

ARTICLE

A mapping study and recommendations for a joint NGO (Think Pink) and Bahrain Government Breast Cancer project

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Abstract

Aims: Breast cancer within the region continues to present challenges to the healthcare services. Strategies to shed light on clinical gaps could better support country-specific circumstances. The aims of the mapping study were to identify the gaps in the evidence base, for the management of breast cancer with relevance to Bahrain and the Gulf Region. In parallel, focusing on areas and directions of research, which are compatible with international and local clinical interests. It was envisaged that the mapping project would expose not only opportunities to improve support to the community but also illustrate the possible engagement of a government entity and a Nongovernment Organization in a private-public partnership.

Method: An extensive literature review of local and international publications from the period between 1979 and 2015 was undertaken. Searches were conducted using free-text terms, singularly or combined, with no limiters, to provide unrestricted retrieval of available English studies.

Results: A total of 326 citations were identified, which after deduplication provided 277 unique citations of which included 236 studies within 13 different categories, relevant to breast cancer within the Gulf Cooperation Council (GCC).

Conclusion: Contextualizing gaps in literature and, therefore, providing evidence-based decisions, not only support the enduser, but better support the country-specific challenges and burdens to healthcare. Three broad but key areas were identified after mapping of the literature, covering: screening and mammography, knowledge translation and dissemination, and lymphoedema postsurgical resection. Similar mapping projects could be undertaken by other national NGO's to better support the government and solidify the framework for a public-private partnership.

KEYWORDS

breast cancer, breast neoplasms, lymphoedema, GCC (Bahrain; Saudi Arabia; Kuwait; United Arab Emirates; Qatar; Oman; Arabian Gulf; Persian Gulf), private-public partnership

1 | INTRODUCTION

Cancer is a major cause of death worldwide and accounts for 8.2 million deaths (around 13% of all deaths) in 2012. Deaths from cancer at global level are projected to continue to rise by up to 70% over the next two decades, with one of the largest percentage increases (26%) in cancer mortality expected in the countries of the Eastern Mediterranean

Region (EMR). The World Health Organization (WHO) has predicted that cancer incidence and mortality within the EMR is likely to double over the next 20 years.¹

In the EMR, breast cancer is the leading cancer for women both in terms of annual incidence (61 525 cases per annum [p.a.]) and mortality (31 832 deaths p.a.).² The average breast cancer Age Standardized Incidence Rate (ASIR) over the period between 2000 and 2010,

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was the highest in Bahrain (52.3/100,000) out of all the Gulf Cooperation Council (GCC) States—with rates in the EMR higher than the world average (39/100,000). However, the ASIR for Bahrain has shown a slight decline in the years 2007 to 2010, to 44.4 of 100,000. Several reports have also indicated that the mean age at presentation (48 ± 2.8 years) is 10 years earlier in the Arab region than in the West and suggested that this may be associated with social and economic differences and that the potential benefits of screening at an earlier age, warrant further investigation.^{3,4}

The prevalence of breast cancer within the region continues to present challenges to regional healthcare services as they strive to reduce the burden of disease and to provide services based on best practice, within individual resource constraints. Our knowledge of the strategies that can be used to prevent, detect, and manage breast cancer is increasing, but significant gaps remain, and much research work still needs to be done, in particular, research that is contextualized to country-specific clinical circumstances and resources. Well-informed decisions and choices should be underpinned by the current best information available on the effects of relevant healthcare interventions. This information should be readily accessible to everyone involved in the decision-making process, including clinician, patient and policy maker, and the content communicated in a way that is both concise and intelligible. It was for this reason that a local NGO initiated a mapping project, both as a mean to identify evidence gaps but moreover to better serve our endusers in Bahrain. It was perceived by the authors that this would benefit the healthcare system while also fitting into the essence of a public-private partnership (PPP) remit. Additionally, the recommendations would provide a direction for the Charity that was patient centered and, thereby, would match its ethos.

2 | METHODS

2.1 | Objectives

Following are the objectives:

1. To identify the gaps in the evidence base for the management of breast cancer with relevance to Bahrain and the Gulf Region.
2. To focus on possible areas and directions of research, which are compatible with international, local, and regional clinical interests. It is envisaged that the mapping would expose opportunities to better support the community, thus, becoming thereafter a direction of travel for Think Pink: Bahrain Breast Cancer Society (TP: BBCS).

2.2 | Evaluation

The preparatory work included a comprehensive literature search of local and regional databases and other resources extending coverage to Bahrain. Inclusion and exclusion criteria were not prespecified prior to conducting the searches to enable as complete a retrieval of citations as possible. Searches were conducted using free-text terms, singly or combined, which were relevant to breast cancer and without

the use of limiters, with no attempt to restrict the number of studies retrieved, albeit to include only those available in the English language. While recognizing that this would provide an extensive number of references to studies, with the possibility that many may be of limited relevance, it was considered that if these were preliminarily sifted, they could subsequently be expeditiously assessed for eligibility by an experienced reviewer. The intention of the preliminary exploration and deduplication of the search results was to facilitate the identification of a core set of relevant studies. Further assessments of relevance or suitability were made based on the abstracts or full-text documents if these were available. Independent advice was sought if a clear decision could not be made. The citations to references were categorized into broad subgroups, and these were then entered on an EXCEL spreadsheet together with additional comments to facilitate their further identification and categorization. Databases and other resources searched included: PubMed, IMEMR (Index Medicus Eastern Mediterranean Region) (<http://www.emro.who.int/information-resources/imemr-database/>), IARC (International Agency for Research on Cancer) (<http://www.iarc.fr/>), Google Scholar, *Medicine and Health care in Bahrain and the Gulf, 1979–2013, A Subject-Classified Bibliography of Articles from the Bahrain Medical Bulletin and the Journal of the Bahrain Medical Society, Bahrain, 2014* (including issues till date),⁵ *Epidemiology of Breast Cancer among Bahraini Women. Data from the Bahrain Cancer Registry*, Hamadeh et al,² Clinicaltrials.gov: a registry and results database of publicly and privately supported clinical studies of human participants conducted around the world. Additional searching of this database was undertaken to identify any GCC region-specific unpublished or ongoing trials in breast cancer.⁶ This search revealed a number of regional ongoing trials in breast cancer-related topics, most of which were international multisite studies and included sites which were predominantly located in Saudi Arabia. The majority of these studies were ongoing or in recruitment phase or the protocol had not been accessed or updated more recently.

2.3 | Patient and public involvement

This research study was part of a nongovernmental organization (NGO) project. The Executive Board of Bahrain Breast Cancer Society consists of 12 volunteers both national and expatriates, three of whom are breast cancer survivors. The board was kept informed of the process throughout the project. Active participation occurred when the recommendations were made clear, and involved discussion of the three options. At this time, a summary of the results of the mapping was made available and discussed comprehensively to ensure an informed decision.

3 | RESULTS

A total of 326 references were identified in the searches, with almost half arising from PubMed and less than half of the remainder from the IMEMR with the balance retrieved from both of the Bahrain-based journals and other bibliographic resources. Just over 15% of the total

TABLE 1 Citations by source

Source	No. of hits
EMB/JBMS	49
PubMed	150
IMEMR	103
Other bibliographical sources	24
Total	326

number of studies retrieved were published in the *Bahrain Medical Bulletin* and the *Journal of the Bahrain Medical Society*, with a similar number in the *Saudi Medical Journal*, which were accessed from the PubMed searches. (See Table 1).

The Hamadeh et al report, which was published in the *Sultan Qaboos University Medical Journal* also provided a valuable source of bibliographical references, which were fully explored and assessed for relevance and eligibility. Deduplication of the results of these search results provided 277 unique citations to potentially eligible studies. After preliminarily assessment for relevance, a total of 41 studies were excluded on the grounds that they were not relevant to breast cancer (See Figure 1). The remaining 236 studies underwent further evaluation and were grouped broadly into 13 categories based on scope and content, while recognizing there would be a degree of overlap (See Table 2). The date range of the citations extended over

the period 1979 to 2015, with a larger proportion of the publications appearing in the years 2008 to 2014, peaking in 2013 (See Figure 2).

Several studies had been published in regional journals based in the other GCC countries, as well as in those from Egypt, Pakistan, and Iran. The remaining studies, although low in number, per individual journal, were published in a wide range of international journals several of which were indexed in MEDLINE and had an Impact Factor, for example, *PLoS One*, *British Journal of Cancer*, *Journal of the Royal College of Surgeons and Edinburgh, Cancer*.

A large proportion (25%) of the total number of included studies focused on the epidemiology of breast cancer, with diagnosis and screening (20%) and studies reporting “risk factors” accounting for 15% of the total. A moderate number of studies (15%) investigated the knowledge and awareness of patients and carers of various aspects of breast cancer, and a selection of management strategies, that is, surgery, chemotherapy, and radiotherapy, which were covered in just under 10% of those identified. The remainder (15%) of the studies covered mostly miscellaneous and broader aspects of topics related to breast cancer. Key topics for the studies specific to Bahrain, which had been published in the two Bahrain medical journals included; risk factors and their prevalence (16%), diagnosis and staging at presentation, the challenges of false negative mammograms, prevention and early detection. These were supplemented by a number of case reports, largely on the pathology of breast cancer and included a substantial

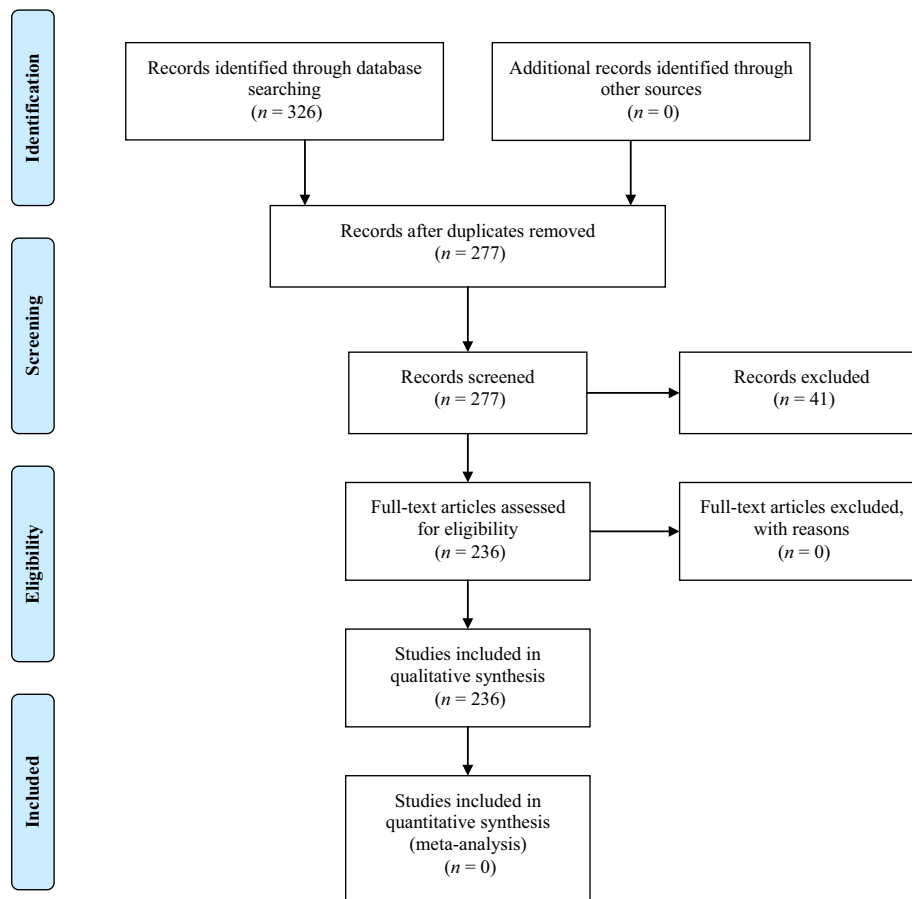
**FIGURE 1** PRISMA flow diagram

TABLE 2 Citations by category

Category	No. of articles
Background	20
Diagnosis	27
Epidemiology	66
Knowledge/awareness	35
Management	16
Quality of life	4
Reconstruction	3
Risk factors	40
Screening	18
Surgery	2
Chemotherapy	2
Radiotherapy	3
Not applicable	41

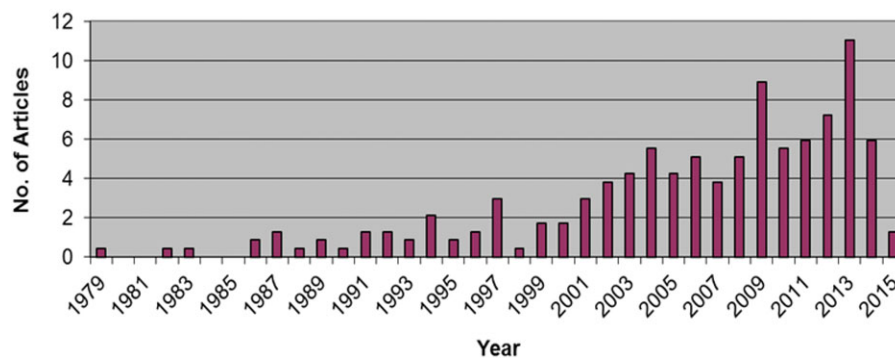
retrospective analysis of diagnoses, based on fine needle aspiration biopsy. Breast cancer and the benefit versus harm of screening was also covered extensively in several overviews and in a number of editorials and short communications. Assessment of the Quality of Life (QoL) in women with breast cancer was conducted in a single cross-sectional study. There was a paucity of reports on surgery, chemotherapy, and radiotherapy but a small number of publications were identified on lymphoedema postsurgical resection and two reports that reported on surgical breast reconstruction. The overall searches had identified eight studies on lymphoedema, the majority of which were from Saudi Arabia and Kuwait but only one of these, a case report from Bahrain of postmastectomy lymphoedema, was considered to be relevant. No reports of studies employing randomized controlled or prospective experimental study designs were retrieved, with many of the reports consisting of retrospective record reviews and analyses of local data, which were generally reported within a regional or international context. One of the most comprehensive and up-to-date analyses of breast cancer data were from the Bahrain Cancer Registry epidemiological study, which was conducted in 2014 and published in an Omani medical journal. The report concluded with a

clear recommendation that further research was required to try to understand why Bahrain had the highest incidence of breast cancer in the GCC.²

A large number (88) of studies covering various aspects of breast cancer in Saudi Arabia were retrieved in the PubMed searches, but most of these had been published in non-Saudi Arabian-based Journals. Many were prevalence studies, and these also included a number of reports of genetic variations and associated susceptibility to breast cancer. Epidemiology, risk factors, causative relationships, burden of disease, and survival were also covered quite extensively in the research from Saudi Arabia. Assessment of the quality of breast cancer care was examined in a single institutional study and the breast cancer burden in Saudi Arabia and a population-based survival analysis of women in Riyadh, were covered in two further studies. The attitude of general surgeons to breast reconstruction was explored in a recent study and a much earlier retrospective study evaluated initial diagnoses by GPs and subsequent referrals for treatment of breast cancer. Knowledge, attitude, and awareness of women, and secondary school students toward breast cancer and breast self-examination were also comprehensively examined in two separate studies.

Only eight reports were identified from Oman, one of which was on sentinel lymph node biopsy with the remainder investigating prognostic factors, association of reproductive factors with incidence of breast cancer, outcome of treatment, and a case report. Out of the 20 reports from Kuwait, two focused on assessment of QoL and, in particular, the validity and reliability of the European Organization for Research and Treatment in Cancer QoL Questionnaire (EORTC QLQ). Association of reproductive factors with incidence of breast cancer, the initial experience with magnetic resonance imaging, accuracy of cytology, and a study on the staging of newly diagnosed breast cancer, were covered in several studies. A retrospective (15 years) record review of neoadjuvant chemotherapy and long-term outcome, emphasized the importance of hormone receptor status.

The 20 articles in the searches from UAE included three studies on the awareness of screening, barriers to screening, and one on breast self-examination knowledge and practice among nurses. Five separate studies explored risk factors including consanguinity related to breast cancer in the UAE. Risk factors, beliefs, knowledge, barriers, and

Number of Articles per Year (1979-2015)**FIGURE 2** Number of articles per year

attitudes toward screening and breast cancer health promotion were covered by the 11 studies identified from Qatar. No published Randomized Controlled Trials (RCTs) or studies with similar study designs were retrieved in any of the searches of the major databases, with the majority of studies identified reporting on the epidemiology of breast cancer and the associated risk factors. The reasons for the comparative absence of any clinical trials on specific interventions for the management of breast cancer remain unclear and would appear to illustrate a gap in the research spectrum. The searches did reveal a concentration of studies in the GCC, which had investigated facets of knowledge, attitude, and awareness of breast cancer and self-examination of women, clinicians, nurses, and students, but there was limited evidence of any follow-up initiatives to address any of the shortcomings, which may have been identified in this research. The QoL of women with breast cancer was emphasized in several studies, one of which evaluated the validity and reliability of a QoL tool and a further cross-sectional study investigated the experiences of Bahraini women with breast cancer. There were some signs, however, of increasing interest in genetic biomarkers and molecular medicine related to breast cancer in the Saudi Arabia-based research.

4 | DISCUSSION

In selecting topics, which were seen as priorities after the literature review, three feasible options emerged in terms of impact while also ensuring that this would not be repetitious research with limited or no direct impact on women's health in Bahrain. The three options for consideration as recommendations for future research included:

1. Screening and mammography: Develop a GRADE compliant evidence-based clinical practice guideline on screening mammography for breast cancer, which is modeled on countries with a similar ASR of breast cancer but takes into consideration the unique characteristics of the population of women in Bahrain.
2. Knowledge translation and dissemination: Conduct a randomized study of women with early-stage breast cancer, assessing their level of understanding and the potential impact of different formats of review summaries on the effects of bisphosphonates and aromatase inhibitors.
3. Lymphoedema postsurgical resection: Conduct an analysis of women's experiences with the methods used to manage lymphoedema following breast cancer surgery to include an assessment of QoL using the EORTC QLQ.

These findings overall reflect and correlate with other reports illustrating a rather low number of experimental studies, and in particular RCTs, which have been conducted and subsequently published in local and regional journals.⁷⁻⁹ The searches that were undertaken in PubMed were designed in such a way as to ensure completeness in identifying any such trials, which may have not been detected in the IMEMR searches and/or because these studies may have been published in nonregional indexed journals.

The challenges and resource implications of conducting clinical trials on breast cancer are not unique to the region and are faced by researchers globally. Thus, the comparative ease of data acquisition via retrospective medical record review, while extremely valuable in terms of providing healthcare policy makers with relevant epidemiological data, may have been in part instrumental in directing the scope and content of many of the research topics that were identified.

There is a wide range of possible breast cancer research topics for consideration, considering not only the importance of these topics and their alignment with the health priorities of Bahrain but also assessing their feasibility and ultimately their potential clinical impact. There has been a substantial amount of research on prevalence and much of the data are being collected and analyzed by the Ministry of Health. Risk factors for breast cancer have also been extensively explored and set in context with other global research. In parallel with this is the idea of this showcasing the merits and implications in a project, which follows the PPP model. Endorsed by the WHO, believing that "creating a PPP entity with a well-defined objective relating to the development of a particular product or technology is required by developing countries."¹⁰ Inclusion and, therefore, collaboration in the development of one of the three recommendations would mean a championing of a project, which leveraged skills and expertise.¹¹ Complementing each other by the contribution, partnerships could be seen to increase the efficiency due to accessibility and is seen as a way of meeting the demand for infrastructure development. Reinvestment of public funding to other resources is due to the private sector (the NGO) financing one of the three options from the mapping process.^{12,13} It could also be said that the partnership could be a way to make health service delivery and recommendations accessible and available on different platforms, that being the NGO's, rather than just traditional spaces, moreover, making informed and shared decision making available to the community at large. Rationale for these topics lies within the findings themselves and can be broken down in relation to the evidence accordingly.

4.1 | Recommendation one: Screening and mammography

Early diagnosis is as important in breast cancer as in other forms of cancer and, thus, screening would appear to be pivotal to any management strategy. However, there continue to be a number of contentious issues regarding screening mammography in terms of the age at which this should commence, the screening interval (annually versus biannually) and most of all a degree of unanimity over aspects of the balance of benefits over harm to women who have been offered screening.

A large number of breast cancer clinical guidelines have been developed by a variety of leading global and national organizations over at least the last 20 years, many of which have been adopted widely at international level. The majority of these provide guidance on mammography screening and are generally directed toward asymptomatic women with an average risk for breast cancer in different age groups. However, these specific recommendations may not be directly generalizable to women with an elevated risk due to factors other than age such as genetic mutations, personal history of invasive breast

cancer, ductal carcinoma in situ, lobular carcinoma in situ, or history of breast irradiation. Many of these guidelines have been updated periodically as new interventions or new evidence has become available but there is a degree of inconsistency among some of them in terms of certain key recommendations and only a limited number have used the GRADE approach to assess the quality of the evidence and strength of recommendations.¹⁴ Policymakers who must make implementation decisions at national level may be unsettled by this dissonance, which may also add confusion and complexity to clinical decision making by clinicians and women at individual level.

An indication of the degree of current uncertainty can be illustrated by Prof. Michael Baum, one of the pioneers of England's £75 million a year screening programme, when he voiced his concerns, indicating that he believes "women are not receiving accurate and complete information on the actual benefits and risks of the procedure." The implication of this statement was that most women are not giving informed consent for breast cancer screening. He more recently questioned "how much is too much breast screening" and stated that "the new data published in the BMJ now suggests that none of the gratifying falls in breast cancer can be attributed to screening."¹⁵

A retrospective analysis was conducted in 2011 of a WHO database on cause of death, which examined data on mammography screening, cancer treatment, and risk factors for breast cancer mortality. The objectives were to demonstrate that the introduction of screening by mammography in some countries in Europe was associated with a steeper fall in mortality from breast cancer than in neighboring countries that had delayed offering this service. The results of the study indicated that paired neighboring countries had experienced the same fall in breast cancer mortality whether or not screening had been introduced. Furthermore, the steepest fall in mortality observed was among the women under 50 years who had not been invited for screening in all of the countries taking part in their study. The investigators concluded that "the recent downward trend in breast cancer mortality was nothing to do with screening but in fact due to improvements in treatment and service provision."¹⁶

The current, (2014) WHO position paper on mammography screening addresses asymptomatic women at average risk for breast cancer in different age groups.¹⁷ The guideline makes a "conditional" recommendation for commencing screening at age 40 years but indicates there is uncertainty about the optimal screening interval and, therefore, makes no recommendation. It also states that due to the much lower incidence rate of breast cancer in the 40-49 age group, and the somewhat lower sensitivity of mammography, the absolute benefits would appear to be small. Moreover, the harm particularly in terms of cumulative false-positive rates seem to be high in this age category. Although the lack of a definitive, albeit "conditional," recommendation for this age group would appear to be appropriate, the comparative ambiguity in terms of the minimal absolute benefits expected may not facilitate confident decision making by the clinician and patient.

The American Cancer Society's recently updated guidelines on breast cancer screening for women at average risk for breast cancer makes the following recommendations. Women aged 40 to 44 years should have the choice to start annual breast cancer screening with

mammograms if they wish to do so, and the risks of screening as well as the potential benefits should be discussed. Women aged 45 to 54 should get mammograms every year. In addition, the Society stated that research does not show a clear benefit of physical breast exams done by either a health professional or by selfexamination for breast cancer screening. Due to this lack of evidence, they state that regular clinical breast exam and breast selfexamination are not recommended.¹⁸

Setting this in the context of Bahrain and the GCC, it is clear that this line of research is of significant importance, which is reflected by the data from Hamadeh et al pointing to a higher rate of incidence and an age at presentation of a decade earlier in the region than in Western countries. The IARC is currently updating their monograph, which will be published subsequently in the IARC Handbook of Cancer Prevention (Volume 15).¹⁹ A Special Report published in June 2015 stated that "the experts concluded that there is sufficient evidence that mammography screening is effective in reducing breast cancer mortality for women aged 50-69 years, and that the benefit of reduced mortality extends to women screened at age 70-74 years. Evidence for the effectiveness of screening women in the younger age group of 40-49 years was considered limited."²⁰ However, what needs to be taken into consideration is that the data that were evaluated came from studies conducted in high-income countries, that is, Australia, Europe, and North America, and which may be dissimilar to those available from less well-resourced countries.

4.2 | Recommendation two: Knowledge translation and dissemination

The searches identified a substantial number of studies conducted throughout the region, which assessed the knowledge, awareness, and attitudes of women and clinicians toward breast cancer, screening, and breast self-examination. Undoubtedly, patients these days gather much of the information about their health status through informal ways such as the popular press, media, and the Internet. Patient leaflets and summaries distributed through more formal means, that is, hospital clinic visits or via a healthcare provider, may appear to be potentially more reliable sources of relevant information but very often these may be "dated" and perhaps do not reflect current best evidence and practice. Different strategies based on the latest technological approaches can be used to disseminate information to assist with clinical decision making and, thus, downloadable podcasts of current clinical hot topics from journals and other clinical resources are increasingly being made available to busy clinicians. The challenges faced with developing similar resources for patients include ensuring that these are contextualized to a variety of cultural settings and which understand women's preferences for information and how best to communicate, for example, the harm and benefits of interventions in a balanced way.

Systematic reviews of randomized trials provide evidence on the effects of healthcare interventions that is vital to well-informed decisions and choices about the interventions. This information needs to be accessible to everyone involved in the decision-making process including practitioners and patients. In breast cancer, the Early Breast Cancer

Trialists' Collaborative Group (EBCTCG) has, for more than 30 years, brought together data from randomized trials across all aspects of the treatment of women with early (operable) breast cancer.²¹ Research groups from around the world share individual participant data on all the women who have joined their trials to allow definitive analyses of the effects of treatment on time to recurrence and death. The reviews produced by EBCTCG have been cited more than 12,000 times in the scientific literature and underpin guidance and policy around the world. Earlier this year, the latest reviews were published, providing evidence on the effects of two classes of drug: bisphosphonates and aromatase inhibitors. The publication of these reviews presents an ideal opportunity to investigate ways to make this information accessible to women with breast cancer and the practitioners who treat them. Researchers may wish to consider the possibility of conducting such a study in Bahrain, which would build on the SWAR-2 (Study Within A Review-2) that has previously been piloted in Northern Ireland.²² The objectives of the study would be to create a variety of summaries (both written and audio) for either or both of these two reviews, in both English and Arabic, which would allow a reliable assessment of their effects on knowledge transfer of information from the reviews. This research project would be conducted in collaboration with the All-Ireland Hub for Trials Methodology Research led by its director Prof. Mike Clarke who has indicated he would provide oversight and guidance throughout its duration and would not require any specific funding.²³

4.3 | Recommendation three

Lymphoedema is considered a debilitating long-term sequela of breast cancer treatment. It is characterized by regional swelling in one or both arms and is due to excess accumulation of fluid in the body tissues as a result of insufficient lymph drainage. The adverse effects of surgery or radiotherapy can result in partial or total destruction of the lymphatic system and may also cause scarring or subcutaneous fibrosis in the skin and subcutaneous tissues.

Lymphoedema is a common occurrence with figures reported ranging widely from 20 to 94% of women affected. A recent systematic review assessed the risk of developing arm lymphoedema to be 16.6%, but the actual rate varied based on the studies which were included in the meta-analysis and the diagnostic methods used in the assessments.²⁴

Arm lymphoedema is often accompanied by pain, heaviness, tightness, and can result in decreased range of motion, which can impede daily function and may severely impact on the QoL of the woman. Treatment options include multilayered bandaging; manual lymph drainage (MLD), self-administered massage, the use of compression bandages, and exercises to promote lymph drainage. These may be offered as multiple combined treatments or sequentially daily for extended periods of time.

A number of studies have investigated the effectiveness of different treatment strategies to reduce the risk of breast cancer-related lymphoedema as well as its management when it occurs.^{25–30} There is inconsistency in terms of the reports of beneficial effects of MLD

across the studies ranging from no benefit to inconclusive benefit and one review even indicating substantial benefit. A Cochrane review, which was published in 2008 identified a single study, which involved 42 women with lymphoedema of the upper arm following treatment for breast cancer.²⁵ The participants were randomized to MLD with compression hosiery or hosiery alone for 12 months. There was no clinically significant difference in limb volume between intervention groups and the review authors concluded that any improvements were due to the compression sleeves and that MLD provided no additional benefit. The other studies included in this review were small sample sizes and had other methodological limitations. A systematic review of effectiveness of current practices of lymphoedema therapy in Finland indicated that compression bandages reduced lymphoedema but additional MLD did not provide any extra benefits.²⁶ Combined Physical Therapy (CPT), that is, skin care, MLD, exercises, and bandaging, and maintenance phase of these together plus wearing a compression sleeve for lymphoedema was assessed in 10 RCTs.²⁷ This systematic review concluded that CPT was effective but it remained unclear which of the individual components were more effective. MLD provided conflicting results as did compression bandaging and hosiery. A more recent (2015) Cochrane systematic review selected volumetric changes in the affected arm as its primary outcome and reported a significantly greater improvement in patients who received compression bandaging and with an incremental extra, but smaller, improvement when MLD was added.²⁸ Pain and limitation of function were inadequately reported in the few studies included in this systematic review and, thus, the effects of these interventions for these specific outcomes could not be assessed. A systematic review of "commonly instigated conservative therapies for secondary arm lymphoedema," which also included pneumatic pumps, oral medications, and low-level laser therapy concluded that the health professional-based therapies provided the greatest volume reductions.²⁹

The discordance in these results is quite significant and may have more to do with the variability in methodological quality and reporting of the systematic reviews rather than the internal validity of the individual trials. The most recent Cochrane review³⁰ has the most up-to-date searches and, while incomplete in terms of a fuller assessment and reporting of the quality of the evidence, provides a more balanced and robust evaluation of the effects of these individual treatments.

The mapping process was critical for the NGO more especially in helping inform the decision to be taken by the Charity. Ensuring championship with the government of Bahrain via the Supreme Council of Health (SCH) and the National Health Regulatory Authority confirmed, the development of a National Breast Cancer Guideline would be the best fit. The multidisciplinary approach, which is inclusive of consumer advocates and patients, is the essence of the Charity's mission and vision. The whole process, which started in June 2016, from mapping to delivery of the completed clinical guideline to SCH took just 18 months.

Notwithstanding the impact of limited human resources, financial costs-budget deficit from reduced oil prices, the NGO was able to provide support with relevant resources and funding, of a robust and internationally peer-reviewed guideline, which was developed using the RAPADAPTE approach. This example clearly showcasing the

WHO's-PPP thematic in Bahrain. The methodological approach was chosen based on its proven track record in Costa Rica,³¹ which ensured a shortened delivery time based on the concept of adaptation, ownership and relevance, and above all tailoring of the scope to the local context. The availability of large number of existing guidelines was not the direction for the Charity and engendered a push way from wanting to "reinvent the wheel" approach.³² The approach that was chosen would also mean that local policy makers, clinicians, and patients would support the process and enable a close cultural relevance, based on local context and the current availability of care. While both affordable and comprehensive, the guideline centered around critical clinical questions that the experts wanted addressing while providing a currency of evidence-based best practice. Opportunities for engagement were presented at each development including one to one's, focus groups and cross multidiscipline meetings. Many times, the developers of the guideline would met within the clinical setting given limited availability.

The development of the guideline involved an inbuilt peer-review process with the use of the Institute of Medicine (IOM) criteria, the AGREE II checklist, and Lenzer's Red Flags and externally through the International Peer-Review panel. This all-encompassing process has enabled a robust document that³³ has reduced common Conflicts of Interest (COI). It is relevance against the current background of privatization of health within the Kingdom is timely. It is an example of how guidelines can be developed at an internationally recognized standard, while being driven by local healthcare providers making it applicable across the healthcare spectrum and to a national population.

5 | CONCLUSION

In conclusion, the mapping of potential focuses of interest has played critically into the direction of TP: BBCS since inception. Enabling evidence-based decision making on behalf of the Executive Team has meant that the community of Bahrain, has been better supported with the decisions made. It is envisioned that this process, once presented, will enable one of the three recommendations to be the new direction of travel for the NGO, and give a rationale as to why this decision has been made. One of the three recommendations, as rationalized within the discussion: Screening and mammography, Knowledge translation and dissemination, Lymphoedema postsurgical resection, will be selected by the NGO.

ADDENDUM

While traditionally governments turn to the private sector to provide financing or development the NGO (Think Pink Bahrain) itself approached the government of Bahrain, via the Supreme Council of Health (SCH) after the decision was made to fulfill one of the three recommendations from the mapping of the gaps. At the time of this article submission, the National Breast Cancer Guideline for Bahrain has been submitted to the SCH (see supplementary document).

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SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

How to cite this article: Sprakel J, Carrara H, Manzer BM, Fedorowicz Z. A mapping study and recommendations for a joint NGO (Think Pink) and Bahrain Government Breast Cancer project. *J Evid Based Med*. 2019;12:209–217. <https://doi.org/10.1111/jebm.12357>