PUTTING PATIENT PERSPECTIVES AT THE HEART OF CANCER CARE

Using Artificial Intelligence (AI) to generate new patient insights in breast cancer

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Thanks to earlier diagnosis and improved treatment, cancer patients are living longer and healthier lives. However, cancer will present significant challenges in the years to come, and nowhere is this more apparent than in Asia.

Asia now accounts for half of the global burden of cancer, and the World Health Organization predicts that incidence will rise from 6.8 million cases in 2012 to 10.8 million in 2030. Incidence of breast cancer alone in Asia is predicted to increase from 651,000 cases in 2012 to 920,000 by 2030, constituting over a third of the global total.

This challenge has both a human and a financial dimension. Too many people will have their lives affected or cut short by cancer, and the costs of cancer will continue to grow. It is therefore vital that we target investment on the support, services and treatments which will make the biggest difference to patients, maximizing the value of cancer care.

It is impossible to do this without understanding the issues that cancer patients face, along with their needs and preferences. There are a range of different ways to capture the perspective of patients, ranging from surveys of experiences or quality of life, to advisory and focus groups. However, technological advances create opportunities to supplement these existing methods, drawing on the experiences and activities of large numbers of patients in their everyday lives.

This report documents the approach and findings of a pilot initiated by IQVIA which used an Artificial Intelligence (AI) platform to explore the key priorities and concerns of breast cancer patients in Singapore. The pilot analyzed online activity among the Singaporean population over the past two years, evaluating more than 46,000 unique online activity patterns to derive insights. It is estimated that these activities were generated by approximately 7,000 people affected by cancer.

This is the first AI study of its kind, breaking new ground in the field of value-based cancer care. The purpose of this report is to provide recommendations on how AI can be used by policymakers, as well as providers of cancer treatment and information services, to make decisions based on the real life needs and preferences of patients.

**SUMMARY OF FINDINGS**

The findings from the pilot confirm many of the quality of life issues established in the research literature and reaffirm the importance of tailoring support and services to individual patients. Breast cancer patients are not a homogenous group, and encounter specific needs and challenges that are unique to each stage.

Patients with early stage (1 and 2) breast cancer appear to seek further support with:

- Advice on insurance and treatment costs
- Information on Emergency Department
- Enhanced information on side effects of treatment

Patients with advanced stage (3 and 4) breast cancer appear to seek further support with:

- Advice about financial affairs
- Information on outpatient appointments and logistics such as car parking
- Enhanced information on pain management
- Support on managing family relationships
- Support on managing sleep
There are also some common areas where support may be required, including:

- Improved support on depression, stress and anxiety
- Information on treatments appropriate to stage
- Information on breast cancer and patient support groups
- Enhanced workplace support
- Information on appropriate physical activity
- Access to spiritual and religious support where this is requested

RECOMMENDATIONS
To fully understand and harness the potential of AI as a complement to other methods for capturing patient insight, the report makes the following recommendations:

Recommendations for information providers

1. Findings uncovered through an AI platform should be shared with patient organizations, as well as health services, who may wish to discuss potential applications for their work and prioritize enhancing information and support in the areas identified.

2. Where specific support requirements have been identified for different stages of cancer, information providers could consider using these findings to assess how best to improve the targeting and accessibility of their support.

Recommendations for health policymakers

3. Health systems should work towards the routine collection of patient insights and consider how these findings inform the development of policy, recognizing the unique perspective and benefits that they can provide.

4. It is important that national cancer control plans set out how feedback and insight will be collected from cancer patients and used to improve services. Patient involvement is recommended at every stage of the development, implementation and monitoring of cancer control plans.

5. All forms of value assessment should routinely incorporate patient voice where possible, using feedback from patients and carers about the issues which they value as part of a broader assessment.

6. When developing plans to capture patient insight, policymakers may wish to consider the full range of techniques, including advisory groups, focus groups, Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs), as well as the potential for new technologies such as AI.

7. If and when AI is routinely used to collect patient insight, it will be important to establish clear protocols for flagging emerging issues to relevant stakeholders.

Recommendations for Singapore

8. Payers and policymakers may wish to consider how they could build on the pilot to establish a leadership position on the use of advanced technology solutions such as AI in capturing and evaluating patient insight.

9. The Singaporean cancer community may wish to consider extending the breast cancer pilot to cover other forms of cancer.

10. Cancer stakeholders could now come together to consider the findings of the breast cancer pilot as well as to discuss the implications for services in Singapore and identify areas for further exploration.
CANCER IN ASIA

Cancer has become a critical health issue in Asia. The region as a whole now accounts for half of the global cancer burden, with incidence set to rise from 6.8 million cases in 2012 to 10.8 million in 2030. Breast cancer is the leading form of the disease among women, with an estimated 651,000 new cases in Asia in 2012 and some 920,000 cases projected in 2030, constituting over a third of the global total.

While remarkable progress is being made to improve cancer outcomes – with earlier diagnosis, new treatments and improved service organization enabling many people in Asia to live longer and better lives – cancer will present significant funding challenges in the years to come. Growing incidence and improved treatments will inevitably increase costs. The rise in diagnoses is projected to be largest in low- and middle-income countries, where at present cancer is often a low priority in healthcare planning and expenditure.

THE IMPORTANCE OF VALUE IN CANCER CARE

Given these challenges, it is important that cancer services seek to deliver good value for the investment that they will inevitably require. The concept of value has gained attention in recent years, particularly given the importance of balancing the delivery of high-quality care with growing costs. This implies shifting from a supply-driven system focused on what physicians do towards a patient-centered system organized around what patients need and want.

Patient perspectives on value can differ significantly from other stakeholders. A study exploring definitions of value among cancer survivors found that, while the efficacy of treatment is essential for many patients, their quality of life and strength of relationship with their healthcare team are also important. Similarly, a study on definitions of value among patients with metastatic breast cancer found that although quality, efficiency, and cost-transparency are essential, patients themselves may be more focused on the quality of the patient-provider relationship than on value relative to efficiency and cost.

Other research suggests that patients place a high value on clinicians who are responsive to their needs, access to and choice of clinicians and services, and treatments that maximize their quality of life and productivity. Patients may value a range of different benefits or outcomes, including:

- Clinical outcomes, such as overall survival, progression free survival and minimal residual disease, which are often measured by healthcare providers or during clinical trials
- Quality of life, which focuses on physical, mental, emotional wellbeing and social functioning, including independence and emotional distress
- Patient experience, which encompasses the range of interactions that individuals have with the healthcare system, including ease of access to services and communication with healthcare professionals

Perhaps the most prominent attempt to measure value is the use of health technology assessments (HTAs) and economic models. These aim to assess the cost-effectiveness and budget impact of cancer treatments, influence the decisions of policymakers and, ultimately, shape clinical practice. However, analyses frequently omit information from the patient’s perspective, limiting decision makers’ ability to make accurate assessments of the true value of interventions.

In Europe and the US, where discussions on value have progressed further than many other regions of the world, a number of professional organizations have developed frameworks which take account of patient perspectives.
in determining value. Nevertheless, even in these mature health systems, the majority of frameworks aim predominantly to help payers with formulary decision-making on cost-effectiveness grounds, and there are ongoing concerns that patient perspectives are still not adequately represented.\textsuperscript{15,16,17}

In Asia, patient engagement is still in its infancy,\textsuperscript{18} and patient reported measures tend to carry relatively limited weight at a national policy level.\textsuperscript{19} However, policymakers in the region are beginning to recognize the importance of achieving value in healthcare from the patient perspective. In Japan, for instance, the Ministry of Health, Labour and Welfare has envisioned a value-based healthcare system that ‘evaluates health care on the value it provides to patients and society, not on the inputs it demands.’\textsuperscript{20} In Taiwan, there are increased efforts among policymakers to introduce broader measures of value into healthcare decision-making.\textsuperscript{21}

Progress is also evident in the area of HTAs. For example, in Taiwan, patient representatives are invited to attend committee meetings and provide submissions to the HTA agency.\textsuperscript{22} Thailand’s Health Intervention and Technology Assessment Program (HTAP) involves various stakeholder groups, including patient representatives and the general public, when nominating interventions.\textsuperscript{23} Patients are also invited to participate in the HTA process in Korea.\textsuperscript{24}

**PUTTING PATIENTS AT THE HEART OF CANCER CARE**

It is now widely acknowledged that the principal focus of any high-quality cancer care service should be to deliver patient-centered care\textsuperscript{25} that is ‘respectful of and responsive to individual patient preferences, needs, and values, and ensure[s] that patient values guide all clinical decisions’.\textsuperscript{26} Patient-centered care can empower patients and improve their experiences of healthcare,\textsuperscript{27} whilst also improving health outcomes,\textsuperscript{28,29} achieving efficiency gains,\textsuperscript{30,31} increasing provider satisfaction,\textsuperscript{32} and creating public value for services.\textsuperscript{33}

The experiences reported by patients of their treatment and care, as well as their quality of life during and after treatment, are health outcomes in themselves,\textsuperscript{34} and can only be measured by involving patients. There are indications that patients in Asia wish to adopt a more active role in their healthcare. The visibility of cancer patient and survivor associations across Asia – particularly in developed healthcare systems such as Korea, Taiwan and Hong Kong – has grown in recent years, suggesting a shift in attitudes to patients being viewed as partners in care, rather than solely as passive recipients.\textsuperscript{35}

**DIFFERENT APPROACHES TO CAPTURING PATIENT PERSPECTIVES**

There are a number of different ways in which the patient perspective can be captured, including through:

- **Advisory groups** - groups of individuals with expertise in a topic, who are often assembled to improve understandings of current needs or to support the development of standards, guidelines, and policies
- **Patient reported outcome measures (PROMs)** - structured questions that capture information on aspects of health status from the patient’s perspective
- **Patient reported experience measures (PREMs)** - structured questions that capture information on patients’ experiences of aspects of their care
- **Focus groups** - facilitated discussions with small groups of participants to elicit insights relating to their attitudes and experiences

\textsuperscript{1} These include the American Society of Clinical Oncology (ASCO Value Framework), the National Comprehensive Cancer Network (NCCN Evidence Blocks), the Institute for Clinical and Economic Review (ICER), Memorial Sloan Kettering Cancer Center (Drug Abacus) and the European Society for Medical Oncology (ESMO Magnitude of Clinical Benefit Scale)
Figure 1. Overview of Advisory Groups, PROMs, PREMs and Focus Groups

<table>
<thead>
<tr>
<th>ADVISORY GROUPS</th>
<th>PROMS</th>
<th>PREMS</th>
<th>FOCUS GROUPS</th>
</tr>
</thead>
<tbody>
<tr>
<td>» Advisory groups are formed to advise on specific topics in health</td>
<td>» Patient-Reported Outcome Measures (PROMs) are self-completed questionnaires that can be generic or condition specific</td>
<td>» Patient-Reported Experience Measures (PREMs) are self-completed questionnaires that are usually generic</td>
<td>» Focus group research involves organized discussion with a selected group of individuals to gain information about their views and experiences</td>
</tr>
<tr>
<td>» Patients may be invited to join as representatives, often attending meetings to provide input from a patient perspective</td>
<td>» Patients respond to various questions relating to their health outcomes</td>
<td>» Patients respond to various questions relating to their experience of healthcare</td>
<td>» Focus group discussions are moderated by trained facilitators</td>
</tr>
</tbody>
</table>

### ADVANTAGES

- » Useful to obtain detailed information about group feelings, perceptions and opinions
- » Provide the opportunity for patients to engage directly with clinicians and other stakeholders
- » Offer the opportunity to seek clarification

- » Useful to measure change in outcomes over time
- » Assist shared decision making by providing platform for discussion between patients and providers
- » Can reach large numbers of respondents
- » Enable respondent anonymity

- » Allow for standardized questions, process and analysis, thus enabling comparability
- » Enable routine collection and use of data
- » Can reach large numbers of respondents
- » Enable respondent anonymity

- » Useful to obtain detailed information about personal and group feelings, perceptions and opinions
- » Can provide a broader range of information and enable new topics to emerge
- » Offer the opportunity to seek clarification

### LIMITATIONS

- » Quality of information highly dependent on facilitation of meeting and synthesis of discussions
- » Logistical effort required to organize meetings
- » Potentially time consuming for participants
- » Patient representatives may not be able to effectively participate if they lack communication skills

- » Challenging to aggregate individual scores
- » Do not enable probing/clarification of responses
- » May suffer from non-response and selection bias
- » May exclude those with limited literacy or lack of familiarity with technology (if online questionnaire)
- » Training required for interpretation and use of data

- » Limited use in assessing changes over time
- » Do not enable probing/clarification of responses
- » May suffer from non-response and selection bias
- » May exclude those with limited literacy or lack of familiarity with technology (if online questionnaire)
- » Training required for interpretation and use of data

- » Quality of data highly dependent on skilled facilitator
- » Logistical effort required
- » Potentially time consuming for participants
- » Complex data analysis
- » Group environment and dynamics may alter responses
Below are some examples of how these methodologies have been applied. The UK, in particular, offers a number of examples due to the existence of its National Health Service (NHS), which collects and publishes population-level data.36, 37

**EXAMPLES OF ADVISORY GROUPS**

- Breast Cancer Care, a national charity in the UK, established a Secondary Breast Cancer Taskforce which brought together healthcare professionals, charities, policymakers and individuals with metastatic breast cancer.38 This national coalition developed standards for breast cancer care with the aim of ensuring that patients receive the best possible treatment, information and support.

- The independent National Cancer Advisory Group in England also includes patient representatives, along with professional bodies and representatives from cancer charities, to support the assessment of progress in implementing the national cancer strategy.39 The group advises on the implementation of the strategy’s recommendations and evaluates the progress being made. Patient representatives attend two to three meetings each year, and can provide comments to the group by email and telephone as required.40

- The National Institute for Health and Care Excellence (NICE), an independent body responsible for providing guidance and advice to improve health and social care, receives input from a Citizens Council. This panel consists of 30 members of the public who reflect the demographic characteristics of the UK and serve for a maximum of three years. The Council provides NICE with a public perspective on overarching moral and ethical issues which are taken into account as the Institute develops guidance and methodologies.41 The Citizens Council has previously voted overwhelmingly that NICE should place a premium on severe and end-of-life disease in its technology appraisals.42

**EXAMPLES OF PATIENT REPORTED OUTCOME MEASURES (PROMS)**

- The NHS in England has been running a national PROMs program since 2009 to measure health gain in patients undergoing hip and knee replacements, and varicose veins and groin hernia surgery,43 with questions before and after surgery to capture changes over time. PROMs data are used by providers to review care pathways and identify good practice, as well as by payers to inform national pricing for services. A number of pilot studies have also been conducted in cancer, including surveys for gynecological cancers.44 These pilots have sought to improve understanding of quality of life outcomes for women following treatment and to highlight variations in outcomes, with the aim of linking these data with existing datasets to better understand the relationship between outcomes and types of cancer treatment.
EXAMPLES OF PATIENT REPORTED EXPERIENCE MEASURES (PREMS)

- In France, the e-Satis initiative measures patient satisfaction and experience in hospitals and includes questions relating to hospital discharge and how well care is coordinated between hospitals and general practitioners (GPs). Regional and national-level data are used by individual hospitals to improve quality, and are incorporated in a pay-for-performance system with financial incentives to achieve good results. The public can also use the information to inform their choice of healthcare provider.

- In the US, the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospital Survey uses standardized questionnaires to measure patient experience. The questions encompass aspects of care such as communication with healthcare professionals, responsiveness of staff, cleanliness of the environment and discharge information. Medicare payment rates are tied to the collection and public reporting of CAHPS data.

- In the UK, patient experience indicators are included in national accountability frameworks, such as the NHS Outcomes Framework which assesses whether patients and caregivers have had a positive experience of care. These measures are increasingly used at policy and management levels as patient experience becomes more accepted across the healthcare system as a marker of quality. In cancer specifically, the National Cancer Patient Experience Survey is conducted annually with over 70,000 patients in England to measure experience across the care pathway, from emotional aspects (such as how a person was told they had cancer) to practical aspects (such as the length of time a person waited before being seen by a hospital physician). Local and national survey data are included in a Cancer Dashboard, which compiles key data in one place and supports policymakers to identify priority areas for improvement.

- In Japan, a patient survey revealed that over a quarter of cancer patients were not satisfied with their diagnosis or treatment, often due to the lack of psychological support and the inadequacy of information provided to them. This has provided an important insight which – if acted upon – could lead to meaningful improvements for patients.

EXAMPLES OF FOCUS GROUPS

- In Australia, the government of the state of Victoria has used focus groups to explore issues facing cancer patients, including the information and support needs of women living with cancer in rural and regional areas, as well as whether existing patient experience surveys adequately capture aspects of care that cancer patients deem important.

- Cancer Research UK uses focus groups to uncover patient perspectives on a range of topics, such as how proposed changes to cancer diagnosis procedures might work in practice, or how public campaigns can be shaped to raise awareness of key risk factors including obesity.
THE POTENTIAL OF NEW TECHNOLOGY TO GAIN PATIENT INSIGHT

Developments in technology provide opportunities to evaluate the opinions, preferences and behaviors of patients in a timely and affordable manner, with the potential to complement existing methods. For example, artificial intelligence (AI) and machine learning are gaining ground within the field of health, with vast volumes of structured and unstructured data offering valuable insights. The interpretation of this information has become increasingly effective using analytics engines, and in healthcare these are being used to bring together large amounts of dynamic and complex information.56

Using machine intelligence that applies deep learning algorithms and probability models, AI platforms can identify patterns and relationships in data to gain an understanding of human behavior and intent. Online activity including search interest, social media, site traffic, app usage and click frequencies are compiled and analyzed, representing behaviors, interests and sentiment that reflect patient perspectives.

Over time, AI has the ability to cover entire populations by automating much of the data collection and analysis process. By gathering information beyond that provided through questionnaires and face-to-face discussions, AI platforms can also limit investment from patients, who are not required to take the time to complete and submit surveys, or be physically present to respond to questions. Results are provided at population levels, thereby ensuring patient anonymity and protecting confidentiality at all times.

An AI platform has a much broader coverage of sources than those used for social media listening, as it aggregates and triangulates data from all search engine activities. While social listening relies on users who are vocal on social media sites, AI platforms analyze the activity of ‘silent’ users. This enables the profiling of over 450,000 behaviors and intents to segment the target population of interest. Data can also be used to perform predictive analytics, using real-time data to plot trajectories.

Importantly, while social listening involves the use of pre-defined keywords to manually ‘deep dive’ for insights, AI employs machine learnt algorithms to conduct searches around topics, with insights emerging from the data. This enables AI to capture the ‘lived experience’ of cancer and deliver insights that may not have originally been considered as areas of investigation.

**Figure 2. Overview of AI**

- **AI ENGINE**
  - Artificial intelligence (AI) enables the analysis of large sets of structured and unstructured data
  - Online activity including search interest, social media and click frequencies can be structured to represent behaviors, interests and sentiment

- **ADVANTAGES**
  - Can gain unprompted feedback
  - Enables routine data collection and analysis by automating process
  - Can reach large numbers of respondents
  - Enables respondent anonymity

- **LIMITATIONS**
  - Does not enable probing/clarification of responses
  - Excludes patients with little or no online presence
  - May only reflect selected aspects of patients’ perspectives
  - Requires high degree of interpretation to convert online activity to meaningful insights
SINGAPORE AI BREAST CANCER PILOT

In order to test the potential of AI to gather and analyze patient insight, IQVIA initiated a pilot focusing on breast cancer patients in Singapore.

RATIONALE FOR PILOT

Singapore was selected given its high internet penetration, as well as the existence of a developed healthcare system providing cancer care in both the public and private sectors. Breast cancer is the most common form of cancer among women in Singapore, accounting for over a quarter of all diagnosed cancers. Breast cancer was considered to be a suitable pilot given the level of public interest in the issue, and the large numbers of women living with or beyond breast cancer.

There have been efforts in Singapore to capture patient reported outcomes and experiences of breast cancer patients through the use of surveys (mainly PROMs) and focus groups. Examples include:

- The collection of PROMs to explore the associations between health-related quality of life and socio-demographic and clinical factors at a single tertiary cancer center
- The use of PROMs to examine how quality of life changes in the years following breast cancer treatment for patients at a single hospital
- Focus groups on breast cancers patients’ experiences of healthcare services as well as the psychological impact of the condition

Whilst these findings provide important insights into the Singaporean breast cancer population, they are relatively small scale in nature. In general, there are currently limited opportunities in Singapore for patients and the public to contribute formally to cancer policies or support their implementation. National advisory groups do not promote direct patient involvement, including within the HTA process overseen by the Agency for Care Effectiveness (ACE). Therefore an AI pilot could help to meet an important need in Singapore, by providing patient insights which are not currently visible.

METHODOLOGY

SQREEM, a Singapore-based company founded in 2007, uses data to better understand the behaviors of communities and individuals, with the aim of helping people to lead happier and healthier lives.

The SQREEM Pattern of Life Experiences (POLE) platform brings together information from numerous sources, including both structured and non-structured data, creating an ecosystem of data sources and information frameworks and using behavioral insight to identify trends, visualize relationships, discover divergent patterns, and uncover connections.

Online activity from the Singaporean population was analyzed over the period of April 2015 to April 2017 inclusive. Over 46,000 unique online activity patterns were analyzed across social media and the internet. These activities are estimated to have been generated by approximately 7,000 people affected by cancer. Inevitably, some individuals who are not breast cancer patients are captured based on their online activity patterns; however, given that the analysis is at a national population level, their impact on the final results will be relatively small.
Breast cancer patients were identified based on their digital footprint, including website searches, clicks, and video and image consumption. A confirmed diagnosis has a different impact on each patient, and varies stage by stage. For example, a stage 1 diagnosis may result in the natural impulse to research a wide variety of options, beyond the stage’s domain, as the patient begins to educate herself about the possibilities for different outcomes and courses of action. There is no fixed, or rules based process to anonymously measure stage-typical behaviors. Each stage has clusters of activity directly indicative of itself, as well as ranges of engagement consistent with other stages, or non-stage specific elements. The blend between stage-typical and atypical activity varies from patient to patient, and as an aggregated collective, it becomes a complex web of clustered behaviors. Stage of breast cancer was therefore derived from the nature of a person’s online activity, with actions to investigate stage-specific information being used to identify the likely stage of cancer.

The AI platform deploys cognitive learning algorithms capable of detecting stage-specific clusters in the overall universe of behaviors, using stage-indicative context and information from Breastcancer.org (http://www.breastcancer.org), a non-profit organization with a mission to provide reliable, complete and up-to-date information about breast cancer.

The analysis involves the calculation of metrics that are presented on a scale between -50 and 50, with 0 representing the average scores among the general Singaporean population. Scores that are higher than 0 indicate that breast cancer patients’ online activity (such as internet searches, click frequencies and social media postings) relating to a particular behavior, interest or sentiment are above the average score for the general population, while scores that are lower than 0 indicate below average activity levels. Scores marginally above 0 can be considered relatively weak indications, and those close to or above 20 are highly significant.

The results are presented in comparison to the Singaporean population as a whole. However, the findings have also been tested using SQREEM’s automated verification system and found to be distinct from the patterns of behavior observed in an approximate age cohort comparable to that of the breast cancer population of Singapore.

As AI results depend entirely on the online activity of the population, there are challenges to specifying

PATIENT DATA

The study has not had access to any patient records or confidential medical information. Instead, it draws on the online activity of people affected by breast cancer to derive insights into their concerns and needs. In relation to the online information which has been analyzed:

- Sourced information is anonymous, and no raw data are ever structured in a way that defines an individual as a unique database entry or enables the identification of a person
- Acquired data are open-source, fair use, and no raw piece of information is ever offered to a third party
- Raw information is transformed into signal patterns, after which any plaintext personal information, names, addresses etc are irreversibly lost
- The transformation process serves as one-way encryption, making it impossible to reverse back to its original form
desired outputs; the source of data inevitably means that researchers have little control over the patterns identified through the platform. The outputs presented below are those that became apparent during the analysis - rather than being defined at the outset of the investigation - and have been categorized according to three key areas of interest:

1. Patient outcomes  
2. Patient experience  
3. Financial concerns

FINDINGS
The results of the pilot validate findings from previous studies using traditional research methods, which have investigated the effects of breast cancer and its treatment. However, the findings also provide insight into the considerable diversity within the breast cancer population. Overall, the findings show:

• Considerable variation according to stage of disease  
• The scale of non-clinical needs  
• The desire for holistic support that extends beyond the healthcare setting

1. Patient outcomes
Our AI analysis provides insight into patient outcomes by highlighting a range of factors that are important to patients, including those relating to quality of life. Assessments of quality of life aim to measure individuals’ wellbeing across various dimensions. Clinicians and public health officials often focus on health-related quality of life, a multi-dimensional concept that relates to physical, mental, emotional and social functioning which can be used to explore the effects of illness, disabilities and treatments on individuals.

There are a number of measurements of health-related quality of life in widespread use. The EuroQOL five dimensions questionnaire (EQ-5D) is the most commonly used generic questionnaire which involves a self-reported description of an individual’s health in five dimensions (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) to produce a single utility score.

Outputs that emerge from the AI platform are not necessarily easily categorized into the traditional dimensions of health-related quality of life. It is challenging to identify factors that are common among the wider population; for example, quality of life measures such as mobility and self-care are universal aspirations. However, the algorithm is able to detect various other factors relating to quality of life - both health-related and in more broad terms - that can provide a clearer picture of the lived experience of cancer among patients.

Daily activities
AI enables an exploration of activities that patients engage in that may impact their overall wellbeing. Figure 4 shows a range of daily activities including religion and spirituality, interaction with animals, outdoor activities and family vacation.

Figure 3. Daily activities

<table>
<thead>
<tr>
<th>Activity</th>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Engaging religion and spirituality</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>0</td>
</tr>
<tr>
<td>Interaction with pets</td>
<td>-4</td>
<td>3</td>
<td>10</td>
<td>12</td>
</tr>
<tr>
<td>Outdoor activities</td>
<td>-7</td>
<td>-3</td>
<td>-7</td>
<td>-6</td>
</tr>
<tr>
<td>Intent to go on family vacation</td>
<td>2</td>
<td>-9</td>
<td>-16</td>
<td>-20</td>
</tr>
</tbody>
</table>

* All calculated metrics are presented on a scale, with 0 representing the average score among the general Singaporean population.
Previous studies indicate that religion and spirituality are often important coping mechanisms for breast cancer patients, and that religious and spiritual wellbeing may be associated with improved patient outcomes. However, few studies have compared patients’ religious and spiritual activity by breast cancer stage. Our findings indicate that online activity around religion and spirituality among patients at earlier stages is higher than the general population, but that there is no difference between the activity levels of stage 4 patients and those in the general population. Further exploration of this topic may be helpful to assess whether patient needs are being met, and if access to religious and spiritual support could be improved, where this is requested.

There is evidence that interaction with animals can improve social and emotional wellbeing among cancer patients as well as promote increased patient communication and engagement in clinical care. Our findings highlight that interaction with pets can be important to stage 3 and stage 4 patients in Singapore.

There is growing international evidence to support the positive role of physical activity during and after cancer treatment, and its potential link to improved health-related quality of life and reduced fatigue among individuals with breast cancer. However, while research over the past decade has increasingly demonstrated the benefits of exercise among women with early breast cancer, there is little information regarding the feasibility or benefits of exercise among women with metastatic disease. A US study attempting to address this gap piloted a moderate-intensity exercise program which had previously resulted in improvements in fitness and physical functioning among early stage cancer patients. The study found that adherence to the intervention among metastatic breast cancer patients was less than anticipated, and that participation did not result in significant improvements in physical function. Our study highlights that interest in outdoor activities is low for patients in Singapore with advanced stage cancer compared to stage 1 cancer patients, and similarly reinforces the fact that activities that may be beneficial to patients at early stages may not necessarily be relevant or appropriate for patients at later stages.

Traveling can be a challenge for breast cancer patients, with obstacles ranging from difficulties in obtaining travel insurance to restrictions on receiving vaccinations during or immediately after chemotherapy. Cancer can also increase fatigue, risk of infection and sensitivity to the sun, which may all affect a holiday experience. Our findings suggest that – relative to the general population – intention to travel reduces substantially for Singaporean patients whose breast cancer is beyond stage 1.

Family life
Breast cancer can have a significant impact upon family life. Figure 4 shows the impact on a number of factors, including spousal relationships, time with family, appearance and sleep.

Figure 4. Impact on aspects of family life

It is well established that a breast cancer diagnosis can disrupt the lives of partners as well as patients. Our findings show that the impact of breast cancer is greatest among stage 4 patients and their partners.
in Singapore but that, conversely, patients with early stage disease appear to have fewer concerns about relationships than the general population.

The impact of breast cancer on family members, often family caregivers, is also widely recognized. Children can be significantly affected, with potentially negative changes in psychological health. Our findings reveal that patients with stages 1, 2 and 3 breast cancer spend less time with their family, potentially as a consequence of treatment appointments, or due to symptoms and side effects that prevent participation in family activities.

Changes in appearance can also have a significant impact on breast cancer patients, with concerns relating to hair loss, changes in breast appearance, scars and weight gain. Our analysis highlights that breast cancer’s impact on appearance is a concern for many patients in Singapore and that these concerns are stronger for patients with stage 3 or stage 4 cancer.

Sleeping problems are common among breast cancer patients. While insomnia in the context of early stage breast cancer is likely to differ from metastatic cancer, individuals at all stages may experience poor sleep, with prevalence estimates ranging from 38% to 61%. An investigation of metastatic patients in the US highlighted that 63% reported one or more types of sleep disturbance, and 37% reported using sleeping pills in the previous 30 days. Our results validate findings by indicating that patients in Singapore, particularly those at stage 4, are concerned with sleeping disorders. The disparity between their scores and the low score for stage 1 patients may relate to the unique effects that a later stage diagnosis may have on feelings of emotional distress that influence quality of sleep. It may also relate to medication, pain or other symptoms and side effects that affect patients’ sleep at these stages. Alternatively, it could result from the role of healthcare providers; for instance, if interventions to address sleeping problems are targeted mainly towards stage 1 patients, patients at later stages who receive insufficient support may be left to explore and address these issues themselves. Our findings highlight a need for open dialogue, particularly among clinicians and patients, to address the impact of breast cancer on sleep.

**Employment**

A breast cancer diagnosis can substantially impact a woman’s ability and desire to work. Some individuals decide not to return to employment, for instance due to the symptoms of cancer progression and ongoing therapies or as a result of changed priorities. However, many others do seek to return for a variety of reasons, including financial concerns or as a way to regain a sense of normality. A survey of women with metastatic breast cancer in the US found that nearly half (47%) of patients continued to work full- or part-time, while a recent study of metastatic cancer patients (including breast cancer patients) concluded that 35% of patients worked full- or part-time, although 58% reported some change in employment due to illness. Figure 5 shows how attitudes towards employment differ, when compared to the general population.

**Figure 5. Employment concerns**

<table>
<thead>
<tr>
<th>Concerned about job security</th>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Above average</td>
<td>9</td>
<td>4</td>
<td>-15</td>
<td>-19</td>
</tr>
<tr>
<td>Below average</td>
<td>-15</td>
<td>-10</td>
<td>9</td>
<td>-19</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Concerned about professional performance</th>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Above average</td>
<td>9</td>
<td>9</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>Below average</td>
<td>-15</td>
<td>-10</td>
<td>9</td>
<td>-19</td>
</tr>
</tbody>
</table>

* All calculated metrics are presented on a scale, with 0 representing the average score among the general Singaporean population.
Most breast cancer patients are less concerned about job security, although stage 3 patients are the exception. Further investigation is required to understand the reasons for this. However, patients across all stages appear to be more concerned about their professional performance, suggesting that there are ongoing concerns about the ability to work effectively. This suggests that enhanced workplace support for people living with cancer could be beneficial.

**Mental ill-health**

Rates of depression can be high among breast cancer patients, with international estimates of prevalence ranging from 8% to 24% in this population.\(^2\) Prevalence is especially high in patients with advanced cancer, although it often remains underdiagnosed and undertreated.\(^3\) Our analysis similarly illustrates that depression is a topic that is explored by breast cancer patients.

Stress appears to be a factor for patients with stages 2, 3 and 4 breast cancer — particularly stage 3 — although not stage 1. Further investigation is required to understand the reasons for this.

Anxiety is a well-known psychological response to breast cancer, relating to the emotional turmoil that diagnosis, prognosis, treatment and side effects can cause.\(^4\) Estimates of prevalence among breast cancer patients vary, with studies from Thailand and Malaysia reporting 16%\(^5\) and 32%,\(^6\) respectively. However, few studies focus on anxiety by cancer stage. Our analysis finds that anxiety is a topic commonly explored by patients at stages 1 and 2. Interestingly, although stress is pronounced among stage 3 and 4 patients, this is not the case for anxiety.

**Side effects and pain**

Treatment side effects are common among breast cancer patients, with a recent study highlighting that 45% of early stage breast cancer patients reported at least one toxicity that was severe.\(^7\) Research at a cancer center in Malaysia found that 83% and 79% of patients receiving chemotherapy experienced nausea and vomiting, respectively.\(^8\) Patients appear to highly value reductions in side effects associated with treatment, with a survey of metastatic breast cancer patients in the US concluding that women were willing to pay over $3,000 a year to avoid side effects such as diarrhea, risk of infection and nausea.\(^9\) However, our results suggest that treatment side effects are not necessarily a key focus among patients at stages 2, 3 and 4 in Singapore.

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* All calculated metrics are presented on a scale, with 0 representing the average score among the general Singaporean population.
This may be due to the fact that although patients are experiencing side effects at these stages, they assume that these are unavoidable, or may have received clear explanations from their healthcare providers and do not feel the need to educate themselves further.

Chronic pain affects 25% to 60% of patients who receive breast cancer treatment. While pain may not occur in early breast cancer, it often increases at later stages. Our analysis similarly finds that pain is a focus for patients in Singapore and that this is most pronounced for patients with stage 4 cancer. These findings can support the development of targeted information and services to address pain that is associated with breast cancer and its treatments.

2. Patient experience
Indicators of patient experience currently vary widely, but effective measurement can be useful to facilitate patient decision-making and drive improvements in service delivery. Our AI analysis highlights aspects of the healthcare experience that may be of particular interest to breast cancer patients.

Cancer information and support

It is unclear whether patients in Singapore regularly explore breast cancer research online, although a hospital-based survey found that many women could identify various key, basic facts about the disease. For instance, two-thirds (61%) of respondents were able to list at least one symptom of breast cancer correctly, and most (91%) were aware that early stage breast cancer can be curable. However, over a third (39%) of women believed they were immune to developing breast cancer in the absence of risk factors, and more than half (51%) thought that mastectomy was the only available treatment. Negative cultural beliefs regarding breast cancer also continue to exist in the country, which can result in misconceptions regarding the disease, as well as treatment. Our AI analysis indicates that while patients in Singapore appear to be interested in general cancer research at early stages, metastatic cancer patients demonstrate limited interest. Results highlight the need to provide information that is clear, relevant and presented in an appropriate format to ensure that all patients can be fully informed.

There is limited research on the use and effectiveness of support groups among Asian cancer patients. However, there is evidence to suggest that both face-to-face and online support groups can have a beneficial impact. Despite this, our results indicate that interest in support groups among early stage breast cancer patients is not significantly greater than the general population and is in fact lower among patients with advanced cancer. This suggests that more could be done to sign post patients to organizations such as the Breast Cancer Foundation and Singapore Cancer Society, which organize support groups and other programs for patients and their families.

Figure 8. Cancer information and support

* All calculated metrics are presented on a scale, with 0 representing the average score among the general Singaporean population.
Treatment considerations

Although patients will receive information on treatments from their clinicians, they will often supplement this with information found online. Figure 9 profiles the information-seeking behavior of patients according to stage of cancer and treatment.

Figure 9. Treatment considerations

<table>
<thead>
<tr>
<th></th>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lumpectomy</td>
<td>7</td>
<td>5</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>Mastectomy</td>
<td>15</td>
<td>4</td>
<td>13</td>
<td>2</td>
</tr>
<tr>
<td>Radiation therapy</td>
<td>25</td>
<td>-4</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>12</td>
<td>-5</td>
<td>13</td>
<td>11</td>
</tr>
<tr>
<td>Hormone therapy</td>
<td>8</td>
<td>-1</td>
<td>-9</td>
<td>5</td>
</tr>
<tr>
<td>Natural and alternative options</td>
<td>3</td>
<td>1</td>
<td>11</td>
<td>7</td>
</tr>
</tbody>
</table>

* All calculated metrics are presented on a scale, with 0 representing the average score among the general Singaporean population.

Most women with breast cancer at stages 1, 2 and 3 are treated with either breast-conserving surgery (lumpectomy) or mastectomy, while surgery is rarely a treatment option for stage 4 patients. Our analysis reflects this difference, indicating that women with stage 4 breast cancer are less interested in surgery compared to their counterparts at earlier stages.

Radiation therapy can be a potential treatment option for breast cancer patients in all stages, although may be used less frequently among stage 4 patients. As may be expected, patients at this stage in Singapore are not focused on this treatment. Stage 1 patients appear to be eager to explore this option, as with other types of treatments, and thus indicate that this patient population may be highly receptive of information on treatment options.

Chemotherapy can be used to treat both early stage and metastatic breast cancer. As may be expected, patients at most stages appear to be exploring this treatment online in Singapore. Interestingly, however, while chemotherapy is often recommended for women with stage 2 breast cancer before or after surgery, our AI analysis finds that stage 2 patients are not focused on this treatment.

Hormone therapy is also used to treat both early and metastatic breast cancer. Our analysis indicates that patients at stages 2 and 3 in Singapore demonstrate limited interest in this type of treatment. As with chemotherapy, this could be due to a number of reasons relating to physician decision-making or appropriateness of treatment for the type of cancer or patient profile.

The use of alternative treatments is common in Singapore; a study of breast cancer patients found that 35% of patients reported using Traditional Chinese Medicine, and the majority of these patients did not inform their clinician of their use of complementary medicine. Our data show that natural and alternative treatments may be considered by breast cancer patients as potential options, particularly those at stages 3 and 4. This highlights a need for open communication between providers and their patients to discuss treatments in order to be aware of potential drug interactions, or to better understand why patients may consider conventional therapy to be insufficient.

Access to care

Access to care is of paramount importance to breast cancer patients. Previous studies have explored barriers to physical access to cancer care, which include inconvenient appointment hours and long clinic waits, as well as variations in healthcare services and procedures. Studies have also uncovered access barriers to diagnosis and treatment among breast cancer patients with mobility impairments. Aspects of cancer services that facilitate access to care are highlighted in Figure 10.
Our findings highlight the features of services that patients are exploring online, illustrating that timely access to care through an effective appointment system and support to facilitate physical access are of particular importance to stage 4 patients. While the results do not conclude whether patients are having positive or negative experiences, they demonstrate that the design and availability of services that ensure a smooth and swift turnaround are crucial for patients at later stages.

Hospital services

Breast cancer patients can be associated with significant toxicities, which can result in visits to the Emergency Department (ED). A Canadian study found that at least one ED visit occurred in over half (53%) of patients with stages 1 - 3 breast cancer receiving curative chemotherapy, with 13% requiring hospital admission.115 Cancer stage was a statistically significant factor associated with probability of an ED visit, with higher stages associated with an increased likelihood. A study in the US focusing on acute care utilization during the last six months of life among women with metastatic breast cancer found that 69% visited the ED. For patients receiving chemotherapy, nearly half of ED visits occurred within seven days of chemotherapy administration.116

While there are significant differences between the Singaporean health system and those of other countries, which can result in different rates and patterns of ED visits, we can expect some level of ED attendance among patients in Singapore. Interestingly, however, our AI analysis highlights that there is relatively limited online activity around ED services in Singapore, particularly among breast cancer patients at stages 3 and 4. This may relate to patients being aware of the availability of emergency services through other sources and thus not exploring these options online to inform their decisions. Alternatively, patients at these stages may have clear contact points within the healthcare system that enable them to receive consistent care and negates the need for emergency services. Higher figures among patients at stages 1 and 2 may relate to a lack of familiarity with ED options. These results could be compared with actual health service utilization data to paint a clearer picture of which services may be of key interest to patients, and how patients make decisions regarding which services they access.

Outpatient visits are frequent among breast cancer patients, with frequency often highest during the first year following diagnosis.117 A US study found...
that metastatic breast cancer patients averaged 24.7 hospital outpatient visits from chemotherapy initiation to end of follow up.\textsuperscript{118} Our analysis paints a mixed picture among patients by cancer stage, with stage 4 patients highly interested in outpatient services but stage 3 patients demonstrating lower levels of interest.

3. Financial concerns
The financial strain of breast cancer on patients and their families can be considerable, impacting quality of life as well as patient experience. Although this financial burden is widely acknowledged, there has been limited research on financial insecurity among breast cancer patients in Singapore and their responses to address the costs of care. Our analysis provides insights into the financial experiences of patients relating to financial security and support, as well as insurance and cost concerns.

Financial security and support
While Singaporeans have access to various schemes to cover medical expenses, including personal Medisave accounts and health insurance plans such as MediShield Life, breast cancer can still pose a significant financial burden. A study of older cancer patients in Singapore found that while various financial schemes may be of assistance, most individuals required additional support to offset their out-of-pocket expenses, particularly for users of targeted therapies and those with poorer health status.\textsuperscript{119} Recognizing the financial challenges, organizations such as the Singapore Cancer Society offer various forms of assistance, including funding targeted towards low income patients, as well as children from families impacted by cancer.\textsuperscript{120} Figure 12 examines different aspects of financial security and support, by stage.

Despite the concerns outlined above, patients are less likely than the general population to explore cash advances or personal loans. The study cannot evaluate whether patients are seeking support, or receiving financial assistance, offline. Unlike patients at earlier stages, metastatic patients do appear to seek financial advice.

**Insurance and cost concerns**
Figure 13 examines the extent to which concerns with insurance are explored online.

Concerns with insurance coverage and treatment cost appear to be particularly pronounced amongst stage 1 patients in Singapore. However, for patients with more advanced stages of breast cancer, concern does not appear to be greater than in the general population and, for stage 3, is actually lower.
IMPLICATIONS OF AI PILOT FOR CANCER SERVICES

The findings from the pilot confirm many of the quality of life issues established in the research literature and reaffirm the importance of tailoring support and services to individual patients. Breast cancer patients are not a homogenous group, and encounter specific needs and challenges that are unique to each stage. Table 1 below sets out some examples of where targeted support may be required, according to stage of cancer.

Table 1. Priority support requirements according to stage of cancer

<table>
<thead>
<tr>
<th>EARLY STAGE (1 AND 2) BREAST CANCER</th>
<th>ADVANCED STAGE (3 AND 4) BREAST CANCER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advice on insurance and treatment costs</td>
<td>Advice about financial affairs</td>
</tr>
<tr>
<td>Information on Emergency Department</td>
<td>Information on outpatient appointments and logistics such as car parking</td>
</tr>
<tr>
<td>Enhanced information on side effects of treatment</td>
<td>Enhanced information on pain management</td>
</tr>
<tr>
<td></td>
<td>Support on managing family relationships</td>
</tr>
<tr>
<td></td>
<td>Support on managing sleep</td>
</tr>
</tbody>
</table>

Table 2. Common support requirements for all stages of breast cancer

- Improved support on depression, stress and anxiety
- Information on treatments appropriate to stage
- Information on breast cancer and patient support groups
- Enhanced workplace support
- Information on appropriate physical activity*
- Access to spiritual and religious support where this is requested

* Although this is not a common area of information-seeking activity for breast cancer patients, evidence suggests that it can be highly beneficial in early breast cancer and so the provision of information should be encouraged.

RECOMMENDATIONS FOR INFORMATION PROVIDERS

1. Findings uncovered through an AI platform, such as these, should be shared with patient organizations, as well as health services, who may wish to discuss potential applications for their work and prioritize enhancing information and support in the areas identified.

2. Where specific support requirements have been identified for different stages of cancer, information providers could consider using these findings to assess how best to improve the targeting and accessibility of their support.
Traditionally, patients have lacked the power to shape the services and treatments they use, or define their value. Tools such as advisory groups, PROMs, PREMs and focus groups can bring to light patients’ views and support a more inclusive and comprehensive assessment of value. It will become increasingly important to capture, analyze and apply patient insight in order to:

- Identify the improvements which will matter most to patients, targeting investment on areas of identified need or which are seen as priorities by patients
- Supplement other forms of intelligence about the quality and effectiveness of services
- Inform discussions about value in care and ensure that assessments to determine the availability of interventions and services are based on patient perspectives

At this stage, AI is an emerging technology that continues to be refined, and is not a substitute for other methods of gaining patient insight but rather a useful complement. Nevertheless, from a policy standpoint, AI offers a potential mechanism to gather data on patient perspectives to assess whether aspects of care with the highest value for patients have been prioritized. AI has the ability to cover entire populations, provide timely results, and uncover areas of importance that may not have previously been considered by policymakers and healthcare providers.

With the burden of cancer continuing to grow, there will be a need to focus resources on the issues which matter most to patients and which deliver the greatest value. It will be impossible to do this without timely and relevant patient insight. New technologies can play a major role in delivering this.

3. Health systems should work towards the routine collection of patient insights and consider how these findings inform the development of policy, recognizing the unique perspective and benefits that they can provide.

4. It is important that national cancer control plans set out how feedback and insight will be collected from cancer patients and used to improve services. Patient involvement is recommended at every stage of the development, implementation and monitoring of cancer control plans.

5. All forms of value assessment should routinely incorporate patient voice where possible, using feedback from patients and carers about the issues which they value as part of a broader assessment.

6. When developing plans to capture patient insight, policymakers may wish to consider the full range of techniques, including advisory groups, focus groups, PROMs and PREMs, as well as the potential for new technologies such as AI.

7. If and when AI is routinely used to collect patient insight, it will be important to establish clear protocols for flagging emerging issues to relevant stakeholders, including policymakers (identifying areas of success or challenge); hospitals and clinicians (learning from good practice and taking action to manage unmet need); charities (designing new support offers and maximizing the cost effectiveness of existing services); and regulators (incorporating feedback into pharmacovigilance).
IMPLICATIONS FOR SINGAPORE
As in many Asian countries, conversations about how to capture patient insights to inform the design of services and drive value-based cancer care in Singapore are in their infancy but growing. In the absence of established methodologies, there are opportunities to test new approaches such as AI without interfering with traditional methods.

We understand that the Singapore pilot described in this document is the first time in which AI has been used in this way. Given the high internet penetration in Singapore, as well as its position as a technology leader, there is an opportunity to establish a leading role on the use of AI and other technologies in gaining patient insight.

Refinement of the AI research methodology is ongoing, and can be further enhanced by involving breast cancer patients and clinicians in discussions that validate or challenge results, and identify additional areas of exploration. A focus on the patient journey, rather than cancer stage, may also bring to light any important changes in priorities that occur along the disease trajectory.

RECOMMENDATIONS FOR SINGAPORE
8. Payers and policymakers may wish to consider how they could build on the pilot to establish a leadership position on the use of advanced technology solutions such as AI in capturing and evaluating patient insight.
9. The Singaporean cancer community could now consider extending the breast cancer pilot to cover other forms of cancer.
10. Cancer stakeholders may wish to come together to consider the findings of the breast cancer pilot as well as to discuss the implications for services in Singapore and identify areas for further exploration.
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