this could also respond to factors specific of the Turkish diaspora. However, the wellness industry is a significant socioeconomic global trend. The market of health goods and services is using different marketing languages to promote preventive measures and lifestyles, and the legitimacy of these services is sometimes perceived higher than it is. Unlike models like the 7k Medicine, the wellness industry includes several services with scarce scientific support (Kickbusch, Payne, 2003).

Today, wellness has gone mainstream. It has become a moral demand and dictates the way we work and live (Cederstrom, et al., 2015). Wellness acts as an ideology, a collection of ideas and beliefs. This is particularly visible on judgements towards those who fail to follow the rules; failure to comply becomes stigma (Cederstrom, et al., 2015). Thus, individual responsibility on wellness becomes a way to increase self-value, an investment on your identity (Kickbusch, Payne, 2003). This promotion of health as a product in a private market of health goods and services is risky, as it moves towards the commodification and privatization of preventive health.

Although preventive medicine exists in public health settings, innovations in preventive and personalized services are condensed as private services. Promotion strategies of these services may be working for the most privileged sectors of the population, but by promoting health as a product, it is displayed as a privilege: a luxury. This is particularly problematic in LIC and MIC, increasing privatization of health promotion (Pilzer, 2002). Thus, "health promotion where access through the market makes healthy individuals even healthier, and leaves those with low health purchasing power behind" (Kickbusch, Payne, 2003:23).

The impact of educational levels on the way people invests in health needs further research. Better educated people are assumed to choose healthcare more efficiently, having more awareness of health risks, understanding guidelines from providers and being able to invest in healthcare services being also from a wealthier status (Carrieri, V; Bilger, M. 2013). However, although the quantitative phase lacked the power to make conclusions on an international level, the discussion brings the need to explore the role this has accessing and demanding preventive and personalized care. Programs like the 7k Medicine model that aim to be accessible in a primary care level, need new strategies and policies to address issues of quality and equity. Expanding the model means dealing with other services in a highly unregulated market, making it crucial to protect consumers as a trusted source of health information. Hence, helping to increase health literacy will become even more essential.

### **Personable and personalized care in a public healthcare setting**

The user-provider interaction, mainly the provider's communication skills, personable care, follow up and flexibility, is one of the main success factors that 7k users report. The close and

personalized care of the 7k Medicine model is engaging, involving users in their own health process; and increasing their health literacy. This gives them something that they cannot find elsewhere that makes them feel heard, understood, and empowered. Although the quantitative results lack power to make these conclusions on an international level, the information so far might still show that the higher the quality of care perceived by patients, the higher their own health perception could be. Regardless of the cultural context, better communication, and empowerment of patients with their processes can have positive effects on their health.

Thus, if the purpose is to translate this factor into primary healthcare settings, it is important to consider the feasibility of it depending on the capacities of each healthcare system. To provide healthcare with this personable and personalized approach, providers would need more consultation time and communication skills, increasing expenses, trainings, and capacities of the system. Endorsing the investment on screenings and tests necessary to achieve a more personalized medicine can be achieved by exposing the long-term benefits and reduction of burden of NCDs to different stakeholders. However, appealing for a change in the way of communicating and relating to users is much more complex. This would require training, structural changes in protocols and attention time, which would also imply a paradigm change not only among stakeholders but also among the medical staff themselves. This becomes even more difficult in LIC and MIC, where access to health is hindered by structural poverty and collapsed healthcare systems.

To be able to manage personalized information on a massive public level, public funding is needed to support biomarker testing, achieving reimbursed access to precision medicine (IQN Path; ECPC; EFPIA, 2021). However, this relates again to the capacities of each system, because some countries lack the sufficient infrastructure or pathways to support equal access for all patients, have a low awareness among physicians of available biomarker tests and their benefits, and have a great variation of availability and test technologies between laboratories (IQN Path; ECPC; EFPIA, 2021). Innovation on personalized and preventive medicine can generate important changes on the prevention of NCDs and the well-being of the population in general, but their application depends on political will and socio-economic structures that still need advocates and work. In LIC, healthcare systems have not changed in many years, with remaining conservative and non-personalized approaches despite the scientific and technological advances, making it very difficult to discuss the need of a new perspective with

stakeholders (Atun, 2021). Gradual changes might be necessary in specific settings, seeking alliances and visibility with different sectors (patient-organized movements, advocates, decision makers) and exploring the possibilities to collaborate with community structures to provide personable and context-specific guidance to achieve in some level the benefits of the close interaction programs like the 7k Medicine model offers.

On the other hand, it is important to think about potential tools to increase the capacity for the management of information and monitoring of user measurements in a public health system. For example, the use of smartphones, smartwatches, and artificial intelligence (AI), which allows for continuous monitoring and interpretation in personalized manners (Andrews, R.A, 2020). Nevertheless, the use of these tools needs to consider the consumer/patient involvement in device development, along with all the current legislation and ethical considerations around personal medical data. Using technology and automated medicine tools might help translate some of the benefits of models like the 7k Medicine to a public setting, but it must always focus on the increase agency of people in meaningful ways, not limited to extracting data from them but considering the potential and effect on the users' empowerment (Prainsack, 2021).

Thus, these considerations must be tailored to each specific country and setting, considering for example the ethical issues that might arise like the possibility of higher premiums depending on genetic profiling or biomarker results. Imposing sanctions for a certain health-related behavior or lifestyle, increasing patients' responsibility for their own health ignores the underlying socio-economic structures behind their choices and may increase social inequality (Gefenas, E. 2011). Also, ethical considerations must address issues like the respect for private life and the right to information (or to wish not to be informed), and the need for appropriate counseling to prevent misinterpretation of results (Gefenas, E. 2011).

### **Community health workers**

Despite the possibility to manage health data on massive levels, studies show that even with information some individuals lack the capacities to evaluate health risks correctly (Viscusi, 1984, 1990) or decide not to invest in preventive actions and choose to run the risk (Carrieri, V; Bilger, M. 2013). This was also present during the qualitative results: users had access to different sources of health information, but their health literacy was also influenced by their relationships and beliefs. These factors might explain the underuse of preventive care in different

communities, particularly on how users approach their providers and the trust and legitimacy they feel about their GPs and the healthcare system overall. Therefore, increasing trust in GPs and the system by improving communication skills and interaction with users is fundamental to implement preventive and personalized measures in a public healthcare setting.

Also, negative perceptions on quality of care and distrust on healthcare systems are common factors on different populations. As seen on the qualitative results, these perceptions are widely spread in different cultures. The gatekeeping strategies restricting access to specialized care, along with the focus on curative approaches and on the efficacy of the system, leaves little time and attention to preventive care and personalized measures. Therefore, GPs adopt a purely gate-keeping role, when they should be the primary entry point to the system and guide patients towards preventive care and health optimization. Including a model like the 7k medicine in public healthcare entails regaining the trust of patients in the health system and its providers.

An alternative could be exploring other provider-user interaction strategies like community health workers (CHWs) or highlighting the importance of family doctors. These roles give continuity to the users' navigation through the healthcare system, also tailoring guidelines and medical advice to the specific needs and behaviors of their communities. Several studies indicate that CHWs are effective in improving NCDs care and health outcomes, particularly with marginalized communities (Kok, et al., 2015; Gilmore, et al., 2013). Thus, articulating efforts with CHWs, proposing trainings on 7k medicine to be able to give and follow guidelines or even take some of the measures and interviews needed during the process, could be a feasible and effective way to apply the model in public settings. This will require funding, appropriate reimbursement, training, and supervision along with policy changes (Brownstein, et al., 2005) but it would contribute to the continuity of care and adherence to treatment of NCDs.

Regarding the theoretical framework that guided the analysis of this project, it should be noted that the concept of health literacy was extremely useful to understand the demand for preventive and personalized medicine. However, in contrast to what was proposed by the model, health literacy in this research was both part of what leads to actions in health and their result. Increased health literacy was the highest reward reported by users, empowering them about their own health management. On the other hand, although "Patient provider interaction" appears in the model as an action, it had a lot to do with communication skills



within the system factors. This caused some overlap during the coding process. For example, users demand certain type of interaction with health providers due to their health literacy (expect to be more involved, more quality of care, legitimacy) but also the provider communication skills might persuade users to alter behaviors or access the program. Overall, analyzing this data with a health literacy framework helped to structure data and make sense of the imaginaries reported by all participants.

### **Strengths and limitations**

The access to international users of the program and the availability of “expats” for the focus group posed a great opportunity to explore the demand of transnational users for preventive medicine and the reasons to go back to their homelands for healthcare, giving important insights on the gaps of access and lack of services in specific countries and settings, a topic that has not been explored in depth. Also, the use of multiple qualitative methods allowed to deepen into the possible reasons from different cultural backgrounds, and the qualitative phase informing the quantitative approach allowed to explore relevant factors on a wider level. Nevertheless, the research had several limitations that should be accounted for in future research:

- The available users of the 7k program are a very small sample. Also, they are mostly men, which makes it difficult to explore possible gender differences present on the demand for these services (only one woman was interviewed).
- Information regarding the abandonment of the program was not available. Reaching this population was not a possibility, so data about reasons to drop out of the program was not gathered.
- Although most of the interviewees spoke English, there were cases (one interview and the consultations observed during fieldwork) in which a translator was needed. Although the process was very thorough, in any translation process some information can be lost.
- Due to the current situation with COVID-19 and the nature of this research (focusing on people located in different countries), the methodology remained virtual. Although this gave access to users located in different countries, the quality of fieldwork in person cannot be replaced. Also, it is important to note that with the pandemic Gentest

reduced their staff due to the economic impact this caused. Thus, although all interns had a lot of support, it was a challenge for the whole team.

- Quantitative data was not available for many countries in the most recent years, so the analysis was done with the most recent available date (2016) with the available countries. This lack of observations and updated information had a big impact on the research analysis.



## 7. Conclusion

The 7k Medicine model, as an example of innovations on personalized and preventive medicine, shows promising opportunities to prevent chronic diseases in public and international levels. Thus, to be able to build a future pilot adaptable to public settings at national and international levels, this research aimed to understand the current demand for this program by international users of the 7k Medicine model, learning from their global perspective and their interest on a preventive service outside of their current healthcare systems. Also, the research learned from the experiences of expats living in several countries, their use of healthcare and demand for preventive and personalized measures. This allowed to compare the findings on 7k users on a wider cultural group, drawing conclusions that permitted to set relevant quantitative indicators to explore the demand on an international level using open global databases (OECD). Based on the results, the following points are proposed for the future expansion of the program:

- Alliance with communitary actors: because personable attention at the same level as Gentest currently implements might be difficult to replicate in public healthcare settings, exploring alliances and articulation of the program with community actors and investing on provider communication skills could help achieve some of the program's success on a primary care level. An alternative could be exploring other provider-user interaction strategies like communitary healthcare workers. Knowing the specific needs and behaviors of their communities, CHWs could provide more accurate guidelines to prevent NCDs and reach a wider population to apply tests and questionnaires. This could help to keep the continuity of healthcare and restore trust on providers and the system.

- Focusing promotion of the program on its scientific background: the scientific legitimacy of the 7k Medicine model, its innovation, and the increase of users' empowerment in their own health is one of the most appealing factors to attract new users. The focus of promotion on these factors can increase interest in potential users and counteract the confusion around preventive health, rehabilitation services and the wellness industry.
- Visibilize preventive and personalized medicine: To counteract the misconceptions around prevention, contributing to the access to reliable and accurate knowledge is important. Increasing health literacy might influence the demand and adherence on preventive and personalized measures both as a public and private service. Therefore, increasing Gentest's communication strategy could be useful, having more online presence (i.e., social media could also appeal to younger users) and spreading information on accessible formats with these tools to create awareness.
- Using advances in technology to monitor and follow up on a public level: Exploring the use of technology tools (like data analysis software, activity and biomarker monitoring apps and tracking devices) can help reach and guide bigger populations. Because increased literacy is one of the main gains reported by 7k Medicine users, these tools can help empower users to achieve their goals providing trusted information. As mentioned before, ethical considerations and data protection measures must always be prioritized and tailored according to each specific region and context.

This research aimed to contribute to the future expansion of the 7k Medicine model. However, several steps should be taken before to reach this goal. Future research in Gentest could focus on the following topics:

- Comparing international data: Exploring in more depth international databases to seek comparisons on preventive and personalized expenditures and quality of care correlations would be useful for the future of the 7k Model's expansion. Although the data on preventive and personalized care is scarce and outdated, further research is necessary.

- The Netherlands and other possibilities: Further research is needed to explore specific context to apply the model. Thus, as The Netherlands already has possibilities due to the current research alliances, researching the demand for preventive care as a previous step to apply the program could be useful to identify factors to reach a Dutch audience.
- Gender differences: Due to the limitations of this research, it was not possible to consider differences by gender. Therefore, it is recommended to take this into account in the future to address how this factor can influence the demand for the 7k Medicine model and in general for preventive and personalized medicine.
- Prevention misconception as part of Turkish diaspora: It could be useful to do a deeper analysis on the misconceptions regarding prevention and wellness among the Turkish diaspora. In contrast, the international focus group did not have such strong reluctance to wellness activities and have a more accurate definition of preventive medicine. Reasons for this could also be related to other factors, so more data would be necessary to draw conclusions.
- Abandonment: Likewise, reaching users who have left the program is beyond the scope of this research. However, ways to include these types of patients or to find general information on discontent among users or why individuals abandon personalized or preventive medicine programs may be considered in the future.



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## 9. Attachments

### Attachment 1: Interview Guide

**Master Interview Guide**  
**7K Medicine - Gentest**  
**2021**

Cover Sheet
Title
Date
Time
Interviewer (s)
Note taker (if any)
Transcription
Duration of interview:
Medium used (i.e., Skype/Telephone/Google chat/WhatsApp):

#### Introduction

Good morning/afternoon, my name is .... and I am a researcher working for the Gentest Institute and the Free University of Amsterdam, the Netherlands, who are together doing a research study.

How is your day going so far? (Small talk)

We are currently doing this research to understand some of the motivation, benefits, and points of improvement of the program from the user's perspective. This will help us evaluate the effectiveness of the intervention and guidance and analyze the demand for Gentest, particularly from users living outside of Turkey.

Your participation is highly appreciated since we would like to know how your Gentest experience has been so far. The interview should take approximately 45 minutes and, if you allow us, it will be recorded to facilitate the analysis. This recording will be transcribed and anonymized at which point the recording will be deleted. I would also like to assure you that your confidentiality is guaranteed, and you can pass on any question or leave the interview at any time. You can of course ask questions yourself at any time.

Was this clear for you, do you have any questions before we start?

If you accept, then I will start the recording, once I start, I will ask again for permission so it can be on tape.

*[The recording has been started]*

This is (researcher name), I am with (interviewed name) today, (date). Do I have your permission to record our interview?

Thank you, let's first start by some introductory questions

- How old are you?
- When did you start at Gentest?
- Where are you living now?

## Previous knowledge, expectations, and wellness

1. What did you know before entering the program about preventive medicine? How did you know this?
  - *What is your study level (primary, medium, high education)? Did you study anything related to medical sciences or healthcare (medicine, nursery, psychology, doula, traditional medicine, others)*
  - *How do you prefer to inform yourself about a topic? (asking relatives/friends, reading literature of the topic, tv or radio, social media, internet research, other)*
  - *Was it easy to get information about preventive medicine for you?*
2. How good do you consider yourself at: Planning, Organizing, Understanding the programs, instructions, Understanding health information? (ask for each)
3. Why did you choose a program in Turkey instead of your current location?
4. Are you currently involved in other wellness activities? (i.e gym, yoga, pilates, mindfulness, traditional medicine, homeopathy, detox treatments, stress management, any other activity aiming for wellbeing) why?

## 'Gentest Experience'

1. Why did you come to Gentest?
  - *Do you have relatives with chronic illnesses? If yes, did this have to do with your decision to enter the 7k program?*
  - *Did you want to improve your diet?*
  - *Were you feeling like you did not have enough energy for day-to-day activities?*
  - *What makes this program appealing to you? What makes it different from other choices?*
2. Do you feel like coming to Gentest helped you to understand/ combat these worries or meet these needs?
  - *Did you feel like they gave you the support you needed? / Enough support*
  - *How do you feel about the physical activity and exercise guidance at Gentest?*
3. What do you think about the people/dietitians at Gentest? Who did you meet? What did you like, and didn't you like about them and the way they treated you? What do you think about Dr. Savaş?
4. What was your experience during your initial consultation session?
  - *Where you provided with explanations for why certain measurements were taken/ why such in depth lifestyle analysis was done?*
  - *Did you feel comfortable during this assessment?*
  - *Were you asked what you wanted to pay more attention to, e.g., healthy eating/ exercise/ disease risk?*
  - *How did you select a suitable Gentest package?*
5. How did your report interpretation go?
  - *Were you hesitant to hear your results?*
  - *Were the staff able to clarify certain sections?*
  - *Did you feel like Gentest listened to your initial goals identified in your initial consultation?*
  - *Were they flexible if you had no access to certain supplements or had concerns over your diet plan?*
  - *Were you provided with recommendations on meal plans or exercise routines?*
  - *What do you think of the Gentest recommendation on physical activity?*
  - *What is your opinion on physical activity?*
  - *Are you currently performing physical activity? If so, what do you do?*
  - *Do you have any recommendations on how Gentest could improve this for future consultees?*

6. If you had any questions/ concerns, were you able to easily reach Gentest over WhatsApp?
  - *Did they respond quickly to your questions?*
  - *How do you experience the communication with the counsellors currently?*
  - *Would you prefer it any other way?*
  - *Did you find this service helpful?*
  - *If not, how do you think this could be done better?*
  
7. Did you find the follow up assessments beneficial?
  - *Did this help you to ascertain your progress?*
  - *Did this give you more motivation/ clarification?*
  - *Did you have regular follow up periods, if not why?*
  
8. Did you manage to incorporate all aspects of the lifestyle recommendations into your daily life?
  - *Which aspects did you find difficult to incorporate/ why?*
  - *What was the easiest to follow?*
  - *Do you have any recommendations for other consultees?*
  - *Do you think that you will follow Gentest's lifestyle plan in the long-term future? Why?*
  - *Do you have any recommendations for other consultees?*
  - *Do you think that you will follow Gentest's lifestyle plan in the long-term future? Why?*
  - *Do you think you have achieved your initial goals/ or see some progress after joining Gentest?*
  
9. Are you happy with how Gentest has helped you to improve your lifestyle to help prevent certain disease risks?
  - *Would you recommend Gentest to family/friends?*
  - *Are there any suggestions that you would like to provide Gentest?*
  
10. Do you have any concerns about the program?
  - *Do you have any concerns about the possible health effects of this program?*
  - *Do you have any concerns about other costs related to the changes you have to do with the program? (Food changes, supplements, others)*
  - *Do you have any concerns about how being in the program is perceived by others? (How your family, partner or close ones feel about it, your work, your GP, others)*
  - *Have you had any warning to not get into the program? If yes, from whom? (Friend, relative, doctor, tv or radio, social media, internet research, other)*

## Attachment 2: Focus group

The Focus group was recruited using contacts from the main researcher (voice to voice recommendation). The interviewees answered a google form ( ) to give their written consent, match the criteria (expats that had used the healthcare system abroad) and choose available timeframes for the activity. The following questions guided the group discussion:

### Focus group Guide:

Hi, welcome to this FG, I am Laura Martínez, and I appreciate so much your time today.

As I told you before, I am currently doing a research during my internship at VU Universiteit with Gentest, in Istanbul, and their 7k Medicine Model. I will introduce you a bit more about the model later. Today, I would like to ask a couple of questions so we can discuss about preventive medicine, your perceptions about it, and your expectations and demands on healthcare being "expats" in other countries (now or in the past).

Before we start, I would like to remind you that all the info you share will be used only for this research and that your names will not appear (all data will be codified, so it will remain anonymous). I will take some notes during this meeting. If you don't want or don't know how to answer something you don't have to do it, or if you need to leave earlier you can at any time.

### Does anyone have any questions?

- First, I would like to know, what do you guys understand when someone talks about preventive medicine? What comes to mind or what do you know about it?
- When do you think it would be necessary to start with preventive medicine or preventive measures, at what age?
- Do you relate preventive medicine with the term wellness? Maybe any practices like mindfulness, yoga, supplements, fitness, etc.?
- Have you previously done any of those practices? What and why?
- Have you heard before about personalized medicine?

- Do you know about genetic profiling for personalized medicine? What have you heard?
- How do you usually get information about health? What are your main sources? (do you always go to your GP, or search online, get recommendations by friends, etc.)
- What makes you trust certain health information or service? What makes it legitimate or real for you?
- As an expat, how has it been to use the healthcare outside of your home country? Was it a good or a bad experience and why?
- Did you feel the need to go back to your country for health care? What did you miss from your home healthcare services?
- Is there a difference on the way doctors and health providers treat you during consultation? Maybe time of the consultation, friendlier or more personable staff, getting you more involved in the treatment (giving you choices or more information), etc.?
- Ok, now for the final part, I would like to tell you a bit more about the 7k Medicine Model.

The 7k model of the Gentest institute started in Istanbul in the early 2000s as a private health service. It creates a plan with health guidelines and a follow up based on the individual's health information, lifestyle factors, biomarkers, and genotype, to optimize health and prevent and detect chronic and complex diseases. It has different packages (for business users with little time, users what want to focus on losing weight, aging package, among others). It is led since its creation by Dr. Serdar Savaş, a very recognized health figure in Turkey. The aim of this services is to help users change towards healthier behaviors and to manage their health according to their priorities.

The 7k stand for

Personalized ("kişiyeye özel")

Predictive ("kestirimci")

Preventive ("koruyucu")



Comprehensive ("kapsamlı")

Precise ("keskin")

Evidence based ("kanıta dayalı")

Participatory ("katılımcı")

All words that start with K in Turkish.

- Would you be interested in something like this? Or who do you think would be involved in this kind of program?
- What is the most interesting factor for you of this model? What makes it appealing?
- Do you think this could be interesting in your home country or in your current country?

The activity was recorded and transcribed to add quotes to this research, using coded names to keep anonymity of participants.

## Attachment 3: Code book for qualitative analysis

Codebook generated by Nvivo

Name	Description	Files	References
Actions in health		0	0
Action	Types of health action involved in the ability to seek and manage health as well as actions outside the health system	0	0
Access and use of healthcare	Start of use of health services	7	11
Self-care	Management of health and illness, following plans and recommendations, adherence	6	9
Broad concepts		0	0
Prevention	Active search to prevent an undesired negative health outcome	4	7
Aging	Measures to avoid/reduce effects of aging	2	2
Illness	Measures to avoid/reduce risks or effects of a particular illness	5	9
Wellness	Active process of awareness and choices towards optimal health and wellbeing	5	6
Diet	Planning for food intake according to goals	5	11
Exercise	Planning for physical activity according to goals	7	10
Genetic testing	Health profiling according to genes	4	7
Supplements	Intake of specific supplements according to goals	5	9
Treatments	Other treatments aimed to increase wellness	0	0
Covid	Covid related factors to account for differences during the pandemic	6	8
Socio-cognitive determinants		0	0

Name	Description	Files	References
Motivation	Will to take action emerging from individual attitudes towards health actions or from perceptions of a specific illness	0	0
Beliefs and attitudes	Beliefs and attitudes regarding health, which can be positive, negative, or associated to emotional or analytical information processes	5	21
Perceived susceptibility	Perception on possible susceptibility to certain illness or health events	3	3
Response costs	Costs that may hinder the occurrence or maintenance of preventive behavior (barriers, socioeconomic losses or unfavorable consequences)	1	2
Response efficacy	The benefits, referring to a belief that adopting a behavior will be effective	4	13
Knowledge and understanding	Services, familiar abstract concepts, disease specific treatments.	5	16
Volitional	Regulation of motivation and emotion during difficult or tedious tasks, contributing to adherence to plans and goal achievement	0	0
Navigation	Moving inside the system, weighing benefits and barriers	2	2
Planning	Organizing, task specific skills	5	10
Self-efficacy	Implementation skills, decision making	7	14
Structural determinants		0	0
External influences	External factors that influence the health knowledge of the individual	0	0
Age	Age specific characteristics regarding health knowledge	3	5
Gender	Gender specific characteristics regarding health knowledge	0	0
Knowledge sources	Referring to selection of sources in health knowledge, like social media, press, tv, others	7	11
Location	Location specific characteristics regarding	6	8

Name	Description	Files	References
	health knowledge (i.e rural, urban)		
Relationships	Indicating references and interests based in friends and relative's opinions and attitudes regarding health	6	15
Socio-economic status	Socio-economic specific characteristics regarding health knowledge	3	3
Individual capabilities	Factors that allow the individual to be able to comprehend and use knowledge in health to make decisions	0	0
Age related cognitive factors	Individual cognitive abilities influenced by age	1	1
Basic literacy or formal education	Knowledge influenced by educational level	3	5
Cognitive capabilities	Individual cognitive abilities	0	0
System factors	Refers to enabling or limiting factors for the individual within the system to access services	0	0
Accesibility	Availability of health services within reasonable reach	4	6
Conflicting information	Conflicting information between providers.	5	7
Current country's healthcare perception	Perception of current healthcare system (expats)	3	4
Healthcare costs	Costs associated to healthcare services	3	6
Patient provider interaction	Provider communication skills, developed trust and sharing decision making.	8	46

## Attachment 4: Copy of the Self-check result by the Ethics review committee of the Faculty of Science (BETHCIE), Vrije Universiteit Amsterdam.

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(\*) Note that in this case you should make sure that you are aware of, and comply to, local guidelines for research ethics.

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### Result of the research ethics self-check:

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Your research project **does not require further evaluation** by the Research Ethics Review Committee. This is because:

- You have indicated that you will ask your participants for informed consent.
- You have indicated that your research poses no risks to participants.
- You have indicated that you will not work with participants who are vulnerable.
- You have indicated that your participants are not exposed to material, social or psychological recruitment incentives that are stronger than usual.
- You indicated that your participants will not be exposed to research material that is distressing, offensive, or age-inappropriate.
- You have indicated that your research poses no risks to the researchers.
- You have indicated that you will not deceive research participants, or you will properly debrief them afterwards.
- You have indicated that respondents in your research will be fully anonymous.

### What to do now?

If you think these results are mistaken, please go back in the form and change your entries accordingly.

If the results are correct, you may want print out this confirmation message for further use.

On the following page, we ask you to confirm that the answers you provided are correct, after which they will be stored in our repository. You will also get a receipt, displaying all answers you provided, for future reference.

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Additional note: Research data management plan required

## Attachment 5: Informed consent, ethical considerations, and data management.

### Informed consent (Turkish)



#### BİLGİLENDİRİLMİŞ GÖNÜLLÜ ONAM FORMU

Bu çalışma için iki onam formu sunulmaktadır.

- Gentest hizmeti alan bireylerin hizmet alım sırasında imzaladıkları onam formu (retrospektif nicel çalışma için)
- Daha önce Gentest hizmeti almış bireylerin yarı yapılandırılmış mülakatlara katılmak için okuyup imzalaması gereken onam formu

#### BİLGİLENDİRİLMİŞ GÖNÜLLÜ OLUR FORMU ÖRNEĞİ (BGOF)

ÇALIŞMANIN ADI: 7K Tıbbi Yaklaşımı ile Geliştirilmiş olan Gentest Kişiyeye Özel Sağlık Hizmet Modelinin Değerlendirilmesi

Aşağıda bilgileri yer almakta olan bir araştırma çalışmasına katılmanız istenmektedir. Çalışmaya katılıp katılmama kararı tamamen size aittir. Katılmak isteyip istemediğinize karar vermeden önce araştırmanın neden yapıldığını, bilgilerinizin nasıl kullanılacağını, çalışmanın neleri içerdiğini, olası yararları ve risklerini ya da rahatsızlık verebilecek yönlerini anlamanız önemlidir. Lütfen aşağıdaki bilgileri dikkatlice okumak için zaman ayırınız. Eğer çalışmaya katılma kararı verirsiniz, **Çalışmaya Katılma Onam Formu**'nu imzalayınız. Çalışmadan herhangi bir zamanda ayrılmakta özgürsünüz. Çalışmaya katıldığınız için size herhangi bir ödeme yapılmayacak ya da sizden herhangi bir maddi katkı/malzeme katkısı istenmeyecektir.

## ÇALIŞMANIN KONUSU VE AMACI :

Bu araştırma 7K Tıbbi yaklaşımı ile uygulanan Gentest modelinin kronik hastalıkları önleme ve/veya ilerlemesini engelleme açısından nasıl etki ettiğini incelemeyi amaçlamaktadır. Elde edilen bulgular ile Gentest'in kimler üzerinde, hangi bağlamda, hangi mekanizmalar ile fayda gösterdiğini ortaya koyan bir 'program teorisi' geliştirilecektir. Ayrıca, 7K Tıbbi'nin dünyanın farklı ülkelerinde kamu sağlık hizmetlerine, özellikle birinci basamak sağlık hizmetlerine nasıl uygulanabileceği konusunda bir araştırma ve geliştirme gündemi geliştirilmesi hedeflenmektedir.

Araştırmanın sizin davet edildiğiniz kısmı daha önce Gentest yaptırmış danışanların 7K Tıbbi ve Gentest'teki deneyimleri ile kendi sağlık algıları ve davranışlarının değerlendirilmesi hedeflenmektedir.

Bu araştırma Vrije Universiteit Amsterdam (VU Amsterdam Üniversitesi) Athena Enstitüsü ve Gentest Enstitüsü iş birliği ile yapılmaktadır.

## ÇALIŞMA İŞLEMLERİ:

Araştırmaya katılan Gentest danışanları ile yaklaşık 1 saat süren yarı yapılandırılmış bir mülakat yapılacaktır. Mülakat VU Amsterdam Üniversitesinde Küresel Sağlık master'ı yapan master öğrencileri tarafından İngilizce yapılacaktır. Danışanın isteğine göre mülakat İngilizce ya da bir tercüman aracılığı ile Türkçe gerçekleşecektir.

Mülakat sesli olarak kaydedilecek ve daha sonra İngilizce olarak yazıya dökülecektir. Bu metinler anonimize edilecektir; yani isim ve diğer kişisel belirleyicilerden arındırılarak analiz edilecek ve araştırma süresince saklanacaktır. Metne dönüştürmeden sonra ses kayıtları imha edilecektir.

## ÇALIŞMAYA KATILMAMIN OLASI YARARLARI NELERDİR?

Bu çalışmaya katılarak ülkemizde ve dünyada kişiye özel sağlık hizmetlerinin yaygınlaşması için önemli sonuçlar elde etmemize katkıda bulunmuş olacaksınız.

## KİŞİSEL BİLGİLERİM NASIL KULLANILACAK?

Çalışmaya katılım gönüllülük esasına dayanmaktadır. Bu çalışmada kişisel bilgileriniz kesinlikle bir başka kişi ya da kurumlarla paylaşılmayacak ve araştırma sınırları içerisinde tutulacaktır.

## SORU VE PROBLEMLER İÇİN BAŞVURULACAK KİŞİLER :

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### Çalışmaya Katılma Onayı

Yukarıdaki bilgileri ilgili araştırmacı ile ayrıntılı olarak tartıştım ve kendisi bütün sorularımı cevapladı. Bu bilgilendirilmiş olur belgesini okudum ve anladım. Bu araştırmaya katılmayı kabul ediyor ve bu onay belgesini kendi hür irademle imzalıyorum. Bu onay, ilgili hiçbir kanun ve yönetmeliği geçersiz kılmaz. Araştırmacı, saklamam için bu belgenin bir kopyasını çalışma sırasında dikkat edeceğim noktaları da içerecek şekilde bana teslim etmiştir.

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Gönüllü Adı Soyadı:

Tarih ve İmza:

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Telefon:

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Tarih ve İmza:

Araştırmacı<sup>2</sup> Adı Soyadı:

Laura Martínez Apráez



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Adres ve Telefon:



2: Gönüllüyü araştırma hakkında bilgilendiren kişi

## Informed Consent Process

Participants may experience embarrassment when asked questions of a sensitive nature, thus they will be ensured that they can stop at any time. The main researcher will be prepared to stop the interviews if signs of distress are observed, giving participants a break or a chance to conclude the interview. Also, every participant will be asked to join voluntarily and assured that their decision to participate or refuse to do so will not have any impact in their process at Gentest. Every participant will be informed about the topics and purposes of the research and will remain anonymous in any publication made. All of this will be explicit in the informed consent.

All potential participants will be invited to join this research initially by Gentest staff, and if they agree to be contacted then they will be approached by the main researcher to do the interview. Participants in the study are screened according to the eligibility criteria (current international users of the 7K Medicine program, with no health conditions that might hinder their ability to participate in the interview process, ideally English speakers). If they are eligible and agree to participate, consent forms will be sent to them to be signed, also read to them in English before starting the interview (during the videocall) to agree on the terms of participation and the confidentiality protocols. This part will be recorded if agreed upon.

## Data management

To protect personal data, the information will be organized using unique numeric ID codes instead of names or other personal information on interview files and data sets. Also, all study data will be stored on password protected computers, using VPNs, encrypted platforms, and locked storages. A data management plan will be constantly updated using the Research Data Management tool online at Vrije Universiteit website: <https://libguides.vu.nl/rdm/dmp>.

Given that this research will access sensitive data concerning personal health related information, the ethical considerations performed for Garton's study (2020) will be followed. This means that all Gentest consultees must give their consent for their data to be used for research purposes of Gentest Institute through a consent statement. Also, according to Turkey's law on the protection of personal data, this research will follow the established data privacy and responsibility measures in accordance with the data storage, anonymization and deletion measures (Personal Data Protection Authority, 2016).

