



# Cash Cow

- EDITORIAL, *C. MAROLT*
- MEASURING HEALTHCARE OUTCOMES TO DELIVER VALUE AND LOWER COSTS, *R. S. KAPLAN & M. E. PORTER*
- REVENUE CYCLE MANAGEMENT, *B. STEWART*
- USE PATIENT SAFETY TO IMPROVE YOUR BOTTOM LINE, *D. B. MAYER*
- DELIVERING HIGH-VALUE IMAGING: A PARADIGM SHIFT FROM EFFICIENCY TO EFFECTIVENESS, *Y. ANZAI*
- PUBLIC-PRIVATE PARTNERSHIPS: A WIN-WIN FOR DANISH HEALTHCARE AND FOR THE INDUSTRY, *H. E. HENRIKSEN*
- DISRUPTION IS COMING TO HEALTHCARE, *R. PEARL*
- HEALTHCARE DATA: CREATING A LEARNING HEALTHCARE ECOSYSTEM, *E. STUPKA*
- DIGITAL TRANSFORMATION FOR MORE EFFECTIVE HEALTHCARE: INSPIRING VBHC INITIATIVES, *F.V. EENENNAAM ET. AL.*

NEW HEALTHMANAGEMENT.ORG EXEC EDITOR-IN-CHIEF, *A. LOURENÇO*

HOW TO INTEGRATE AI INTO RADIOLOGY WORKFLOW, *B. V. GINNEKEN*

RESILIENCE: THE AIRBAG FOR NURSES AND OTHER HEALTHCARE PROFESSIONS, *I. MEYENBURG-ALTWARG*

LEADING BREAST RADIOLOGIST WINS 2019 RSNA ACCOLADE, *F. GILBERT*

BRIDGING THE RADIOLOGIST STAFFING GAP WITH NEW TRAINING INITIATIVE, *C. RUBIN*

MEDICAL IMAGE EXCHANGE IN THE CLOUD: A MORE EFFICIENT WAY, *M. CABRER*

THE FUTURE OF CARDIOVASCULAR MEDICINE – TECHNOLOGY, GENDER BIAS AND TREATMENT STRATEGIES, *M. A. MAMAS*

CULTIVATING INNOVATION CULTURES IN HEALTHCARE, *D. MICHAELIDES*

THE ROLE OF EIT HEALTH IN TRAINING THE EUROPEAN FUTURE WORKFORCE, *A. DUCHER & U. MÜHLE*

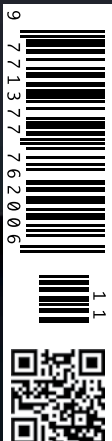
2020: ANOTHER YEAR OF RADICAL CHANGE IN HEALTHCARE, *L. DONOSO-BACH ET AL.*

THE IMPORTANCE OF BODY LANGUAGE, *A. NOOTEBOOM*

MEASURING THE NATION'S HEALTH, *H. DUNSFORD & C. NORRIS*

THE ABC OF PATIENT ENGAGEMENT: TIME TO BREATHE NEW LIFE INTO OLD STORIES, *E. SUTCLIFFE*

CREATING THE DREAM TEAM IN RADIOLOGY, *L. MARTÍ-BONMATÍ*





# The ABC of Patient Engagement: Time to Breathe New Life Into Old Stories

## Emma Sutcliffe

Director, Patient Engagement and Innovation  
NexGen Healthcare  
Communications  
London, UK

emma@nexgenhc.com

Summary: A medical communications expert looks at how industry's relationship with the patient has changed over 25 years and what is necessary for successful future liaison.



It is twenty-five years since I first started working in medical communications and with patient organisations. In 1995 there was no such thing as 'patient-centred behaviours.' There was clinical research, some communication

with physicians and the occasional reference to 'quality of life' or disease awareness campaigns. Patient organisations existed as offshoots of traditional fundraising - medical charities where at best a patient, or their carer, might be able

to retrieve a 'patient information leaflet' which was usually a woefully inadequate listing of the potential adverse events of a pharmacotherapy. The concept of real world evidence, patient-relevant communication or a patient-reported

## BREATHE Principles

- **BOOST:** Patients want tips, interventions, and interactions that help them live not that boast about a product
- **TRUST:** Let patients know you, your people, your aspirations, your dedication, your services – then your products
- **REAL:** Issues need to be authentic and products must work in the real world
- **HELP:** Provide channels and tech that are practical in customer-friendly modes and open a long-term dialogue
- **ENTERTAIN:** It is hard work living with a condition that affects your quality of life; make light where appropriate
- **EARN:** The final rule is to empower YOU to be more visible. It is ok to be here. With us. As fellow patients
- **ACTION:** Don't inundate; activate. Let people contribute, share, donate, add their skills to the mix

**Figure 1.** BREATHE Principles: Simple Rules to Breathe Life into Patient Engagement

outcome was the antithesis of the clinical trial protocol or the clinical study programme. Patients were seen and not heard; their lives outside of a hospital, trial centre or their GP surgery was non-existent. On reflection, it is no surprise that for medicine and research to become holistic it took a ruthless level of activism to make the pharmaceutical industry and medical leaders take notice of patients – it was the 'Act Up' patient organisation who first translated rhetoric into research.

### Reflections and Ruthlessness

Act Up was the near-militant activism group lobbying for better research for treatments for people living with HIV. In 1995, following almost a decade of political campaigning and refusing to capitulate to hysteria in place of research, the breakthrough, life-saving medications in the form of protease inhibitors achieved the unachievable. The beginning of the end for 'the killer virus' was

the drugs that took the surrogate marker for drug efficacy to combat HIV – viral load level – down to 'undetectable,' the nirvana for an antiretroviral treatment. As a trainee medical writer in 1995, the first work I ever did on 'patient voice' was writing a video for a European HIV Activist Group about these drugs; I will never forget the fax from the lab with 'undetectable' listed as the response to treatment. Nor will I forget meetings I attended with medical leaders on different continents in follow-up as the drugs were launched and introduced – where the clinical met the real world. It is one thing reading lab data; it is another thing entirely listening to how difficult it is to use drugs, to be adherent to a treatment regimen, to cope with side effects of medication when you don't have 24/7 support. Even today, there is still stigma and medication-fatigue from the 'mental load' of living with a now chronic condition. It is important to deal with the psychological impact

of the acute and the chronic on the everyday life of a patient.

Therein lies the explanation of why patient-centricity and treating 'the whole patient' counts more than facts on a page. The eponymous 'Ward 5b' hospital transition to 'patient-centred care' for people with HIV, for example, was another 'first;' health managers altered their viewpoints on things that matter to a patient, such as no limits on visiting hours, saying hello to a patient, showing care. In pharmaceutical companies, we started to understand that like it or not, HIV activists would challenge every aspect of a clinical trial and would be relentless in their pursuit of better treatments and beyond-the-pill support that would enable their response to therapy and return to a life worth living. The foundations for a patient-first mentality were laid (HIV.gov 2016).

### Recrudescence: The Rare and the Share

As we enter the next decade of patient-centricity, the striving to keep patient-focused in drug development prevails. We are still trying to find the right ways to equilibrate the sedulous necessity of the clinical trial with the holistic needs of the patient. Industry struggles to recruit and retain patients for the duration of a trial and for people living with or caring for patients with a rare condition, 'trial sinking' is an action that people are still willing to consider if they don't feel that the answers are arriving fast enough (Ledford 2018). In October 2019, Dr. Eric Topol, described the way that we communicate to patients as 'woefully inadequate'. There is still work to be done to collaborate and progress the concept of treating the 'whole patient' (Topol 2014).

To hear and understand the needs of patients, companies must initiate projects through social channels, invest efforts into creating Patient Reported Outcome tools using digital technologies and enable/sponsor connected, real-world concierge services that build patient-generated evidence of

confidence in pharma and a company's products.

A company that demonstrates good patient engagement will commit to providing the ABC:

- Awareness of the customer's needs.
- Behavioural health change support; and
- Care and contribution services that are enduring.

Several companies have consolidated all ABC elements into 'Branded Services offerings' for patients; examples of industry standards include Vertex Pharmaceutical's branded GPS programme, Biogen's 'Above MS', Genzyme's MS One to One portfolio programmes, AstraZeneca's AZ & Me clinical education and prescription savings programmes and Abbvie's MyHUMIRA support programme for all of Humira's autoimmune indications. The 'MS for the 21st Century' is an outstanding example of an 'ABC' project and I have worked closely with Grunenthal to launch and contribute to the creation of 'Painsolve,' a health and wellness platform assimilating insights around the underlying pathology of multiple pain conditions.

When companies commit to creating a whole patient 'ABC culture' where patients are regarded as subject area experts it expedites collaboration ensuring that patients can be active partners in research. At last, we are starting to recognise that we have a lot to do to improve patients' capacity to be in control of their conditions. We are thinking about how to improve patients'

abilities to manage their conditions, and take that insight and embed it within clinical trial programmes that extend to a person's entire life.

### Reputation and Rules

At NexGen, we bridge POs and phar-

“ ERIC TOPOL HAS DESCRIBED THE WAY THAT WE COMMUNICATE TO PATIENTS AS WOEFULLY INADEQUATE ”

maceutical companies by urging both parties to incorporate the 'BREATHE Principles' into their patient support programmes (Figure 1). We try to encourage that all patient initiatives and engagement start with a simple call-to-action. We embark on whole patient collaborations that question; 'patients live with their condition every day – do you?' hopeful that the answer to this will illustrate how to get closer to patients on their terms with the things that matter to them.

The consolidation of patient engagement activities generates multiple pockets of representative data which assemble to provide big data and broad insights. Every engagement is a touch-point opportunity with patients; ensuring quality engagement at the 'little data' level unlocks big data that is accurate, insightful and reflects the voice of both the masses and the individual. This

approach is a progressive one, which provides the foundation for a long-standing and trusted set of relationships with patients. Reciprocally, this means a company with a 'whole patient' culture will be uniquely positioned as a patient-preferred partner with an implicit understanding of their disease, their unmet need and their therapeutic burden (Dreyer and Rodriguez 2016).

A quarter of a century since my first foray into patient education and communication can be summarised into one key learning; pharma companies must treat the entire patient not just 'the disease.' Your reputation and your survival depends on it. ■

### KEY POINTS



- Twenty five years ago there was no concept of 'patient-centred behaviours.'
- Patient advocacy activism was necessary to change the attitude of industry towards patients.
- Companies should initiate projects through social channels to keep in touch about patient needs.



### REFERENCES

Dreyer NA, Rodriguez AM (2016) The fast route to evidence development for value in healthcare. *Current Medical Research and Opinion*, 32(10): 1697-1700

HIV.gov (2016?) A Timeline of HIV/AIDS. Available from [hiv.gov/](http://hiv.gov/)

[sites/default/files/aidsgov-timeline.pdf](https://www.aids.gov/sites/default/files/aidsgov-timeline.pdf)

Ledford H (2018) How Facebook and Twitter could be the next disruptive force in clinical trials. *Nature*, 563(7731): 312-315

Sutcliffe E (2018) Patient Centricity Frameworks: A Practitioners

Guidance. Independent Publication - Industry White Paper.

Topol E (2014) *The Patient Will See You Now: The Future of Medicine is in Your Hands*. New York: Basic Books