



Personalised Cancer Care in the Eastern Mediterranean Region

Position Paper

October 2022

Prepared by



**Personalised
Cancer Care
Alliance**

Contents

Contents

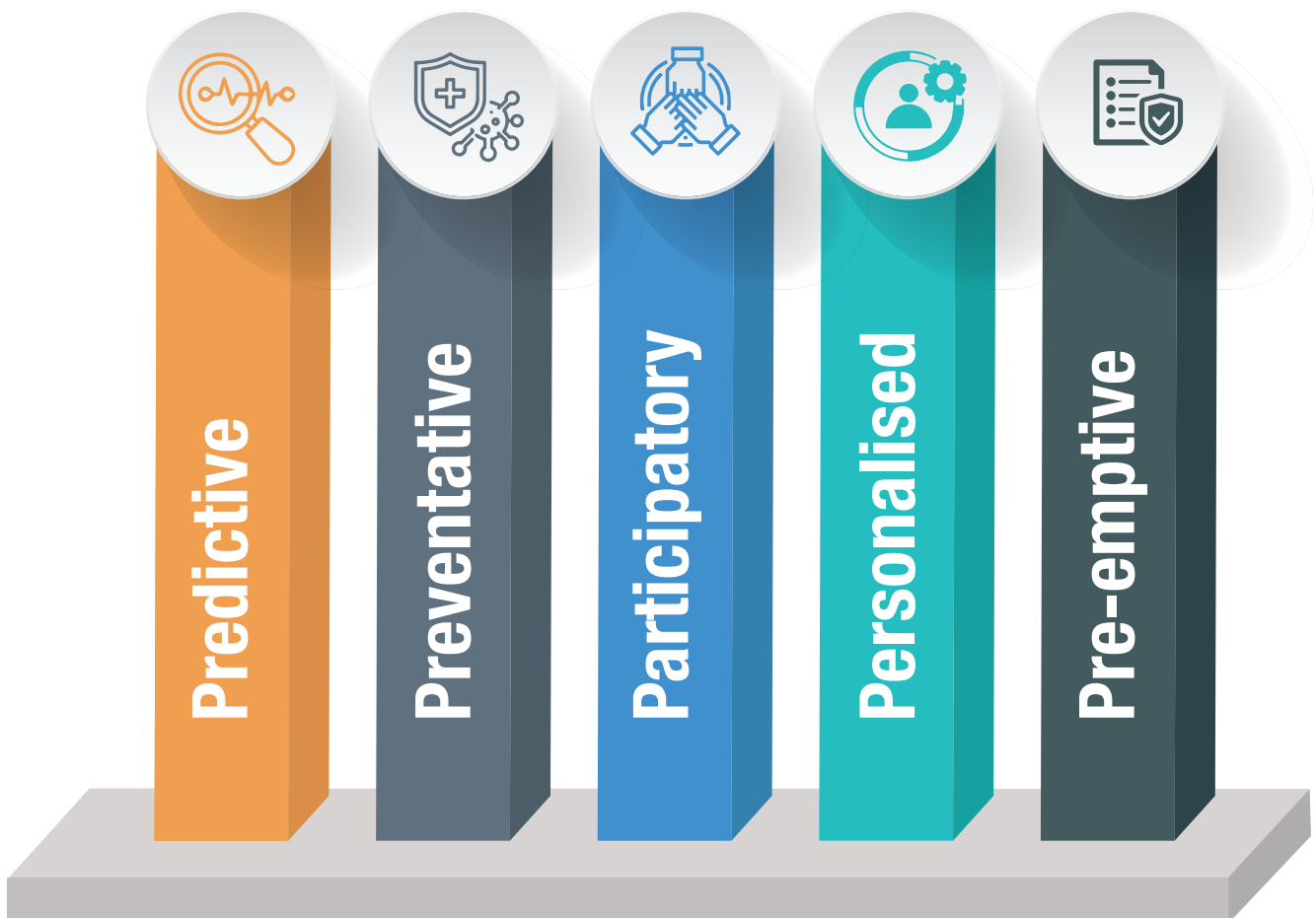
1. Introduction & Background	03
2. The Five P's and Cancer	04
3. Personalised Cancer Care Alliance	06
4. PCC in the Eastern Mediterranean Region	08
5. Current situation in regards to PCC in the EMR	09
6. Specialist Thought Pieces	10
7. Our Region "Unity in Diversity"	16
8. Recommendations	17
9. Conclusion	28
10. About	29

Introduction & Background

Personalised cancer care (PCC) aims to give the right treatment to the right patient at the right time. This gives us better outcomes and patient safety, particularly reduced risk of adverse events.

We now have health technologies (like, PCC) at our disposal that can help our health systems to become predictive, preventative, participatory, personalised, and pre-emptive (Five P's)

“Innovations in PCC have the potential to change not only the way patients receive care, but also their quality of life. It's the **FUTURE** of cancer care.”



The Five P's

The Five P's and Cancer

Predictive

The health ecosystem, including patient organizations, can very early go on to identify individuals and sections of the population who may develop cancers and other diseases. This helps segregate at risk populations and prioritise services for them accordingly. National Cancer Control Plans can be fine-tuned to population's needs. **To be predictive you need high quality screening, cancer data collection, and analysis.**

Preventative

In a forewarned position, the segregated high-risk patients can then be monitored and treated to prevent onset of disease at a very early stage in their life. Cancers diagnosed at Stages I and II have far better outcomes than those diagnosed at Stage III and IV. **Member States (MS) need extensive health promotion and health education programmes to be preventative orientated.**

Participatory

Patient co-creation and co-development is important in ensuring our health systems are effective, efficient, and delivering value for money.

Patient insight, experience and voice **MUST** be used to incorporate patient preferences into a full spectrum of essential, quality health services, from health promotion to prevention, early detection (screening), treatment, rehabilitation, palliative care and survivorship across the continuum of care.

Personalised

We can diagnose the right patient and treat them with the right treatment, at the right time, at the right locations, and make the experience as good as possible for them. This yields the right outcomes desired.

Personalised cancer care or precision oncology “when integrated with digital health strategies” has a great potential to address many of the failing in current cancer control and treatment protocols.

Pre-emptive

By being pre-emptive, health systems address a situation before it becomes worse. At an individual level, upon discovering that she has BRAC 1 gene, Hollywood actress Angelina Jolie was pre-emptive and underwent a double mastectomy to reduce her chances of getting breast cancer.

Pre-emptive means building back better now.

The Five P's and Cancer

The Five P's Can

- Improve patient health outcomes, patient experience, matching patient preferences
- Support our health systems becoming effective, efficient, safe, acceptable, and accessible whilst delivering quality healthcare in a compassionate and humanistic way.

Personalised Cancer Care have their greatest application in cancer control and care. We can transform and personalise the way in which, and how fast, cancer is detected, diagnosed, and treated without disrupting lives and their families.

From **the perspective of the State**, health economics and the health system, PCC helps us reduce unnecessary treatments and their direct and associated cost (This saves the system and the economy direct costs (medicines, hospital costs, surgeon, and health professional time) and it also saves the indirect costs like sick pay, loss of income tax, disruption etc.)

From **patients' perspective**, this helps patients to be on the right “Personalised” treatment. Further, **from the healthcare system perspective**, PCC gives us more control and certainty on the resource allocation and use “but also allows us” to maximise treatment outcomes within our populations. **When aggregated, all these effects improve the sustainability and efficiency of healthcare.**

Reference:

Jennifer Gill; Anna-Maria Fontrier; Aurelio Miracolo and Panos Kanavos (2020). 'Access to Personalised Oncology in Europe', London School of Economics <https://doi.org/10.21953/5zsbeehvd3u8>

Personalised Cancer Care Alliance

At the 2021 World Health Assembly, the International Alliance of Patients' Organizations (IAPO) made a statement supporting that patients in lower- and middle-income countries must have access to Primary Healthcare, Liquid Biopsies, Biomarkers, and general genomic based health technologies. (Statement WHA74)

In a bid to operationalising this, IAPO set up the Personalised Cancer Care Alliance (PCCA) in 2022 with the support from PhRMA MEA. The Alliance is an initiative to build back better cancer services post-COVID-19, and promote fast track regulatory and health technology assessment pathways to Primary Healthcare, Liquid Biopsies, Biomarkers so that patients can have improved access to innovative cancer medicines and personalised healthcare. This access will go partway into reducing waiting lists and in alleviating patient anxiety and concern due to suspended cancer diagnostic, treatment, and other care services.

“

One size fits all cancer care is not serving the patient or society well. We now must look at alternatives. We can now offer services and treatments that are 'genomic informed' and individualised to the patient, based on the patient's own genetics, their metabolic profile, environment, and habits.

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Personalised Cancer Care Alliance

PCCA is an alliance of cancer patients, carers, and representatives of patient organizations from the Middle East & North and Sub-Saharan Africa created to advance health literacy in cancer, advocacy skills and education on personalised cancer care.

It was set up because we now know that not all patients are the same, and not all cancers are the same, nor are all treatments the same.

Personalised Cancer Care Alliance

During 2022, the Personalised Cancer Care Alliance started its work with the aim to produce this position paper to advocate PCC and access to it. Working with regional leaders in patient advocacy, oncology, science and many more, the PCCA efforts in 2022 can be summarized as:

- A regional Delphi's assessment of the situation on cancer care and health technologies available in the region
- A series of webinars (total of 4) all links are available below
- A regional consultation

The work of the PCCA is bridging the efforts between Sustainable Development Goals (SDG) Goal 3, SDG Goal 5, SDG Goal 9 and SDG Goal 17.

This position paper is using the Five P's Framework to arrange the various recommendations and discussions we had during the webinars and consultations. The Five P's approach help the patient advocates, health system managers, the State policy makers, and the frontline clinical team leaders to advocate for personalised cancer care with authority and in a systematic and systemic way.

This position paper will have a ranked policy recommendation matrix, case studies and specialist thought pieces.



Webinar 1	Webinar 2	Webinar 3	Webinar 4
Cancer Burden and Cancer Control Plans in the Middle East & North and Sub-Saharan Africa	Innovation just for you: How Can Personalised Cancer Care Improve Diagnosis, Treatment, Care and Outcomes?	Access to Personalised Cancer Care Innovation	WHO EMRO Position Paper Planning
Link for Webinar 1	Link for Webinar 2	Link for Webinar 3	Link for Webinar 4

PCC in the Eastern Mediterranean Region

In their publication “Early detection of cancers common in the Eastern Mediterranean Region” (2017), the WHO Regional Office for the Eastern Mediterranean (WHO EMRO) indicates that:

An important component of cancer control is the early detection of major types of cancer that benefit from effective treatment. Early detection of cancer aims to detect the disease in its early stages when treatment is simple and affordable, resulting in higher cure rates. Early detection is an umbrella term consisting of two main strategies – early diagnosis and screening. Early diagnosis is universally applicable across all countries, whereas screening programmes require substantial investment and a solid healthcare infrastructure.

WHO EMRO has recommended specific policies calling for the implementation of an early detection programme to detect breast cancer, cervical cancer (elimination strategy) and colorectal cancer in women. This is because the precancerous lesions at this early stage are small and localized and treating them reduces the mortality from breast, cervical and colorectal cancers.

The PCC/PO approach has helped detect cancers early and accurately. We can coproduce better cancer care treatment plans with better outcomes with the patients and their carers.

IAPO and the Personalised Cancer Care Alliance held various webinars and consultations from spring to autumn 2022 about Personalised Cancer Care and what it means to patients in WHO’s Eastern Mediterranean Region.

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Cancers that have responded well to personalised cancer care approaches using precision oncology methods have been breast, colon, and lung cancers. We have had very good outcomes here.

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Reference: Krzyszczyk P, Acevedo A, Davidoff EJ, Timmins LM, Marrero-Berrios I, Patel M, White C, Lowe C, Sherba JJ, Hartmanshenn C, O’Neill KM, Balter ML, Fritz ZR, Androulakis IP, Schloss RS, Yarmush ML. The growing role of precision and personalized medicine for cancer treatment. *Technology (Singapore)*. 2018 Sep-Dec;6(3-4):79-100. doi: 10.1142/S2339547818300020. Epub 2019 Jan 11. PMID: 30713991; PMCID: PMC6352312. <https://pubmed.ncbi.nlm.nih.gov/30713991/>

Current situation in regards to PCC in the EMR

The Personalised Cancer Care Alliance now wants WHO Eastern Mediterranean Region's Member States to come together in regional solidarity and national unity and COLLECTIVELY invest in PCC health technologies to boost the health and economic development of their populations in the region. It's a call to build back a better post-pandemic WHO in the EM Region.

Currently there is no publication by the WHO mentioning or highlighting Personalised Cancer Care

EPIDEMIOLOGY

Reference for 5 first points:
WHO Health statistics and information systems:
https://www.who.int/healthinfo/global_burden_disease/projections/en/

With the current WHO EMRO epidemiological data, we can compare with other WHO regions that while the incidence of some cancers is low in EMR, the mortality however can be high when compared to other regions.

Inter and intra-regional epidemiology reveals EMR has anomalies of incidence, morbidity, and mortality in the Member States of the region

Cancer is now 4th largest cause for premature death in EMR

Incidence rate to double in EMR in next two decades

EMR has the second highest incidence case in all WHO regions

There are big access barriers, delays, and disparities in EMR specifically big barriers of access to new treatments because of regulatory or poor Health Technology Assessment (HTA). These prevent use of effective medicines in eligible patients.

Specialist Thought Pieces

Biomarkers and future of Cancer Control in the EMR region



Dr Asif Quadri, MD

Consultant Anatomical Pathologist

National Reference Laboratory/Cleveland Clinic Abu Dhabi

United Arab Emirates

The rapid and vast advancement in our knowledge about cancer and the different genes orchestrating its biology, along with the linked explosion in developing molecules and techniques which destroy or detect cancers cells and/or the drivers, has been second to none. Taking breast cancer as an example, 20 years ago when I started to practice, we cared about Estrogen Receptor (ER) status, then human epidermal growth factor receptor 2 (HER2) status, eventually low ER and now even low Her2 and Homologous recombination deficiency (HRD) tumors and who knows what next....allowing treatment of subsets of breast cancers differently leading to better patient outcomes.

This treasure of knowledge and valuable science has provided us all - human beings, healthcare workers, organizations, and policy makers, with an amazing opportunity to work all together. The one goal would be to make all these diagnostic techniques, biomarkers, therapies and, most importantly, experiences available and affordable to share between us human beings. The fruit will be early detection, better survival, and much improved quality of life for all cancer patients.

“

Biomarker diagnostic technologies are one promising opportunity that allows early diagnosis and detection of recurrence of cancers, making late diagnosis of cancer and its inappropriate treatment a thing of the past

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Specialist Thought Pieces

Patients organizations commitment towards a 5P's cancer healthcare ecosystem



Kawaldip Sehmi

CEO

International Alliance of Patients' Organizations
United Kingdom

My commitment towards a Five P's cancer care health ecosystem that is predictive, preventative, participatory, personalised, and pre-emptive is not just a theoretical or an ideological commitment: It is born out of personal experience as a colorectal patient.

Not having the Five Ps resulted in the late diagnosis and treatment of my colorectal cancer. I had to endure an abdominoperineal resection (APR) that completely removed the distal colon, rectum, and anal sphincter complex using both anterior abdominal and perineal incisions, resulting in me having a permanent colostomy. Had I had the Five Ps, especially the biomarkers, liquid biopsies and early preventative screening, my colorectal cancer would have been diagnosed and treated earlier using the most effective health technologies without me needing the APR.

I joined the Personalised Cancer Care Alliance (PCCA) as a patient and as the CEO of the International Alliance of Patients' Organizations.

We are at a pivotal moment in healthcare history in WHO EM Region. An unprecedented convergence of medical knowledge (genomics), health technology and data science are revolutionising cancer care. The Personalised Cancer Care Alliance hopes to be spearheading the next generation of patient co-produced healthcare with partners around the globe. PCCA hopes that by bringing together a unique understanding of human biology with new ways to analyse health data, our vision to ensure that the screening, diagnosis, prevention, treatment and care cancer will become more faster, effective and efficient and transform the lives of people everywhere in the WHO EM Region- ensuring the right treatment for the right patient at the right time.

Five P's offer an opportunity to have better outcomes and patient experience, whilst ensuring health systems become clinically and economically effective and efficient: improving patient outcomes and experience.

With the 75th anniversary of the WHO Constitution coming in 2023 (it came into force on 7th Apr 1948), I am deeply committed the Right to Health in cancer care is promoted, protected,

Personalised Cancer Care Alliance

Specialist Thought Pieces

and fulfilled by all Member States and Stakeholders.

The WHO constitution says that health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. It then adds that the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.

The Five Ps approach can support and frame the delivery of this Right to Health and ensure the whole of government, whole of society and the whole of the patient community can respect, protect, promote, and fulfil the right to health in cancer care throughout their health systems by ensuring innovative cancer care is:

- Available
- Accessible by being
 - Non-Discriminatory
 - Physical Accessible
 - Economically Accessible (Affordable and UHC 2030)
 - Patient and people centred having information that is accessible
- Acceptable (patient and people centred)
- Quality and safe

The countries in the Gulf Co-operation Council (GCC) can work with the huge genomic medicine and digital health hubs developing in Egypt and Morocco to pull up the rest of the region and ensure that universal health coverage in WHO EM Region is based on the firm foundations of the Five Ps. I would like to see the Right to Cancer Care is respected, protected, promoted, and fulfilled in all WHO EM Region Member States.

“

Having family and friends in the WHO Eastern Mediterranean Region and having lived in and visited many of the Member States, I believe that WHO EM Region is a pivotal moment and transiting from being a net recipient of health technologies to that of a net exporter of home-grown of health innovation to the world in genomic medicine and digital health related health technologies.

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Specialist Thought Pieces

Patients and their families - The important stakeholder



HE Dr. Wahid Ali Al Kharusi FRCS

President

Oman Cancer Association

Cancer patients and their families must be at the epicenter of the holistic approach to cancer prevention and control, especially in personalised cancer care (PCC). The Middle East and North Africa (MENA) region faces a diverse set of challenges with a unique multiethnic, multicultural genetic pool, wealth disparity and geopolitical instability and uncertainty to name a few. These unique realities demand innovative approaches to realize sustainable Personalised cancer care. Cancer patients themselves and their caregivers and advocates urgently need to be trained and empowered with a view to affording them ownership of the program in order to ensure their successful and effective contribution to the success of PCC in their respective localities.

Genetic profiling is the essential provision of the PCC. For those who cannot afford this facility they need support within the region. Personalised Cancer care is not only the best for the patients and their families but it supports reintegration of the cancer patients within the society with positive socio-economic benefits. Frontier technologies should be employed towards this effort and artificial intelligence (AI) utilized as an integral supportive component of PCC programs and schemes. The International Cancer Prevention Consortium (ICPC) is supportive to overcome these challenges.

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Cancer patients and their families must be the epicenter of the holistic approach to cancer prevention and control, especially in Personalised Cancer Care.

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Specialist Thought Pieces

Undersanding cancer risk through genetics



Eitan Friedman MD PhD

Professor of Medicine and Genetics, School of Medicine
Tel-Aviv University

Founder the Oncogenetics service and the Meirav High risk clinic
Sheba Medical Center, Tel-Hashomer, Israel Head

The Ministry of Health Ethics committee for genetic studies
Tel-Aviv, Israel

A pivotal and clinically significant breakthrough over the past two decades is the ability to stratify the population by their cancer risk, in a more objective, genetically driven manner. Firstly, the generation of polygenic risk scores (PRS) that can be applied to the average risk population in order to define high risk individuals and target these for a more enhanced earlier age surveillance scheme. For example, individuals deemed high risk for colorectal cancer should be offered colonoscopies from age 30-40 at 3-5 year intervals. However, the specific SNPs used to generate the PRS have only been based on Caucasian, mostly North European and American population. A PRS. An urgent and unmet need is to validate and redefine the specific SNPs in the Middle east region that may differ from the currently used PRS. Another innovative aspect that affects the ability to genetically define cancer risk is the ability to detect pathogenic sequence variants (PSV) in single genes that dramatically affect the lifetime risk for developing cancer: a female BRCA1 PSV carrier has a X6 risk and X25 risk for developing breast and ovarian cancer, respectively compared with the general population. Consequently, an early detection scheme and/or risk reducing surgery can be offered to asymptomatic PSV carriers. The spectrum of PSVs in cancer susceptibility genes has yet to be defined in the under studied populations in the Middle East. Moreover, extrapolating from the experience in other ethnically homogeneous populations a small subset of PSVs maybe defined that opens the door to possible population screens. Thus, from the perspective of oncogenetics, redefining the applicability of PRS as well as determining the spectrum of PSV in cancer susceptibility genes defining the penetrance of recurring possibly founder PSVs and subsequent populational genetic screens along with establishing a high risk follow up clinics seem to be urgent and possibly life saving for the middle eastern population.

Specialist Thought Pieces

Digitally enabled Personalised Cancer Care



Dr. Elfatih Abdelraheem

Director, Expert in digital health

United Kingdom

The Personalized Cancer Care success depends on a proper and excellent communication and transfer of data, bio-samples and other documentation across a complex ecosystem. The ecosystem starts from the patient, samples transportation, hospital, lab, manufacturing facility, and then transportation back to the patient. To ensure proper collaboration between the various stakeholders and nodes in this complex ecosystem, a digital system with full data security that can track and trace samples and treatment and include full traceability features that provide information of the environmental conditions (temperature and humidity), location and custodian identity will be required. Such system should also include a dashboard and alert system to direct the attention of the stakeholders should the environmental conditions change while being transferred and/or stored (sudden change in temperature beyond the required margins for viability of the sample or treatment). The diagram below demonstrates the ecosystem and integrated digital approach required.

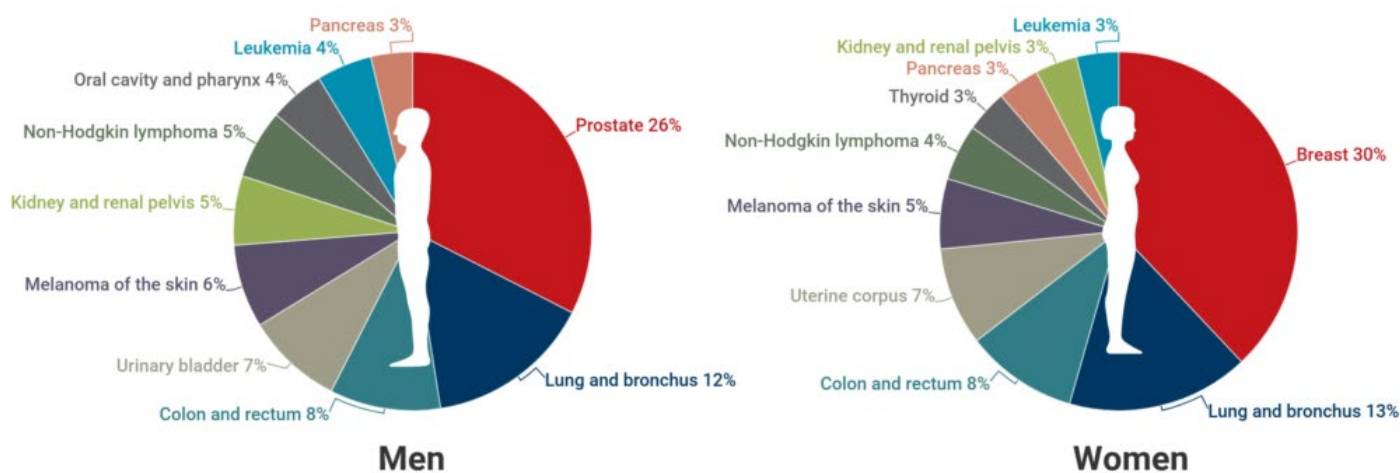
It is recommended to use a blockchain platform for such digital system, as the key features of blockchain (encrypted security, immutability and interoperability) allows the greater collaboration without jeopardizing patient's identity or privacy. It also allows interoperability with Internet of Things (IOT) such as temperature and humidity sensors which will ensure viability of samples throughout the ecosystem.

It is strongly recommended that that Member States regulators should establish and control blockchain based digital systems to ensure compliance with data security, viability of samples and interoperability.

Our Region “Unity in Diversity”

The WHO Regional Office for the Eastern Mediterranean (WHO EMRO) has indicated that the growing impact of the cancer burden in the EMR region is very high, and it now necessitates implementation of suitable and effective cancer control policies and health technologies quickly.

The urgency of this call to action is heightened in the case of breast, colorectal and lung cancers as these are now the most common cancers in all Member States of the EMR, and their burden and impact is growing even faster.



Cancer incidence in the EMR region

Reference: <https://www.cancertherapyadvisor.com/home/cancer-topics/general-oncology/american-cancer-society-2021-statistics-show-continuous-decline/>

The WHO EMRO comprises 22 heterogeneous Member States in the Middle East and North Africa, with a total population of around 730 million. This position paper has used WHO EMRO reports to group the 22 members into 3 main groups:

Group A	Group B	Group C
High-income countries (Bahrain, Kuwait, Oman, Qatar, Saudi Arabia, and the United Arab Emirates)	Middle-income countries (Egypt, Islamic Republic of Iran, Iraq, Jordan, Lebanon, Libya, Morocco, Palestine, Syrian Arab Republic, and Tunisia)	Low-income countries (Afghanistan, Djibouti, Pakistan, Somalia, Sudan, and Yemen)

Not every WHO Eastern Mediterranean Region Member State has the requisite ecosystem to often adopt, adapt and implement policy recommendations made by the WHO and non-State Actors.

Recommendations

Recommendations in this Position Paper have been divided into two categories (Category A & Category B)

Category A Recommendations

These are general recommendations that are targeting the overall PCC scene in our region,

Recommendation one:

We advocate the establishment of personalised cancer care in the region.

A clear policy by the WHO and looking in the future for “investment case” best buy approach

We want high level leaders to see the vision of how these health technologies can transform the WHO EM regional cancer care landscape. Most importantly they must commit to invest in this new ecosystem so that patients in the region can have PCC and Five P’s health systems. Discharging the duty of care for all in the region: Amana on our shoulders (WHO EM Regional Director)

BARRIERS AND WAY FORWARD

Without a comprehensive digital health strategy and cancer registers, Personalised Cancer Care cannot take-off in the region.

WHO EM Regional Health Informatics and Bioinformatics resourcing and infrastructure need to be strengthened.

“Every aspect of our social, commercial and public life has been revolutionized by the digital revolution, modern Patients expect the state to invest in personalised medicine and digital healthcare so that they do not get inappropriate one size fits all treatment. We now expect that in the same cancer ward, we will have stratified treatment approaches”

Recommendations

Recommendation two:

Awareness and shifting paradigms from cost benefit effectiveness to value-based

The policy makers must be aware of all the policy instruments and the health technologies available to them and start changing their health system and cancer care frameworks to push the change through.

PCC also supports value-based healthcare approaches as we can get clearer patient preferences. As we know $\text{Value} = \text{Patient Preferred Outcomes} / \text{Costs of achieving these outcomes}$. From existing surveys and studies like Patient Reported Outcome Measures (PROMs), Patient Reported Experience Measures (PREMs) and Innovative Medicines Initiative (IMI) Patient Reported Outcomes (PROs) recommendations, patients prefer treatments that are personalised to them and result in fewer side effects, adverse events and are least disruptive to their work, social and personal lives. PCC can help fine tune these care pathways and treatments (As per the [Patient-Centered Outcomes Research Institute](#))

The PCCA is also concerned about health literacy in genomic medicine overall and cancer care. We want to have a standard controlled vocabulary. Currently many terms are interchanged and an infodemic can ensue. Personalised medicine is incorrectly and interchangeably being referred to by different terminology.

E.g. genomic medicine, personalised medicine, precision oncology) here to better illustrate what we are talking about, instead of leaving them in the section below “barriers and way forward”

BARRIERS AND WAY FORWARD

We do not have a controlled vocabulary in English for these innovative health technologies. This then complicates the regional discussion in Arabic, French and other languages. We cannot clearly define the terms in both scientific and lay language.

A family of terms are used interchangeably to apply to the same technologies: genomic medicine, personalised medicine, precision oncology

Recommendations

Recommendation Three:

Piloting, where patients' organizations can play a great role in their respected country

Patients and Society (Public) must become aware of PCC and 5Ps ecosystem and start advocating for these changes for the greater good of all-pull the change in!

The establishment of a Public-Patients- Private partnership (PPPP)

BARRIERS AND WAY FORWARD

In most countries, NCCPs have a resourcing issue. In the EMR, NCCPs have key human resources issues like lack of staffing, workforce expertise, training as well as research.

Many NCCPs are facing full implementation challenges as the appropriate resources have not been allocated to them. The costing and financing have not developed when the NCCPs were designed.

Over the last ten years innovation in patient engagement in health system decision-making, regulatory affairs, health economics (HTA) and other structures and processes has been institutionalised through legal, policy, practice, standards and over all constitutional arrangements.

This engagement is not for the sake of engaging, it is engagement to ENABLE co-creation and co-production to improve the availability, quality, safety, acceptability, accessibility, affordability, and equity of health technologies (medicines and devices).

This all has an impact upon delivering patient preferences outcomes, value and makes health systems effective and efficient.

Recommendations

BARRIERS AND WAY FORWARD

In the European Union, the Innovative Medicines Initiative (IMI) has spawned new programmes. IMI Prefer and IMI Get Real. These programmes have recommendation on innovation in eliciting patient preferences and use of real-world data.

IMI Prefer has used patient engagement and co-creation to bring out patient preferences in many healthcare settings and health technologies. IMI has now issued recommendations: <https://www.imi-prefer.eu/recommendations/>

IMI Get Real has advocated the use of real-world data to improve patient outcomes and experience. <https://www.imi.europa.eu/projects-results/project-factsheets/getreal>

The Patient-Centered Outcomes Research Institute (PCORI) is an independent, nonprofit research organization that seeks to empower patients and others with actionable information about their health and healthcare choices. They funded comparative clinical effectiveness research (CER), comparing two or more medical treatments, services, or health practices to help patients and other stakeholders make better informed decisions. <https://www.pcori.org/>

Recommendations

Category B recommendations:

(The Policy Recommendation Matrix)

The policy recommendation matrix is driven from all the presentations, discussions and debates we had during the PCCA webinars and small groups discussions from spring to autumn 2022. The matrix has ranked the most appropriate recommendations from a list of some 147 statements. We have divided the recommendations according to the 5Ps: predictive, preventative, participatory, personalised, and pre-emptive.

The Matrix will target each of the three EMR country groups having considered what is feasible within their capabilities to adopt, adapt and implement these recommendations. We have used the conventional approach in recommending measures as Strongly Recommended, Suggestively Recommended and Optionally Recommended.

For example, for Group A countries, this position paper has Strongly Recommend the full spectrum of personalised cancer care service reform and has requested that the Group A Member States implement them within the next 5 years.

This position paper by the Personalised Cancer Care Alliance acknowledges that the WHO EMR Member States will be circumspect about our recommendations, and depending upon their underlying health system arrangements, institutions and general framework of legislation, policy, practice, and standards currently in place, consider engaging with us further on these recommendations.

The position paper has considered the following characteristics of the EMR Member States before putting the policy recommendation matrix:

- Existing healthcare system infrastructures
- Adequacy of qualified and trained health professional and ancillary staff employed
- The knowledge and skills of current policy makers around personalised healthcare and precision medicine
- The competency of the current medicines and health regulators
- The current economic position and the maturity and depth of the Universal Health Coverage (UHC)
- The existence and maturity of any health technology assessment bodies and the financial arrangements and budgets in place to adopt innovative health technologies
- The general health ecosystem and adoption of any past Cancer WHO resolutions, strategies, projects, and measures recommended in past WHO EMR Regional Committees.

The Policy Recommendation Matrix According to the Five P's

1. PREDICTIVE		
#	RECOMMENDATION	STRENGTH OF RECOMMENDATION
1	<p>Member States must ensure that their NCCPs are set to address key evidence findings and needs highlighted in their population screening, diagnostics, mortality, and morbidity programmes and data.</p> <p>The NCCPs must be What has been revealed by quality national epidemiological data sets:</p> <ul style="list-style-type: none"> • What types of cancers are common? • What stages are we discovering them, and where regionally? • What is the Gender/Age/Ethnicity and other data? 	<p>Strongly Recommended for Group A Member States</p> <p>Suggestively Recommended for Group B Member States</p> <p>Optionally recommended for Group C Member States</p>
2	<p>Member States that have not started putting their NCCPs into action must do so immediately to start building back better.</p>	<p>Strongly Recommended for ALL Group A B C Member States</p>
3	<p>We recommend that Member States establish quality cancer patient registries. MSs that do not have quality registries cannot harvest timely, accurate and relevant epidemiological data (ED) to analyse. This has implications for future artificial intelligence use as well. If you are not counted, you do not count!</p>	<p>Strongly Recommended for all Member States in A, B, C Groups</p>
4	<p>We recommend Member States should have robust and evidence based legal/policy/practice/standards frameworks governing cancer registers and their financing, resourcing, training, and recording.</p>	<p>Strongly Recommended for all Member States in A, B, C Groups</p>

Recommendations

5	<p>Member States should start adopting electronic medical records. They should endeavour to move the paper based and offline patients records into electronic medical records. EMR will improve patient, epidemiologist and other researcher access and help improve the timeliness, accuracy, relevancy and quality of the EMRs and cancer registers. Personalised cancer care cannot flourish without EMRs.</p>	<p>Strongly Recommended for Group A Member States</p> <p>Suggestively Recommended for Group B Member States</p> <p>Optionally recommended that through bilateral and GCC aid and cooperation. Group C countries could be endowed the Information Technology and Software needed to join.</p>
6	<p>Member States must invest in biomarker technologies as they can be used across their full range of healthcare and for the purposes of:</p> <ul style="list-style-type: none"> ● Predictive - to define the patients who may develop a disease and will most likely benefit from an appropriate matching therapy. ● Prognostic - unlike standard diagnostics, this PM approach picks out the aggressive nature of each cancer and then fast track patients and treatments. Also, very patient-centric treatments can have an informed conversation (no false hopes) about what the likely outcomes are irrespective what treatment given (k-Ras). ● Early Diagnostic - opportunistic screening in symptomless patients can pick up a disease which conventional tests cannot. Very low-level presence detected. (PSA) 	<p>Strongly Recommended for Group A Member States</p> <p>Suggestively Recommended for Group B Member States</p>
7	<p>Member States must realise that in treatment choice, biomarkers presence and levels are good indicators of likely pharmacologic response to therapeutic interventions. They help set up predictive approaches as we know what clinical outcomes will be. They aid personalised treatment strategy.</p>	<p>Strongly Recommended for Group A Member States</p> <p>Suggestively Recommended for Group B Member States</p>

Recommendations

2. PREVENTATIVE		
#	RECOMMENDATION	STRENGTH OF RECOMMENDATION
1	Based upon the cancer registers, cancer epidemiology, mortality and morbidity data, prioritise cancer prevention programmes in key target and high-risk populations.	Recommended Strongly for ALL Group A, B, C Member States
2	Introduce breast cancer and colon cancer screening services by applying liquid biopsies and biomarker health technologies and adding these to existing health technologies (Mammography and Colonoscopy).	Recommended Strongly for Group A countries Member States
3	Member States must ensure that their NCCPs use best-buy strategies (evidence-based strategies) to support setting up services like screening in certain age groups, to ensure no late-stage presentation, and to select appropriate treatment.	Strongly Recommended for ALL Group A B C Member States

3. PARTICIPATORY		
#	RECOMMENDATION	STRENGTH OF RECOMMENDATION
1	Member States must advertise and promote their National Cancer Control Plans so that their strategy and approaches are widely known or shared by whole of government, society and patient community.	Strongly Recommended for all Member States in A, B, C Groups
2	Member States must create an ecosystem for patient and family engagement within national cancer control efforts. Make NCCPs a whole of government, whole of society and whole of patient organizations initiative. We must work in national unity and regional solidarity on cancer control.	Strongly Recommended for ALL Group A B C Member States
3	We recommend that all Cancer Registers in the region should have patient participation, engagement, and oversight. Patient and carer deep insight should be a part of quality cancer register co-creation, co-production, co-management, and co-reporting: Nothing about us without us.	Strongly Recommended for all Member States in A, B, C Groups

Recommendations

4. PERSONALISED		
#	RECOMMENDATION	STRENGTH OF RECOMMENDATION
1	<p>National Cancer Control programs:</p> <p>Member States must appreciate that the cancer control programs can become more effective once we have identified a cancer gene (BRAC 1 etc). We can then, through early PCC/PM diagnostics and early detection, point out if the patient or/and their family member is at risk.</p> <p>Once identified at the earliest, patients appreciate an accurate multiple health technology application to enhance the diagnosis like the use of MRI, liquid biopsies, and biomarkers. They get a very accurate diagnosis through molecular profiling, genomics, and proteomics. This helps us individualise (personalise) the treatment.</p>	<p>Strongly Recommended for Group A Member States</p> <p>Suggestively Recommended for Group B Member States</p>
2	<p>Cancer Registry:</p> <p>Through use of a rich and diverse information collection and ‘meshing’ of cancer etiology with spatial and lifestyle data, we can incorporate the social determinants of cancer into our registers. Cancer Registers should move away from being 2D representations of the cancer incidence and the patient identity. Personalised cancer care can only flourish if the Cancer Registers record other important and relevant genomic (geno/pheno type), lifestyle, social determinants information to aid PCC services. We need to have accurate data on Cancer Staging and outcomes etc. This can help us become predictive and preventative.</p>	<p>Strongly Recommended for Group A Member States</p> <p>Suggestively Recommended for Group B Member States</p>

Recommendations

<p>3</p>	<p>Health Systems:</p> <p>Member States should move away from reactive, paper and analogue based health systems. To control Cancer in WHO EM Region, we must start building back better and look at digital healthcare and artificial intelligence solutions to give us real time and real-world data: our epidemiological data remains a snapshot of the past (the past can be 3,5,10 or even 20 years old).</p> <p>This paradigm shift is vital as it will support health systems to adopt genomic and digital health technologies as ONCO-genes clearly tell us that cancer is a genetic disease in all its aspects.</p>	<p>Strongly Recommended for Group A Member States</p> <p>Suggestively Recommended for Group B Member States</p>
<p>4</p>	<p>Diagnosis:</p> <p>Member States should invest to have a sufficient quantity of accessible and quality cancer diagnostic and genomic services available for their populations, for example, Biomarkers technologies and liquid biopsies.</p> <p>This means timely, sensitivity and specificity in cancer diagnosis. By matching the right patient with the right treatment we get the best outcome with less side effects and better quality of life for the patient.</p>	<p>Strongly Recommended for Group A Member States</p> <p>Suggestively Recommended for Group B Member States</p>
<p>5</p>	<p>Member States must invest in regional cancer DNA data Libraries (genomic banks).</p> <p>WHO MS can ensure that we can fingerprint each tumor type and compare to existing databases. We can then tailor make (precision match) treatment to that tumor and avoid a hit and miss approach. It's a selected and carefully planned attack for the benefit of the patient.</p>	<p>Strongly Recommended for Group A Member States</p> <p>Suggestively Recommended for Group B Member States</p>

Recommendations

5. PRE-EMPTIVE		
#	RECOMMENDATION	STRENGTH OF RECOMMENDATION
1	Member States must invest in National Cancer Control Plans (NCCP) to support them in prioritising cancer control in their national health policy and disease management initiatives within a holistic perspective.	<p>Strongly Recommended for Group A Member States</p> <p>Suggestively Recommended for Group B Member States</p> <p>Optionally recommended that through bilateral and GCC aid and cooperation Group C countries should be supported in their NCCPs</p>
2	Member States, through patient participation and dedicated investment in digital health, must not allow NCCPs to become outdated. They must be updated and refreshed regularly with the latest epidemiology and clinical evidence to keep them live.	<p>Strongly Recommended for Group A Member States</p> <p>Suggestively Recommended for Group B Member States</p>
3	<p>The Member States must ensure that their NCCPs are quality assured to ensure that the most resource-efficient actions are deployed and address the most urgent priorities at the right time.</p> <p>Member States must ensure that their NCCPs can address health inequality and equity issues. Women's breast cancer as an example.</p>	<p>Strongly Recommended for ALL Group A B C Member States</p>
4	<p>Member States must ensure their Cancer Registers are capturing high level and accurate personalised genomic information that can then help them understand which cancers are predominant in their population, at what stage they are found, and what is the prognosis. It can help you prioritise which treatments are best buys and need to be invested in the NCCP.</p> <p>Slow advancing cancers can go on the lower tier, fast advancing cancers on the top. Sadly, some may only be offered as palliative care.</p>	<p>Strongly Recommended for Group A Member States</p> <p>Suggestively Recommended for Group B Member States</p>

Conclusion

This “position paper” is the first of its kind globally to put the Personalised Cancer Care in the spot light while paving the road for patients’ organizations and civil societies to advocate and lobby for PCC within their own communities and with policy makers in the EM region.

This paper was produced by the Personalised Cancer Care Alliance (PCCA) with the help and support of IAPO, PhRMA, leading scientists in the field, oncologist and most importantly patients’ organizations and civil societies in the region, making it a seminal reference when it comes to Personalised Cancer Care with “actual” patients’ voices being integrated within the paper.

The way the recommendations were presented in this position paper, they provide a comprehensive road map and a way forward to make sure that Personalised Cancer Care will be accessible to all patients in our region (even in Low and middle income countries). Innovations in PCC has the potential to change not only the way patients receive care, but also their quality of life. PCC the FUTURE of cancer care” and we need to act now to make sure to realize this future.

Looking ahead and as a way forward, 2023 will be an important year for all patients’ organization and civil societies in the EM Region to start their advocacy journey on multiple levels to make the FUTURE of Personalised Cancer Care a reality in the EM Region.

About



IAPO - the International Alliance of Patients' Organizations is the global alliance representing patients of all nations across all disease areas. We have been advocating for patient-centred healthcare worldwide for over 22 years with the collaboration of almost 300 member organizations, and developing regional patient alliances to empower patients, drive research and shape law and policy to improve quality, safety, accessibility, acceptability, affordability and equity in healthcare.

<https://www.iapo.org.uk>



Pharmaceutical Research and Manufacturers of America, formerly known as the Pharmaceutical Manufacturers Association, is a trade group representing companies in the pharmaceutical industry in the United States. Founded in 1958, PhRMA lobbies on behalf of pharmaceutical companies.

<https://phrma.org>



PCCA is an alliance of cancer patients, carers, and representatives of patient organizations from the Middle East & North and Sub-Saharan Africa set up to advance health literacy in cancer, advocacy skills and education on personalised cancer care. It was set up because we now know that not all patients are the same, and not all cancers are the same, nor are all treatments the same.

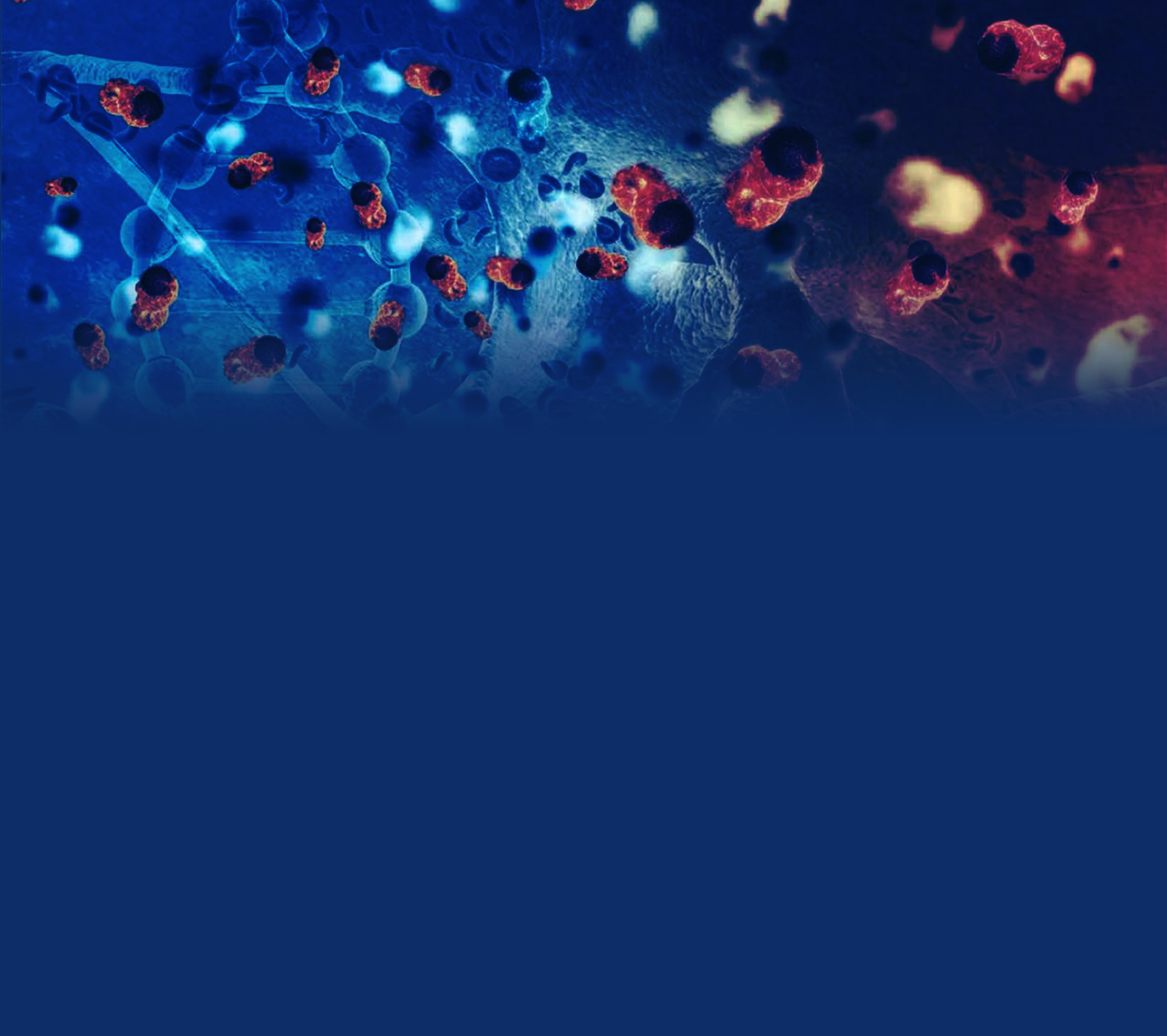
Produced by:



Personalised Cancer Care Alliance

Dr. Sawsan A. Al Madhi (MD, MSc Healthcare Management)

Advocacy Advisor
CEO & Founder
www.AlignnEfficient.com
Dubai | London



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