

EDITION #11

SMILES THAT SAVE LIVES

—
Making happier,
healthier patients

A large, bold, red graphic of the number '11' is positioned at the bottom center of the page. The '1's are thick and have a slight slant at the top. To the left of the '11' is a faint, light gray circular graphic consisting of two concentric circles. To the right of the '11' is a faint, light gray geometric shape resembling a stylized '1' or a bracket, with a small gray oval above it.

**SMILES THAT
SAVE LIVES**

—
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healthier patients

11

**SMILES THAT
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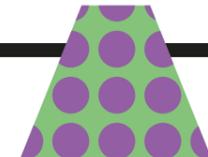
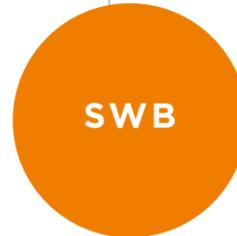
" We think our job is to ensure health and survival, but really it is larger than that. It is to enable well-being, and well-being is ultimately about sustaining the reasons one wishes to be alive. "

Dr. Atul Gawande, BBC Radio 4 Reith Lecturer for 2014⁶

WORTHWHILE

WHY
A SMILE
IS SO...

Make a person smile and they'll feel better, not just emotionally.



1. ScienceDirect. Subjective Well-Being. Available at: bit.ly/2Y3ix5g Accessed: July 2019.
2. Tay L, Diener E, Xuereb C and De Neve J. (2013).
3. Arlington S *et al.* (2012). Pharma 2020: From vision to decision. Available at: pwc.to/1sIQfok Accessed: July 2019.
4. YouTube. Evian Roller Babies. Available at: bit.ly/2OcBcHo Accessed: July 2019.
5. Campaign. Evian roller babies makes Guinness Book of Records with 45 million online views. (2009). Available at: bit.ly/32l2ro Accessed: July 2019.
6. BBC Radio 4. The Reith Lectures. Dr. Atul Gawande. (2014). Available at: bbc.in/2Lk5Rq Accessed: July 2019.

The link between happiness and health is well documented. More accurately referred to as subjective well-being (SWB)¹, it's been demonstrated that a positive outlook is not only the result of good health, but the cause of it. According to studies, SWB can have a significant impact on a broad spectrum of health issues: improved cardiovascular, immune and endocrine systems; lowered risk of heart disease and stroke; increased speed of recovery; improved cancer outcomes; reduced inflammations; better adoption of healthy behaviors; and even increased longevity² (see study below).

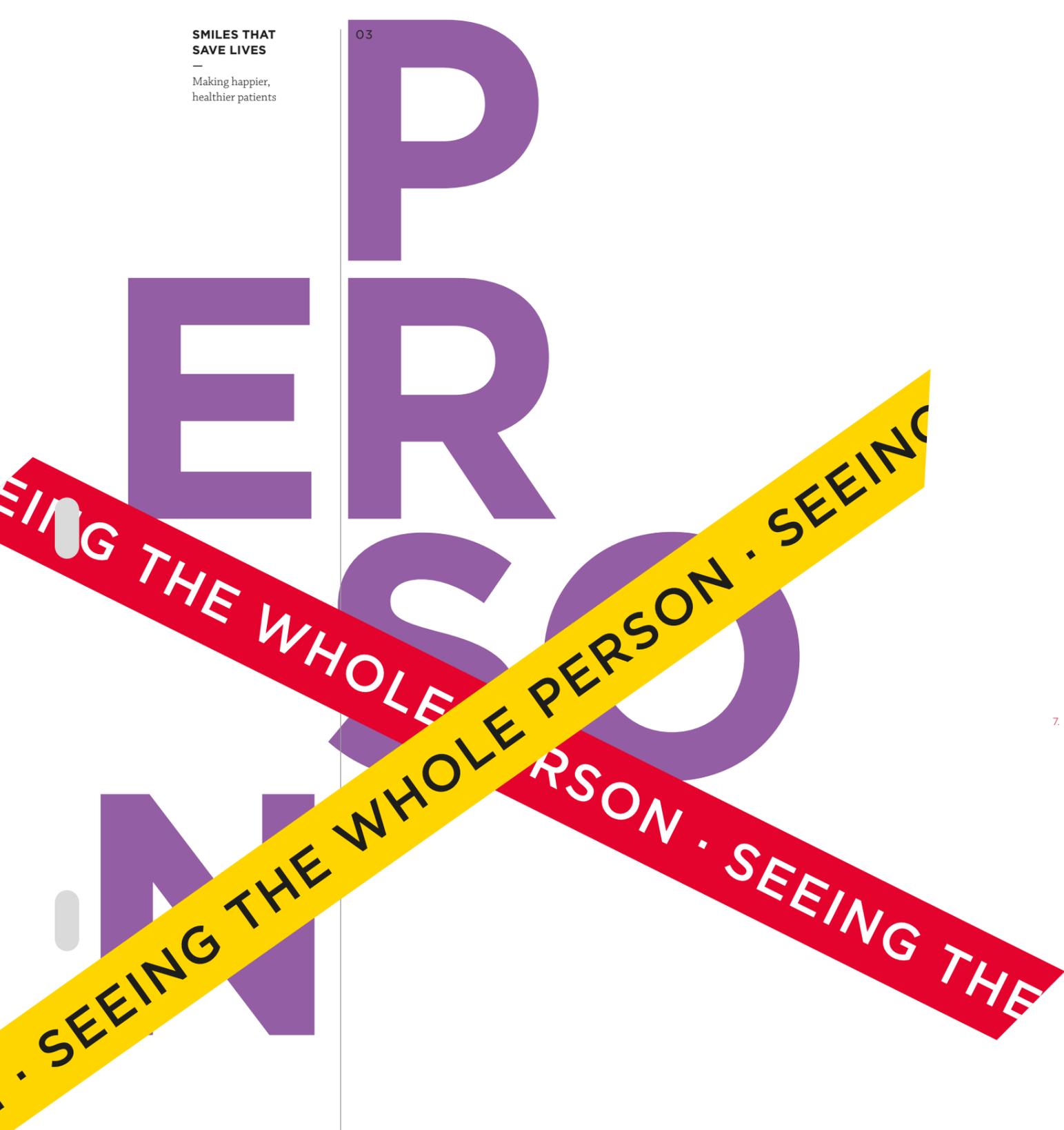
Even given the briefest consideration, the connection seems perfectly logical. What makes less sense, is that this potential positive outcomes catalyst isn't better utilized within the healthcare industry. The focus is always on 'getting patients better,' but do we give their happiness the consideration it deserves? Should treatment suppliers take greater responsibility for patients' overall emotional well-being?

In the modern era of healthcare, pharmaceutical companies no longer simply sell drugs or treatments. They supply outcomes, a fact that is increasingly dictated by the value-based purchasing models of healthcare providers around the world.³ Thus, if a patient's SWB is the key to unlocking improved outcomes, then it's also vital to the success of a treatment brand.

More than just a commercial obligation, for the healthcare communications sector this represents a fantastic opportunity. It's a chance to utilize the talent within the industry, to offer a point of difference, and to transform lives. The ability to elicit emotional responses from people is one of the core crafts of good communications, as ads such as Evian's 'Roller Babies'⁴ demonstrate. The film's wit and imagination so charmed its viewers that in 2009 it broke the Guinness World Record for the most viewed online advertisement,⁵ delivering a 7% bump in sales and a 13% improvement in market share in the process. The needs in healthcare might be more complicated and diverse, but significant work doesn't always have to be serious. Throughout this paper there are examples of interventions that have dramatically improved health by introducing joy and pleasure into peoples' lives; from a physical therapy tool that has boosted efficacy by turning exercises into exciting gameplay, to a care home that has reduced prescriptions and mortalities by surrounding residents with plants and animals. If we're to meet the greater well-being needs of patients then what we offer them must be imbued with vitality.

DOES HAPPINESS TRUMP HOLINESS?

A study by Danner *et al.* (2001) found that happier nuns lived about 10 years longer than their less happy colleagues. The nuns all lived in similar conditions and had similar diets, leading researchers to conclude a causal relation between positive moods and longevity.



SEEING THE
WHOLE PERSON

Happy patients do not live within the cramped confines defined by their condition; they're people after all. However, healthcare systems around the world sometimes fail to recognize this.

7. Preston C et al. (1999).

Pathways are fragmented and disease-specific. In a bid to alter this, healthcare providers have sought to become more responsive to patient views. However, like the pathways they assess, the measures they use to evaluate have been criticized in the past for exaggerating the importance of amenities at the expense of more important issues such as outcomes and relationships.⁷ Sometimes systems struggle to adequately accommodate patients with complex conditions, let alone a patient's needs outside of treatment itself.

PATIENT NEEDS

INFORMATION

COMMUNICATION

EMOTIONAL
SUPPORT

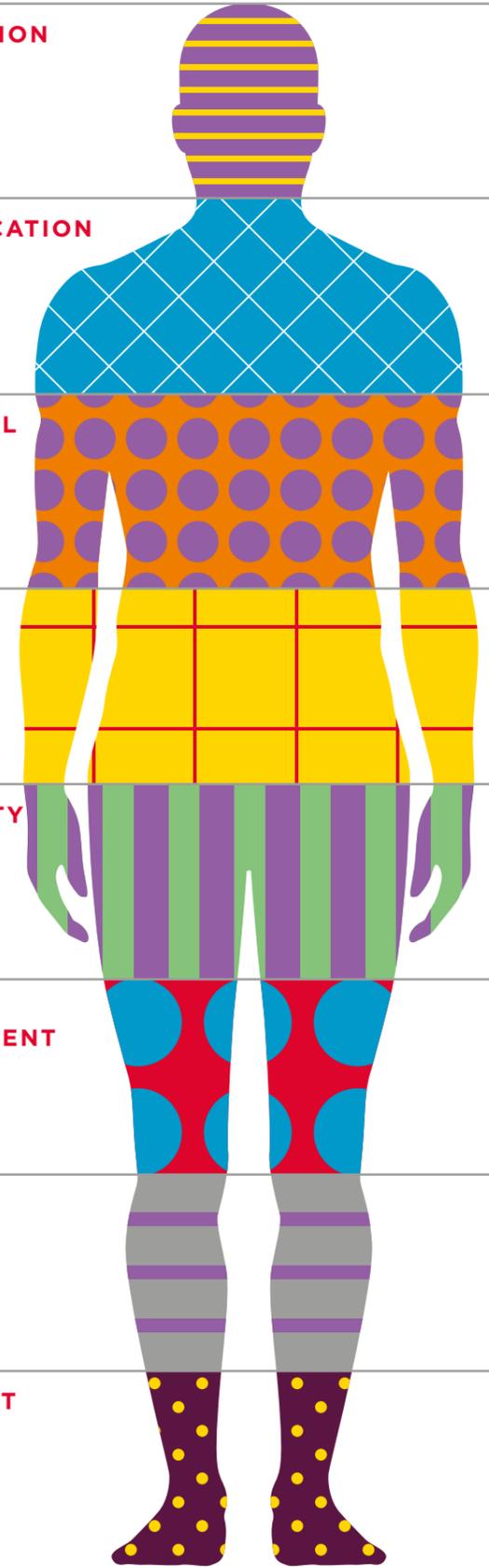
CONTROL

CONTINUITY

GOOD
ENVIRONMENT

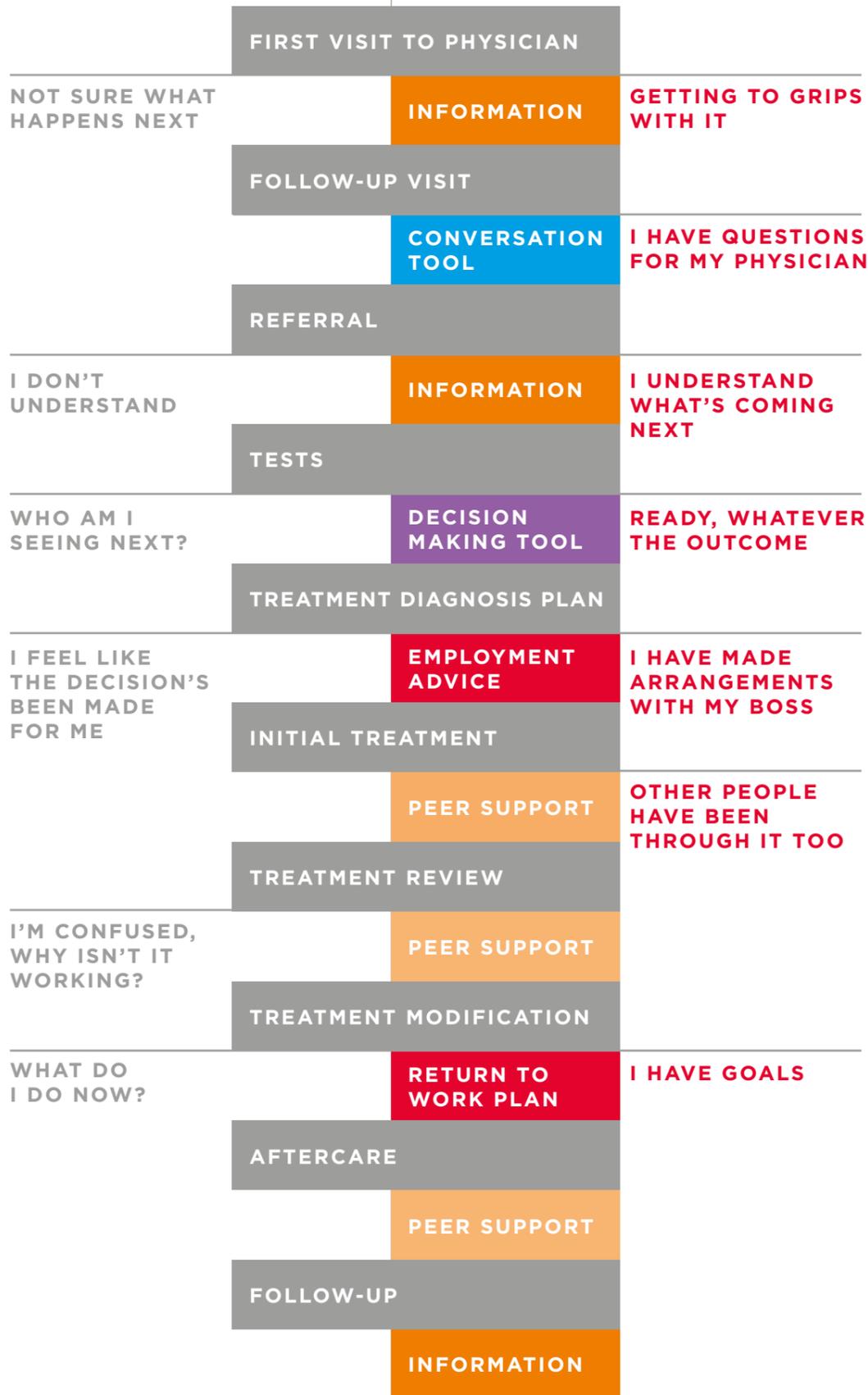
STABILITY

TREATMENT



UNSUPPORTED PATIENT PATHWAY HAS LOTS OF GAPS

HOLISTIC SUPPORT FILLS THOSE GAPS



“ Consultants look at you, and they see a blood test not a person. ”

Lucy May Middleton, holistic support advocate and educator

If these pathways are to promote more positive and engaged patients (and therefore better health outcomes) then perhaps pharma can help to broaden their focus, so that they are not only defined by treatment considerations but encompass a broad and holistic range of patient needs. The treatment itself is just one of a patient's concerns; they need to:

- communicate their needs with professionals in order to be appropriately referred (Getting In)
- understand their condition and come to terms with its emotional impact (Getting To Grips)
- make decisions about their treatment and necessary changes to lifestyle, and manage the associated different appointments and schedules (Getting What You Want)
- position themselves in a comfortable and healthy environment (Getting Comfortable)
- make arrangements regarding work and financial support (Getting On)

All of the above are significant in supporting the overall well-being of a patient, and any treatment will struggle to fulfill its potential within a system that fails to acknowledge this. By addressing these needs as part of an end-to-end support model, holistic support from pharma could supplement existing healthcare systems to fill potential gaps in treatment pathways. Thus ensuring that a patient's journey is guided as much by their feelings and experiences as it is by clinical interventions.

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*" Everywhere I see
the mistake of ignoring
that people have
priorities in their
lives besides merely
surviving another day.
Even in severe illness
and frailty people
desire connections to
others and purposes of
their own choosing. "*

Dr. Atul Gawande, BBC Radio 4 Reith
Lecturer for 2014⁶

6. BBC Radio 4.
The Reith Lectures.
Dr. Atul Gawande.
(2014).
Available at:
bbc.in/2Llk5Rq
Accessed: July 2019.

8. Havas Lynx Group
White Paper.
Personalized
Medicine. (2016).
Available at:
bit.ly/32vwqYv
Accessed: July 2019.

In a speech at the 2013 Havas Health Global Summit, Google's Head of Industry for Health, David Blair, discussed the importance of supporting key moments in the patient journey. Blair asserted that the critical patient actions (and decisions) that affect outcomes don't necessarily occur in consultations with healthcare professionals, but in a series of unannounced moments that take place outside of these meetings. What's important, is that pharma helps patients to take informed and appropriate action in these instances, or as Blair puts it, to 'win the moments that matter.'

These moments aren't fixed; they don't abide by the prescribed stages of a treatment pathway; they occur and reoccur throughout and beyond it. As such, in meeting patients in these moments, pharma will need to develop flexible solutions.

Even more crucially, interventions should offer patients progression. Understandably, it's highly important to them. A study by Preston *et al.* (1999) into opinions of primary and secondary care found that the key issue amongst patients was the concept of progress. To the patients involved, progression meant more than passing through a system of care; it included the notion of moving from illness to recovery, or where recovery was not possible, adjustment to an altered state of health.

Progression is a significant motivating factor, whether used in an overarching strategy or in the implementation of gamification techniques. It is a powerful influence on subjective well-being that can mitigate the impact of treatment setbacks and relapses when utilized successfully.

In addressing these moments, pharma will not usurp healthcare professionals but augment their activities. Personalized Medicine, a white paper from Havas Lynx Group,⁸ discusses how the pharmaceutical industry can assist professionals more directly in holistic aspects of care.

GETTING IN

COMMUNICATION

It goes without saying that communication is vital in patient-professional interactions. Whilst success in this area is in part dependent upon the professional, there are things that can be done to help patients get the most from interactions. Consultations are very time-pressured and patients can leave wishing they had asked more. In an interview with Havas Lynx Group (see 'Introducing Lucy'), diabetes patient Lucy May Middleton stated that 'a lot of the time you don't even know the questions you should be asking.' Preparing patients with appropriate information in the build-up to consultations can enable them to be better equipped to get the most out of these meetings.

Dr. David Rosenman, of the highly regarded Mayo Clinic⁹, has discussed the impact the Khan academy has had on education and its relevance to healthcare.¹⁰ He described the 'flipped classroom' effect caused by the online academy; students watch and learn at home and then bring challenging areas to the attention of the teacher during class. Rosenman believes that there is 'a lot of opportunity to apply this model to healthcare,' and such an approach could certainly help maximize the value of precious face-to-face interactions.

CASE STUDY INTRODUCING LUCY



Lucy May Middleton is an advocate for improved support in and around the patient pathway. As a type 1 diabetes patient, Lucy has been through a difficult treatment process, eventually receiving a simultaneous pancreas and kidney transplant after a prolonged period of complications. Nowadays she is a regular contributor to a HCP leadership training program, and is in the process of setting up a support group in a bid to offer the kind of emotional support that her own journey lacked.

Lucy May hopes that sharing her story will help improve future patient outcomes, and recently she spoke to Havas Health and You CEO West, David Hunt, about her experiences. Extracts from their discussion are included throughout this paper, or for more, see the Havas Lynx Group YouTube channel.

11. Tickit Health. Available at: tickithealth.com Accessed: July 2019.

ACTIVATION

Interventions need not be complex; encouraging the patient to think about what they want to discuss with their physician in advance brings focus to interactions, and can be achieved by something as simple as a questionnaire. The iPad and desktop survey tool Tickit¹¹ has applied a sophisticated digital rendering to this methodology. Patients complete the survey in the waiting room before their appointment, with important issues immediately flagged to professionals, so that both parties are more switched on to the things they need to discuss in the consultation. The discretion that the app provides makes it easier for patients to answer questions about private and delicate matters that they may otherwise find too embarrassing to initiate into conversation with a professional. Tickit utilizes graphics and interactive features to make the surveys engaging and accessible to a range of literacy rates.

Applications such as Tickit are extremely valuable in extracting information from patients that can lead to a better diagnosis, in some cases helping patients to objectify symptoms that they feel are subjective and therefore ignore. Reservations about the validity of symptoms can be a barrier to patients presenting health issues, as outlined by a participant in the Preston *et al.* (1999) study referenced previously: 'It's all subjective, pain in the back, so you feel that perhaps they don't believe you.'

Allowing patients the opportunity to accurately validate the severity of their condition can help allay these fears. This was a feature of the Psoriasis360 campaign Havas Lynx Group developed with Janssen. A suite of tools enabled patients to assess their psoriasis; the Severity Calculator rated physical symptoms along a clinically recognized scale, whilst the Impact Questionnaire measured the emotional effect the condition was having. As well as providing a score, both tools offered advice on what steps patients should take next. They featured on a patient website, Facebook page, and mobile application, and were completed over 75,000 times during the course of the campaign. By providing tools from a trusted source (an issue in patients seeking information without direction), the campaign gave patients the confidence to present their issues to professionals, which in turn, should have initiated more timely referrals.



GETTING TO GRIPS

INFORMATION

- 12. From 2012 CQC survey quoted in The Telegraph. (16th April 2013).
- 13. Kishokai Medical Corporation. Mother Book. (2014). Available at: bit.ly/1gOIFor Accessed: July 2019.

When it comes to information, patients can find themselves underserved or overwhelmed. One in five patients treated by NHS England feel that they're not given enough information about their condition or treatment,¹² whilst those who look online for supplementary information may quickly get lost amidst swathes of unreliable content.

Scepticisms about whether patients value pharma-produced information can make brands hesitant to invest, but there's clearly a desire for trusted and quality content. And by focusing on the quality of their materials, pharmaceutical companies might find that they overcome their own doubts, as well as any that may be held by patients. If it's good enough, people will want to use it.

Creativity in delivery is important here; patients have a lot to take in and if you can make a message resonate with them, it can prove to be a real shortcut to unlocking their understanding and acceptance. Mother Book¹³ is a beautifully engineered pregnancy diary produced by Dentsu for Kishokai Medical Corporation. Each page has been embossed to produce a topographical rendering of a mother's 'bump' and breasts, which change size and shape as you progress through the different stages of pregnancy in the book. Rather than pack the book with written information, every page has been illustrated to help parents understand their baby's condition at that point. For example, on the 26 weeks page, the bump has been illustrated to look like a pear, to communicate that the baby can now taste the food that the mother eats.



"I think some of the anxiety and fears could have been alleviated if I'd had more information. I did look on the internet but there just weren't the resources."

Lucy May Middleton, holistic support advocate and educator

CASE STUDY

THE POWER OF MEETING PREFERENCES



People can have very different attitudes and approaches to how they deal with health issues. Personalization has been a hot topic, though patients' needs should be understood to be circumstantial as well as individual; what they want can change. Research into cancer patient preferences showed a decreased desire for information in the later stages of treatment, whilst emotional needs rose.¹⁴ The release of information should be carefully curated to match these needs. Often, patients receive the majority of information at diagnosis, when they may be shocked, scared and unable to process it without feeling overwhelmed. Timely, informative support embedded throughout the pathway can be better absorbed and far more effective. A number of studies and reviews have evidenced the power of patient preferences, with correlation shown between met needs and improved well-being¹⁵ and outcomes.¹⁶

It can be helpful to actively engage patients in information about their health. Patients who are more 'switched-on' to their condition will generally fare better than those who have passively accepted professional diagnosis without establishing their own personal understanding. The rise of wearable technologies and ingestible sensors (such as Proteus Digital Health's 'Discover'¹⁷) will in time facilitate greater patient understanding of their own health.

Once again, the potential of this understanding is in part dictated by how we render it. Zamzee (pictured bottom left) is a platform designed to help children be more active.¹⁸ To children, an exercise program with information about living well could easily prove boring, so Zamzee's content is wrapped up in a game. Exercises are posed through a series of challenges, which children complete (as measured by a clip-on sensor), in order to score points that earn rewards. Similarly, MIRA¹⁹ transforms instruction for physical therapy exercises into a video game. Children interact with the game via a motion sensor that allows them to use their exercise movements to (for example) navigate a submarine through an underwater adventure. Professionals have found that MIRA has helped train children with a range of neurological impairments to achieve improved motor activity and balance.

GETTING TO GRIPS

EMOTIONAL SUPPORT

The importance of subjective well-being (SWB) was noted at this paper's outset, but it's worth noting how widespread the issue of poor SWB is, especially amongst those with chronic conditions. Approximately 50% of newly diagnosed cancer patients experience levels of anxiety and depression severe enough to adversely affect their quality of life.²⁰ Reportedly, the percentages aren't much better for patients who suffer with heart attacks, Parkinson's or MS (at least 40%).²¹

In her interview with David Hunt, Lucy May discussed how, at times, her condition was very isolating. Physically limited, with no support groups in her local area, she believes the opportunity to talk to people going through the same thing via an online peer network would have made a real difference to her: 'I still don't actually know any patients that have had a pancreas and kidney transplant.'

For the most part, pharma is still hesitant to be the provider of this social link, although those operating in other sensitive arenas may offer some inspiration. Child helplines have been providing young people with telephone counseling for decades. Over the years, they have expanded their offerings to include forums and social channels, bringing vulnerable young people together and giving them a sense of solidarity.

CASE STUDY

CHILDLINE'S ZIPIT APP



ChildLine (a UK counseling service for children and young people) has always made a point of tackling delicate issues head on, in a manner that attracts the attention of its audience. In 2013 ChildLine produced an app called Zipit²² to help young people deal with sexting. As well as information and advice, the app includes a gallery of amusing memes that users can use to diffuse potentially uncomfortable situations.

Who's to say pharma couldn't be so brazen and well-humored; of course some conditions are sensitive, but patients often take solace in being able to see the lighter side.

If social presents too many barriers, then other interventions can help, especially if they encourage taking action to improve well-being. Tools such as the Distress Thermometer²³ (for cancer) and Psoriasis360 Impact Questionnaire (see 'Getting In') help patients translate emotional distress into positive action they can take to address their issues. Being faced with a tangible score of how unhappy they are can be just the jolting realization patients need to seek help.

"I was about to go onto dialysis and I was still in denial."

Lucy May Middleton, holistic support advocate and educator

MEET INFORMATION NEEDS

DEVELOP UNDERSTANDING

IMPROVE SENSE OF AUTONOMY

INCREASE MOTIVATION

GREATER ADHERENCE

ADOPTION OF HEALTHY BEHAVIORS

MORE PRO-ACTIVE OUTLOOK

BETTER OUTCOMES + BETTER WELL-BEING

20. Armes J et al. (2009).
21. WebMD. Dealing With Chronic Illnesses and Depression. (2014). Available at: bit.ly/1AgriG2 Accessed: July 2019.
22. Zipit app. Available at: childline.org.uk Accessed: July 2019.
23. NCCN Distress Thermometer: Cut off Points and Clinical Utility. Available at: bit.ly/30MQLa7 Accessed: July 2019.

GETTING WHAT YOU WANT

CONTROL

Enabling patients to take control of their care management actively engages them in their treatment, instilling a can-do attitude and generally benefiting their well-being.¹⁵ However, keeping track of the advice of different care teams and communicating this at various different appointments can make care management a real headache for patients.

Healthspek²⁴ is a free app that manages all personal and family health information in one secure place, accessible from multiple devices anywhere in the world. The app helps consumers manage their medications, track vitals and access care. Users can also record physician, insurance and emergency contacts, as well as allergies, medical charts and more. The app's mailbox receives medical records and facilitates electronic communications with providers; with the patient's permission, physicians can access health records.

Pharma's specialist expertise in certain disease areas, particularly those which are more complex, has already helped the industry to design some similar systems (see 'Continuity'). Digital is the making of these interventions, although printed treatment diaries with room for notes and letters may still offer patients value.

25. Curtis S. Digital medical records: do Patients Know Best? The Telegraph. (20th March 2014). Available at: bit.ly/1d72CG6 Accessed: July 2019.

" My patients sometimes refuse treatment or fail to take it because they don't feel they have ownership – they feel that their treatment is being imposed on them. "

Dr. Susan Hill, consultant gastroenterologist at Great Ormond Street²⁵

CONTINUITY

Patients expect to see a range of healthcare professionals throughout their treatment. The expertise of physicians with specialist training is something they both appreciate and take great comfort from. What they don't appreciate, is the conflicts and confusions that can come with disparate sources of care.

Lucy May describes the ideal patient journey as a relay race; each party involved should do their best to give the patient the care they need and then ensure that the next professional has a firm grip on the patient's situation, before releasing the baton and dropping back. In reality, this isn't quite the case and sometimes information is lost or not communicated, and can fall through the gaps.

Other sectors employ people whose sole purpose is to ensure continuity; for example, banks have relationship managers. It's difficult for any one person to fulfill this role in healthcare, with specialist nurses probably coming the closest.

Pharma can help here, by building systems that fit around treatment through partnerships with healthcare providers. This can sound grander than it is, as often good communication is the key; offering patients a consistent thread that runs throughout rather than reshuffling hospital structures.

This is how Care4Today (C4T) Orthopaedics functions, a system developed by Havas Lynx Group in partnership with Janssen. C4T Orthopaedics is designed to improve the consistency and quality of care for patients undergoing hip or knee replacement surgery. The platform allows patients to track their progress, informs them of upcoming appointments, provides them with a customized exercise program (with videos of patient exercises), and lets them communicate directly with their hospital team. Unlike Patients Know Best, C4T guides patients along a defined pathway to recovery, providing the comfort of knowing what (and who) is coming when. So far, trials of C4T Orthopaedics have resulted in a reduction of patient hospital bed stays, demonstrating the potential to lead to significant savings.

15. Street *et al.* (2012).

24. Healthspek. Available at: healthspek.com Accessed: July 2019.

GETTING COMFORTABLE

ENVIRONMENT

26. Havas Lynx Group White Paper. Pushing the Right Buttons. (2014). Available at: bit.ly/2YODNlj. Accessed: July 2019.
27. IDEO. Sacred Care for St. Joseph Health. (2012). Available at: bit.ly/1BrT2HH. Accessed: July 2019.
28. Macmillan Cancer Support. Cancer environments. Available at: bit.ly/1wvbmIR. Accessed: July 2019.

The significance of the environment in which a patient receives care demands more than cleanliness and tidiness. As well as accessibility considerations, a patient's privacy and dignity, comfort and well-being, and personal choice and control should all be taken into account. As with any user experience, the central questions are what are they there for and what do they feel.

A nursing home in New York overcame the sense of depression and dependency amongst its residents by filling its premises with plants, animals and children (see case study). More than the act itself, it's the thought behind it that is worthy of recognition. Filling the home with life was an acknowledgement that people had come there to live, not die, and deaths fell by 15%.

Such consideration and innovative thinking does not always need to be applied on a grand scale. In their work improving patient experience at various sites, IDEO have demonstrated that even the smallest interventions can make a patient's day happier. At one site they attached wing mirrors to beds so that patients could see and talk to the porters that wheeled them around.²⁶ At another, the change was smaller still. They adjusted the form that administrators filled in when patients first reported to the hospital, adding a space for a short description of what the patient looked like.²⁷ Thus, when a professional came to collect the patient, they wouldn't be shouting the name of someone they'd never seen before across a busy waiting room. Instead they could use the appearance notes, and approach and welcome them directly and with discretion. Such a small step dramatically improved the dignity of a situation in which patients are often especially vulnerable and scared.

Pharma can, if it wishes, play its part in such interventions. The life-led revolution at Chase Memorial Nursing Home was funded by a New York State innovation grant. Macmillan Cancer Support in the UK provides expertise and funding to assist in the creation of quality cancer care environments.²⁸ Whether the relationships are financial-based or expertise-based, pharma could take the opportunity to partner with healthcare providers by innovating some powerful patient experiences.

"Every time I go for a check up I have to sit alongside women going for scans and experiencing the joy of being pregnant, knowing that my womb cancer has robbed me of the chance to have my own child."

Charlotte, a patient living with cancer²⁹

CASE STUDY

CHASE MEMORIAL NURSING HOME: A HOME FOR LIFE³⁰



When Bill Thomas took the job of Medical Director at Chase Memorial, he was depressed by what he saw. People who were once active members of the local community had been made dependent, not only by their age, but by the culture that surrounded the home. So he sought to attack what he termed the Three Plagues of nursing home existence (boredom, loneliness and helplessness) by bringing life into the home; literally. With the help of his staff he transformed the home, such that its inhabitants now include one hundred parakeets, four dogs, two cats, a colony of rabbits, and a flock of laying hens. There are hundreds of indoor plants throughout the home, and a thriving vegetable and flower garden outside. Thomas has even brought children into the home, introducing on-site child care for staff and an after-school program.

Researchers studied the effects of the initiative for two years, comparing Chase with another nursing home nearby. Results showed that Chase's total medication

spend fell to only 38% of the comparison facility, and that deaths fell by a huge 15%. 'I believe the difference in death rates can be traced to the fundamental human need for a reason to live,' Thomas said, 'people who we had believed weren't able to speak started speaking. People who had been completely withdrawn and nonambulatory started coming to the nurses' station and saying, "I'll take the dog for a walk."'



GETTING ON

FINANCIAL AND WORK SUPPORT

Everyday matters to do with work and money can be a considerable source of stress and anxiety for patients with chronic diseases. At best, adjustments will need to be made and patients may have to alter their expectations. At worst, things that were once taken for granted can become a dominating pressure that curtails a patient's well-being.

For those who can't work, gaining access to grants and state support can be difficult and draining, the last thing someone who's already sick would want. The manner in which Barclays bank, in the UK, has dealt with digital literacy offers a guide to possible interventions. Following surveys of customers aged 65 and older, Barclays discovered that customers were missing out on the services and savings afforded due to a lack of tech know-how. Responding to the problem, Barclays launched Digital Eagles in 2013.³¹ The initiative has placed 7,000 tech specialists in branches around the UK, with the express purpose of helping digital novices understand how to use the internet and apps to enhance their daily lives.

In the same way that Barclays helped customers overcome the barrier of digital literacy to improve their financial health, could pharma help patients overcome barriers to financial support in order to improve their personal health? Sessions and one-to-ones run by financial experts, explaining what support patients are entitled to and how they can access it, could help direct patients to financial assistance much earlier on in their pathway, saving considerable stress and allowing them to focus on their recovery.

" You kind of imagine that the state will be there...will come to your rescue. And it didn't... We had to sell everything we had...It was this feeling of a system wanting to just break you, just really break you. "

Nicky Begley, wife of David, an MS patient³²

Even for the well-informed, gaining state assistance can be a battle field, as Nicky and David Begley found.³² David suffers from Multiple Sclerosis (MS), and his condition has deteriorated to the point whereby he can no longer work. It took a 13 month battle, and two incorrectly refused applications, before the couple was granted Disability Living Allowance. In the face of complex and changeable benefits systems, perhaps pharma could find ways to use its clout and resources to help those who aren't getting what they need to lobby for change. Actively supporting patients in this way, in times when other authorities are letting them down, could turn around some desperate situations and enable pharma to communicate a commitment to the well-being of patients. It's an ambitious proposition, but one that could deliver significant and long lasting improvements in outcomes whilst building equity for the sector.

Helping patients access financial support doesn't have to be quite so revolutionary; even good quality signposting delivered early-on in the patient pathway can make a difference. The strengths of Macmillan's materials is how accessible they make information; financial support on the Macmillan site is segmented into different needs and sub-needs, so that users can quickly navigate to the information that's relevant to them and drill down into the detail of it.

Not all patients will need to cease work of course, and employment can provide patients with a focus and stimulation that helps to improve their health. To enable this, employers and employees need to develop a good mutual understanding of what is required of both parties, a process that could be difficult to initiate unassisted.

'Work, MS and You'³³ is a very useful document produced by the MS Society that communicates a lot of useful information in an easily digestible style. As well as information for employees and employers, the guide features a large toolkit of templates, including workplace adjustment agreements, situation assessments and future planning documents. The templates are not just intended to facilitate formal agreements. A lot of them are for employees with MS to use to really think about their work situation, posing important questions and enabling them to formulate practical and realistic strategies to help them work around their condition. Despite its simple execution, documents as useful as this are hard to come by. If anything, the opportunity for pharma to deliver support in this quarter is best evidenced by the absence of existing interventions and infrastructures in some therapy areas.

31. Barclays. Digital Eagles / Turning silver surfers into savers. (2014). Available at: bit.ly/1kijg1S Accessed: July 2019.

32. David and Nicky feature in MS Society Stop The MS Lottery - Financial Security. (28th April 2013). Available at: bit.ly/1GsQpVT Accessed: July 2019.

33. MS Society. Work, MS and You. Available at: bit.ly/2JNwhaj Accessed: July 2019.

CARING FOR THOSE WHO CARE

34. Reuters. The future of U.S. caregiving: High demand, scarce workers. (2017). Available at: reut.rs/32x2co3 Accessed: July 2019.

35. WHO. Current and future long-term care needs. (2002). Available at: bit.ly/1GsRq04 Accessed: July 2019.

So far this paper has focused on patients alone, although almost every mention of patient could be read as ‘patient and carer,’ such is the constancy of carers’ presence and importance in patient journeys.

Many patients simply couldn’t manage without the family and friends that look after them, and they are of ever increasing value to healthcare and more broadly society. Paul Osterman, professor of human resources and management at the Massachusetts Institute of Technology’s Sloan School of Management, predicts that in 2030 there will be a national shortage of 151,000 paid direct care workers and 3.8 million unpaid family caregivers,³⁴ whilst in 35 years time China will find that for every five working members of its population there is one person requiring daily assistance.³⁵ In the developing world, the situation seems even more severe; the World Health Organization (WHO) anticipates that in some developing nations, needs will soar by over 400% in the coming decades.³⁵

Pharma companies are not immune to the importance of carers, and treatment pathways are usually developed with a solid awareness of their role in mind. However, it’s rare to find pharma initiated interventions aimed at carers.

The information and emotional support landscape is dominated by charity organizations, whilst medical technology is proposing some interesting ideas, namely Proteus Digital Health’s ingestible sensor (mentioned very briefly earlier, in ‘Getting To Grips’). Alongside its professional function, the medical tracking system seems largely aimed at carers.

Every time the sensor (worn on the patient’s arm) detects the signal of an ingestible chip included in their oral meds, the carer receives a text message letting them know. The system also allows patients and carers to set-up ‘nudges’ to remind patients to take medication or exercise. This could all feel a little Orwellian for the patient, although the intention is to alleviate the matronly pressures carers face.

36. Dr. Atul Gawande. Slow Ideas. The New Yorker. (29th July 2013). Available at: nyr.kr/1B5zKDO Accessed: July 2019.

37. AARP. National Alliance for Caregiving. Caregiving in the U.S. (2015). Available at: bit.ly/32lwy7r Accessed: July 2019.

Carers are an absolutely vital force in the health and well-being of many patients. But are we paying enough attention to **their** well-being?

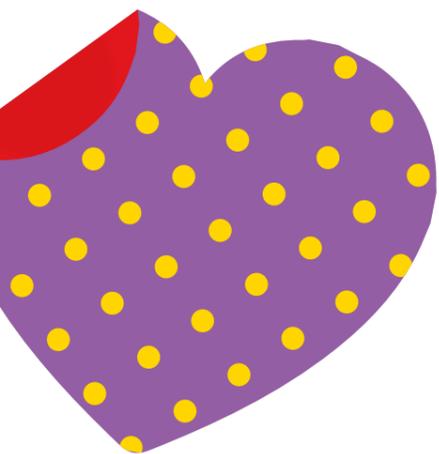


Whilst Proteus’ sensor operates at the forefront of modern medicine, arguably the most successful carer-based intervention of all time predates the invention of the World Wide Web. In 1980, Bangladeshi non-profit organization BRAC set out to tackle diarrheal disease. At the time, it was the world’s biggest killer of children under the age of five. Dealing with remote rural communities often isolated from medical help, BRAC initiated an education campaign to empower mothers as caregivers and drive them to treat their children with oral rehydration solutions. The campaign was a huge success; child deaths from diarrhea plummeted more than 80% in the next 25 years.³⁶ As other countries adopted Bangladesh’s approach, global diarrheal deaths dropped from five million a year to two million, even in the face of a massive world population increase.

The key to BRAC’s success was the delivery of the message. Workers visited villages one-by-one and spoke to mothers in person, teaching them the dangers, symptoms, and treatment for diarrheal disease in the simplest terms. This included a recipe for rehydration solution that was specially developed for people who had no precise measuring implements.

The BRAC story demonstrates the power of engaging carers and, whether operating in a developing country or not, pharma should endeavor to do whatever it can to support them. After all, the outcomes of many treatments are as dependent upon the efforts of carers as they are healthcare professionals and patients themselves. If the industry is to move towards providing greater holistic support to patients, then it makes sense to extend these efforts towards carers too. In the US, 38% of caregivers consider their caregiving situation emotionally stressful.³⁷ Those caregivers with the highest hours spent caring experience higher emotional stress, financial strain and decline in their own health.³⁷

As an industry, pharma might ask itself: how can we make carers feel valued; make their day a little easier; make them smile? Is there any way to alleviate the pressure on their relationship with the patient, by transforming care duties into something that strengthens rather than strains familial ties? If it’s possible to turn exercise regimes and physical therapy treatments into fun games, then could a sense of fun be introduced into the caring paradigm? Can we make administering care an enjoyable experience for patients and carers to share?

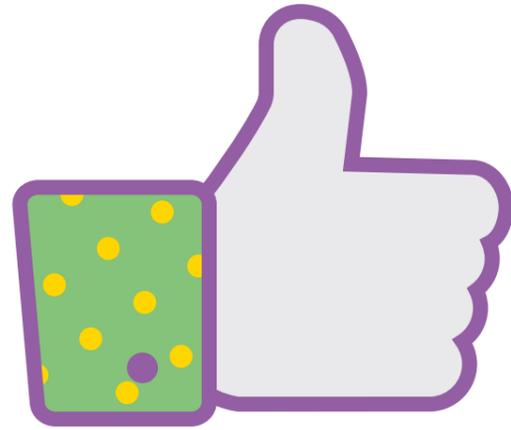


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38. TED. Rebecca Onie.
What if our healthcare
system kept us healthy.
(April 2012).
Available at:
bit.ly/1ntWvzc
Accessed: July 2019.

It's time for pharma to **broaden**
its **focus** far, far beyond the pill.

"If we know what it takes to have a healthcare system, rather than a 'sickcare' system, then why don't we just do it?"

Rebecca Onie, health services innovator and founder of Health Leads³⁸

Much of the industry's progress to date has been based on innovating around the molecular, on tackling problems in the minutiae of the atomic arena. It has brought some incredible advances and delivered great success in changing lives.

However, when you reflect on where patient journeys begin, where they end up, and how long it can take to get there, the need to start thinking bigger rapidly becomes apparent. We need to look beyond the pill and see the patient, then look further still and recognize the array of moments that lie between the patient and a positive outcome. Whether it is getting in to see a physician for an appointment they've been putting off, looking for information online to help them get to grips with their condition, or arranging a meeting with their employer to discuss getting on with work, each moment is important. Each is an opportunity for pharma to have a profound effect on that patient's well-being. Every intervention is a chance to instill the happiness, confidence and encouragement to strive towards their goal.

If pharma only ever innovates around the pill then it can only ever deliver treatments. Treatments that patients might not receive, that they might ignore, or that might only take them so far before they falter.

But if we innovate beyond this, from the very beginning of the patient pathway, through the twists and turns until its end, then we can deliver progression. Progression that delivers positive patient outcomes.

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