

# Assessing Attitudes

**Research into how to create and maintain patient engagement within clinical trials has taken many forms. One approach that examines such an issue is that of Behavioural Economics**

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Achieving high levels of patient recruitment, adherence, and retention is essential for the successful completion of a clinical trial, yet it remains a significant challenge faced by researchers. Poor patient recruitment, adherence, and retention can adversely affect a trial by lengthening timelines, adding cost and risk to the validity of the data and delaying product approval.

Numerous factors contribute to the process of attracting the patient to consider participating in clinical research studies. These include lacking an awareness of the critical role that clinical trials play; limited access to knowledge about clinical trials; lack of understanding about rights; and safety and benefits. These are among the most common reasons for low participation. In terms of retention in the trial, these can involve patient-centred factors, such as demographic and psychosocial, comprising of their beliefs; attitudes, motivation and severity; therapy-related factors such as treatment complexity adverse reactions and lack of therapeutic impact; and social and economic factors, including the inability to take time off work, lifestyle patterns, etc. Other factors could include clinical trial site location, frequency of clinic visits and clinic staff. In contrast, patients are motivated to participate in clinical trials for reasons including advancing their medical knowledge and gaining access to promising treatment.

The development and integration of patient recruitment and retention strategies that address the issues of a patient's perceived benefits, barriers, and burden by leveraging both technology and communication is essential to address patient recruitment. However, an additional challenge exists that researchers should consider when developing such strategies. This is the need to take into account the subtle and complex mechanisms that shape people's behaviour such as whether or not to participate in a clinical trial. This requires an approach, which, to quote Jules Berry, "shines a light on the factors that influence our actions" in an attempt to better understand the subtle and complex mechanisms that impact patient behaviour. It is, to paraphrase Jules Berry, to view the solutions through the prism of Behavioural Economics (BE) (1).

## What is BE?

BE is a multi-factor approach to the understanding of human behaviour that represents a paradigm shift in the thinking that behaviour is always rational and is changing how people consider the way they make decisions. Instead, the principles of BE are that behaviour is, to a great extent, unconscious, irrational, and socially driven.

Running through BE is the belief that two systems for decision-making exist. System 1 was first defined by Stanovich and West and used by Daniel Kahneman to describe the mental processes people use to make decisions (2). System 1 runs on autopilot, is fast to react, difficult to control, is influenced by emotion and learns gradually over time. The primary role of this system is to assess and give updates on what is going on in the world around us. Meanwhile, System 2 is slow to react, analytical, self-aware, and controlled. It monitors all decisions (which require attention), is slow, effortful and considered when deliberating whether or not to take part in a clinical trial, but, once engaged, has the final word. However, System 1 has a significant influence on day-to-day behaviour.

Both Systems 1 and 2 are important for understanding human behaviour. Therefore, for any clinical trial recruitment strategy to be truly patient-centric, it needs to take account of both systems thinking on patient behaviour throughout the different phases of a clinical trial.

The key characteristics of human behaviour outlined in BE are:

- **Personal factors:** People do not like change, live in the here and now, are averse to loss, want a positive and consistent self-image and will thus behave accordingly. How people feel at the time of making a decision results in a particular behaviour
- **Social factors:** People are heavily influenced by others and behave in a way that is expected of them
- **Choice environment:** The social environment is important and capable of non-consciously impacting behaviour, which depends on the available options and how they are presented. The environment matters, thinking is hard work and choices are guided by salience of information and mental shortcuts

## BE in Practice

When analysing the contributing attributes of BE, they can be broken down into several distinct factors:

### Personal Factors

People think short-term and avoid loss rather than achieve loss aversion. In other words, loss is felt more keenly than gain. For example, offering a number of points at the start of an intervention programme as part of a clinical trial that could be exchanged for items or money on programme completion – which, would be withdrawn for failure to adhere



to the programme – is likely to be more effective in attaining adherence than accumulating points from zero.

Human beings do not like change; preferring the familiar and the stable is known as the status quo bias. People tend not to alter their behaviour unless the incentive for doing so is strong. In the context of participating in a clinical trial, a requirement for a change in behaviour is likely to occur, and the incentives for doing so must be explicit.

People also have a desire to maintain a positive self-image, which makes them feel better about themselves, but are often threatened by their outward behaviour. Refusal to participate or remain in a trial can lead to tension in the inconsistency between the person who they would like to be and one who they appear to be. This inconsistency is often addressed through rationalisation, in which actions are justified after the event so one can co-exist with a particular behaviour, eg 'drug companies are only interested in making a lot of money' or 'I've tried every type of medication on the market.'

#### **Social Factors**

In addition to the need to retain a positive self-image, individual decision-making is heavily shaped by others; this is the power of the messenger, rather than of the message itself. It is certainly true that behaviour can be influenced by not only experts and authority, but peers, patient groups and networks, and their communications – through social media and mobile phone apps, for example – can have a significant effect on trial recruitment and retention. This is particularly relevant where people find themselves in ambiguous situations and look to others for guidance. This is known as informational influence.

#### **Choice Environment**

When it comes to making a judgement or choice, as humans, people do not like to think too much. They cannot attend to and process all available information. Too much information and too many messages leaves them unable to cope, and System 1 thinking – perceptual, intuitive and influenced by emotion – kicks in to help people make the choices that come easily to mind.

When choosing to participate or remain in a clinical trial, it is likely that the patient is faced with a number of decisions, such as the likelihood of being better or worse off at the end of the trial. The more complex the choice is, the less likely a person will be to make an informed conclusion and consequently revert to a position where the decision maker does nothing (default). Putting the options to patients in a more simplified way (choice environment) or feeding back the choices others have made

can have a significant impact on the selections made (normative influence).

Choosing is relative to what people can have, it is not absolutely about what they want. Simply, behaviour depends on the options available. In broad terms, choice architecture concerns itself with how people gather information when making a decision and how absolute values are crowded out by other influences. Apart from the importance of how choices are presented in the decision-making process, things that come to mind easily are also considered important, and decisions are often influenced by the excess of information that is readily available.

People use a mental shortcut to remember the most salient aspect of an experience. For trial participants, this would not necessarily be the overall experience of participating in the trial to the point that comes to mind, but, for example, how they were made to feel the last time they attended the trial site or experienced an adverse reaction.

Ensuring trial participants have a positive experience at the trial site is critical for ongoing patient participation, not only for increasing the salience of that positive experience – for example, through one-to-one discussions with patients about their wellbeing, attitudes, and experiences participating in the trial – but also as an opportunity to reinforce the feeling of positive aspects of the trial.

As individuals, people prioritise information that supports their existing beliefs, filter information that confirms those beliefs, and seek information that maintains them (confirmation bias). This can be seen in the way people mentally prioritise small probabilities within anecdotal stories. An example of this could be knowing someone who had a negative experience with a trial and consequently withdrew or someone who deems smoking to be of little risk because they had a family member who heavily smoked and lived to 95 (availability heuristic). These people are more likely to negatively influence a person to not participate rather than what a rational model would predict.

Related to this is anchoring, which occurs when people are presented with a piece of information that is then used as an anchor for all subsequent information. For example, if patients are told that, in previous studies, the chances of an adverse reaction were 8%, this would serve as a pillar for the expected adverse reactions in the current study as to whether this is high or low. Information such as this can be communicated in different ways, which can have a profound effect on choice. For example, at the trial recruitment stage, if patients are informed

there is a 20% risk of experiencing an adverse reaction, they will likely be more concerned than if presented with an 80% chance of no reaction. While both these values are true, they provide a perspective known as framing within the choice environment, which is presenting descriptions of the problem or outcomes in different ways.

While being aware that all messaging must be Institutional Review Board approved and devoid of any potentially coercive content, developing messages that resonate with potential trial participants is central to the development of a patient recruitment strategy. Clearly knowing the audience and determining their motivation to participate in the trial, such as seeking new treatment, is essential. However, when framing messages, remembering that emotion drives every motivation and decision is important; without emotion, there will be no action.

Messaging can be either gain- or loss-framed depending on the circumstances, which will indicate what type of framing might be more effective. In the health and wellness area, research has shown that gain-framing tends to be more effective in driving prevention such as treatment behaviours (eg taking prescribed medications), but loss frames may work better to motivate detection behaviours (eg breast screening) (3,4).

## Applying BE

Below are some examples of how BE can be applied to the development of a clinical trial strategy and how it can provide possibilities for hypothesis testing:

### Personal Factors:

- Consistency: Make all incentives explicit
- Value perception: Reinforce the value of the participant's engagement in the trial
- Feedback: Provide ongoing individual feedback via an app

### Social Factors

- Social-proof: Show how people perform the desired behaviour, describe what most do in a particular situation, and use the power of networks and social media

### Choice Environment

- Default: Avoid complex messaging and provide choices to patients in a more simplified way and make an option the default, which makes it more likely to lead to action

### Salience

- Prominent display of messages and options and provide additional material (eg brochure, pamphlet, video)
- Framing: Select the framing approach that is most applicable for all messages within the targeted group

## Final Thought

BE challenges the traditional assumptions that individuals

are socially isolated with relatively unchanging preferences, whereas people are really socially connected with changeable preferences. It also challenges the view that choices are always the result of slow, analytical, controlled thinking; in fact, choices can be influenced by the context at any given moment.

Throughout the development of a recruitment and retention strategy, one should ensure that all messaging must be devoid of any potential coercive content. This article has sought to show how an appreciation of factors not necessarily considered in clinical trial recruitment strategy development might enhance the way research is approached by using BE as a framework to understand human decision-making.

Through the careful assessment of personal, social, and choice environment behavioural factors and using different research techniques, a framework can be built that helps explain how these relate to behaviour in different situations. However, questions are still to be answered as to whether the factors are equally important for different disease groups and trials. Despite this, BE does have the potential to be a real game-changer in understanding some of the subtle and complex mechanisms that influences patient participation in clinical trials.

## References

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## About the author



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