

## Translation and validation of Awareness and Beliefs about Cancer (ABC) questionnaire as a standard tool for cancer awareness studies in Iran

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**Background:** In Iran, cancer is the third leading cause of death. Obtaining basic data about knowledge of general population regarding cancer is necessary to program a proper primary cancer prevention plan. The previously collected data in Iran about cancer knowledge was not based on a comprehensive, standard questionnaire. Therefore, the aim of this study was to prepare an appropriate questionnaire to fill this gap.

**Methods:** The Awareness and Beliefs about Cancer (ABC) questionnaire was chosen as the ideal tool for data collection. The questionnaire was translated, back translated and modified based on the comments of experts. The clarity and appropriateness of the translated version of ABC was tested by interviewing a select population of 30 Iranian individuals.

**Results:** We developed a Farsi version of the ABC questionnaire containing 47 main questions corresponding to the original ABC. Slight modification and additions were applied.

**Conclusion:** The Farsi version of the ABC questionnaire is an appropriate tool for the evaluation of the knowledge, attitude, and behavior of the Iranian population regarding cancer prevention.

**Keywords:** cancer, awareness, questionnaire

## INTRODUCTION:

It was estimated that in 2012, 14.1 million new cases and 8.2 million deaths of cancer occurred across the world<sup>1,2</sup>. Although the combined incidence of cancers is higher in higher-income countries than lower-income countries, mortality rate is a maximum 15 percent higher in these countries<sup>2</sup>. The age-adjusted survival rate of most cancers is higher in developed areas compared to developing areas<sup>3</sup>. This means that most deaths from cancer occur in less developed countries<sup>4</sup>. After ischemic heart disease, stroke, lower respiratory infections and chronic obstructive pulmonary disease, cancer is known as the fifth most common cause of death worldwide<sup>5</sup>. In Iran, cancer is the third leading cause of death, after cardiovascular diseases and injuries, and is responsible for 13% of mortality rate<sup>6</sup>. The awareness of the general population about the alarm signs, risk factors and screening methods of cancer is recognized as an important prognostic factor<sup>7</sup>. Early detection of cancer, which is a result of proper knowledge and awareness about cancer warning signs and screening methods, might lead to a higher chance of recovery and survival<sup>8</sup>. In addition, it is necessary to assess the population's level of knowledge before setting cancer prevention goals and taking action<sup>9,10</sup>. Increasing public awareness of cancer risk factors such as smoking, obesity and lack of physical activity makes people more likely to improve their lifestyle and consequently health condition. Awareness and attitude is a key indicator of cancer control<sup>10</sup>. Recently, there has been greater focus on people's awareness about diseases, and the impact of that on the delay between first symptom occurrence and physician consultation, so called patient delay<sup>11,12</sup>. Early detection of cancer and reducing patient delay would significantly improve disease prognosis and therefore reduce mortality<sup>13-15</sup>. In Iran, a considerable number of studies have been performed worldwide to obtain in-

formation on cancer awareness. Some of these studies were nationwide<sup>12,16</sup>, while some were conducted in just a few cities<sup>17-19</sup> and few of them spanned several countries<sup>20</sup>. These studies were usually focused on a specific type of cancer, making it difficult to make inferences about the public's knowledge about cancer in general. In some studies, a combination of Awareness and Beliefs about Cancer (ABC), Cancer Awareness Measure (CAM) and other standard questionnaires were used to collect data<sup>21-24</sup>. Mostly, studies in different countries targeted awareness of special cancers, not neoplastic diseases in general, and studies were usually limited to a selected population<sup>25-28</sup>.

Several studies have been conducted in different cities across Iran, using a variety of questionnaires and addressing specific cancers such as breast cancer, gastric cancer, oral cancer, etc.<sup>19,34-38</sup>. As was expected, the result of these studies did not provide us with comprehensive data on the awareness of the Iranian people about the different aspects of cancer; such as early symptoms, warning signs and risk factors. The diversity of the previous studies and inability of results to provide us with a comprehensive grasp of the state of nationwide general cancer awareness, increased the necessity of using a standard and comprehensive questionnaire to assess awareness and beliefs of the general population about cancer in Iran<sup>39</sup>.

## METHODS:

First we aimed to find a standard, comprehensive and valid questionnaire to evaluate general cancer awareness and beliefs. A literature review was performed to gather those studies that were related to the different aspects of cancer awareness. Different combinations of keywords such as "cancer, awareness, knowledge, prevention, KAP studies, and questionnaire" were used to search Medline, Embase and Google scholar. Mesh

**Table 1. Examples of cancer awareness questionnaires developed in recent 6 years**

Questionnaire	Explanation
<b><u>Cancer Awareness measure (CAM)</u></b>	CAM was developed by Stubbings et al as a valid measurement tool to assess cancer awareness in the general population, the most popular standard tool for cancer awareness studies. Not only for assessment of general awareness and knowledge about cancer, CAM was also specified for bowel, breast, cervical, lung, and ovarian cancer <sup>26,29</sup> .
<b><u>Awareness and Beliefs about Cancer(ABC)</u></b>	ABC was developed by Simon et al as an internationally valid measure of cancer awareness and beliefs. Recently, new adaptations of ABC for bowel cancer <sup>30</sup> were used.
<b><u>Ovarian and Cervical Cancer Awareness Measures</u></b>	Simon et al developed and validated this questionnaire as measures of awareness of symptoms and risk factors for ovarian and cervical cancer <sup>31</sup>
<b><u>Breast and cervical cancer literacy assessment tool</u></b>	This questionnaire was developed by Han et al and same as the questionnaire above, is limited to specific cancers
<b><u>Breast Cancer Literacy Assessment Tool (Breast-CLAT)</u></b>	designed by Williams et al to measure functional understanding of breast cancer <sup>32</sup>
<b><u>A questionnaire concerning experience of symptoms and subsequent consequences</u></b>	Within a cohort study, Rasmussen et al developed a comprehensive questionnaire to assess cancer symptom experience and related factors <sup>33</sup> . Part of the questionnaire was adopted from ABC questionnaire.
<b><u>Farsi modified version of ABC measure</u></b>	Developed in current study

term equivalent of key words were considered while using PubMed. We checked studies in recent ten years to find frequently used or newly developed questionnaires. References of about 50 selected articles were reviewed to make sure all important study have been included. Most questionnaires have been designed to be used in only one particular study. In a limited number of studies, standard questionnaires such as the Cancer Awareness Measure (CAM) and Awareness and Beliefs about Cancer (ABC) were employed<sup>16, 37, 39-41</sup>. Five criteria were used to find the most appropriate questionnaire, as follows: Comprehensiveness, ease of use, internationality, average time-consumption and exhaustiveness. The following two questionnaires

best matched our criteria: Cancer Awareness Measure (CAM)<sup>41-43</sup> and Awareness and Beliefs about Cancer (ABC) questionnaire[44]. Considering the above-mentioned criteria, we selected the Awareness and Beliefs about Cancer (ABC)<sup>12, 20, 39, 40</sup> questionnaire for translation and adaptation to the Farsi language. The ABC questionnaire consists of 56 questions in five main categories:

- A. 26 questions related to awareness of early cancer symptoms, comprising one open question (symptom recall), and 15 closed questions, (symptom recognition).
- B. 8 questions regarding help-seeking attitude and general health condition
- C. 11 questions about cancer prognosis

D. 21 multi segmented questions to assess beliefs and attitude about cancer; the outcome and importance of early detection (8 questions), and risk factors (13 questions)

E. Other questions related to demographic and background information.

Two translators independently translated the ABC questionnaire to Farsi. A third person compared the two translations, and their differences were discussed among the translation team. Finally, a combined translation from the ABC questionnaire was prepared. This was then translated back to English by a native English speaker. The latter version was compared with the original ABC questionnaire. The differences were discussed in a meeting with the translation team members and the Farsi version of the questionnaire was modified wherever necessary. We used the Farsi ABC questionnaire and interviewed 30 people and assessed clarity, accuracy and comprehensibility. The participants were

chosen from among healthy patient companions in the Imam Khomeini General Hospital Complex, in Tehran (n=15), and Al-Zahra Hospital in Isfahan city (n=15). Both hospitals known as referral hospitals in major cities of Iran. The interviewees were asked for answer the questions and mention if there were any ambiguous clauses, phrases or words, and share their opinions and suggestions vis-à-vis the contents of the ABC questionnaire<sup>45</sup>. The participants' comments were used to modify the questions and prepare the final version of the Farsi ABC questionnaire. The design and structure of the form were changed to make data collection and extraction more convenient.

## RESULTS:

We invited 50 individuals to take part in the questionnaire properness study and cognitive interview, 30 of which signed written informed consent forms and

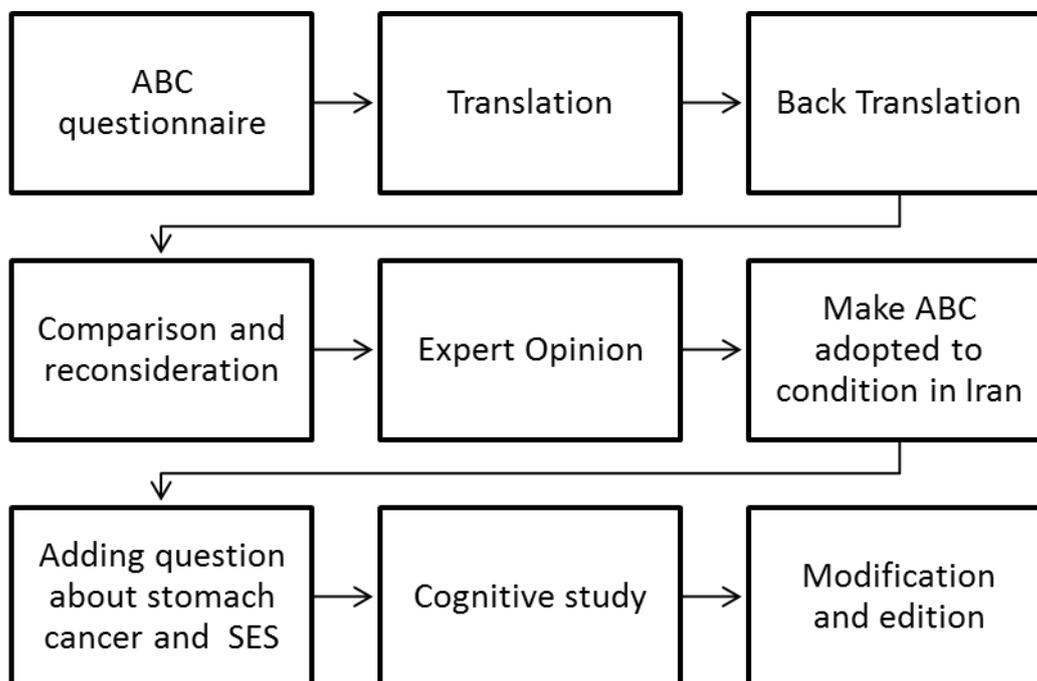


Figure 1. Flow chart of the study design adopted from Protocols discussed in previous studies<sup>45,48</sup>

agreed to participate in the cognitive study. It took around 30 minutes for each participant to complete the interview. We used the comments and suggestions obtained from the participants in the study to modify the Farsi ABC questionnaire. In addition, some questions (such as questions related to ethnic groups and language) were modified based on local context. Also, we added nine questions about socioeconomic status including chattel and non-chattel properties, insurance and occupation. Due to the high incidence rate of gastric cancer in Iran<sup>46,47</sup>, we added one question about stomach cancer.

## DISCUSSION:

We translated a standard tool (i.e. the ABC questionnaire) and modified it based on the local culture and context to evaluate cancer awareness among the Iranian population. Based on inclusion criteria, the ABC questionnaire was deemed fit for our purposes. After

translation and back-translation, we added several questions about socioeconomic status (SES) and one item on five year gastric carcinoma survival rate. Obtaining more detailed information on SES could help us to determine the most important target group for interventions and improve awareness at the regional and national level. Considering the educational system and distribution of ethnic groups in Iran, we made changes in questions on background data. The main ethnic groups in Iran are Persians, Azerbaijanis (Turk) Kurds, and Lurs<sup>49</sup>. The validity and reliability of the questionnaire had been confirmed in previous studies<sup>39</sup> and we did our best to retain the main structure of the questionnaire. Therefore, validation study was deemed unnecessary<sup>22,50</sup>. Based on comments received from participants, we made necessary changes in the Farsi ABC questionnaire for an awareness survey in Iran. In order to reduce ambiguity, Revisions to the Farsi ABC questionnaire following the cognitional study were mostly in questions related to general cancer signs and

**Table 2. Details of modifications of original ABC questionnaire**

Topics of additional and modified questions	Details
<u>Stomach cancer</u>	CAM was developed by Stubbings et al as a valid measurement tool to assess cancer awareness in the general population, the most popular standard tool for cancer awareness studies. Not only for assessment of general awareness and knowledge about cancer, CAM was also specified for bowel, breast, cervical, lung, and ovarian cancer <sup>26,29</sup> .
<u>Screening of cervical cancer</u>	In addition to bowel and breast cancer screening attitude and knowledge questioned in original ABC, 4 questions with same structure about cervical cancer were inserted in Farsi version of ABC
<u>Socioeconomic status</u>	A multi segment question regarding occupation, two questions regarding insurances, two questions about chattel and three questions about non-chattel possessions were added
<u>Educational status and ethnicity</u>	Appropriate changes based on local context were applied

symptoms and warning signs,. Since these items were not limited to a specific type of cancer, participants found it confusing to relate the warning sign to a certain type of cancer, as opposed to questions directly related to ovarian, bowel, head and neck, breast cancer, etc.<sup>36,42,51</sup>. One of the limitations of the Farsi ABC questionnaire is its application at the national level. Although Farsi is the national language in Iran and it is spoken throughout the country, Iran is a multiethnic country and therefore some people, especially among the elderly living in villages and remote areas may not speak Farsi<sup>52</sup>. Therefore, the Farsi ABC should be applied to young and middle-aged people in these specific populations. 61%, 16%, and 10%, of the Iranian population speak Farsi, Azari and Kurdish, respectively<sup>49</sup>. It might be useful to prepare different version of the ABC questionnaire in Iran for assessment of cancer awareness in different parts of Iran. There has been no

questionnaire in a language or accent other than Farsi in Iran, due to the great diversity of spoken languages. The Farsi ABC questionnaire is applicable in the Iranian community for epidemiologic studies and conducting cancer awareness surveys. The ABC questionnaire was first developed in the UK by Simon et al<sup>39</sup>. It was then used in Australia, Canada, Denmark, Norway, Sweden and the UK to assess awareness of the elderly about cancer<sup>12,20,40,54</sup>. Later, it was specified to be used in a study on bowel cancer awareness<sup>30</sup>. Specific Danish version of ABC was developed by Hvidberg, et al<sup>55</sup>. Recently, ABC was used in the UK, Denmark and Australia to assess people's beliefs, awareness and performance related to cancer<sup>12,22,30</sup>. To the best of our knowledge, there is no Asian or African version of the ABC questionnaire. ABC has the capacity to be modified and adopted for conducting surveys in non-European countries. Analyzing results in different countries

**Table 3. Modified versions adapted from original ABC questionnaire**

Translated and modified ABC versions	Year	Number of studies	Results
<b><u>Danish version of ABC</u></b>	2014	4	1. People with a low educational level and a low SES were more likely to have a lower awareness of cancer symptoms and risk factors and negative opinion about cancer. Also they had increasing risk of cancer with age <sup>12,56</sup> . 2. Cancer survival was higher in Sweden although cancer awareness in the Danish population was higher compared to the Swedish.
<b><u>Bowel-ABC</u></b>	2014	1	54.1% of all women and 65.7% of men in Australian study population had taken screening test for bowel cancer in the previous 5 years. Belief that screening was only necessary when experiencing symptoms was more common among people aged 65 years and older, also among Non-English-speaking immigrants compared to other groups, and citizens in metropolitan versus non-metropolitan areas.
<b><u>ABC-O</u></b>	2014	1	Most of the study population recognized post-menopausal bleeding, persistent pelvic and abdominal pain as ovarian cancer symptoms. Elderly, people with lower education and single ones had lower knowledge about ovarian cancer <sup>21</sup> .

provides us with information about cancer awareness at the international level and assess the impact of cancer control programs. These results can provide insight on the strengths and weaknesses of cancer awareness interventions in different populations. In conclusion, the Farsi ABC questionnaire was prepared to assess the level of cancer awareness among the general population, and can be used as a tool for monitoring cancer prevention programs at the regional and national level. Using an international tool such as the ABC questionnaire can bring an opportunity for us to compare survey results and exchange experiences with other countries across the globe. We strongly suggest ABC translated and modified use in the region of EMRO\_WHO to understand situation and do appropriate interventions.

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