



What this world needs is not another diabetes drug. No, what this world needs is a diabetes drug that patients will take. It's a relatively simple mantra. And as healthcare systems around the world undergo reform, adherence is quickly becoming a word that just won't go away.

So let's remind ourselves of just how difficult it is becoming. According to the World Health Organisation, half of all patients with chronic diseases do not take their drugs as prescribed; UK patients with type 2 diabetes who are non-compliant with their medication cost the NHS more than £100 million in avoidable treatment costs per year, while shifting all hypertensive patients to a position where they are compliant would result in treatment savings in excess of £390 million per year.

Social media is the only source that allows patients to paint the complete picture of living with a disease, and with half of chronic patients not taking their medicines as prescribed, this might be just the information pharma needs

A picture of health

On top of this, medicines worth £300 million were wasted in the UK in 2009, including £110 million returned to pharmacies and £90 million flushed down the loo or thrown out with the scraps. And it's not just a problem in the UK – estimates suggest non-compliance costs the US healthcare service between \$70 billion and \$300 billion a year. The point is, adherence isn't just about not taking a drug; it's also about the financial implications of not taking it for both the healthcare system and pharma.

“Non-adherence is slowly becoming a hot topic again because pharma has realised that in the absence of new drugs it pays to ensure patients refill scrips of their old ones,” says Maria Relaki, senior account director, patient adherence, at Bioaxis Healthcare. “With the market becoming more competitive, adherence will play a significant role in uniting the stakeholders and giving the patients the support they need.” But despite their increasing importance in securing that critical market position, adherence programmes are still low on pharma's agenda, a Bioaxis survey found. “It is still a last resort marketing action rather than an important self-standing market access procedure,” Relaki points out.

So what exactly is pharma to do? Developing a once weekly oral formulation might go some way towards improving compliance, but that's really just scratching the surface. Increasingly, as healthcare moves to a patient centred approach, getting behind the scenes and understanding the root cause of why patients stop taking their drugs needs to become a priority for pharma. Whether

it's because the patient genuinely forgets, can't face taking eight different tablets every day, or the side effects are just too unpleasant, understanding the reasons why a patient doesn't comply is fundamental before you can really start tackling the problem, says Dr Richard Jones, director, transplant and oncology, region Europe, Genzyme. “When looking at patient compliance, clinical studies report excellence rates of 80% plus. This is a result of patients being generally better motivated and under close medical supervision compared with those receiving therapy outside the clinical trial setting,” Jones adds. “In ulcerative colitis, for example, the real world compliance rate can be much lower, about 40%-60%... So monitoring conversations and adverse events will help pharma better understand the real world experience of their medicines.”

Enter social media

Now at pharma's fingertips is a plethora of information about patients and their medicine-taking behaviour. Diabetes alone, for example, has a massive presence online mainly because it affects a wide range of people who are often forced to have hands-on responsibility for managing their disease. As a result they seek guidance from other patients, says Andy Pilkington, research executive at WaveMetric.

Last year, the company monitored online discussions relating to compliance and non-compliance for diabetes, high cholesterol, multiple sclerosis and psoriasis; it found that drug effectiveness and ease of use were the most likely

reasons to result in a patient taking their drugs. On the other hand, side effects were the primary reason given for patients not taking their drugs (54%), with lack of efficacy (8%) and ease of use (6%), as well as forgetfulness (6%), also mentioned as drivers of non-compliance. However, perhaps most interesting is that negative communication from other patients about the drug – either via the media or online word of mouth – contributed to 11% of the reasons given for non-compliance.

“If you accept that adverse event monitoring in general leads to better drugs and patient outcomes, it then stands to reason that monitoring adverse event mentions online will do the same,” says Pilkington. What is more, adds Daniel Ghinn, director of digital engagement at Creation Healthcare, patients won't refer to adverse events as adverse events, so social media can act as an “early warning system” and identify side effects patients may not know could be attributed to their medication.

So monitoring and listening to these conversations online can give pharma more insightful information than a lot of traditional research, says Pilkington. “By learning more about adherence and patient behaviour, pharma can tailor its offline marketing or create an educational push; it may even help refine the product's development.”

Paint a picture of the disease

But the beauty is these aren't just conversations on efficacy, safety and tolerability, says David Williams, chief marketing officer, head of business

◀ development at PatientsLikeMe.

“The most telling topics surround quality of life and the impact on the patient’s experience from living with the disease, such as how patients attribute quality of life improvements, whether they are medication-related or not... Pharma should be interested in the holistic experience patients have with the disease, and social media is the only source that allows patients to paint the complete picture.” Furthermore, it’s not just about getting information on the patient’s drug-taking behaviour, Pilkington adds. Pharma can also use social media to find out about patients’ relationships with healthcare professionals and other stakeholders, what information is being shared and how it is being used in decision making, such as prescribing and drug switching behaviour.

But while this is good take away information for pharma, there is still the tricky issue of adverse event reporting, which, as Pilkington notes, is “reasonably ill defined” in the social media space. According to Ghinn, many side effects reported online are not considered “reportable” by regulatory standards because they do not make up the minimum requirement for reporting.

Regulations, a lack of guidelines, and fear of losing control have all contributed to pharma’s hesitancy to engage fully in social media. However, there are significant opportunities to improve medicines adherence by taking a more

active, online approach to increasing awareness and providing education, says Pilkington. It’s going right to the source of the problem and providing a solution, it’s more direct and people are more likely to listen.

And it is much easier to engage in an online adherence programme than an offline one, adds Jones. “Social media can help create a support structure around the patient and make them take more ownership of their condition and the need to take their medicines. Offline programmes such as patient leaflets are ‘static’ and quickly end up in the bin. But because social media is becoming a part of everyday life, it presents a fantastic channel to improve adherence.”

How does pharma go about it?

This is all very well, but with patient interaction a no-go area for the industry, how does pharma go about this?

Regulations are only part of the problem, says Jean-Francois Delas, vice president at Kinapse. The other aspect is trust – patients doubt how genuine pharma is with its engagement. This has been seen recently, for example, with Janssen and the launch of its new social media suite for psoriasis, which is looking to establish its own community rather than partnering with already established ones. This has led to suggestions, Delas

says, that the company might be using social media to influence rather than truly support patients.

“The best way for pharma to get involved is via existing online, non-branded communities,” he believes, such as Novartis and UCB’s link up with the PatientsLikeMe social network. An alternative, Delas says, is to develop partnerships with other organisations that work in the same disease areas. “When companies put resources together for the same cause it doesn’t run the same risk of being seen to be pushing one’s own brands and products.”

However, he adds, pharma shouldn’t focus only on patients. “There is an opportunity here to equip providers and carers with the right information and tools to provide support for their patients... and social media can be a very effective and convenient way of doing that.”

But while social media can add value to an adherence programme, Relaki stresses it’s only part of the picture. “Pharma needs to focus on patients’ needs, re-evaluate anachronistic methods and really try to use modern technology and innovative effective ideas to support patients. If a patient can go online through the patient adherence programme and read, share, talk about the same issues that he or she is dealing with, it automatically makes the whole procedure much more humane, and the chances are that adherence levels will rise.”

Improved adherence undoubtedly equals better outcomes. And outcomes are what the healthcare world is pushing for. Delas says adherence programmes will increasingly become part and parcel of pharma’s future offerings: “This is about delivering better outcomes to patients and that is much more than just the drug. It is about wrapping services around the product to manage the patient care continuum.”

“Whatever pharma can do on the side to help the patient is the way forward.” Jones agrees. To this end, social media can be a powerful tool and something “we – pharma, society, governments and the healthcare system – should embrace”. **PT**

