Why is it that patients, of their own free will, voluntarily book an appointment with their physician, take the time to attend that appointment and listen to the advice, and yet they fail to follow through on the advice that they sought in the first place?

The actual rate of mal-adherence, by which I mean all instances where patients do not follow the advice of their physician, is difficult to estimate, but is thought to be around 50 per cent. This results in poor health outcomes for the patient, lower than expected response from the line of therapy prescribed and has an impact on the healthcare system in terms of higher cost and wastage.

Understanding and improving rates of adherence are in everyone’s interest in the healthcare sector.

There is a perceptible shift in the pharmaceutical industry’s focus from patient acquisition to patient retention, while health authorities focus more strongly on patient outcomes and quality of life measures. However, it is not possible to impact adherence until you understand why it is happening, and can assess which groups of patients are more likely to respond to adherence intervention in a positive way.

Here are 10 ways to help you think more deeply and hopefully differently about the issues surrounding adherence.
Patients are consumers and have all of the characteristics of consumers when it comes to their health...

1. PATIENTS ARE CONSUMERS WHO HAVE AN ILLNESS

Healthcare and how we in the industry approach it is a very logical equation: Symptom A + Patient B = Therapy C

It is how medical professionals are trained; it’s how treatment guidelines are put together; it’s how clinical trials are set up. Unfortunately, however it is not how patients work.

Patients are consumers and have all of the characteristics of consumers when it comes to their health, except that they are considering their wellbeing, rather than a purchase or other type of action. This means that they do not think in terms of a linear process. Instead, they can comfortably hold contradictory views and exhibit contradictory behaviours without any sense of conflict, and often they do so without consciously holding a contradictory position.

For how many people do you know who would claim they are ‘Green’ and carefully and conscientiously recycle their waste every week, yet the same person sees no conflict in taking a long-haul flight to far-flung holiday destination?

How many people do you know who will say they have healthy lifestyles and always make healthy food choices and yet when it comes to looking in their fridge, the contents alone would tell a completely different story?

These are typical consumer behaviours that patients exhibit with regard to their health and their medicine. Patients, particularly those on long term medication, will say that they are in tune with what their body needs and so will dose up or down accordingly. This is the reality of the patient as a consumer and the behaviour they will exhibit.

2. THE COST OF MAL-ADHERENCE IS SUBSTANTIAL

Estimates for the impact of mal-adherence vary greatly. Some claim that in the US alone poor compliance costs the healthcare system over $175bn.

Lack of medication adherence can lead to unnecessary disease progression, complications and a reduced quality of life. In addition, the subsequent lack of efficacy physicians see from a particular regimen can have implications for how they use that line of therapy in the future. It is not always clear whether the patient is mal-adherent or if a therapy simply does not work.

The impact or ‘cost’ of mal-adherence goes beyond the financial and health outcomes, however. In some cases it is causes the fundamental erosion of the relationship between physician and patient. While mal-adherence is not intended wilfully, there is an implicit erosion of trust between the two parties.

3. ADHERENCE IS AN EMOTIONAL JOURNEY

The patient as a consumer has illogical thought processes and justifications for their behaviour. In addition, their reasons for mal-adherence are typically multi-faceted, complex and varied. However, emotions and aspirations are often the key drivers of behaviour.

For patients, health is a very emotional subject. These emotions are also strongly felt in adherence issues. However, the emotions felt vary considerably by condition, person and where they are in their treatment journey. For example, the psychological impact of a diagnosis of Type 2 diabetes can be devastating for a patient. They feel a tremendous amount of guilt that they have ‘brought this condition on themselves’, and are threatening the stability of their family and their own health outcomes.

It should not be surprising to learn that these patients can entirely justify their non-compliance when it comes to food stuffs and what they should or shouldn’t eat. The simple fact of a diagnosis does not mean that they will suddenly start reading labels in the supermarket or understand what healthy choices are. While there are whole industries set up to support this type of patient, their overwhelming feeling
is of being alone and confused by their diagnosis and what it means for them. This sense of being out of control is very different to that typically experienced by patients who find themselves in long term chronic pain. Their emotional experience is one almost of resignation to the pain they experience, which is a condition they feel they face alone. When you talk to chronic pain patients, they express their feelings as being ‘chained up’ to their pain, or having to ‘drag their pain’ along behind them.

In terms of issues such as mal-adherence, many patients will talk about understanding their body and its needs, and medicating accordingly. When talking to patients about their condition and adherence issues you must take into account the illogical and emotional manner in which people think. Having a formal and sophisticated tone of language often will not produce this type of insight.

4. MAL-ADHERENCE CAN BE JUSTIFIED (IN THE PATIENT’S MIND)
As an industry we tend to talk in negative terms about mal-adherence (even the phrase itself sounds negative). However, this isn’t always the case in the mind of the patient. Some patients believe that their lack of adherence gives them more control over their condition, as they understand their body better than anyone else. For them, it’s a positive action that they are choosing to take on the management of their condition.

There can also be a number of passive emotions patients experience when it comes to mal-adherence. This is particularly true of asymptomatic conditions, such as high cholesterol, where there are positive passive reactions to not taking an action, such as refilling a prescription. While patients feel a sense of disappointment in themselves, they also feel at peace or normal in their actions. They believe they are ‘OK’, so missing out on medication is not the end of the world.

These are important considerations when developing language for a support programme to increase rates of adherence. Patients have significant emotional drivers in their behaviour and its subsequent justification, which will change based on their underlying condition and the stage they are at in their adherence journey.

5. DON’T BLAME THE PATIENT
Lack of adherence may be common among patients, but rarely is it wilful. There are few patients who want to physically or mentally cause themselves harm by not taking the advice of their physician or their medication as prescribed.

Improving adherence is not about getting the patient to indicate in writing that they are prepared to follow their physician’s instructions; it’s about reinforcing the message so that once the consultation is over, the patient remembers and acts on the instruction.

The majority of patients will remember what they are diagnosed with, but a significant proportion will forget what the instructions are for action, maybe because they are overwhelmed by, or focusing on, the diagnosis.

6. FOLLOW THEIR JOURNEY AS THEY EXPERIENCE IT
One of the problems of generating insights into mal-adherence issues is that the more you probe and explore the issue, the more you influence the outcomes. While it may not be politically correct to talk about compliance issues any more, the essence of the subject of adherence or mal-adherence implies ‘not doing as you were told’, which leads to patients being defensive about their actions, or providing a version of events they think you want to hear.

In a similar way, how often does keeping a food diary actually lead to the person either consuming less or denying what they have consumed – relatively frequently I would argue.

It’s easier to follow the patient journey through using longitudinal prompts rather than direct questioning, or ideally through passive listening.

If you provide the patient group with a platform from which to communicate, and provide them with set prompts, not only do you remove the bias a potential interviewer may introduce, but you allow the patient
the freedom to express themselves to their peer group and generate insights which wouldn’t otherwise be uncovered.

7. YOU CAN’T CHANGE EVERYONE’S APPROACH

Most patient adherence approaches currently treat all patients as the same. However, not everyone is equal. In the same way that patients are irrational and have emotional drivers, there is no one-size-fits-all adherence programme.

It is also not financially feasible to develop personalised intervention programmes that will ultimately produce the greatest improvements in adherence.

However, there is a third way. To make a significant difference you don’t need to change everyone’s behaviour. Focus first on those who have attitudes and behaviours that are easiest to influence. Some patients will always be mal-adherent while others, with the right support, could significantly reduce their rate of mal-adherence to positively impact their overall quality of life.

If you understand the different stages of mal-adherence in a therapy area, and the different underlying emotions that patients experience, then you can develop groupings of patients and tailor adherence programmes to target the highest potential or the most-likely-to-respond group.

8. TAILOR PROGRAMMES IN THE LANGUAGE OF THE PATIENT

Addressing mal-adherence at a general, none targeted level will produce generalities and only address superficial or rational reasons for poor adherence.

Instead, if you identify those groups of patients who are most likely to respond (and these aren’t necessarily the largest groups of patients) and focus on the occasions on which they are non-adherent, you should have two specific insights:

• Targeted adherence occasions (refilling prescription or missing a dose)
• Precise profiles of target groups (the emotional drivers of non-adherence).

The outcome of this is a focused approach with maximum impact, without the need for a personalised approach. For instance, you would have a different support network if you had a group of patients who were sceptical about filling their prescription and were not convinced by the therapy versus if you had a group who were shocked and embarrassed by their inability to remember to take their medication on time. One group needs education and convincing; the other support, through devices and tools to aid their memory.

9. ADHERENCE PROGRAMMES NEED TO BE STIMULATING

When developing the right adherence programme for the appropriate occasions and target group, the outcome doesn’t always have to be another patient leaflet. Sometimes simple creativity can be what patients need. For example, tear off stickers to put on a calendar to remind them when to take their next medication – as one patient told me, it’s what works for remembering her dog’s flea treatment, so why not her diabetes medication?

10. AND FINALLY.....

Mal-adherence is a critical challenge for patients, physicians, healthcare authorities and the pharma industry. Constructing effective methods for improving rates of adherence requires a deep understanding of a point in time and an emotion which is difficult to capture.

Only by grouping occasions and emotions and developing a targeted strategy will a more effective approach be achieved, rather than generic and broad brush programmes - after all, you wouldn’t market a drug through a general catch-all programme, so why would you do the same with your adherence programme?

Sarah Phillips, Head of Health at Ipsos. Contact her on 020 8861 8062 or at sarah.phillips@ipsos.com

“Most patient adherence approaches currently treat all patients as the same. However, not everyone is equal”

“In the same way that patients are irrational and have emotional drivers, there is no one-size-fits-all adherence programme”

“Constructing effective methods for improving rates of adherence requires a deep understanding of a point in time and an emotion...”

A practical guide by Sarah Phillips