Insights Series

Emotional care: the overlooked element in the cancer pathway

Integrated approaches with medical technology and digital tools to support patients and clinicians

A thought leadership paper on "Innovating personalized care"

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Preface

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Innovating

personalized care

Achieving

operational excellence

Transforming

the system of care
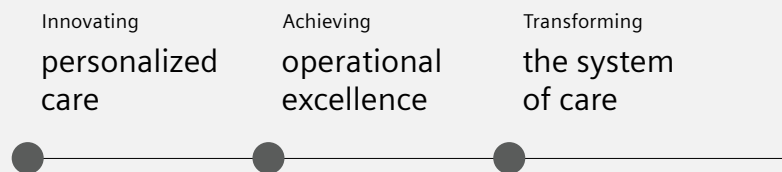
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Executive summary

Stress, anxiety and emotional distress are present along the entire cancer care pathway. These factors impact the efficiency of diagnosis and treatment, patient outcomes, time to recovery, and cost of care. But most important, they are significant burdens for the patient, as well as family, friends, clinicians and society. Interest in positive patient outcomes beyond survival is growing among people with cancer, and is increasingly of interest to clinicians as well as those who pay for cancer services. The mitigation of anxiety and depression needs, early identification, followed by effective interventions. Traditionally, this has been done by clinicians face-to-face with the individual patient. In current times, face-to-face consultations have been constrained with many interactions limited to digital interfaces. However, the most pressing challenge, now and in the future, remains the scarce time of clinicians. Those dealing with the backlog of cases do not have, usually, this additional time. Indeed there is the possibility that the "cancer backlog" in some countries might not be cleared until 2033 unless more healthcare professionals are hired.[1] Simply asking professionals to find additional time is fruitless. Other methods need to be tried and evaluated, for example digital methods and integrated approaches with medical technology.

The "Third Healthcare Revolution", refers to the revolution driven by individuals, digital and medical technology advances, and shared knowledge. This paper, based on a study we have implemented,[2] proposes an easily applicable approach for early detection of stress, anxiety, and emotional distress, along the entire cancer pathway, using digital resources in connection with medical technology. It proposes a systematic application of integrated therapies to improve clinical outcomes and the well-being of patients. It also highlights the collaboration of healthcare providers, the medical technology industry, individuals, the oncological disciplines of radiology, radiotherapy and chemotherapy that are required for this revolution for integrated care to become a reality globally.

Emotionally accompanying patients on the diagnosis and treatment phases of the cancer pathway can have a positive effect on the patient experience and contribute to greater efficiency of healthcare institutions.

The challenge

Present and future challenges related to cancer

+ 47%

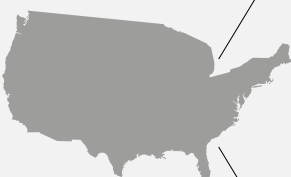expected increase of cancer cases by 2040 relative to 2020

50%-60%

of anxiety and depression goes unrecognized

€170 billion

Annual cost of mood disorders and anxiety in Europe

$110,650

is the avarage cost of treating a cancer patient in the U.S.

$235,337

is the avarage cost of treating a depressed cancer patient in the U.S.

Cancer rates, together with the related anxiety, stress, and depression continue to increase worldwide. The International Agency for Research on Cancer project projected 28.4 million new cancer cases worldwide by 2040, a 47% increase from the corresponding 19.3 million cases in 2020.[3] More than half of patients diagnosed with cancer suffer from moderate to high anxiety and depression, directly impacting the care experience and outcomes. It is estimated that between 50%-60% of anxiety and depression goes unrecognized[4], and 50% of major depressions are untreated.[5] For patients diagnosed with cancer, the cost of mood disorders and anxiety in the EU is about €170 billion per year, and in the U.S. the estimated costs of treating a depressed patient are more than twice as high as treating a non-depressed patient: $235,337 compared to $110,650.[6] Compared to individuals currently in the risk age of cancer, the problem is expected to worsen with Millennials and Generation Z, many of whom already feel generally anxious most of the time independent of a health problem.[7,8]

"The problem is expected to worsen further with Millennials and Generation Z, many of whom already feel generally anxious most of the time independent of a health problem."

Delmar N.
The Irish Times[8]

For many healthcare providers, anxiety and depression are difficult to detect; up to 80% of the psychological and psychiatric morbidity of patients with cancer goes unrecognized and untreated.[4] An additional challenge is stigmatization of the topic, misconception that anxiety is a problem not to be treated in the clinical environment, combined with a general resistance to integrate emotional relief along the care pathway. Anxiety and depression affect workflows in healthcare, for example, additional preparation time is needed, joint-decision making is hindered, and patient and staff engagement are reduced. Most healthcare systems manage patient anxiety and depression separately from the main oncology care pathway. Processes and technology have been focused on dealing with cancer detection and treatment, while psychological distress has not yet been fully integrated. All of these affects the evaluation of care and health outcomes, represents a significant burden for society and healthcare systems.

High anxiety associated with cancer risk can often become an issue during diagnostic imaging consultations, whether they are onsite or online, as well as during the recommended treatment programs. The patient who turns up anxious and uninformed for a consultation with a clinician, who in turn is overwhelmed by data and reports, may find it difficult even to express what is worrying them most, let alone remember what the clinician says. These issues may trigger a negative disposition from the patient, or even states of anxiety, or depression. Furthermore, in current times expecting clinicians to spend more time per patient is not a realistic option.[9] Further exploration of how emotional needs of patients and families affect key performance indicators can be found in the Siemens Healthineers Insights paper "Reframing patient experience".[10]

The "Third Healthcare Revolution", happening now, is propelled by three powerful drivers: information, digital and medical technology advances, and people. It has increased demand on personalization, providing access to care, and improving quality of care including emotional well-being. Considering the statistics previously mentioned, cancer pathways are first to be impacted.

80%

of the psychological and psychiatric morbidity of patients with cancer goes unrecognized and untreated

The solution

Patient experience along the cancer pathway is much more than just about the practicalities of the process. It is about the emotional response to the early concerns, magnified by the confirming diagnosis, leading to the decision-making and process of treatment. Each step generates a range of emotions and stress, for the individual, the caregiver, and the healthcare professionals in contact with the patient at each specific point along the pathway.

Measurement of patient outcomes has progressed from only measuring mortality to measuring a person's functional ability. The Karnofsky Scale or the ECOG Scale (Eastern Cooperative Oncology Group)[11], or patient-reported outcome measurements (PROM) provide a patient's perspective on quality of life. However, in order to create a holistic experience to reframe the cancer

patient pathway, it is necessary to detect and measure psychological and emotional distress as early as possible. Collecting information about the stress of screening or diagnosis or the burden of treatment could be made by healthcare professionals skilled in experience and distress recognition; however this requires additional dedicated clinician time. An alternative is for the process to be done digitally with intelligent systems and context analysis of, for example, self-reported reviews. In the future it could even be enhanced by integrating the digital potential of wearables, diagnostic or treatment medical technology interacting in real-time with the individual patient along the cancer pathway. Departments with a high level of medical and digital technology such as radiology, oncology, and radiotherapy, or where patients have frequent touchpoints throughout their pathway may play an important role in this regard.

Early identification of emotions and distress
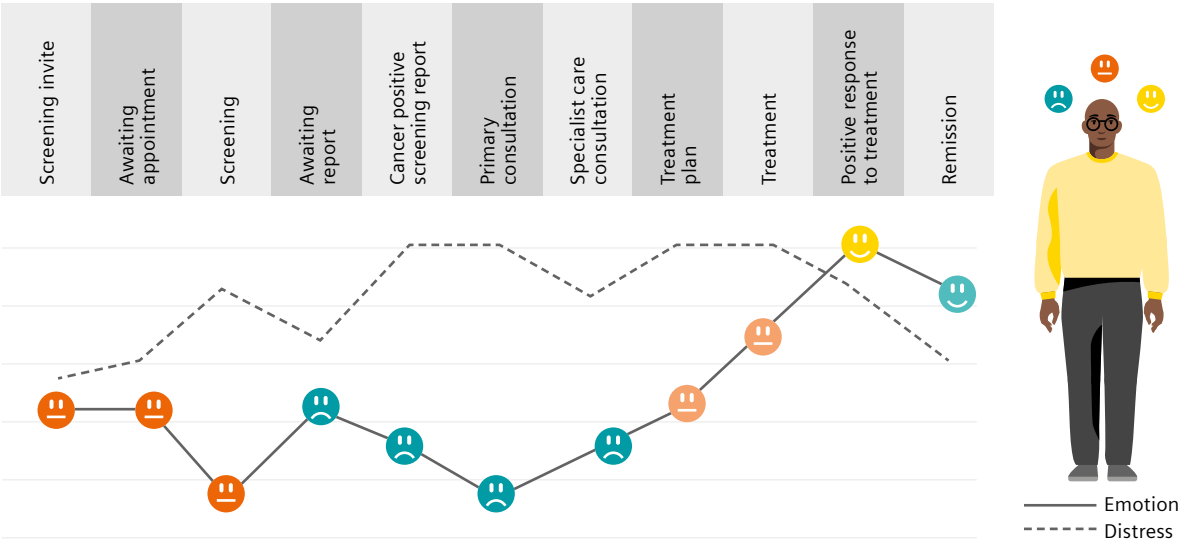
Emotion
Distress

New ways to obtain information about distress and anxiety with digital tools

In 2018, Siemens Healthineers and iWantGreatCare set out to explore the range of emotions experienced by patients (on breast and prostate cancer pathways), their partners and families, and their care teams, with the aim to identify the type of intervention which might help mitigate distress along the cancer pathway. This exploratory study was conducted to specifically examine the potential use of digital resources. Anonymized free text self-reported reviews of the healthcare service coupled with machine learning analysis were used to detect affective states and identify possible and actual points for anxiety and emotional distress in the breast and prostate cancer pathways. Breast cancer produced a total of 594 breast cancer reviews, clearly separated into 134 reviews for breast screening, and 460 reviews for breast cancer diagnosis; for prostate the total number of compliant reviews was 110. It was a first pilot with the vision to assess emotional distress and anxiety along the cancer pathway and define critical points for the patient experience.[2]
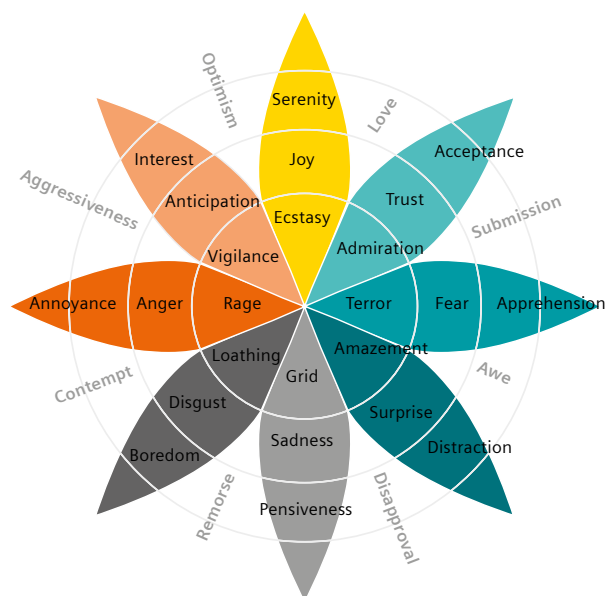
How to analyze the information of distress and anxiety?

Plutchik's psychoevolutionary model of emotions served to aggregate the data. This model is used in affective analysis and identifies eight basic emotions (trust, joy, fear, surprise, sadness, disgust, anger, anticipation) and secondary emotions e.g. optimism, submission, and aggressiveness. This model was used to consolidate affective states, rate intensity, and map the corresponding basic emotion for each stage of the cancer pathway.

Common across both cancer types and particularly in the initial stages of the pathways were: fear and apprehension, sadness alongside trust emerged shortly afterwards, clearly evident were anger and distraction. Serenity and vigilance appeared later in the various pathways. Overriding throughout the pathways, and according to Plutchik's secondary emotions, submission (trust and apprehension), awe, disapproval, remorse and love (trust and acceptance) were strong emotions felt by individuals, families, friends, partners, and healthcare professionals. Optimism featured as the lowest level of emotion, below aggression and contempt.

Plutchik's model
This psycho-evolutionary model of emotions can be used for aggregating and analyzing data of affective states in combination with distress analysis.

Furthermore, there is a high degree of alignment of sentiment analysis with qualitative studies and exploratory sessions with groups of patients. A Design Thinking workshop was undertaken in the Center for Radiotherapy in Freiburg (Zentrum für Strahlentherapie Freiburg) with patients in different stages of care to understand and optimize breast cancer patient needs during their entire pathway.[12] Various themes were confirmed and further explained, for example, strain levels are high and vary throughout the pathway. The patients' experience is about both: a medical experience and a 24/7 private life. During the medical encounters, the patient feels passive, without freedom of choice and control versus private life, where there is a demand to be very proactive on self-care. This impacts the levels of strain and anxiety.

Although a patient needs and gets a lot of information along the pathway—provided by someone or proactively gathered via digital media such as the internet—often it may be unrelated to the situation and inadequate to the individual situation, causing anxiety or reduced caution. Providing personalized information to the patient and family at a fitting moment in relation to the pathway and via the correct medium is a factor to reduce distress.
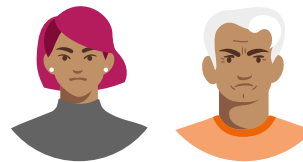
In general, early detection of distress, negative affect, anxiety or possible depression and appropriate mitigation is critical in the cancer pathway: treatment outcomes can be compromised, loss of motivation for self-care, damage social support, as well as, affect efficiency in healthcare systems.

Key findings for breast and prostate cancer patients

Factors in the clinical setting contributing to positive affect (emotion):

- Friendly, helpful and kind staff
- Being put at ease by staff
- Efficient service
- Professional attitudes

Factors in the clinical setting contributing to negative affect (emotion):

- Poor communication
- Waiting times
- Poor facilities
- Insufficient information
- Feeling anxious

"Early detection of distress, negative affect, anxiety or possible depression and appropriate mitigation is critical in the cancer pathway."

Isabel Nieto Alvarez, MSc
Senior Key Expert

A benefit for transparency and efficiency

The identification achieved in the breast and prostate cancer pathways of affective states aids the possible derivation points for anxiety and emotional distress. For example, it may be possible to anticipate stress and anxiety for individuals related to the medical equipment, before they face an unfriendly or intimidating diagnostic, radiotherapy planning or treatment procedure.

Early detection of distress or anxiety has been an important element of clinical practice for centuries. During face-to-face consultation, such detection has been relatively straightforward. During the pandemic, with much doctor-patient communication taking place through digital channels and platforms, making these observations becomes more challenging. Connecting with patients empathetically, while being efficient and establishing trust remains essential for clinicians, as described in the Siemens Healthineers Insights paper "Strengthening patient trust".[13] However, picking up clues through digital consultations as to the patients' level of anxiety, emotional distress, or if they are feeling overwhelmed requires a different approach.

Imagine

In the future, medical technology such as diagnostic imaging and radiotherapy equipment may provide additional physiological measures for identification of stress, negative affective states and distress management.

As the current paper proposes, it is increasingly feasible to use digital methods, especially via self-reported free text analysis, data analysis and data modeling, to collect and identify anxiety and affective states. In the future, the potential offered by interaction with wearables, and medical technology such as diagnostic imaging and radiotherapy equipment may provide additional physiological measures for identification of stress, negative affective states and distress management.

A vision for the future

Technological solutions could, in the future, help identify early-stage stress and emotional burdens. Identifying these burdens and anxieties as early as possible is essential, and digital tools -for example, wearables- can make it much easier for caregivers to provide information to patients and monitor aspects such as physical exercise or mindfulness practice. Data gathered from patients can also be integrated into subsequent treatment or diagnostic appointments, providing a fuller picture of the patient's activities, stress levels and emotions. Opportunities to better assist patients with the non-clinical aspects of cancer can also be enhanced through intelligent systems that improve access to nurses or other experts. These types of systems can lead to patients receiving more personalized decisions and advice at precisely the right point along their own cancer pathway.

Although the need for face-to-face interaction with a psychologist or psychiatrist will continue to be of great importance, the opportunity for digital-enabled solutions for people less severely affected would improve access to this type of care. An important factor in moderating stress, negative affect, depression and anxiety are mindfulness and an early assessment of an individuals' physical activity levels.[14,15] In the future, it would be easy to assign mindfulness groups to help cope with anxiety and depression or provide training programs for relaxation techniques to be practiced during the stages of diagnosis or treatment. In the last five years there have been many systematic reviews on the benefits of exercise for people with breast cancer, the knowledge needs to be put into practice. The benefits of tailored exercise, prescribed by a health professional who specializes in the prescription and delivery of exercise, combined with appropriate support and encouragement

Imagine future intelligent systems

Intelligent systems could connect to nurses, or experts to aid with the non-clinical aspects of cancer, and personalizing information for diverse populations, and for the appropriate moment in the cancer pathway.

early in the respective cancer pathway can improve outcomes. Such a practice could be extended for the family, friends or partners, or even healthcare professionals' as part of the social support of the individual. Once the activity profile is established, interconnection with medical equipment could provide a more systematic delivery and monitoring of activity. The diagnostic and radiotherapy departments for example could integrate imaging and laboratory results on progression, observe both physical and mental progress in the exercise programs along the care pathway, and any resulting changes to the receptivity of treatment.

With the "Third Healthcare Revolution" the traditional model of care, the old approach of referral from one professional to another, face-to-face communication between each healthcare provider and the person with cancer is to be supplemented, complemented, and enriched by digital means and innovative medical technology—personalized and provided at the right moment along the care pathway.

"The latest healthcare revolution, propelled by three powerful drivers: citizens, knowledge, and technology including digitalization, is focused on extending healthy life expectancy and centered around physical and emotional well-being."
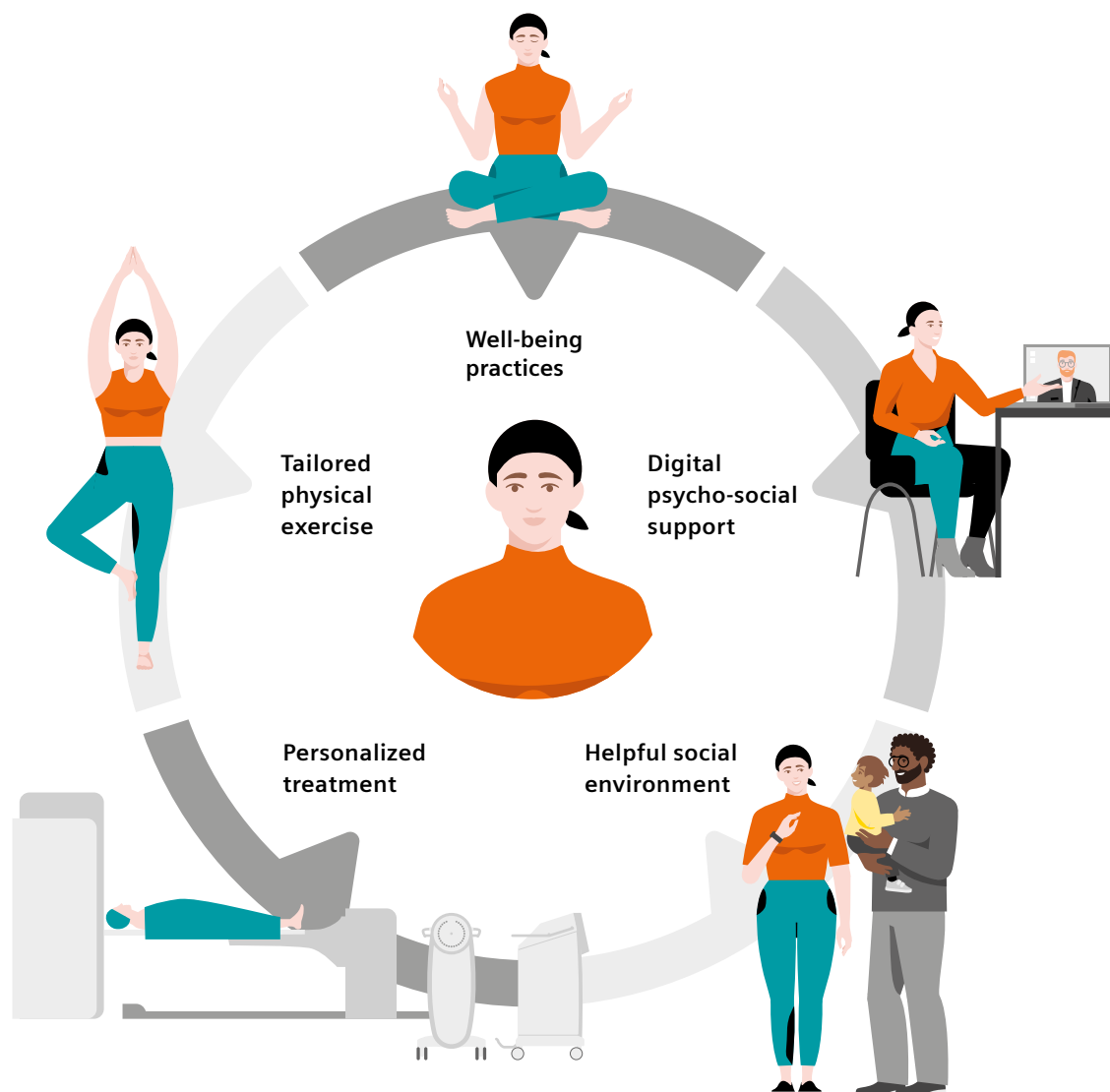
Sir Muir Gray, CBE, MD
Executive Director of the Oxford Centre for Triple Value Healthcare

Integrative management of stress, anxiety and the emotional burden

Innovative future technologies may present opportunities to physically sense and identify early-stage stress and emotional burdens. Information could be integrated in the encounters a person has for diagnostic or treatment interventions, as these moments are opportunities to engage and help maintain progression and stability along the entire pathway.

Well-being practices

Tailored physical exercise

Digital psycho-social support

Personalized treatment

Helpful social environment

Conclusion

Emotionally accompanying the patients along their cancer pathway is a "must" in order to have a positive effect on the recovery and enhance the overall efficiency of healthcare institutions.

This paper has identified ways to make the emotional side of patients relevant as a separate module in the recovery and treatment phases, and has proposed a first-of-its kind approach for early detection of emotional distress with digital resources and medical technology. Furthermore, this paper provides practical approaches to ease emotions in patients' cancer pathway through the systematic application of integrative interventions to mitigate distress and consequently improving clinical and patient-reported outcomes, for example reported depression.

Whilst we continuously engage in finding cures and the means of prevention for cancer patients, the recent revolutionary advances in healthcare offer a huge potential for improving not only survivorship and service satisfaction, but also the patients' well-being.

Emotionally accompany patients and families along the cancer pathway.

Improve early detection of emotional distress with innovative approaches e.g. digital resources and medical technology.

Implement integrated interventions to mitigate distress during diagnosis, recovery and treatment phases of cancer.

Improve clinical and patient-reported outcomes.

Enhance the overall efficiency of healthcare institutions.

ℹ Information:

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Christina Triantafyllou, Ph.D. is Siemens Healthineers' Global Head of Improving Patient Experience, where she explores ways in which this field can be enhanced and made more accessible to healthcare providers. She develops strategic approaches to deliver high value care, by providing patient experience focused solutions, best practices and thought leadership content. Christina began her healthcare career at Harvard Medical School, Boston, where she worked as a medical physicist developing imaging technology for the study of brain anatomy and function in disease. At Siemens Healthineers, she served as the Director of Global Ultra High Field MR Solutions, focusing on business strategy, KOL-based collaborations in innovation/clinical translation, and product management for the first worldwide clinical 7T MR system. Christina holds a Ph.D. in Medical Physics from Kings College, University of London, UK. Prior to joining Siemens Healthineers, she held appointments at Harvard Medical School, and at Massachusetts Institute of Technology in Boston.

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Isabel Nieto Alvarez, MSc. is passionate about innovating and transforming the experience of care to be human centered. She is an expert of the Siemens Healthineers Global Innovation Network on mental and physical stressors in the experience of care. Isabel leads cross-functional teams in innovative projects on patient experience. Prior to her current role, she has served as a marketing manager and business developer for the company, and as Professor at the Universidad Anáhuac, México focused on sustainability in healthcare for medical students and psychology. Passionate about improving the patient and care team experience, she presents and writes globally on the subject. She is a biomedical engineer from Universidad Iberoamericana in Mexico, holds a Master in Science on Mind and Body Medicine from Saybrook University in California, U.S. and Certifications on Leadership in Healthcare without Harm and Design Thinking. Her scientific background on mind and body health and neuroscience, combined with experience in medical technology innovation are cornerstones of her expertise and passion.

Sir Muir Gray, CBE, MD
Executive Director of the Oxford Centre for
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Sir Muir Gray has worked in the Public Health Service in England since 1972. He is a physician and professor who has held senior positions in screening, public health, information management, and value in healthcare. Muir Gray is now working with both NHS England and Public Health England to bring about a transformation of care with the aim of increasing value for both populations and individuals and provides oversight as Chief Knowledge Officer for iWantGreatCare. He has published a series of How To Handbooks for example, How To Get Better Value Healthcare, How To Build Healthcare Systems and How To Create the Right Healthcare Culture. Muir's work focuses on providing training to healthcare professionals on value-based healthcare. He received a CBE in 2000 and was knighted in 2005 for services to the National Health Service. Sir Muir is an internationally renowned authority on healthcare systems and has advised governments of several countries outside the UK including Australia, New Zealand, Italy, Spain and Germany.

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Built on a history of innovation going back more than 125 years and with unique strengths in patient twinning, precision therapy, as well as digital, data, and artificial intelligence (AI), we are well positioned to take on the biggest challenges in healthcare. We will continue to build on these strengths to help fight the world's most threatening diseases, improving the quality of outcomes, and enabling access to care.

As a leader in the industry, we aspire to create better outcomes and experiences for patients no matter where they live or what health issues they are facing. We innovate sustainably to develop scalable solutions that can be tailored to the needs of healthcare providers, and the local health infrastructures.

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