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Review article

Review of interactive digital solutions improving health literacy of personal cancer risks in the general public

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ABSTRACT

Background: Health literacy is crucial in understanding the many risk factors for cancer. Low health literacy is associated with low adherence to medication, poor health status, and increased health care costs. Modern technology allows us to educate the general public on their risks. We focus herein on the available mobile applications and online web tools for the evaluation of cancer risk in the general public.

Methods: A systematic search was performed for cancer risk calculators mobile applications on both Google Play and the App Store and for online cancer risk calculators using Google, Bing, Yahoo! and Baidu.

Results: For mobile applications, out of 250 different apps found on GooglePlay, 16 Android applications were retained for evaluation in this review and for the AppStore, out of 10 different apps, 7 Android applications were retained for evaluation in this review. Only three apps were available for both Android and iOS systems. For web tools, a list of 20 tools was retained and evaluated.

Conclusion: This review presents the most popular and prominent tools and their strengths and possible weaknesses are evaluated. We discuss not only its current state as it relates to general knowledge about cancer risks, but also barriers and future directions. It is imperative that as developers continue to create and improve such tools, health care providers remain aware of these efforts in order to properly guide patients towards appropriate resources and educate them on both their usefulness and limitations.

1. Introduction

Health literacy is defined as the possession of literacy skills that are required to make health-related decisions in a variety of different environments (home, community, health clinic). [1] It has now been well established that low health literacy is a major contributing factor to poor health status and outcomes, but also results in higher premature mortality rates, lack of adherence to medical recommendations, and higher direct and indirect health costs. [2,3] As such, governments of several countries, including the United States and China, have developed national strategies and targets to improve health literacy in their populations [4–6].

Cancer, as the second leading cause of death globally, responsible for about 1 in 6 deaths [7], could benefit from an improvement in health literacy. Studies have investigated the association of health literacy with cancer-related attitudes, knowledge, and behaviors [8], inquisitiveness after discussions [9] and even self-management capacity [10].

The great majority of reported interventions to improve health literacy have been in clinical settings, and generally focus on it's task-directed, functional aspects. The improvement of health literacy in community populations remains poorly studied [11]. The advent of new technology may ameliorate this finding. Relatively simple interventions like use of a web portal and even a brief multimedia presentation have been found to improve attitudes [12,13]. Digital health technology has been identified as a potential enabler of health care access and literacy [14].

Alongside the more traditional outlets for eHealth, defined as the use of information and communication technologies (ICT) for health [15], we now also have mHealth, which encompasses the use of mobile wireless technologies for public health. In 2016, The WHO acknowledged that mobile technologies were becoming an important resource for health services delivery and public health due to their ease of use, broad reach and wide acceptance [16]. By 2018, after consideration of the report on mHealth, it passed a resolution urging Member States to prioritize the development and greater use of digital technologies in health, as a means of promoting Universal Health Coverage and advancing the Sustainable Development Goals [17].

This article attempts to give an overview of the most important

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digital resources that are available to patients worldwide and could be used to improve the health literacy of patients, whether it results from a personal initiative, or an organised, general and societal approach. Due to the ubiquity of both the internet and mobile phones, there is a pressing need to evaluate these tools. Our hope is that health care professionals can use our findings to tailor their messaging to the resources described. Mobile applications (or 'apps') and web applications are listed separately.

2. Methods

Searches were conducted for both mobile applications and web tools;

Table 1
Publicly Available Mobile Tools.

Name	Availability	User score (a)	Developper	Number of cancers included	Cost	Strong points	Weak points	MARS (b)
Melanoma Test	iOS	Not available	Dermatology clinic of the Third Medical Faculty of Charles university	1	Free	- based on ABCDE criteria - provides photographic examples	- requests data	3.9
CORAL: Prostate Cancer Risk and Survival	iOS	Not available	CORAL medical applications	1	Free	- calculators for the relevant risks at every stage of prostate cancer	- completely dependant on PSA values	4.4
BCSC RISK CALCULATOR	iOS	Not available	Breast Cancer Surveillance Consortium	1	Free	- based on their own, published, risk-prediction model (hh) - also available on the BCSC website	/	4.4
ROMA Calculator	iOS	Not available	University of Rochester Wilmont Cancer Institute	1	Free	- based on trademarked algorithm	- completely dependant on serum biomarkers CA125 and HE4	4
Cancer Risk Calculator	iOS, Android	4.8, 4.5	WestFour	32	Free	- Extremely large number of cancers - Extremely large number of risk factors - Detailed references	/	4.6
CanCell Cancer	iOS, Android	Not available, 3.9	Narodowy Fundusz Zdrowia (National Health Fund of Poland)	2	Free	- developed to direct users to appropriate resources	- large sections only available in Polish	3.2
Rotterdam Prostate Cancer Risk	iOS, Android	4.0, 4.3	Prostate Cancer Research Foundation, Rotterdam (SWOP)	1	One-time purchase	- based on their own, published, risk-prediction model (r)	- dependant on PSA values - not free	4
Lung Cancer Risk Predictor	Android	4.2	Pavel Chtcheprov (private developer)	1	Free	- based on Tammemagi scoring criteria	/	4.1
Breast Cancer Risk Assessment	Android	2.8	mizSoftware	1	Free	/	- requests access to a lot of unnecessary personal information, including the current location, camera, Wifi-connections, device IDs and photos - very low number of risk factors	3
Various Proactiff '*Cancer Risk Assessment Tool*' applications	Android	Not available	Proactiff	1 per application, total of 9	Free	- Includes more rare cancers	- Non-functional after last update - Account necessary, which requires not just an e-mail address but also a lot of unnecessary personal information	/
Prostate Cancer Calculator	Android	3.7	Borinfer LLC	1	Free	- combines several calculators concerning prostate cancer, including an IPSS (International Prostate Symptom Score) calculator and PSA Density/ Velocity/ Doubling time calculators	- Several bugs	3.3
Indonesian prostate cancer risk calculator (IPCRC)	Android	5	Solusi Karya Kita untuk Semesta (SEKATA)	1	Free	- Very easy to use - Prediction risk model of prostate cancer based on the Indonesian population (p)	- completely dependant on PSA values and prostate volume	3.4

a: User rating on App Store (iOS) or Google Play (Android), out of a total of 5. (Accessed May 2021 from Liège Belgium).
b: Mobile Application Rating Scale; App quality mean Score (Stoyanov et al., 2015).

details are provided in the relevant subsections. Because we wish to focus on tools that might impact health literacy within the general public, we have excluded tools that:

- Could not be widely used by lay people without medical training
- Require complex tests or imaging
- Only provide information on risk factors and do not allow for individual risk calculation
- Were not available in English
- Do not focus on the risk of developing cancer, but rather survival after a cancer diagnosis, risk of recurrence or risks related to specific findings

2.1. Mobile applications

Mobile applications are available through specialised digital distribution platforms developed and maintained by large technology companies and nowadays designed to run on a specific operating system. The two largest platforms, namely Google Play (formerly Android Market) by Google LLS and App Store by Apple Inc., dominate the global app download landscape (mm). We have therefore limited our search to these two platforms. Both platforms only include apps designed to run on a specific operating system. Unsurprisingly, these are the operating systems designed by technology companies that developed the platforms, meaning Android for Google Play and iOS for the App Store.

A search for 'cancer risk calculator' was conducted on both platforms. For Android, this retrieved 250 different apps, 79 of which were medical. Two apps were excluded because they were not available in English, 30 were excluded because they were not focused on cancer, one app was excluded because it was a companion app to a commercial hereditary cancer test and one app was excluded because it was a diagnostic tool. A further 22 apps were excluded because they were not or insufficiently interactive. Finally, 7 apps were excluded because they focused on diagnosis, recurrence, prognosis or mortality, leaving a total of 16 Android applications that are evaluated in this review.

For iOS, this retrieved 10 different apps. One app was excluded because it did not focus on cancer and 2 apps were excluded because they were diagnostic apps for lung nodules, leaving a total of 7 Android applications that are evaluated in this review. Only three apps were available for both Android and iOS systems. (Table 1)

We have scored these applications using the Mobile App Rating Scale (MARS), developed by Stoyanov et al. [34], but have also included the user scores for the respective app stores if they were available.

The MARS Score is an average of scores on four sections, who are themselves averages of scores on several subsections. They are:

1. Engagement – Entertainment, Interest, Customisation, Interactivity, Target group
2. Functionality – Performance, Ease of use, Navigation, Gestural design
3. Aesthetics – Layout, Graphics, Visual appeal
4. Information – Accuracy of app description, Goals, Quality of information, Quantity, Visual, Credibility, Evidence base

For example, the score for the 'Melanoma Test' application, breaks down as follows:

$$[((0+4+3+4+5)/5)+((4+4+3+4)/4)+((5+5+5)/3)+((3+3+5+4+5+3+2)/7)]/4 = 3.88$$

2.2. Web tools

We conducted a systematic search of the internet to identify all sites with a risk calculator for any cancer. We searched the terms "cancer risk calculator" (without quotes) in each of the following search engines using the Google Chrome browser: Google, Bing, Yahoo! and Baidu. The first 200 hits from each search were visited to determine whether they included a cancer risk calculator.

After excluding non-English sites, duplicate sites, sites that focused on diagnosis, recurrence, prognosis or mortality and sites that did not adequately explain the algorithm, model or source material used a list of 20 sites was generated. (Table 2)

3. Discussion

The overwhelming majority of the calculators focus only on the most common and most lethal cancers, namely breast, prostate and lung cancer. This is not surprising, since these cancers have the best known and validated risk prediction models [18], but the degree to which other cancers have been excluded is nothing short of extreme. In fact, many cancers - namely anal cancer, bladder cancer, cancer of the brain or nervous system, gallbladder cancer, Hodgkin lymphoma, Kaposi's Sarcoma, laryngeal cancer, liver cancer, mesothelioma, myeloma, non-Hodgkin lymphoma, non-melanoma skin cancer (of al kinds), cancer of the oral cavity and pharynx, penile cancer, thyroid cancer and cancer of the vulva or vagina - are only included in the 'Cancer Risk Calculator' app. It is also remarkable that most of these tools only deal with one cancer. And even when tools that discuss more than one cancer are considered, only three of them -namely the '*Cancer Risk Calculator*' app, the online *Qcancer* tool and the online '*Your Disease Risk*'™ tool - deal with 10 or more cancer types. Moreover, many of the calculators do not include well-known risk factors and consider only the most frequent ones. It's also notable that there is currently only one calculator for the general risk of developing cancer at any site and that only a minority of calculators even mention mortality.

Some of the applications also raise concerns with data protection, readability standards, lack of references and lack of information updates. More generally, some experts are concerned about the lack of involvement of healthcare professionals in app development. It is well known that their participation and contribution in the elaboration of apps increases content accuracy, app downloads and buy-in [19,20], whatever the medical specialty.

An encouraging finding is that the size of the reviewed medical applications remains very reasonable, with even the largest app being just 100 Mb in size and most being much smaller. This is good news, since this does not put undue pressure on bandwidth limitations and ensures that these tools remain accessible to a broad audience.

It also seems clear that for the moment, online calculators for cancer risk remain more numerous than mHealth risk calculators. Furthermore, based on the number of tools that are reviewed but not listed here, it seems likely that risk calculators in general -including those that deal with survival after a cancer diagnosis, risk of recurrence or risks related to specific findings- might remain more numerous online than those in mHealth apps. For example, The Cleveland Clinic library of risk calculators contains 67 different, high-quality calculators, 35 of which relate directly to cancer [21]. Other prestigious cancer centres, such as Memorial Sloan Kettering Cancer Center [22] and MD Anderson Cancer Center [23] also have calculators available.

The balance between online and mobile tools will most likely shift in the near future. The ubiquity of mobile phones has reached such a level that there are currently places where people are more likely to have access to a mobile phone than to clean water or electricity [24]. Furthermore, the total number of apps downloaded globally each quarter has doubled in the five years since 2015, reflecting both increased smartphone penetration and the increasingly prominent role of apps in our lives [25].

The economic impact will likely follow a similar trajectory. The global mHealth apps market size is expected to expand at a Compound Annual Growth Rate (CAGR) of 44.7% and is projected to reach USD

Table 2
Publicly Available Web Tools.

Name	Technology	Link	Developer	Number of cancers included	Strong points	Notes
Your Disease Risk™	Wordpress	https://siteman.wustl.edu/prevention/ydr/	Siteman Cancer Center	12	- Also includes 6 other important chronic diseases - Personalized advice for prevention	- Was known as the Harvard Cancer Risk Index until 2004
Cancer Risk Assessment Tool	Javascript	https://bcrisktool.cancer.gov/calculator.html https://mrisktool.cancer.gov/calculator.html https://ccrisktool.cancer.gov/calculator.html	National Cancer Institute (NCI)	3	- Source code available for download - Detailed references	- The Melanoma calculator is also available as an app for Apple devices. It is not free.
Assessyourrisk	Vue.js JavaScript	https://www.assessyourrisk.org/	Bright Pink	2	- Personalized advice for prevention	- Requests access to a lot of unnecessary personal information, including users' full name, e-mail address and health insurance details
B-RST™	ASP.NET	https://www.breastcancergenescreen.org/	Georgia Center for Oncology Research and Education	2	- Very detailed input of family history	- Very narrow scope; designed to identify who should be referred for cancer genetic counseling
Cleveland Clinic Risk Calculator Library	Express.js	https://riskcalc.org/	Cleveland Clinic	2	- Part of a large library of risk calculators	/
SWOP Prostate Cancer Risk Calculators	PHP	http://www.prostatecancer-riskcalculator.com/seven-prostate-cancer-risk-calculators	Prostate Cancer Research Foundation, Rotterdam (SWOP)	1	- Different calculators depending on the information the user has available and the exact outcome that is desired	/
Lung Cancer Screening Decision Tool	ASP.NET	http://nomograms.mskcc.org/Lung/Screening.aspx	Memorial Sloan Kettering Cancer Center	1	- Displays the risk of dying from lung cancer with and without screening, the chance of saving a life and the number of people like the user that would need to be screened in order for one of them to benefit.	/
	ASP.NET		American Association for	1	- Shows the risks based on four risk	/

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Table 2 (*continued*)

Name	Technology	Link	Developer	Number of cancers included	Strong points	Notes
Lung Cancer Risk Assessment Tool		https://www.aats.org/aatsimis/AATSWeb/Resources/Lung_Cancer_Screening/AATSWeb/Association/About/Resources/Lung_Cancer_Risk_Assessment_Tool.aspx	Thoracic Surgery (AATS)		models(Spitz, LLP, Hoggart, PLCO, and Bach)	
iPrevent	Javascript	https://iprevent.net.au/iprevent/?21	Peter MacCallum Cancer Centre	1	- Detailed disclaimer, particularly concerning people unsuitable for the calculator - Excellent visual representation of results - Very detailed familial history component	- Absolutely no information on the impact of risk factors
Breast Cancer Risk Calculator - Princeton Radiology	Wordpress	https://www.princetonradiology.com/	Princeton Radiology	1	- Intuitive and esthetically pleasing imput screen	- No risk factors other than age and family history are considered - Absolutely no information on the impact of risk factors
Tyrer-Cuzick Risk Assessment Calculator	PHP	https://ibis-risk-calculator.magview.com/	Magview	1	- Allows for downloading of underlying model (IBIS v8 risk assessment model)	/
Omnicalculator	PHP	https://www.omnicalculator.com/	Omni Calculator	2	- Automatically suggests other calculator included on the sites concerning relevant risk factors	/
Lung Cancer Screening	React	https://shouldiscreen.com/	University of Michigan	1	- Provides detailed information on screening efficiency and goals	/
Breast Cancer Risk Assessment Tool for Women With Benign Breast Disease	ASP.NET	https://www.mayoclinic.org/breast-cancer-risk-prediction/itt-20150095#:~:text = The%20BBD%2FAH%2DBC%20model,and%20prevention%20of%20breast%20cancer.	Mayo Clinic	1	- Strictly for women who have had some type of benign breast disease	- Currently non-functional
Snehita Breast Cancer Risk Assessment Tool	Javascript	http://snehita.in/risk	Snehita Women's Health Foundation	1	- Uses the A-J Model, which was made specifically to asses risk for Kerala women	/
Symptom Based Risk Calculator	PHP	http://www.orlhealth.com/	(Unknown)	1		/

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Table 2 (*continued*)

Name	Technology	Link	Developer	Number of cancers included	Strong points	Notes
for Head And Neck Cancer Referral					- Based on both versions of the HaNC-RC model	
Prostate Cancer Nomograms	Drupal	https://www.mskcc.org/nomograms/prostate/biopsy_risk_dynamic	Memorial Sloan Kettering Cancer Center	1	- Specifically estimates the risk of high-grade cancer on prostate biopsy	/
Prostate Cancer Risk Calculator	Wordpress	https://www.prostaterisk.ca/prostate-risk-calculator/	Robert Nam, University of Toronto	1	- Includes free:total psa ratio	/
CanRisk Web Tool	Python Javascript	https://canrisk.org/	University of Cambridge	1	- Incorporates the new version of BOADICEA, the Breast and Ovarian Analysis of Disease Incidence and Carrier Estimation Algorithm.	- Requires creation of an account on the website
QCancer	PHP	https://qcancer.org/	Qresearch (collaboration between the University of Oxford and EMIS)	13	- Incorporates general cancer risk and several specific cancer risks	/

236.0 billion by 2026 [26] These numbers might even underestimate the situation, as a 65% global upswing in medical app downloads in peak COVID-19 lockdown month vs January 2020 has been reported [27].

This is particularly important because traditional health care services appear to be slow in adapting mobile applications. Research has revealed that less than 11% of providers offer proprietary apps that have at least one of the three functions that consumers want the most [28]. When assessing mobile app use among the 100 largest U.S. hospitals, it was found that they only manage to engage 2 percent of patients via mobile apps, putting as much as $100 Million in annual revenue at risk per hospital [29].

However, insight is growing and efforts are underway to push this technology. Even governments are already taking advantage of these innovations, often depending on the specific needs of their populations. In Malaysia, 65% of colorectal cancers are detected at stages III and IV, giving rise to a lower 5-year relative survival by stage as compared with other developed Asian countries. This late detection is thought to be partly because of the low participation in screening among Malaysians. Hence, an initiative has been started to develop a mobile app for community education on colorectal cancer, apparently with encouraging results [30].

Risk calculators are undoubtedly part of this effort. In addition to the general risk calculator apps aimed at specific national communities such as Polish and Indonesian populations mentioned above, an intelligent CRC screening app has been developed in Taiwan based on a data mining approach using decision tree algorithms [31].

Considering the landscape of tools as it stands, we would encourage designers of future tools to do the following. First, to consider focusing their efforts on the types of cancers for which there are currently only limited resources available. Second, to describe the underlying methodology and clearly mention the model and risk factor literature used, with appropriate references as needed. And finally third, to take the time to write not just a disclaimer, but also a detailed privacy policy. Considering not just the current climate of data collection, but also the extremely personal nature of various risk factors for cancers, to do otherwise is simply unconscionable.

Other authors have already emphasised the large potential cancer risk calculators have to provide a public health benefit by educating individuals about their risks, and hence encouraging preventive health behaviors [32].This seems particularly important considering that there are studies linking low health literacy with poor appreciation of health risk analyses and even inadequate screening participation [33]. This, in turn, suggests a large potential for development and utilization of applications in secondary prevention, which could be an interesting field of future research. If developed appropriately with responsible governance, they could play important roles in modern-day cancer management [18].

4. Limitations

Evaluating digital tools remains challenging for various reasons, limiting the scope of our conclusions. For mobile applications, we have included scores based on the MARS, which has been shown to be multidimensional and flexible, but it's rating criteria are based on relatively few peer-reviewed journal articles and interrater reliability of some subsections is poor [34].

As for websites, most of the literature on the evaluation of sites focuses mostly on technical aspects, typically presented as checklists, and while there appears to be agreement about key criteria concepts [35], these invariably assess the site as a whole, rather than any specific tool. In the current context, this would mean that the entire NCI website would have to be evaluated when considering the calculators found there, which poses obvious problems.

It also bears mentioning that some common criteria for the evaluation of tools - like entertainment (through processes like

gamification), graphics or probability of repeat usage - may not be suitable when considering the applications presented here and might be downright inappropriate. For instance, the IPCRC application is a very simple application that is intended to be used once (or at most a handful of times), by a very select group of users for a very specific purpose. Current evaluation criteria are simply not adequate to consider such tools, which is illustrated by the large discrepancy between its relatively poor MARS score and its extremely good user score, a feat all the more impressive when considering that the user score for this application was based on scoring by a very large number of users.

Finally, while we think that the list of mobile applications can be considered complete, the same cannot be definitely stated for the web applications. Due to the vastness of the internet and our relying on various search engines and their underlying algorithms, we cannot exclude the possibility that there are tools that were overlooked.

Summary Points

What was already known on the topic

- Studies link low health literacy with poor appreciation of health risk analyses.
- There is a large potential for cancer risk calculators to provide a public health benefit by educating individuals about their risks, and hence encouraging preventive health behaviors.
- It has been acknowledged that mobile technologies are becoming an important resource for health services delivery and public health due to their ease of use, broad reach and wide acceptance.

What this study added to our knowledge

- The majority of the calculators focus only on the most common and most lethal cancers, namely breast, prostate and lung cancer.
- Most of these tools only deal with one cancer and for many cancers there is only one tool available.
- For the moment, online calculators for cancer risk remain more numerous than mobile risk calculators, but this balance will likely shift in the near future.
- Mobile applications are poised to impact all aspects of cancer care, with initiatives by both governments and private developers.

5. Conclusion

The time seems to be ripe for more detailed studies on the impact of cancer risk calculators, preferably in a prospective setting. These risk calculators could improve the health literacy of patients and encourage them to adhere to preventive health measures.

Authorship confirmation statement

All authors have taken part in writing the manuscript, reviewing it, and revising its intellectual and technical content.

Authors' disclosure statements

Westerlinck P. has been a collaborator for the Cancer Risk Calculator application.

Coucke P. has nothing to disclose.

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