



A MEMBERSHIP ORGANISATION  
**FIGHTING CANCER TOGETHER**

# Coursebook

Multisectoral Approaches to Patient Engagement  
for Better Cancer Control



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## Course Description

### Towards Patient-centred cancer control

Patient engagement in decision-making processes along the care continuum is a key aspect of patients' rights and, as such, it is an essential prerequisite of the quality of cancer care in all health systems. Achieving a patient-centred system requires that all stakeholders take into consideration the patient perspective in their activities related to cancer research and care. It is also of utmost importance that patient organisations get the necessary knowledge regarding the opportunities to voice their perspectives and feel empowered to have their say in research, care, and support as well as survivorship programmes and be considered as a driver for change in all health systems.

### Sharing best practices across sectors

This course will draw on practical examples and approaches from across sectors to outline how the engagement of patients in decision-making processes along the cancer control continuum leads to better quality in cancer care. Reflecting multisectoral perspectives is critical to ensure that this landscape of patient engagement is comprehensive, and that the patients' voice is considered at every step of the cancer care continuum.

This course will take advantage of the unique position of UICC as the “union” of the global cancer community to gather all in one place the expertise of its members, partners and other stakeholders, therefore offering a multifaceted learning journey to its audience.

### A learning journey for practical impact

The methodology of this course will combine: an online series of webinars by experts from all sectors (civil society, patient groups, public and private sector), complemented by the “Cancer Patient’s Voices” podcasts, consisting of 5 min inspiring interviews with a representative of a patient, survivor, or caregiver, on the specific topic discussed by the experts.

The online component will also benefit from advanced education technologies offered by UICC’s eCampus platform, providing a one-stop shop with key resources, interactive content and link to opportunities for each module. All materials from the course will be designed for a sustainable use as a comprehensive introduction to Patient engagement in cancer control.

## Learning objectives

After completion of the course participants will be able to:

1. Provide participants with the latest findings and knowledge about strategies and tools to reinforce patients' engagement in cancer care and beyond.
2. Ensure a People-Public-Private Partnership approach through the contribution of experts from all sectors to provide their insights on various aspects of patient engagement.
3. Engage participants in concrete practical exercises to experience situations and opportunities to voice the patient or caregiver's perspective.

## Syllabus

In the table below you will find the syllabus, including the name of the webinar or podcast, and the name of the speaker/s and their organisation.

Block	Module	Webinar/Podcast	Speaker/s, organisation
Strategies	Basics of Patient Engagement	Patient rights	<b>Hayley Jones</b> and <b>Rachel Kitonyo Devotsu</b> , McCabe Center for Law & Cancer
		Patient engagement – why it matters	<b>Ratna Devi</b> , International Alliance of Patient Organisations (IAPO)
		<i>Cancer Voices Podcast</i> : "Why my engagement is important? Interview with a cancer patient activist"	<b>Ranjit Kaur</b> , Breast Cancer Welfare Association Malaysia
		<i>Cancer Voices Podcast</i> : "Why engaging patients is important?"	<b>Sanja Njelic</b> , Roche (F. Hoffmann La-Roche Ltd)
	Evidence for patient engagement	Changing the conversation around efficiency in cancer care	<b>Alex Filicevas</b> and <b>Kathy Oliver</b> , All.Can
		The power of patient data	<b>Frances Reid</b> , World Ovarian Cancer Coalition
		<i>Cancer Voices Podcast</i> : "How my experience can improve the lives of others: Interview with a patient and survivor about sharing insights and participating in shaping the future of cancer care."	<b>Fabian Bolin</b> , War on Cancer
Tools	Using Narratives for Representing the Patient voice	The power of storytelling: building narratives to share voices of people living with cancer and other NCDs	<b>Manjusha Chatterjee</b> and <b>Diana Gittens</b> , NCD Alliance
		The Power of Stories: Crafting personalised healthcare narratives	<b>Eyedith Comenencia Ortiz</b> , Roche (F. Hoffmann La-Roche Ltd)
		<i>Cancer Voices Podcast</i> : "Why and how I am sharing my stories to inspire and support others?"	<b>Bahija Gouimi</b> , AMAL

	Developing Tools for Scaling up patient support	Overview of tools to engage as a patient group	<b>Nicholas Brooke</b> , Patient Focused Medicine Development (PFMD)
		Digitalising patient support	<b>Christiana Mitsi</b> , Hellenic Association ow Women with Breast Cancer “Alma Zois”
		<i>Cancer Voices Podcast</i> : "How to digitalise patient engagement?"	<b>Dave Fuehrer</b> , GRYT Health
Opportunities	Patients Engagement for better access to quality care	What is Health Technology Assessment (HTA) and why patients should be involved in HTA?	<b>Antonella Cardone</b> , European Cancer Patient Coalition (ECPC)
		A holistic approach to cancer care: improving quality of life through supportive programs	<b>Carolyn Taylor</b> , Global Focus on Cancer
		<i>Cancer Voices Podcast</i> : "How I became a patient-expert in cancer quality of care"	<b>Viji Venkatesh</b> , The Max Foundation
	Patients as Leaders for Change	Growing influence: advocacy nurtured by science	<b>Anna Cabanes</b> , Global Focus on Cancer
		Engaging Survivors for Better Integration, Inspiration & Advocacy	<b>Karen Khoury</b> , Children’s Cancer Center of Lebanon (CCCL)
		<i>Cancer Voices Podcast</i> : "Leaders of change in policymaking"	<b>Alexandra Núñez</b> , Unidos Contra el Cáncer - Costa Rica
		<i>Cancer Voices Podcast</i> : "Interview of a childhood cancer survivor engaged in the Children’s Cancer Center of Lebanon’s Champions’ Circle programme in Lebanon"	<b>Lynn El Hage</b> , Children’s Cancer Center of Lebanon (CCCL)

## Biographies of Speakers and Podcast interviewees

(Alphabetically ordered by first name)

### Alex Filicevas



Alex Filicevas serves as the President of All.Can International - an international non-profit organisation working to reduce inefficiency in cancer care worldwide, while focusing on what matters to patients, since April 2020. Before All.Can's establishment as a non-profit organisation, Alex has been a member of its Steering Committee since 2018.

Alex Filicevas is also the Executive Director of the World Bladder Cancer Patient Coalition (WBCPC) where he leads the work of the organisation to foster an international community of strong bladder cancer patient advocates.

Before joining the World Bladder Cancer Patient Organisation, Alex was leading EU affairs work at Europe's largest cancer patient umbrella organisation. His work focused on advocacy activities, capacity building of member patient organisations and policy initiatives with a particular focus on overarching issues faced by cancer patients and their carers in Europe. As a consultant, Alex has also supported a number of private and non-governmental organisations in successful advocacy efforts at the EU level on a range of disease areas and issue-specific public health challenges.

### Alexandra Núñez



Alexandra Núñez is a leader and patient advocate. Founder and President of *Unidos Contra el Cáncer* since 2012, formerly known as *Asociación Tour Rosa*.

She was diagnosed with advanced lung cancer in 2011. Since then, she has joined her personal experience to give value and integral support to patients with any type of cancer in Costa Rica being the legal aspect of such support one of her passions in which she has been working for 8 years.

She has promoted initiatives such as the *Proyecto Más Vida* (More Life Project) for metastatic breast cancer patients and directs the first diagnostic stage of the Breathing Hope Project: "Lung Cancer in Costa

Rica: Current situation and challenges for a person-centred approach" (*Proyecto Respirando Esperanza: "Cáncer de Pulmón en Costa Rica: Situación actual y retos para un abordaje centrado en la persona"*). She has also participated as a speaker in national and international forums representing the voice of the patient before decision makers.

Alexandra is currently studying Law at the Universidad Autónoma de Centroamérica and holds a Diploma in crisis management leadership at CAEP.

## Anna Cabanes



Anna Cabanes is a cancer epidemiologist and non-profit executive with 20+ years of experience in research, epidemiology, health systems strengthening, community mobilization and evidence-based advocacy. A strategic thinker, she is passionate about disease prevention and provision of care for cancer control globally.

Cabanes is currently research advisor at Global Focus on Cancer. She worked 9 years with the non-profit Susan G. Komen (USA) directing all community health and global programs. Prior, she held positions in cancer research (Georgetown University, USA) and cancer surveillance (Centro Nacional de Epidemiologia, Spain).

She has a record of leadership and achievements in public health. Her goal is to maximize the impact of scientific research leading to innovations in policy and practice for global cancer control. She has worked with advocates, healthcare organizations, and governments, to innovate and integrate new cancer programs within healthcare systems or in new environments; to develop national policies and establish successful care delivery models; and to mobilize communities through evidence-based advocacy.

A native of Barcelona, she has lived and worked in Halifax, Jerusalem, Madrid and Washington, DC. She holds a PhD from the Autonomous University of Barcelona and an MPH from Johns Hopkins University.

## Antonella Cardone



Antonella Cardone is the Director of the European Cancer Patient Coalition. She has over twenty years of international activity in health, social and employment sectors. Prior to ECPC, Antonella was the Executive Director of the Fit for Work Global Alliance, a multi-stakeholder coalition championing change in health and work policy. She also worked with the European Multiple Sclerosis Platform, a patient organisation, on the "Ready for Work" project. She was previously Director of the Global Smokefree Partnership of the American Cancer Society, leading a movement of over 100 members among civil society, universities, and ministries of health to coordinate the development of smoke-free laws in 40 countries. Antonella has managed over 40 large EU co-funded

projects across all EU member states. She holds a Master's in Business Administration. She is mother tongue Italian, with a good knowledge of French and Spanish and is fluent in English.

## Bahija Gouimi



Bahija Gouimi is the Founder and President of AMAL (*Association des Malades Atteints de Leucémies*) in Morocco. She has been a leukaemia patient for more than 18 years. She is also the co-founder of CML Life Africa, part of the Max Global Network, the collection of patient support associations focused on chronic myeloid leukaemia (CML). She is also a member of the CML Advocates Network Steering Committee as a representative for Africa and Middle East since 2011.

She has written wrote four books (two in Arabic and two in French) about her story with cancer and has given many interviews on TV and radio programs. In 2017, she won the First civil personality Prize by the Moroccan Ministry of civil society.

She lives in in Marrakesh with her three children, where she has been working as a communication teacher for 26 years. She speaks Arabic, French and English.

## Carolyn Taylor



Carolyn Taylor, is the founder and executive director of Global Focus on Cancer (GFC), a US-based non-profit organization established in 2011 to act as an agent of simple and effective change to help reduce the global burden of cancer through programs in cancer awareness, advocacy, support and networking in countries where access to information about cancer is critically lacking.

Carolyn is a global cancer care advocate, serves as a content expert with the Women's Empowerment Cancer Advocacy Network, sits on ASCO's Gynecologic Cancer Guidelines Committee and was a contributing author to the Lancet series 'Health, Equity and Women's Cancers' [Nov 2016].

Carolyn is a frequent speaker/moderator at global cancer conferences and since 2015, has served as the co-founder and co-chairman of the annual SE Asia Breast Cancer Symposium. In addition to her work with GFC, Carolyn is a professional photographer and cancer survivor, who uses her talent and personal passion to share images that remind us that regardless of race, religion, nationality or economic status, we are all one in the battle against cancer.

## Christiana Mitsi



Christiana Mitsi is the Scientific Director at the Hellenic Association of Women with Breast Cancer "Alma Zois", an NGO for breast cancer in Greece which was established in 1988 by breast cancer survivors and aims to provide psychological, legal and peer support to breast cancer patients all over Greece and to implement programs for breast cancer awareness and advocacy. Alma Zois is a patient's group with all members being women with personal breast cancer experience.

Christiana holds a bachelor's degree in Psychology and a Master's degree in Cognitive Science. She is also an accredited Cognitive Behavioural Psychotherapist (CBT) and a trained Dialectical Behavioural Therapist.

Through her 12 years' work in the Hellenic Association of Women with Breast Cancer "Alma Zois" she has been active in finding the emerging needs of breast cancer survivors in Greece, in designing, implementing and coordinating programs in order to increase awareness, support and advocacy for breast cancer patients and in advocacy.

Christiana's ultimate goal is to raise awareness about the importance of improving the communication between doctors and breast cancer patients, with the objective to improve the quality of breast cancer patient's healthcare.

## Dave Fuehrer



Dave Fuehrer is a two-time cancer survivor, oncology researcher and patient experience champion. He is CEO and co-founder of GRYT ("grit") Health, a digital health company that connects individuals with similar experiences and engages them to inform, support and facilitate improved disease management and patient well-being.

Through GRYT's global oncology platform and work with the top healthcare organizations, we help advance the treatment, care and experience of those affected by cancer. We do this through research, patient education and clinical trial services that put people and caregivers first, integrating the patient experience – from early stage treatments through long-term survivorship – to ultimately improve health outcomes.



Dave has a BS in Technical Communication and MBA in Technology Management, from Rochester Institute of Technology. He has completed Executive Education at Harvard Business School in Building New Ventures and at MIT in Corporate Strategy.

## Diana Gittens



Diana Gittens holds a BSc. in Biology from the University of Guyana and MSc. Public Health Nutrition from the University of Technology (Jamaica). She is also a trained teacher, with an Associate Degree in Secondary Education.

She functioned on the Board of Directors of the Dominica Cancer Society for five years as Secretary and President. Her areas of work are advocating for access to treatment, diagnostic screening and psychosocial support for persons affected by cancer. Ms. Gittens is a cervical cancer survivor and a global advisory committee member of the NCD Alliance's Our Views Our Voices initiative.

Diana currently works with the Guyana Telephone and Telegraph Company, a private telecommunications company, as the coordinator for Guyana's largest cancer awareness and fundraising initiative. She manages the company's corporate social responsibility initiatives, including the grant application process for cancer-related funding for NGOs across the country. Prior to her current role at the company, she served in the capacity of Business Partner for Health and Wellness. Diana is passionate about using health promotion and advocacy as tools to fight the scourge of NCDs in the Caribbean and around the world.

## Eydith Comenencia Ortiz



Dr Eydith Comenencia Ortiz is the Patient Partnership Group Director, Pan-Oncology and Hematology at Roche. In her role, she leads Roche's global engagement with patients and patient advocacy groups in the Pan-Oncology and Hematology space.

Eydith has over 10 years of experience in patient partnering and advocacy engagement, driving meaningful collaborations with patient communities across more than 20 different oncology, rare, immunology and neurology disease areas. She is very passionate about the incorporation of the patient perspective and experience in the development and delivery of new therapies. Prior to her current

position, Eydith held similar roles at Genentech (a member of the Roche group), Global Blood Therapeutics, and Biogen. At Biogen, Eydith also held roles in Government Affairs, Science & Regulatory Policy, and Regulatory Development.

Eydith is a scientist by training. She has a PhD in Neuroscience from Tufts University Medical School and a Bachelor's in Biology from the University of Puerto Rico, Cayey Campus. On her spare time, Eydith serves as a mentor to young high school and college students interested in pursuing careers in science and medicine.

## Fabian Bolin



Fabian Bolin is the CEO and Co-founder of War On Cancer, the social network app for everyone affected by cancer.

Events in Fabian's own life are what led him to embark on what he now feels is his purpose in life: helping everyone affected by cancer. Following business studies at Stockholm School of Economics in 2011 Fabian went on to pursue a career at an American investment bank in London. After two years of working as a bonds trader Fabian resigned to follow his passion to work in the film industry. Two years into his new career in July 2015 he was diagnosed with acute lymphoblastic leukaemia and he is currently in remission following 900 days of chemotherapy.

After being diagnosed Fabian began documenting his cancer battle on a blog which quickly gained global attention. His first post shared almost 13000 times on Facebook has led to over 100,000 messages of support to date. By recognizing the power and potential of sharing stories and combining it with a strong urge to find a solution to the mental health problem for everyone affected the idea of the War On Cancer App was born.

## Frances Reid



Frances Reid has been the Programme Director for the World Ovarian Cancer Coalition since 2017. In that time, Frances devised and led the peer reviewed Every Woman Study™ (2018) charting global experiences of women with ovarian cancer. Findings from this study inform her current role as the lead on the Coalition's Global Ovarian Cancer Charter (2020) bringing together multiple key stakeholders.

Her work with women who have ovarian cancer began in 2003. Five years later Frances co-founded Target Ovarian Cancer in the UK where she worked as Director of Public Affairs and Services. The power of patient experience is fundamental to her work, and has been transformative in bringing together patient, clinical and policy viewpoints.

She developed the Target Ovarian Cancer Pathfinder Study whose results inspired the establishment of an All Party Parliamentary Group on Ovarian Cancer, and informed a raft of policy decisions and targeted interventions to improve survival and quality of life for women.

Frances has what she would describe as a 'blended career', including 14 years at the BBC as a radio programme maker, a teacher and maker of breads from her home-based micro-bakery, and freelance consultancy centred on patient experience and impact reporting.

## Hayley Jones



As Acting Director of the McCabe Centre, Hayley Jones leads the McCabe Centre team, managing operations and driving forward its mission to promote the effective use of law to prevent cancer and ensure equitable treatment and supportive care for people affected.

Dual qualified in Australia and the UK, Hayley's background is in access to justice initiatives for children, migrants and people living in poverty, and for the organisations which support them, focused on ensuring no one is left behind.

## Karen Khoury



Karen Khoury Gemayel is currently the Public Relations & External Affairs Manager at the Children's Cancer Center of Lebanon (CCCL) based in Beirut; a leading regional centre pioneering in the treatment of kids with cancer at no cost to their parents, since 2002.

Karen holds a bachelor's degree in Business Administration & Marketing from the American University of Beirut (AUB) and is a certified ISO quality management internal auditor.

With almost 15 years at the CCCL, Karen has been actively involved in the centre's strategic planning & development, quality management, traditional and digital communications, public relations, fundraising, events management, audiovisual production, and media relations.

Early 2018, she has launched the CCCL's PR & External Affairs Department aiming to increase the centre's global reach and presence, in addition to developing new growth opportunities and maintaining external stakeholders and the CCCL leading image. She hopes to expand the CCCL's reach and services to more patients in need regionally, and further develop the centre to be among global advocates of paediatric cancer control and improving the lives of people living with and after cancer.

## Kathy Oliver



Kathy Oliver is Chair/Founding Co-Director of the International Brain Tumour Alliance (IBTA), a global network established in 2005 as a dynamic worldwide community for brain tumour patient organisations and others involved in neuro oncology.

On behalf of the IBTA, Kathy campaigns for equitable access to brain tumour therapies; encourages the establishment of brain tumour patient/caregiver support groups in countries where they don't yet exist; and raises awareness of the challenges of this devastating disease. She's involved in cancer patient rights-based advocacy and is a co-author of The Brain Tumour Patients' Charter of Rights. Kathy, a frequent speaker at international cancer conferences, participates in high-level international projects/committees focusing on patient reported outcomes, quality of life, guidelines, rare cancers and palliative care. She edits/publishes Brain Tumour magazine (14,000 copies annually sent to 111 countries) and has authored/co-authored a range of journal papers and magazine articles.

Recently, Kathy helped spearhead an IBTA initiative for sub-Saharan Africa, alongside the Society for Neuro-Oncology (SNO) and the Zimbabwe Brain Tumour Association (ZBTA) to help improve outcomes for African brain tumour patients. The result of this activity, with support from SNO, was the establishment of the Society for Neuro-Oncology Sub-Saharan Africa (SNOSSA).

Kathy's son, Colin, was diagnosed with a brain tumour in 2004, age 24, and passed away, age 32, in 2011. Kathy cites her son's "incredible courage, determination and fortitude" as the driving force and inspiration behind her involvement in the international brain tumour and rare cancer communities.

## Lynn El Hage



Lynn El Hage is a brave childhood cancer survivor. She started treatment for Leukaemia when she was NOT even two years old. She relapsed in 2008, when she was almost 7 years old and finished treatment in November 2010. Lynn has been engaged in the Children's Cancer Center of Lebanon's Champions' Circle programme in Lebanon.

She is currently waiting to start her first year as a freshman at the American University of Beirut, where she aims to study to become a psychologist.

## Manjusha Chatterjee



Manjusha Chatterjee is Capacity Development Manager at the NCD Alliance and focal point for the Our Views, Our Voices initiative dedicated to promoting meaningful involvement of people living with NCDs in the NCD response. Her work focuses on evolving a people-centred approach to NCD prevention and control and supporting civil society coalition building and advocacy in various geographies.

Prior to joining the NCD Alliance, Manjusha worked with leading health CSOs in India including the Public Health Foundation of India, managing media, communications, advocacy activities, coordinating global youth engagement campaigns, and developing public information and technical

resources for India's Ministry of Health and WHO. Manjusha has worked extensively with national-level health coalitions in India, including the Healthy India Alliance.

Manjusha holds a Masters in Global Politics, specialising in Global Civil Society from the London School of Economics and past degrees in conflict transformation and peacebuilding as well as journalism. Manjusha has previously worked as a reporter with Thomson Reuters and speaks English, Bengali and Hindi.

## Nicholas Brooke



Nicholas Brooke is Founder of The Synergist, a collaboration platform incubator that brings key players together with the express aim of solving significant societal problems through collective action. Under Nicholas' leadership, The Synergist acts as a backbone, providing vision, strategy, stakeholder alignment and execution on multiple international, multi-stakeholder programmes.

He is the Executive Director of Patient Focused Medicines Development (PFMD), a global collaborative platform dedicated to stimulating innovation in medicine development through systematic engagement with patients.

## Rachel Kitonyo Devotsu



Rachel is the McCabe Centre's Regional Coordinator for Africa. Based in Nairobi, Kenya, she leads the components of the McCabe Centre's training and capacity-building programs that relate to the African region and provides technical support to governments in the African Region.

Rachel is renowned for her work in tobacco control policy in Africa and around the world, for which she was recently honoured with a 2020 World No Tobacco Day Award.

## Ranjit Kaur



Ranjit Kaur, a breast cancer survivor since 1998, has a basic qualification in Physiotherapy, and a Master of Science degree in Community Disability Studies (University College London, UK).

Ranjit is a Patient Advocate and she holds the following positions: President of Breast Cancer Welfare Association Malaysia; Board Member for Reach to Recovery International, a global breast cancer support and advocacy programme; Board Member for the ABC Global Alliance representing LMICs; Member of the Presidential Task Force for the Global Alliance of Pain Patient Advocates under the International Association for the Study of Pain (IASP); Patient Advocate for the Union for International Cancer Control (UICC).

Ranjit conducts training in peer support in cancer care. Her article on *Cancer - My Personal Account* was published in The Lancet, Issue no. 9472, May 14<sup>th</sup> 2005, Vol 365, Page 1742. Ranjit received the 2004 Outstanding UICC Volunteer Award and the Theresa Lasser Award conferred by Reach to Recovery International in 2011.

She has held the following positions in the past: President of Breast Cancer Welfare Association Malaysia (2002-2011), President of Reach to Recovery International (2003-2007), and Board Member of UICC (2006-2010).

## Ratna Devi



A medical doctor, public health and management professional, Dr Ratna Devi brings more than 30 years of experience working to improve health outcomes in India. She spent her initial 10 years in the government and for the past 20 years, she has worked with national and international NGOs for public health initiatives. Dr. Ratna has demonstrated experience managing large-scale programs for success and scaling-up innovative pilot programs across India, at national and state levels.

Dr. Ratna Devi is the CEO and Co-founder of DakshamA Health and Education, an organisation that is dedicated to working for access to health, patient education and advocacy. She leads a cross disease

Patient Alliance in India called Indian Alliance of Patient Groups (IAPG) and is the Chair of Board, IAPO (International Alliance of Patient Organisations, Board member HIA (Healthy India Alliance – the National NCD Alliance in India) and I – ORD (Indian Organisation for Rare Diseases). She holds an MBBS degree from Sambalpur University and a dual MBA from SYMBIOSIS and Manipal Institute of Distance Education. Dr. Devi also holds advisory positions at several NGOs and has contributed to research as well as publications.

Her work spans across policy initiatives for Non-Communicable diseases, Rare diseases and Patient safety, focusing on changing the way healthcare is perceived and delivered in India, bringing in best practices and patient perspectives for designing, implementing and measuring health outcomes. As a strong patient safety advocate, she works with government as well as patient organisations to advocate for better quality and safety not in hospitals and other healthcare delivery institutions but safety at home, educational institutions and workplaces.

Her work with International Alliance of Patient Organisations (IAPO) as a Board Member contributes to Universal Access to Healthcare in a global context focusing on the Sustainable Development goals, Migration and healthcare and Healthcare in disasters. She is a member of technical groups, advisory committees and working groups in India and internationally.

## Sanja Njelic



Sanja Njelic is the Global Head of Patient Partnership at F. Hoffmann La-Roche Ltd (Roche). She is responsible for facilitating early and systematic engagement with patient communities across the product lifecycle through industry-leading partnerships. She is strongly committed to ensuring that patients have a voice in medicine's development and works across departments to find innovative ways to involve patients across the whole lifecycle.

Sanja brings a unique combination of expertise in pharmacy, engineering, business, and patient engagement to her role. She has worked in the pharmaceutical industry for over 20 years in different leadership capacities, with nearly 10 years of experience in patient engagement in Europe and internationally.

## Viji Venkatesh



Viji Venkatesh brings with her 34 years of professional experience in cancer patient care and support in her role as Region Head, India & South Asia at The Max Foundation.

Viji began with The Max Foundation in 2001 by leading the administration of the Glivec International Patient Assistance Program (GIPAP) in India. Today, she is in charge of the Max Access Solutions (MAS) Programme in the region which has absorbed and taken under its umbrella of management all patients who were receiving support from the earlier programme.

During the last seventeen years alongside these access programs, she has developed the Friends of Max (FOM) patient support group, which began in Mumbai and now has 21 local chapters throughout India with over 320 core group volunteer leaders representing more than 18,000 members.

Through the years, Viji has served many community leadership roles in the cancer care arena; including her time as the Asia Coordinator for the International Union against Cancer (UICC) where she developed and led symposiums, workshops and learning programs. She was also instrumental in help setting up the Preventive Oncology Department at Tata Memorial Hospital in 1991, where she has contributed to the renowned institute as an active member of its Ethics Committee.

She is also one of the Executive Committee members of the Marrow Donor Registry India and the Terry Fox India Committee. She is a Trustee of the Being Human The Salman Khan Foundation as well as the Friends of Max Charitable Trust.

## Course structure

In the table below you will see the length and scheduled release date of each learning activity. Please note that the estimated time to complete each activity is approximate and it will vary according of each participant working and learning pace.

	Learning Activity	Estimated time (minutes)
<b>Block 1</b> Strategies	<b>Module 1: Basics of Patient Engagement</b>	
	<b>Webinar</b> <Patient rights>	24
	<b>Webinar</b> <Patient engagement – why it matters>	22
	<b>Podcast</b> <Why my engagement is important? Interview with a cancer patient activist>	9
	<b>Podcast</b> <“Why engaging patients is important?”>	7
	<b>Assessment:</b> Quiz	8
	<b>Module 2: Evidence for patient engagement</b>	
	<b>Webinar</b> <Changing the conversation around efficiency in cancer care>	14
	<b>Webinar</b> <The power of patient data>	17
	<b>Podcast</b> <How my experience can improve the lives of others: Interview with a patient and survivor about sharing insights and participating in shaping the future of cancer care>	11
	<b>Assessment:</b> Quiz	8
	<b>Total time for Module 1</b>	
<b>Block 2</b> Tools	<b>Module 3: Using Narratives for Representing the Patient voice</b>	
	<b>Webinar</b> < The power of storytelling: building narratives to share voices of people living with cancer and other NCDs>	26
	<b>Webinar</b> <The Power of Stories: Crafting personalised healthcare narratives>	19
	<b>Podcast</b> <Why and how I am sharing my stories to inspire and support others?>	11
	<b>Assessment:</b> Quiz	8

	<b>Module 4: Developing Tools for Scaling up patient support</b>	
	<b>Webinar</b> <Overview of tools to engage as a patient group>	22
	<b>Webinar</b> <Digitalising patient support>	15
	<b>Podcast</b> <How to digitalise patient engagement?>	6
	<b>Assessment: Quiz</b>	8
	Total time for Module 2	1 h 55 min.
<b>Block 3</b> Opportunities	<b>Module 5: Patients Engagement for better access to quality care</b>	
	<b>Webinar</b> <What is Health Technology Assessment (HTA) and why patients should be involved in HTA?>	15
	<b>Webinar</b> <A holistic approach to cancer care: improving quality of life through supportive programmes>	15
	<b>Podcast</b> <How I became a patient-expert in cancer quality of care>	5
	<b>Assessment: Quiz</b>	8
	<b>Module 6: Patients as Leaders for Change</b>	
	<b>Webinar</b> <Growing influence: advocacy nurtured by science>	15
	<b>Webinar</b> <Engaging Survivors for Better Integration, Inspiration & Advocacy>	15
	<b>Podcast</b> <Interview of a childhood cancer survivor engaged in the Children's Cancer Center of Lebanon's Champions' Circle programme in Lebanon>	5
	<b>Podcast</b> <Leaders of change in policymaking>	5
	<b>Assessment: Quiz</b>	8
	Total time for Module 3	1 hour 30 min.
	<b>Assignment: Complete a patient engagement strategy template</b>	1 hour
	Total time for the course	6 hours 30 min.





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