PATIENT CENTRICITY TO INTEGRATION: ENHANCING CANCER OUTCOMES
The evolution to create the revolution in patient outcomes
INTRODUCTION

This is a golden age of cancer therapy. Advances in science and technology have ushered in an exciting era of breakthrough treatments for patients who have genuine prospects of living longer with better quality of life.

An explosion of knowledge about cancer biology has opened the gates to new forms of transformative therapy. The pipelines are brimming with innovations and even rare and previously intractable diseases are the subject of life-prolonging therapies and potential cures.

The pharmaceutical industry has invested billions in research and development of these treatments and the next challenge for the medical community is to make sure they reach the right people at the right time.

Although there has been an R&D revolution, the evolution of how HCPs engage with patients across this shifting oncology landscape has been slow. The dynamic progress from laboratories through to clinical trials and manufacturing has yet to be matched with significant advances in patient engagement or genuine integration of their voices into shared decision-making.

There are calls for change. The act of partnering with patients, which is recognised as a critical step to better health outcomes, was enshrined as the cornerstone of clinical care and research in the 2023 ASCO Presidential address.

This is critical as more people are either cured or living longer with cancer – with some as a chronic disease – resulting in many opportunities along the disease trajectory to strengthen contacts and ensure that patients are informed sufficiently to request and make the most of new and emerging therapies. Education for HCPs, pre and post therapy launch, regarding the need to practice more patient-centred engagement, is an element with the potential to transform patient outcomes.

Listening to patients, understanding their perspectives, and integrating their voices into care plans are the keys to unlocking the maximum potential from existing and new therapies. Refining the language, tone, and timing of engagements also enables HCPs and patients to share better relationships that can enhance a multiplicity of important outcomes.

It is a challenge, but the good news is that Medscape Education’s expertise can help all HCPs foster more collaborative approaches that benefit the types of relationships with their patients that encourage and improve shared decision making and ongoing care.

This White Paper discusses how targeted education programmes that integrate patient voices and effective communication can equip HCPs with skills that power an informed, knowledgeable, and effective conversation with the patient/caregiver and establish a strong platform for patients to take an active role in their treatment, and have a more positive perspective on their treatment.
HCPs can benefit from gaining deeper understanding of patients and the range of concerns and constraints they face such as: their life goals and expectations, learning styles, vital questions they have but often do not ask, perceptions and misconceptions about cancer treatment, the impact of their treatment, and what psychological support they might need.

This level of engagement – driven by tailored education programmes – potentially sets the patient and their family up for greater success. It is also in step with efforts being made by many in the pharma industry to ensure the patient voice is heard at every level and at every point from proof of concept to bedside.

Nevertheless, there is still a gulf between intention and action so this White Paper further reveals how the patient voice can be given extra clarity, volume, and effect as part of a comprehensive independent educational curriculum. Working with and partnering with patients and Patient Advisory Groups in both design and education to represent the global patient voice provides rich connections and insights. It also powers HCPs to generate more understanding during consultations – for both themselves and their patients.

It is the next, obvious endeavor required to realise the full potential of patient centricity in the management of cancer.

THE NEED FOR CHANGE

The scientific and pharmacological advances of recent years show no signs of slowing down as the intricate genetics of more than 100 cancer types are decoded and characterised and novel ways of mitigating their proliferation are engineered.

Progress in immunotherapy, gene editing, epigenetics, structural biology, and medical chemistry is opening pathways to target cancer proteins once considered undruggable, cites the American Association for Cancer Research, quoting its President Elect Philip D. Greenberg, professor and head of programme for the Immunology Clinical Research Division at the Fred Hutchinson Cancer Center in Seattle, US: “I think the ability to create new therapies that benefit more patients is here right now.”

The statistics underscore the sentiment: trials and approvals, fuelled by a receptive regulatory process, are running at historically high levels with oncology trial starts up 22% from 2018, according to IQVIA research, which also reported that 21 novel active substances (NASs) for oncology were launched in 2022 following on from 2021’s record level of 35. Its Global Oncology Trends 2023: Outlook to 2027 study also recorded that cancer medicine spending hit $196Bn globally in 2022 and, driven by continued innovation, is expected to reach $375Bn by 2027.

All the metrics indicate intensifying demands on HCPs and healthcare systems with global cancer incidence forecast to climb by 55% between 2020 and 2040 while better diagnostics and treatments have created a surge in cancer survivorship, with the number of cancer survivors predicted to increase by 24% over the next decade in the US.

“The significant change of pace comes as the proportion of the world’s population aged over 60 is growing from 12% in 2015 to 22% in 2050, by which time the number of people aged 80 years or older will have tripled to 426 million.”

The confluence of greater availability of more effective therapies and an ageing population presents a golden opportunity for improved societal health but, in the eyes of many observers, the two will not find harmony until patients and their insights from lived experience are integrated into every aspect of their care.

These advances also need to be translated from a technical language that many patients, facing already daunting discussions about their treatment, view as ‘science babble’. “I think the ability to create new therapies that benefit more patients is here right now.”

“The significant change of pace comes as the proportion of the world’s population aged over 60 is growing from 12% in 2015 to 22% in 2050, by which time the number of people aged 80 years or older will have tripled to 426 million.”

This increases the need for improved communication training and redefining the lexicon of cancer to be more patient friendly.”

Steve Clark, a 10-year cancer survivor, patient voice, campaigner, fundraiser at Bowel Cancer UK and an advocate and advisor at Bowel Research UK.

“My background is biochemistry but I could not fully grasp what I was being told at my diagnosis.”

“Healthcare systems with global cancer incidence forecast to climb by 55% between 2020 and 2040 while better diagnostics and treatments have created a surge in cancer survivorship, with the number of cancer survivors predicted to increase by 24% over the next decade in the US.”

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THE PATIENT VOICE

The voice of every patient is rich with experience and detail that frames a window into their care journey. Even silence and omissions illuminate and inform as indicators of behaviours that may influence their outcomes.

A patient-centric approach to all medical encounters that gives confidence and freedom to patients pays dividends by liberating them from anxiety, fear, misunderstanding, and doubt, ensuring their condition and any side effects of treatment are well managed, and encouraging active participation in their own management, thus improving how they cope with cancer.

This is a sharp focus across the healthcare and pharmaceutical industry landscape but adopting practices that generate better HCP-patient engagement requires extra skills that can be delivered through education.

Creating a landscape where patient integration is a standard component is the missing link in the movement for more effective cancer care.

Professor Dame Lesley Fallowfield, a leading professor of psycho-oncology and world-renowned expert in HCP-patient communications, is passionate about enabling more holistic relationships to develop by giving the patient the platform, confidence, and awareness to communicate with their clinician who, in turn, must develop flexible skills to engage with their patients.

“One of the biggest problems that confronts most of our doctors and nurses when they’re dealing with a new patient is ‘how can I possibly put the complexity of why we’re going to recommend one treatment strategy rather than another into simple enough terms to ensure that they are actually making an informed and educated consent?’”

Professor Fallowfield leads the Sussex Health Outcomes Research and Education in Cancer (SHORE-C), Brighton and Sussex Medical School, University of Sussex, United Kingdom, which specialises in evidence-based communications programmes that help healthcare teams develop language, tone, and delivery skills that improve patient understanding of their diagnosis, treatment plans, and clinical trial recruitment. The department’s insights are powered by around 7,500 video and audio tape recordings of real interviews with patients and clinicians.

She says: “If patients are to be able to make educated and informed shared decisions with their doctors, then HCPs have to be able to put quite complex information into lay terms, all against a backdrop of fear and anxiety.”

Steve Clark, an advocate for increased patient integration, believes educating HCPs in the best way to explain and engage with their patients is every bit as important as Research and Development programmes.

“There have been incredible steps forward in terms of pharmacological treatments and surgery and survival rates are improving phenomenally. I have stage 4 colorectal cancer and I’ve just celebrated ten years and, importantly, I am not an outlier any longer,” adds Mr Clark, who founded the not-for-profit organization, Strive for Five and Beyond, and is a Cancer Research UK Campaigns Ambassador.

“Oncology has changed more over the last 15 to 20 years than any other disease area and people are surviving five, ten years and beyond. More and more people are going past five years and are not
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just hanging on or surviving. They are living fulfilling lives. Stage 4 has become, in some cancers, a chronic condition and because of that the psychological approach to care needs to evolve significantly.”

The quest for patient centricity is demanding as individual patients respond to different impulses depending on their socio-economic, cultural, and religious characteristics, and their education levels.

A standardised approach will inevitably not work for all and as Lorna Warwick, chief executive of the Lymphoma Coalition, a charity representing 90 organisations in 55 countries that support patients living with the condition, observes: “Patient centricity means creating an environment where each individual patient has a voice that is listened to, acknowledged and respected, to ensure patients get the best care aligned with their priorities when they need it. “

While healthcare providers are clinically trained, many are not taught about how to deliver the clinical information to their patients. We see a direct correlation between poor information levels and worse patient experiences that impact on quality of life.

“Patients tell us they want to receive the information they need from their doctors but often they leave with little understanding as they hear the word cancer and kind of shut down. The resources they are given that direct them to good websites – rather than letting them run free on the internet where they find all kinds of bogus stuff – is also important.

“All of this acts on how a patient is feeling and how comfortable they feel raising issues with their doctor. If they didn’t understand what the doctor was saying at the first appointment then they are less likely to raise questions that are important to them and to develop a good relationship with their doctor.”

“Integrating the patient voice into education – from planning to execution – can be the glue that strengthens HCP-patient relationships and empowers shared decision making along the care journey to optimize outcomes.

Speaking at an event held at the 2023 European Hematology Association (EHA) Congress 2023, facilitated by Medscape Global Oncology, Ms Warwick also commented: “It’s very important that we include the patient voice in any communication, including both traditional medical education and education aimed at enhancing communication skills.

It’s difficult for clinicians and HCPs to really understand what a patient needs if they haven’t actually done the work to understand what’s behind that in the first place.

“It is very easy for a patient to make a comment about a particular treatment and say ‘I don’t want that’. If you really understand why the patient is making that decision, you may find out that there are other reasons that are fixable and the patient can still have that treatment – and you’re happy as a clinician, because you’re able to give the patient the best treatment.”
ENHANCING INTEGRATION AND COMMUNICATION SKILLS

The sweep of new therapies has the promise of longer and better quality of life, but their complexity can make it difficult for patients to understand and, without that, treatment plans can be less effective.

Recognising the value of integrating patient voices and boosting communication skills across oncology care teams was a central theme at Medscape’s EHA event – chaired by multiple myeloma specialist Professor María-Victoria Mateos, a recent winner of the Lifetime Achievement Award from the International Myeloma Foundation – where a distinguished panel discussed how haematologists and oncologists can incorporate patient centricity into their practice to optimise outcomes.

Professor Mateos commented: “It is very important to incorporate the patient voice in medical education. And the main reason is because the disease, the owners of the disease, are the patients. We usually discuss about prognosis, about treatment, about the side effects and how to manage them but we don’t incorporate the voice of the patient. And sometimes, if we incorporate them and we listen to them, maybe we can change in some ways the practical management of our patients.”

Professor Fallowfield underscores the need for communication skills to match the medical potential of new generation therapies. “Advances in the understanding of molecular and cell biology have led to the development of better targeted therapies but have also significantly increased the complexity of cancer, the logic and rationale for different treatment recommendations,” she says.

“Sadly, not everyone is good at putting this potential into simple, non-patronising language, so the patient can be very confused, particularly when you understand that these complex discussions are set against a backdrop of fear and anxiety.”

Her mantra is: “Be simple, be succinct, and then be even simpler.”

She emphasizes that healthcare delivery is a “serious, multidisciplinary team business” with the patient encountering different professionals along the journey. “All of them have got to be on message,” she says. “But it is often where problems for patients occur because the team does not have a consistent message.”
Professor Fallowfield feels that many HCPs get stuck on a too-rigid belief that patient centricity is defined by getting a patient to act in a certain way, which can miss out on vital clues from their demeanour, their use of language, and how they respond to information and advice, all of which have a bearing on their ability and willingness to follow, and feel a part of, treatment plans.

She adds: “If HCP-patient communication is better, then the patient is more likely to understand the significance of many of the recommendations that are going to need to be followed. Whether that is lifestyle changes, adherence to tablets, or the exercises they need to do after different forms of surgery, if you haven’t communicated enough in a manner in which the patient has taken away the key things, then you’re not going to realise half the medical benefits that you expect.  

“You cannot just say ‘Well, I told the patient what to do and gave them information’. What is said is not the same thing as what is heard and understood.

“You are going to have a huge impact on a patient’s life and that responsibility demands trust. You will be asking them to do things that are going to be painful, sometimes unpleasant, will have a degree of intimacy about them and that is difficult.

“Doctors are not specifically trained on communications skills, but they should be. They need to be taught more effective ways of communicating, what tone and language to use, and to be aware that every patient is different.”

HCPs are passionate and committed to ensuring their patients get the right treatment and understand every aspect of it but they can learn new skills and tools that will enhance their ability to be flexible in communicating with individual patients across a spectrum of learning styles and personal characteristics.

THE ONCOLOGY FRONTLINE

It is clear that the paradigm shift in treatment outcomes needs to be matched by similar progress in how clinicians and oncology care teams engage with patients across a range of metrics including diagnosis delivery, the quality of information, its language and tone, and how to encourage feedback from patients who range across a spectrum of behavioural responses.

Oncologists are on a pioneering front line where time demands are soaring due to the larger cohort of surviving patients under their care and resources are strained by lingering backlogs from the pandemic.

Often, the information leaflets and brochures they lean on to help patients understand their diagnosis and future prospects are locked in an era of limited hope and are weighted with scientific terminology and jargon that can trigger debilitating reactions of confusion and fear.

Patient organisations, with their closer understanding of patient experience and behavior, often produce much better and more patient-friendly information than many ‘official’ sources, highlights Ms Warwick.
A Mission to Explain

How ‘explaining’ is handled is pivotal to a patient’s potential response to treatment plans and has a huge influence on their treatment adherence, how they cope with their cancer and, in consequence, achieve better outcomes which benefit them, their families, their carers, oncology care teams, and the wider healthcare system.

Ms Warwick is adamant that the benefits of clear, positive relationships radiate across every aspect of care.

“There are huge benefits from this and there is a body of research that says patients who have better managed psychological health have better overall disease outcomes – better for them and for the doctor, as they need to visit clinics or hospitals less and there is less burden on healthcare systems.”

“It is a massive piece that needs to be addressed,” she says. “We cannot expect doctors to solve everything and patients accept that. They know they won’t feel perfectly well throughout their therapy. But if you have a dialogue with your HCP and feel that action is being taken, whether it works out or not, you feel like your voice is important.”

The Lymphoma Coalition surveys almost 10,000 patients every two years to generate a unique understanding of behaviours and views. Its research reveals that an estimated 30 to 40% of cancer patients experience psychological issues that are not identified by their medical team and are not referred to appropriate therapy.

“The number one word that comes up when we interview patients is confidence,” says Ms Warwick. “Confidence, confidence, confidence; the word keeps coming up because if they have it they can take an active role in their health, which is what we want them to do.

“There are huge benefits from this and there is a body of research that says patients who have better managed psychological health have better overall disease outcomes – better for them and for the doctor, as they need to visit clinics or hospitals less and there is less burden on healthcare systems.”
Resonating with Patients

Studies have shown that better engagement and an open environment, where patients can talk and express concerns, leads to a range of emotional and physical health benefits. Although HCPs strive for clarity and meaningful engagement, their intention does not always resonate with the patient who may struggle to understand and therefore feel disconnected and uninformed.

Evidence on the importance of creating a strong HCP-Patient relationship has been gathering since 1989 when Kaplan’s landmark paper detailed the physical health benefits that were consistently related to physician-patient communication.7

“Physicians who are informative, show support and respect for the patient, and facilitate patient participation in care generally have patients who are more satisfied, more committed to treatment regimens, and who experience better health following the consultation.”

Communication in medical encounters matters along with the need to identify specific communication features that have direct or indirect influences on improving a patient’s health and well-being, argued Professor Richard L. Street in his paper ‘Physicians’ communication and perceptions of patients: Is it how they look, how they talk; or is it just the doctor?’8

It cites multiple sources to state: “Physicians who are informative, show support and respect for the patient, and facilitate patient participation in care generally have patients who are more satisfied, more committed to treatment regimens, and who experience better health following the consultation.”

Other research has probed the importance of communications skills and their critical role in connecting with patients from different backgrounds and experiences to deliver complicated information in a style that suits an individual.

It is clear that patients will care more about a clinician’s knowledge and expertise, and therefore be prepared to develop a positive relationship, when they are convinced that the clinician understands them and cares about them.
Appreciating the psychological currents that charge through every consultation is a route to more productive relationships, according to Professor Fallowfield, who adds: “Patient centricity is definitely a feeling that a consultation has been a meeting between two experts: patients are experts in themselves and a doctor has their clinical expertise. They are sharing a conversation about what’s going to happen and, if you have a holistic awareness of who that person is, you’re going to experience a much better exchange that is more likely to be two-way.”

Professor Fallowfield believes that an approach that enshrines active listening and a response geared to the individual patient is achievable despite rising demands on HCP time and squeezed resources.

Patients are not delivered from central casting; they have different socio-economic, religious, cultural, ethnic, and educational backgrounds that are further shaped by distinct personalities. The challenge for HCPs is to finesse delivery so that each individual, regardless of their psychological characteristics, gets a message that is unburdened with technicalities that obstruct understanding.

“The scientist Richard Feynman put it well when saying there was always a way to explain complexity to a lay person and if you couldn’t, you didn’t understand it yourself,” Professor Fallowfield says. “Sadly, many doctors rarely permit much uninhibited talk at the beginning of consultations in which patients can express their concerns and feelings. Doctors say this is because they have too little time.”

She adds that an experimental study by Beckman and Frankel reported that patients were interrupted by doctors after only 18 seconds during consultations with only one in 52 being permitted to finish, yet it took an average of only one minute for most patients to communicate all their concerns.

“The contention that there is not enough time to listen to patients’ list of concerns is indefensible,” says Professor Fallowfield. “Of course, an HCP has a lot of information and data to give to a patient and collect from them but, unless you give the patient an opportunity to tell you what they are most worried about, you could be firing in completely the wrong direction.

“If you start with an open-ended question, it encourages a genuine two-way exchange and an understanding of what the patient is focused on, which might be something completely different from what you are most worried about. If you don’t focus on the patient’s concern, they may close down.”
CLOSING THE COMMUNICATION GAP

Patient integration and raised communication skills are vital factors in the future of oncology and Professor Fallowfield feels they need to be high on the agenda of discussions about how to maximise the benefits from new therapies.

Speaking after the Medscape Global Oncology Patient Centricity meeting at EHA 2023, she said: “So many of the things that we touched upon during the meeting were the salience of different words. The order that perhaps you use those in, and actually just how important it was to get lots of feedback from patients themselves about the things that they need if they’re going to make a truly educated and informed decision about what might lie ahead for them.

“If patients are to really engage in a way that most of them want to, then the doctors have got to find flexible, non-patronizing ways of explaining all these exciting advances.”

Mr Clark comments: “There’s a big communication gap and it is widening. It’s not just verbal interactions. Patients are now almost always copied in on the letters that go between oncologists and the GP and that is written in medical language. We get people posting copies of their letters online in forums asking questions such as: Can somebody explain this? Should I be worried?

“They are asking people they have never met who have no medical training for guidance. This should never happen. They are also sent away with information leaflets which are often not fit for purpose and can be scary things. The role of the written word in these relationships is very important and needs to be under the microscope as much as the physicians’ use of language, tone, and their ability to truly listen to the patient.”

Mistiming communications can drive patients to supplement their lack of understanding with advice from friends, families, and the internet. It is a trigger for myths and misconceptions to proliferate.

“There are issues with HCP time but there are many engagements that can be performed by nurses but it is important that they are introduced by doctors to the patient as an integral, knowledgeable and valued member of the care team.”

The understanding gap is compounded by the fact there is often a lull between diagnosis and the treatment plan; a gap that patients fill, or is filled for them by well-meaning friends and family, and visits to the internet that generate inaccurate and frightening information,” adds Mr Clark.

“Patients feed off those scare stories and crazy stuff on the internet and come into the treatment consultations with preconceptions that are almost never identified and addressed.”

Ms Warwick believes improved communication needs to be applied across the oncology care team with oncology nurses and other staff involved in direct contact with patients, also being offered training.

“There are issues with HCP time but there are many engagements that can be performed by nurses but it is important that they are introduced by doctors to the patient as an integral, knowledgeable and valued member of the care team,” she says.
Reframing the language of cancer

Mr Clark, through his personal journey and feedback from countless patients, echoes the call for a much more inclusive approach with clear language and appropriate tone from consultations.

“There is a language that is peculiar to cancer – a patient is labelled incurable or curable early on and there is no other disease where that applies,” he says. “We don’t talk about incurable diabetes or hypertension. It is a label reserved for cancer, and it can be a curse. “Cancer consultations have a distinctly bleak language and that can have a negative impact. If you are scared and think you are going to do badly then you are more likely to have a bad experience. Quite rightly, we need total transparency and full disclosure, but in oncology that has come to mean pessimism so that doctors cannot be accused of overpromising.

“A simple change of language and tone would make such a difference. We’re not talking about forcing positivity. We’re not saying promise the world to the patient. We’re not trying to make patients falsely positive. We’re trying to take away the false negatives – things that don’t need to be preying on their minds, those misconceptions that might push them into a negative mindset.

“Doctors are under enormous time pressures but if patients leave without as clear as possible an understanding then they won’t be ready or able to take an active role in their care. It can lead to further complications and really is a false economy in the long run.”
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THE MEDSCAPE LEARNING JOURNEY

So where does Medscape come in?

Medscape is the leading online destination for physicians and HCPs, providing evidence-based information, outcomes-led education, and expert perspectives to a global audience.

It is championing a holistic approach to advancing outcomes in cancer by deploying additive patient-centric education, alongside disease and treatment-centric education, to help HCPs further their ability to connect appropriately with individual patients, develop and adapt tone and language, and conduct an effective conversation.

“Integrating patient perspectives and effective communication into HCP education, alongside disease- and treatment-centric education, powers an informed, knowledgeable, and effective conversation between the HCP and the patient/caregiver. This builds trust and ultimately empowers patients to have an active role in their journey with cancer,” says Dr Victoria Harvey-Jones, associate director, Clinical Strategy Oncology, who is leading the patient-centricity and integration initiative at Medscape, and has collaborated with Professor Lesley Fallowfield, Lorna Warwick, and Steve Clark to bring this to life.

“We are committed to integrating patient voices into our education for HCPs from planning to execution, thereby providing patients with a seat at the table to help shape our activities and be involved in the most appropriate way to further optimize outcomes. This mirrors the evolving and integrated role of patients working with pharma in the clinical development of cancer treatments, from clinical trial design to practical application.”

Medscape’s additive educational programmes, which include webinars, panel discussions, micro learning, patient journey videos, symposia, and extra materials that are designed for easy assimilation, have all been constructed to have a practical impact on HCP-patient relationships and elevate outcomes.

“The challenge in developing impactful patient-centric education is to apply HCP expertise and clinical practice to all the different patients our learners may meet and, in doing so, truly bring global patient voices to life. Our tailored, holistic approach to HCP education works across the oncology care team to integrate insights from haematologists/oncologists, nurses, other specialists involved in the care of patients with cancer, and then importantly patient advocacy groups, expert patients, and specialists in HCP-patient communications.”

Powered by Insight

Medscape’s mission is to empower connections and elevate care, improving how the individual person lives with cancer. It achieves that with a vision to strengthen HCP and patient/caregiver relationships through education. Its goal is to empower patients and caregivers to become actively involved in their care and become integral members of the team collaborating for optimised outcomes and quality of life, both clinically and personally.

Just as cancer is not one condition, a patient’s behaviour and response is not universal. They have different challenges across all aspects of their life and health. HCPs need the knowledge, skills, and confidence to coax that information from patients and react to nuances of behaviour which include passive, collaborative, and active, each with their specific challenges.
“The education is powered by insights, particularly from global survey data from patient advocacy groups and patient testimonials which reveal their response to elements of their care pathway; what worked, what didn’t, their feelings after the first conversation and diagnosis, how their relationship with a doctor evolved, and what more they wished the care team had provided,” adds Dr Harvey-Jones. “These data and testimonies reveal the personal impact of care journeys and help us pinpoint good practice and drill down into the different challenges that individual patients and caregivers face. This is critical to HCPs’ ability to frame their approach and questions in the right way.

“We’re not saying that clinicians aren’t doing this already but we are committed to developing methods to consider HCP-Patient relationships in different ways and to deploy the tone, language, and questions that lead to even stronger relationships.”

Feedback from a recent Medscape patient-centric education programme in lung cancer, which integrated patient perspectives and effective communication, reported that oncologists believed the education they accessed helped them deliver better care because they could match their communication methods to a patient and their family’s learning style, thus gaining a deeper understanding of a therapy’s influence on their life, and gave them the ability to modify treatment plans to positive effect in response to patient input.

“The aim of the education is to help people live better lives with cancer,” says Dr Harvey-Jones. “Patient centricity also involves the family and caregivers who are increasingly being recognised as critical to outcomes because, if you support and engage them, you are able to better support the patients as well.

**CONCLUSION**

There is a pressing desire to make cancer therapies perform to their maximum capability so patients have improved outcomes both personally and clinically.

Evidence around the need to develop and strengthen HCP-Patient relationships has been building over recent decades with studies revealing how poor consultations and engagement have a detrimental impact on a patient’s health and quality of life prospects.

Integrating the patient voice into treatment plans in a more personalised, holistic fashion is a gateway to better health with elevated confidence and self-esteem, and patients being empowered to take an active role in their care.

Liaising closely with patient advisory groups and expert patients is critical to education planning, design, and execution that can make a difference to outcomes. This aligns with the pharmaceutical industry’s movement to integrate the patient voice from early stage clinical research through to approval.

It also brings healthcare system rewards in terms of increased enrolment in clinical trials, medication coming on stream faster, and cost reductions across healthcare.

Integrating patient perspectives and addressing language, tone, and engagement styles is a vital component of an additive educational approach to oncology that will create multiple dividends. Getting it right means that we can maximise the benefits from existing and new therapies and help create even better ones in the future.

Equipping HCPs, with an armoury of skills and techniques to better connect with patients, is the missing link in the mission to harness the dynamic benefits of this new era of oncology that empowers every person involved in every aspect of cancer care.

These skills – delivered from an evidence-based programme – improve an HCP’s capability and flexibility to connect with individual patients, leading to a cascade of benefits across the HCP-patient/caregiver relationship: adopting them ushers in a new era of patient centricity.

Professor Fallowfield frames the essential element of patient centricity by saying: “What continues to make the practice of oncology and medicine infinitely fascinating is seeing patients as people.”

This is an evolution that could create a revolution in patient outcomes.
References

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ABOUT THE INTERVIEWEES

LESLEY FALLOWFIELD, DBE, BSC, DPHIL, FMEDSCI  
Sussex Health Outcomes Research and Education in Cancer (SHORE-C)/Brighton and Sussex Medical School University of Sussex/ Brighton, United Kingdom  
Dame Lesley Fallowfield is Professor of Psycho-oncology at Brighton and Sussex Medical School, University of Sussex, where she is also Director of the Sussex Health Outcomes Research and Education in Cancer (SHORE-C) group. Dame Lesley originally trained as a nurse at Guy’s Hospital, London, before undertaking a BSc in Experimental Psychology at Sussex University. Research for her doctorate examining the perceptual correlates of optic nerve damage in demyelinating diseases was completed at the Universities of Sussex and Cambridge.

In 1991, she became the full-time Director of a psychosocial oncology group and was awarded the first European Chair in Psycho-oncology from University College, London, in 1997. Her research interests are wide and include the measurement of quality of life in clinical trials of cancer therapy and training healthcare professionals about communication skills, specifically those related to treating patients with cancer.

She has published over 450 papers, many book chapters, 3 textbooks and numerous DVDs with training handbooks. She lectures and runs training workshops throughout the world in psychosocial oncology, quality of life assessment and communication skills. She is a Fellow of the UK Academy of Medical Sciences, an Honorary Fellow of the Association of Cancer Physicians UK and was made a Dame Commander of the Order of the British Empire in 2016.

“For me, patient centricity means collaborative, shared decision-making; no decision about me, without me”

STEVE CLARK  
Patient Advocate; Campaigns Ambassador, Cancer Research UK; Founder, Strive for Five and Beyond  
Steve Clark was diagnosed with stage 4 colorectal cancer in 2013 and has since become an active patient advocate. He is a regular speaker for audiences of patients, healthcare professionals, researchers, and industry representatives as well as volunteering with several charities including being a Campaigns Ambassador for Cancer Research UK. Steve is a patient representative to several studies and study groups and has been co-author on several papers.

In 2017 he set up www.StriveForFive.org, a not-for-profit organization with the mission to give hope to fellow patients with stage 4 cancer and to advocate for improved care for those with advanced cancer.

He is a business and marketing consultant for the pharmaceutical industry with Redwood Brand Curators and has worked in UK and global pharma for over 35 years in business management and global marketing.

Steve is a former Chairman of the Pharmaceutical Marketing Society and was awarded Healthcare Communications Advocate by Communiqué.

“For me, patient centricity makes the person with cancer the focus, rather than the cancer”
Lorna Warwick is the CEO of the Lymphoma Coalition (LC), a worldwide network of patient organisations that support those affected by lymphoma, including chronic lymphocytic leukaemia (CLL). LC acts as a central hub for reliable and current information, as well as advocating for equitable care globally. Its mission is to enable global impact by fostering a lymphoma ecosystem that ensures local change and evidence-based action.

Lorna was appointed CEO of the LC in December 2018, to provide vision and leadership for the over 80-member strong organisation, having previously been the Coalition’s Director of Strategic Communications and Engagement. Lorna firmly believes that LC’s work must be grounded in solid evidence. During her tenure, the Coalition has expanded the breadth and use of the rich data procured from the biennial Lymphoma Coalition Global Patient Survey on Lymphomas & CLL (GPS), ensuring its increased use by Member organisations locally, as well as its inclusion at leading scientific conferences and in multi-stakeholder research projects. The GPS dataset allows LC to truly understand and report on the global patient experience, by subtype, therapy area, geography, gender, and age.

Lorna has successfully held senior leadership roles in health charities for more than twenty years and has a diverse background in patient advocacy, mission development, communications, and strategic planning. Her efforts have been focused on haematological cancers since 2003, at a national (Canada) and global level. Lorna is recognized and respected for strong leadership skills, breadth of knowledge, critical thinking, and patient-focus.

As a result of her years of experience in evidence-based advocacy and especially in the haematology field, she is frequently asked to present on patient experience, emerging trends, and important issues in the lymphoma and CLL landscape.

“For me, patient centricity means creating an environment where each individual patient has a voice, that is listened to, acknowledged and respected, to ensure patients get the best care aligned with their priorities when they need it”

Victoria Harvey-Jones is a Clinical Strategist at Medscape where she designs independent medical education for HCPs focused in solid tumours and hematological malignancies that aim to have a positive impact on the knowledge, competence and confidence of clinicians and ultimately the lives of their patients.

Victoria has an exceptional academic background with a first-class degree in Medical Sciences and a PhD in oncology. She also has 3 years’ post-doctoral experience, including time spent at the University of Oxford and the MD Anderson Cancer Centre in Houston, Texas, and has spent the last 14 years in the medical education and communications industry.

Victoria is passionate about bringing the patient voice into medical education, supporting clinicians to understand patient and caregiver perspectives, and have the confidence to empower them in collaborative decision-making to optimize patient outcomes, both clinically and personally. She is also an advocate of educating about effective HCP-patient communication to ensure the language of cancer is accessible to all and the time for conversation is maximized in a positive way during each HCP-patient/caregiver connection.

“For me, patient centricity is focusing on what is important to the individual person and their family, listening to their challenges, their treatment and life goals, their preferences, and ensuring those are integrated into a holistic approach to patient care alongside key disease and treatment considerations”

For more information on integrating patient-centricity into HCP education, please contact Victoria Harvey-Jones, associate director of Clinical Strategy, Medscape Oncology Global, at vharveyjones@webmd.net
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