

LIVESTRONG®

FOUNDATION

The Global Cancer Stigma Index

The Fight against Cancer Stigma

The LIVESTRONG Foundation is working around the world to fight cancer stigma and dispel myths about cancer so that people affected by cancer can get the services and support that they need. Our anti-stigma work is a result of rigorous research conducted across ten countries from 2007-2008 which included over 4,500 interviews with healthcare providers, cancer survivors, organizational leaders and community members, investigating the nature of cancer stigma and its impact. The [data](#) illustrated that cancer stigma is pervasive, existing across countries, cultures, and communities. In response to these findings, the Foundation initiated a large-scale program in 2008 to both better understand, and address cancer stigma around the world.

The Foundation launched large-scale pilot projects between 2009-2012 which aimed to change perceptions about cancer by empowering survivors to share their stories and elevate a public dialogue about the disease. We implemented these media and community outreach campaigns in South Africa and Mexico with measurable success. To learn more about our successful anti-stigma campaigns, visit our [website](#).

The global cancer stigma index was developed by the LIVESTRONG Foundation and the RAND Corporation during 2011-2013 to empower policymakers, researchers, and NGOs to assess levels of cancer stigma within a population and inform their planning efforts to address it.

About the Global Cancer Stigma Index

The Global Cancer Stigma Index can empower local organizations, institutions, and governments in countries around the world as they develop cancer awareness or anti-stigma campaigns. The index can identify key areas in which a population could benefit from education to change perceptions about cancer and address misinformation. The index can also be used cross-culturally to rank countries based on their level of cancer stigma. For more information about how to implement the Global Cancer Stigma Index, contact the LIVESTRONG Foundation: Rebekkah.schear@livestrong.org.

English to Mandarin Translation

Item #	Content
Q1	I would feel uncomfortable talking to a person with cancer 与癌症患者交谈，会令我感到不安
Q2	Treatment and support are useless for someone with cancer 治疗与情感支持对癌症患者没用
Q3	Uncomfortable sitting next to someone with cancer 假如我在公交车或私驾车上与癌症患者相邻而坐，我会感到不安
Q4	Uncomfortable sending own child to school with another child with cancer 让我的孩子与癌症患儿同校，会令我感到不安
Q5	Uncomfortable if someone with cancer lived nearby 如果邻居是癌症患者，我会感到不安
Q6	If close friend had cancer, I would avoid him/her 假如某位密友患了癌症，我会避开他/她
Q7	Uncomfortable being friends with someone with cancer 如果朋友与癌症患者相处，会令我不安
Q8	People can only blame themselves for getting cancer 癌症患者得了癌症只能怪自己
Q9	If had cancer, would be ashamed 假如我患了癌症，我自己感到羞愧
Q10	Would feel isolated/alone if received treatment for cancer 假如我接受抗癌治疗，我会感到孤立无援
Q11	If spouse had cancer, would be ashamed of him/her 假如我的爱人患了癌症，我会为他/她感到羞愧
Q12	If spouse had cancer, would consider leaving him/her 假如我的爱人患了癌症，我会考虑离开他/她

Cancer is a death sentence item:

I automatically think a person will die if I hear they have cancer
当我听到某人患有癌症时，我会不由自主地想到此人不久即将离世

43

Response options for all items

English	Mandarin
Not at all	一点也不认同
A little bit	认同一点点
Somewhat	有些认同
Quite a bit	颇有几分认同
Very much	非常认同

English to Spanish Translation

Item #	Content
Q1	I would feel uncomfortable talking to a person with cancer Me sentiría incómodo hablando con una persona con cáncer
Q2	Treatment and support are useless for someone with cancer El tratamiento y el apoyo no sirven de nada a una persona que tiene cáncer
Q3	If I was on public or private transport, I would be uncomfortable sitting next to someone with cancer Si yo estuviera en un medio de transporte público o privado, me sentiría incómodo sentarme al lado de una persona que tiene cáncer
Q4	I would feel uncomfortable letting my child go to school with another child who has cancer Me sentiría incómodo de dejar que mi hijo vaya a la escuela con otro niño que tiene cáncer
Q5	Uncomfortable if someone with cancer lived nearby Me sentiría incómodo de vivir cerca de alguien que tuviera cáncer
Q6	If close friend had cancer, I would avoid him/her Si un amigo cercano tuviera cáncer, evitaría encontrarme con él
Q7	Uncomfortable being friends with someone with cancer Me sentiría incómodo de ser amigo de una persona con cáncer
Q8	If I had a serious illness, I would blame myself Si yo tuviera una enfermedad grave, yo me culparía
Q9	If I had cancer, I would be ashamed of myself Si yo tuviera cáncer, me sentiría avergonzado de mí mismo
Q10	Would feel isolated/alone if received treatment for cancer Si recibiera tratamiento para el cáncer, me sentiría aislado o solo
Q11	If spouse had cancer, would be ashamed of him/her Si mi esposo/a tuviera cáncer, yo sentiría avergonzado/a de él/ella
Q12	If spouse had cancer, would consider leaving him/her Si mi esposo/a tuviera cáncer, yo pensaría en dejarlo

Cancer is a death sentence item:

	When I hear that someone has cancer, I automatically think that person is going to die
	Cuando oigo que alguien tiene cáncer, automáticamente pienso que esa persona va a morir

Response options for all items

English	Spanish
Not at all	No, para nada
A little bit	Un poquito
Somewhat	Algo
Quite a bit	Mucho
Very much	Muchísimo

Scoring the 12-Item Cancer Stigma Index

As described in the full body of the Cancer Stigma Index report, development of the 12-item cancer stigma index is based on formative work with individuals of Middle Eastern and Chinese descent, and field testing among four distinct language and region samples: individuals residing in Jordan or Egypt and responding in English (the originating sample), individuals residing in Jordan or Egypt and responding in Arabic, individuals residing in China and responding in English, and individuals residing in China and responding in Mandarin. The IRT and DIF analyses established the 12-item cancer stigma index with items that function equivalently across these languages and cultures. Thus, while the mean level of cancer stigma may vary across these groups, the underlying properties of the items remain the same, allowing for direct comparison of scores across these languages and cultures (e.g., cancer stigma scores from an individual living in Jordan who speaks Arabic may be compared to a Chinese individual who speaks Mandarin). However, because the items have not been evaluated in other languages or cultures, their characteristics among these untested groups are unknown. Making direct comparisons across regions or languages other than those tested here would be inappropriate. Thus, prior to introducing the index to novel groups, it is recommended that formative work be conducted to capture any nuances particular to the culture and/or language, and that field testing be conducted to allow for DIF evaluations using IRT (as was done in this developmental work) to ensure that the item-level properties are the same in the new culture/language. Following, there is a score translation table for the 12-item cancer stigma index. This table allows individual scores from the scale to be quickly and easily evaluated. The first column contains the "total score" or the summed score for the 12-item index. Each item is scored on a 1-5 scale, so the minimum score is 12 and the maximum score is 60. The second column provides the "T-score" or the total score transformed on a T-score metric with a mean of 50 and standard deviation of 10. The T-score scale provides a standardized metric (using the JE sample) for meaningful score comparisons. To assign a score, simply locate the observed total score in columns 1 or 3 that represents the sum of the 12 item responses and find the associated T-score (in columns 2 and 4). For example, an individual with a total score of 29 has a cancer stigma standardized T-score of 60, or just slightly higher than one standard deviation above the mean. An individual who responds in the lowest item category (1) to all items would receive a total score of 12 and a T-score of 42, or approximately .8 standard deviation below the mean. The mean level of cancer stigma is associated with a total score of about 19. As a general guideline, this scoring technique is only appropriate when six or more of the 12 items have responses. If six or fewer items contain missing values (i.e., were skipped by the respondent), it is possible to impute the mean of the non-missing items, rounded to the nearest integer, to the items with missing values to obtain the total score on the 12-item scale. A more detailed description of this procedure follows the score translation table. We do not recommend generating scores for respondents who provide fewer than six non-missing item responses.

12-Item Cancer Stigma Index Total Score to T-Score Translation Table.

Total Score	T-Score	Total Score	T-Score
12	42	37	69
13	43	38	70
14	44	39	71
15	46	40	72
16	47	41	73
17	48	42	74
18	49	43	75
19	50	44	76
20	51	45	77
21	52	46	78
22	53	47	80
23	54	48	81
24	55	49	82
25	56	50	83
26	57	51	84
27	58	52	85
28	59	53	86
29	60	54	87
30	61	55	88
31	62	56	89
32	64	57	90
33	65	58	91
34	66	59	92
35	67	60	93
36	68		

Mean imputation of missing values (where responses to at least six of the 12 items are non-missing):

Total score = (sum of non-missing items) + [(sum of non-missing items)/(number of non-missing items)] x (number of missing items)

Guidelines for Using Cancer Stigma Index in Other Countries

Before the index can be used in any other country, four steps must be pursued. A checklist for each of these steps is provided below:

1. Translate the scale into desired language(s) for selected country.
2. Conduct a focus group to review the translation for stigma concepts and quality of translation. Check for cultural and linguistic appropriateness.
3. Revise translation based on Step 2 and conduct short interviews to discuss interpretation of scale (i.e., what do items mean to respondent?).
4. Pilot scale for general length and readability.

Step 1. Translate scale into desired language.

- Identify translation expert, preferably from country of origin. If not, identify individual with time spent in country.
- Conduct forward translation of index.
- Conduct backward translation of index, using English version.

Step 2. Conduct focus group to review scale and stigma concepts.

- Share translated stigma index with country residents for review.
- Query participants about translation quality and whether words are appropriate and clear.
- Ask participants about formality of language, and whether colloquialisms are appropriately used.
- Query participants about underlying stigma concepts. Will issues of blame, shame, fate, and so forth resonate in specific country, with particular population, and/or specific communities? What is missing?

Step 3. Revise translation and conduct short cognitive interviews.

- Change terminology based on Step 2, preserving the content meaning of original index.
- Conduct individual interviews with respondents of varying backgrounds (e.g., age, race, gender, education).
- Ask participants to complete index, circling items that are confusing.
- Query participants about each item. What did the item mean to the participant? How did they respond and why? If circled, why was the item unclear or confusing?

Step 4. Pilot scale for general readability and length.

- Finalize index based on Steps 2 and 3.
- Document any changes to language for comparison to other countries and populations.
- Conduct broader pilot test with diverse sample to test for general ease of use in the field.
- Conduct analyses with data, using scoring guidelines.