# Empowered patients improve outcomes

March 2018

# Empowered patients improve outcomes

Non-adherence to medication is not a new global healthcare concern but with more people living with long-term conditions the problem is increasing.[1] A difficult problem to solve, this multifaceted phenomenon[2] can have a variety of negative effects for society and for the individuals involved.

So why is non-adherence happening, what makes a person not take the drug, or take it incorrectly? Is it purely down to lack of understanding or motivation or is there something bigger going on? Historically when looking at how to address this challenge, the Life Science Industry has focussed primarily on product centric solutions (e.g. adherence reminders), not necessarily patient centred ones.

Lack of patient engagement across our industry appears to be fuelling the problem. The patient solutions of the future need to empower patients to engage with their disease, as more engaged patients are more likely to take their medicine as prescribed, adopt recommended lifestyle changes and achieve the improvement in outcome they deserve. To enable that to happen, patients and carers need to both define the need and co-create the right patient empowering solution.

## So why are patients often disengaged with their conditions?

There are a myriad of reasons with multifactorial disease and patient specific factors at play. They include:

Lack of knowledge or education on their condition or treatment

Not believing the treatment will make a difference

Information overload (they don't remember how to manage their condition)

Feeling that the side effects are worse than the illness itself

Insufficient quality time spent with their healthcare professional (HCP) so tend to self-manage their conditions

Not achieving the best treatment outcomes (due to poor adherence or discontinuing their treatment)

Simply forgetting to take their treatment

As a result, there is no simple magic bullet solution to non-adherence.

Although the importance of patient engagement, (actively seeking feedback and insight from patients to design a service or solution around their needs) is now being recognised by many pharma companies, there is still a long way to go.

A survey run by the PM Society's Patient Engagement Interest Group (PEIG), investigating the current perceptions and challenges the industry face, revealed 100% of respondents believed that Pharma could be doing more to engage with patients,[4] with 89% believing this approach was extremely important.[3] This survey highlights the huge challenge that lies ahead; people believe in the approach but still need to be persuaded to apply it and then get the buy in from all stakeholders.

**8.9/10** (average)

Respondents considered it extremely important for pharma to be engaging with patients

**100%**

of respondents felt there is more pharma can be doing to engage patients

And what do the patients think? Interestingly, another survey by Wolters Kluwer Health in the US has highlighted that patients actually want to increase their engagement. They want to improve their disease awareness and be involved with their condition and its management. 86% of healthcare consumers agreed that to ensure better quality of care, they must take a proactive role in managing their own healthcare. In addition, 46%, recognised the benefits of taking control of their own health, by stating that it made them feel empowered and good about their quality of care.[4]

## So, in an ideal world we need to get more patients to take a proactive role in their own health but what is the evidence behind this?

More and more evidence highlights the importance of effective self-management of long-term conditions and the positive impact it has on health outcomes, including better experience of care, healthier behaviours and fewer episodes of emergency care.[5,6] All of which lead to lower costs for healthcare services.[7]

Recent research from the US using a Patient Activation Measure score (a 13-item instrument which assesses patient self-reported knowledge, skills and confidence for self-management of one's health or chronic condition) has now clearly shown the benefits of patient engagement.

According to the measure, highly activated individuals, are more likely to obtain preventive care (e.g. health screenings, immunisations) and to exhibit other beneficial behaviours, such as maintaining a good diet and routine exercise, self-management behaviours (e.g. monitoring, adherence to treatment); and health information seeking.[8]

By knowing a patient's activation level, we as an industry can tailor health messages and self-management goals to create effective communications.[8]

An intervention with tailored messages has also been proven to lead to greater improvement in the patients' biometrical clinical indicators, in their adherence to prescribed medication regimens and to a reduction in hospitalisations and use of the emergency department.[6] Showing that a one-size fit approach will not work. All patients are different, have different needs, levels of understanding and motivations.

As there is evidence that patient activation has been proven to be a changeable characteristic,[9,10] we have a responsibility to help patients take responsibility for their own health. An unengaged patient has the potential to become an engaged patient through effective tailored health messaging.

Behavioural science is emerging as a means of predicting patient events and outcomes based on their behavioural characteristics. Artificial Intelligence is an analytical enabler of this emerging science that consists of huge data volumes, all of which can be overlaid on top of other datasets, including genetic and clinical data records. This science will ultimately help empower patients to connect with their disease in ways not possible previously.

There are obviously real tangible benefits to improving patient engagement, for both patients (they have better treatment outcomes) but also pharma and all healthcare stakeholders (patients stay on their treatments and improved outcomes are seen).

An unengaged patient has the potential to become an engaged patient through effective tailored health messaging.

## Esperity - understanding preferences of an under-served population

To understand how to empower patients effectively it is critical to understand patients' needs by validating assumptions in every phase of the patient pathway.Online portals offer a channel to validate some of these assumptions.

Esperity is an online community for cancer patients and family caregivers, aiming at improving quality of life of those afflicted by cancer.

Esperity was approached by a patient organisation in the USA, the Latinas Contra Cancer (LCC), wanting to understand more about patient preferences in the Latino population in relation to genetic testing and clinical trials. Together with University of Texas, LCC and Esperity set up a survey to understand more about the health literacy in terms of clinical trials and genetic testing, and to understand the preferred channels to receive more information based on the user profile. This information was then used to develop tailored material for the Latino population in order to maximize the uptake of information, that would promote shared decision making. Shared decision making is acknowledged as one of three key behaviours of patient empowerment.

## Precision Medicine For Me - an example of real public empowerment

A group of respected patient organisations, advocates, start-ups and industry leaders collaborated on an initiative to get people with Lung Cancer in North America the very best of personalised information to make informed decisions on research and treatment opportunities.

Through this initiative patients are not only informed of the opportunities of genetic profiling, they are provided with the testing itself and a subsequent report tailored to their individual genetic profile, to discuss research and treatment options with their own healthcare team. This is patient empowerment in action.

Like the two case studies, there are a number of siloed memorable and effective patient pathway solutions that companies have generated. Unfortunately, these are not as endemic in healthcare as they should be. One of the issues at hand is that companies still perceive these programs as opportunities to competitively differentiate themselves from one another. As a result, healthcare providers can struggle to choose which ones to adopt and the effective solutions also struggle to scale and be sustainable. The opportunity is for companies to work together with all relevant stakeholders, as in the collaborative 'Precision Medicine For Me' initiative, to generate the right patient centric scalable and sustainable solutions. Companies differentiate on their science; collectively all have a vested interest in ensuring the healthcare system works as effectively as possible to best serve the patient need.

In conclusion, patient empowerment is all about enabling people to take more personal responsibility for their own healthcare. There is no longer a place for the paternalistic perspective that 'we know what's best for you'. Through patient engagement, our industry needs a more holistic approach that makes the great science we do, more relevant for people living in our society today. If not a patient today, we all will become one in the future: patient empowerment will help us to manage our illness more effectively, adhere to our medicine and improve our outcomes. The Life Science industry has a responsibility to help us do just that.

**Developed as a collaboration between**

Caroline Benson – Director, Cuttsy+Cuttsy

Dr Liz Walder – Scientific Team Leader, Cuttsy+Cuttsy

Guy Yeoman – Founder, MediPaCe

Mitchell Silva – CEO, Esperity

Cuttsy+Cuttsy MediPaCe

For more information, contact Caroline at
carolinebenson@cuttsyandcuttsy.com

www.cuttsyandcuttsy.com

1. Clyne W, et al. *BMJ Open* 2016; 6:e009610.
2. Kvarnström K, et al. *BMJ Open* 2018;8: e015332. doi:10.1136/bmjopen-2016-015332.
3. PEIG survey 2017
4. Wolters Kluwer Health Survey, Dec 2012
5. Hibbard JH, et al. *Am J Manag Care* 2009;15(6):353-360.
6. https://www.england.nhs.uk/ourwork/patient-participation/self-care/patient-activation/pa-faqs/
7. Hibbard JH, et al. *Health Serv Res* 2005;40(6 pt 1):1918-1930.
8. Rask KJ, et al. *The Diabetes Educator* 2009;35:622.
9. Frosch D, et al. *J Am Geriatr Soc* 2010;58(8):1476–1503
10. Hibbard JH, et al. *Heal Serv Res* 2007,42(4):1443–63.