

# Decisions about medicines: scientific evidence in context

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## Professor Rob Horne

*Oversight group member, and Professor of Behavioural Medicine and Director of the Centre for Behavioural Medicine, University College London*

## Introduction

The Academy of Medical Sciences' report, 'Enhancing the use of scientific evidence to judge the potential benefits and harms of medicines', was stimulated by the belief that '*scientific evidence should be at the heart of decision-making about the use of medicines*'. This is essential for the regulators, healthcare organisations and healthcare professionals whose decisions determine the medicines that are offered to patients. The Academy report also states that '*patients too should be able to access reliable evidence, and this should be presented in an intelligible form that allows them to use it in their own decision-making*'.

Few would argue with this. However, the need to present scientific evidence in an 'intelligible form' presents two major challenges. The first is how the scientific evidence for the potential benefits and harms of the particular treatment can be presented in a way that enables patients and the wider public to understand the relevant probabilities of benefit and harm. This is important if these constituencies are to make an informed choice rather than one that is based on a mistaken estimate of loss or gain. Essentially, this is about the communication of uncertainties and probabilities in an accessible form. Our understanding of how to do this has improved significantly and it is increasingly easy to present data in multiple ways that can be tailored to user needs and capabilities (see Spiegelhalter *et al.* for a review).<sup>1</sup>

The second challenge is how to convey scientific evidence in a form that is compatible with the way people actually make decisions about treatments. Communicating probabilities and uncertainties in ways that can be understood is essential but may not be enough. Treatment decisions might not be solely based on a calculation of the likelihood of accruing benefit and harm derived from scientific evidence. As recognised in the Academy's report, deciding whether to take a treatment is influenced by many internal and external factors, such as beliefs, experiences and sociocultural environments.

This paper provides a perspective of these factors. It is not intended as a comprehensive review of decision-making but rather as an introduction to the scientific literature on how patients make choices about taking or not taking treatments (see Gigerenzer & Gray for a discussion of medical decision-making). Its purpose is to highlight the contextual factors that influence how (and even whether) scientific evidence impinges on our decisions about using medicines.<sup>2</sup>

## Decisions about medicines are often complex and dynamic

The decisions that people make about medicines occur in various settings and at various times. The decisions themselves

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<sup>1</sup> Spiegelhalter D, Pearson M & Short I (2011). *Visualizing uncertainty about the future*. *Science* **333**, 1393-1400.

<sup>2</sup> Strüngmann Forum Reports (2011). *Better Doctors, Better Patients, Better Decisions: Envisioning Health Care 2020*. Gigerenzer G & Gray JAM eds. MIT Press. Cambridge, MA, USA

include choices between taking a medicine or another form of treatment, or doing nothing. The selection of the medication route then entails a further decision about which type of medicine. Decisions about medicines are often taken over the long term. In developed health economies the prescription of a medicine is one of the most common interventions. For many of the long-term conditions, such as cardiovascular diseases, diabetes and asthma, and adherence to prescribed medicines is a crucial part of treatment. In considering the decision-making processes involved, three types of decisions can be delineated: (1) the decision to start treatment, i.e. initiation; (2) the decision to follow the treatment recommendation (e.g. to take the treatment as advised as opposed taking it a different way), i.e. execution; and (3) the decision to continue with the treatment rather than stopping altogether, i.e. persistence.<sup>3</sup> Although some of these decisions occur within consultations with healthcare professionals, it is important to recognise that many occur separately.

To understand how to improve decision-making around medicines, particularly regarding the use of scientific evidence about their potential benefits and harms, it is important to appreciate the wide range of intrinsic and extrinsic factors that influence the outcome of these decisions, both within and outside medical settings. Before exploring how people make decisions about medicines, it is helpful to understand the basics of the psychology of decisions.

## What are choices and how are they made?

Studies of the psychology of decision-making often distinguish two systems or processes: System 1 and System 2, which the behavioural economist Daniel Kahneman labels respectively as 'thinking fast' and 'thinking slow'.<sup>4</sup> System 1 operates quickly and with little sense of effort or voluntary control. Here, thought processes seem automatic and are often described as 'instinctive' or 'intuitive'. In contrast, System 2 processes are slower, demanding more attention. They are often associated with the subjective experience of making deliberate choices or calculations. For example, detecting hostility in a voice or face fits within System 1 whereas comparing two TV sets for performance and value fits in System 2. Or in a health context, System 1 processes may make us feel 'instinctively' reluctant to try a new synthetic food that is luminous green in colour, whereas in deciding whether to vaccinate a child against influenza individuals might weigh up the pros and cons of vaccinating vs not vaccinating using System 2 processes.

The 'instinctive' decisions or 'gut-reactions' based on System 1 often use heuristics, or rules of thumb.<sup>5</sup> These are valuable mental shortcuts that can help people make quick decisions with limited information.<sup>6</sup> For example, if people experience an acute headache they may be more willing to take a familiar pain relieving drug recognised by brand, than one that is unfamiliar, without an exhaustive examination of the scientific evidence on the potential benefits and harms of the specific drugs. Here, a 'recognition heuristic' is being applied. There are many types of heuristics but other examples include the 'availability heuristic', where precedence is given to more recent information making judgements biased towards recent news, and the 'affect heuristic', where decisions are influenced by current emotions.

Many of the heuristics that inform quick (System 1) decisions can be associated with predictive accuracies above chance.<sup>7</sup> They have served people well from an evolutionary perspective, enabling individuals to act fast to avoid danger or grasp transient opportunity.<sup>8</sup> They are cognitive processes; however, they can lead to unconscious biases that cause errors of judgements, potentially resulting in sub-optimal decisions. In the availability heuristic, people overestimate the probability of an infrequent event occurring when the event can be easily and vividly brought to mind. For example, the likelihood of death from dramatic events such as terrorist attacks are often overestimated whereas more commonplace causes, such as diabetes or hypertension, are frequently underestimated. The 'affect heuristic' highlights the role of emotion in decision-making, explaining why messages that activate emotions may be more persuasive than factual information alone in risk communication.<sup>9,10</sup>

There is some debate about whether Systems 1 and 2 are best thought of as separate cognitive processes or as a

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<sup>3</sup> Vrijens B, et al. (2012). *A new taxonomy for describing and defining adherence to medications*. British journal of clinical pharmacology **73**, 691-705.

<sup>4</sup> Kahneman D (2011). *Thinking, fast and slow*. Farrar, Straus and Giroux. New York, USA.

<sup>5</sup> Gigerenzer G (2007). *Gut feelings: The intelligence of the unconscious*. Viking. New York, USA.

<sup>6</sup> Gigerenzer G & Gaissmaier W (2011). *Heuristic decision making*. Annual review of psychology **62**, 451-482.

<sup>7</sup> *Ibid.*

<sup>8</sup> Todd PM (2001). *Fast and frugal heuristics for environmentally bounded minds*. In Gigerenzer G & Selten R eds. (2001) Bounded rationality: The adaptive toolbox. MIT Press. Cambridge, MA, USA.

<sup>9</sup> Keller C, Siegrist M & Gutscher H (2006). *The role of the affect and availability heuristics in risk communication*. Risk analysis **26**, 631-639.

<sup>10</sup> Gigerenzer G, Wegwarth O & Feufel M (2010). *Misleading communication of risk*. BMJ **341**, c4830.

continuum.<sup>11</sup> However, it is thought that the impressions, feelings and biases attributed to System 1 can influence the explicit evaluations of benefits and harms that we associate with more deliberate and considered decision-making associated with System 2.

It is important to recognise that the impact of psychological processes on decisions is heavily influenced by social environments in many ways. This can include the impact of social norms, for example people may favour treatments that are selected by others.<sup>12</sup> The effects may also be more direct and complex. For example, the treatment choices on offer and the decisions we make vary geographically<sup>13</sup> and by socioeconomic status.<sup>14</sup>

## How do people make choices about medicines?

The scientific process provides a means of obtaining objective evidence on the potential benefits and harms of medicines. As noted in the Academy's report, while there are many ways of acquiring knowledge, the scientific method is the most reliable as it is the only type that is systematically open to check and challenge. It might therefore be expected that decisions about taking or not taking a medicine would be informed by the best available scientific evidence about the potential benefits and harms.

Although there are few studies into whether providing patients and carers with the scientific evidence about the potential benefits and harms of medicines influences decision-making about medicines, a systematic review and meta-analysis of a small number of studies showed that providing information about the benefits and harms had no overall impact on decisions about whether to start and continue medicines, although it did increase knowledge and reduce decisional conflict.<sup>15</sup> In other words, information on benefits and harms did not seem to influence the decision that was made but did tend to make the person more comfortable with their decision. Unfortunately, limitations in the design and power of the studies included in the review mean that it is difficult to explain this apparently anomalous finding. However, the authors of the review point out that that information about the potential benefits and harms could have influenced some recipients towards medicines and others away from them, thereby cancelling each other out. They also suggest that decisions about medicines were not influenced by the scientific evidence alone but by contextual factors such as patients' beliefs about the medicine and the degree to which the information impacted on these beliefs.

## Beliefs about medicines and their role in treatment decisions

Patients' beliefs about medicines have been quite extensively studied, usually in the context of explaining variations in adherence to prescribed treatments. Early studies delineated two types of beliefs: *general* beliefs about pharmaceutical medicines as a class of treatment versus *specific* beliefs about the particular type of medicine under consideration.<sup>16</sup>

When asked to talk about medicines, people seem to draw on beliefs relating to medicines as a *class* of treatment sharing certain general properties.<sup>17</sup> Many seem to have a fairly negative opinion of pharmaceuticals, perceiving them to be fundamentally harmful, addictive substances that should not be taken for long periods of time but that tend to be over-prescribed by doctors.<sup>18</sup> Moreover, the dangerous aspects of medication are often linked to their 'chemical'/'unnatural'

<sup>11</sup> Sanfey AG, *et al.* (2006) *Neuroeconomics: cross-currents in research on decision-making*. Trends in cognitive sciences **10**, 108-116.

<sup>12</sup> *Ibid.*

<sup>13</sup> Nattinger AB, *et al.* (1992). *Geographic variation in the use of breast-conserving treatment for breast cancer*. New England Journal of Medicine **326**, 1102-1107.

<sup>14</sup> Woods L, Rachet B & Coleman M (2006). *Origins of socio-economic inequalities in cancer survival: a review*. Annals of Oncology **17**, 5-19.

<sup>15</sup> Schwartz A, *et al.* (2011). *Impact on decisions to start or continue medicines of providing information to patients about possible benefits and/or harms: a systematic review and meta-analysis*. Medical Decision Making **31**, 767-777.

<sup>16</sup> Horne R, Weinman J & Hankins M (1999). *The Beliefs about Medicines Questionnaire: the development and evaluation of a new method for assessing the cognitive representation of medication*. Psychology & Health **14**, 1-24.

<sup>17</sup> Britten N (1994). *Patients' ideas about medicines: A qualitative study in a general practice population*. British Journal of General Practice **44**, 465-468.

<sup>18</sup> Horne R, Weinman J & Hankins M (1999). *The Beliefs about Medicines Questionnaire: the development and evaluation of a new method for assessing the cognitive representation of medication*. Psychology & Health **14**, 1-24.

origins and to suspicions of the pharmaceutical industry.<sup>19,20,21</sup>

The origins of this view are unclear. One possibility is that information about a particular medicine (e.g. speculation in the press that anti-depressants are 'addictive') might feed into a 'general schema' and be extrapolated to mean that 'most medicines are addictive'. Negative views about medicines in general appear to be related to a broader 'world-view' characterised by suspicion of chemicals in food and the environment<sup>22</sup> and the perception that complementary therapies (e.g. homeopathy/herbalism) are more 'natural' and therefore safer than medicines.<sup>23,24</sup> This coincides with an increasing suspicion of science, medicine and technology within Western cultures.<sup>25,26</sup> There is also some evidence that general beliefs about medicines may vary across cultural and ethnic groups within the UK.<sup>27,28</sup> However, variation within groups is likely to be greater than between groups.<sup>29</sup>

As well as having beliefs about medicines as a class of treatment, people seem to vary in their perceptions of personal sensitivity to their effects, with many believing that they are more sensitive than other people to the effects of medicines. People with this view tend to be have more negative views about medicines and vaccination and to be more reluctant to take medication or receive vaccinations.<sup>30</sup> Taken together these sets of beliefs about medicines and about self in relation to medicines can be thought of as 'pharmaceutical schema', or how ideas about pharmaceuticals are organised. Negative pharmaceutical schema are linked to wider concerns about scientific medicine and may influence preferences for treatments (e.g. medication versus natural remedies).<sup>31,32</sup>

These general beliefs characterise our orientation towards specific treatments. When people are presented with the scientific evidence about the potential benefits and harms of a particular medicine, they view the information through the prism of their previous experiences and beliefs about pharmaceutical medicines as a class of treatment and their sensitivity to their effects. Pharmaceutical schema may bias the interpretation of scientific evidence. Negative pharmaceutical schemas are associated with greater concerns that specific medication will result in harm and with greater doubts about the personal need to take it.<sup>33,34,35</sup> They influence the way in which information about the potential benefits and harms of a specific treatment are processed. In experimental studies, people with more negative pharmaceutical schema are more likely to think that symptoms are caused by the drug (i.e. attribute symptoms as side-effects)<sup>36</sup> and less likely to recall side effects correctly.<sup>37</sup>

## Evaluating prescribed medicines: the Necessity Concerns Framework

Our motivation to start and persist with prescribed treatment regimens is influenced by the way in which we judge our personal need for the treatment (or 'necessity belief') relative to our concerns about potential adverse effects of taking it as

<sup>19</sup> *Ibid.*

<sup>20</sup> Britten N, Riley R & Morgan M (2010). *Resisting psychotropic medicines: a synthesis of qualitative studies of medicine-taking*. *Advances in Psychiatric Treatment* **16**, 207-218.

<sup>21</sup> Pound P, *et al.* (2005). *Resisting medicines: A synthesis of qualitative studies of medicine taking*. *Social Science & Medicine* **61**, 133-155.

<sup>22</sup> Gupta K. & Horne R (2001). *The influence of health beliefs on the presentation and consultation outcome in patients with chemical sensitivities*. *Journal of Psychosomatic Research* **50**, 131-137.

<sup>23</sup> Horne R, Weinman J & Hankins M (1999). *The Beliefs about Medicines Questionnaire: the development and evaluation of a new method for assessing the cognitive representation of medication*. *Psychology & Health* **14**, 1-24.

<sup>24</sup> Green DW, Horne R & Shephard EA (2013). *Public perceptions of the risks, benefits and use of natural remedies, pharmaceutical medicines and personalised medicines*. *Complementary Therapies in Medicine* **21**, 487-491.

<sup>25</sup> Faasse K, Cundy T & Petrie KJ (2009). *Medicine and the Media. Thyroxine: anatomy of a health scare*. *BMJ* **339**, b5613.

<sup>26</sup> Petrie KJ, *et al.* (2005). *Worries about modernity predict symptom complaints after environmental pesticide spraying*. *Psychosomatic Medicine* **67**, 778-782.

<sup>27</sup> Kumar K, *et al.* (2008). *Beliefs about medicines in patients with rheumatoid arthritis and systemic lupus erythematosus: a comparison between patients of South Asian and White British origin*. *Rheumatology (Oxford)* **47**, 690-697.

<sup>28</sup> Horne R, *et al.* (2004). *Medicine in a multi-cultural society: the effect of cultural background on beliefs about medications*. *Social Science & Medicine* **59**, 1307-1313.

<sup>29</sup> *Ibid.*

<sup>30</sup> Horne R, *et al.* (2013). *The perceived sensitivity to medicines (PSM) scale: an evaluation of validity and reliability*. *British Journal of Health Psychology* **18**, 18-30.

<sup>31</sup> Calnan M, Montaner D & Horne R (2005). *How acceptable are innovative health-care technologies? A survey of public beliefs and attitudes in England and Wales*. *Social Science & Medicine* **60**, 1937-1948.

<sup>32</sup> Green DW, Horne R & Shephard EA (2013). *Public perceptions of the risks, benefits and use of natural remedies, pharmaceutical medicines and personalised medicines*. *Complementary Therapies in Medicine* **21**, 487-491.

<sup>33</sup> Watkinson A, Chapman S & Horne R (In press). *Beliefs about pharmaceutical medicines and natural remedies explain individual variation in placebo analgesia*. *Journal of Pain*.

<sup>34</sup> Horne R, *et al.* (2009). *Patients' attitudes to medicines and adherence to maintenance treatment in inflammatory bowel disease*. *Inflammatory Bowel Disease* **15**, 837-844.

<sup>35</sup> Chapman SC, *et al.* (2014). *Patients' perspectives on antiepileptic medication: Relationships between beliefs about medicines and adherence among patients with epilepsy in UK primary care*. *Epilepsy & Behavior* **31**, 312-320.

<sup>36</sup> Heller MK, Chapman SC & Horne R (2015). *Beliefs about medication predict the misattribution of a common symptom as a medication side effect - Evidence from an analogue online study*. *Journal of psychosomatic research* **79**, 519-529.

<sup>37</sup> Heller MK, Chapman S, & Horne R (2017). *No Blank Slaters: Pre-existing Schemas about Pharmaceuticals Predict Memory for Side Effects*. *Psychology & Health* **32(4)**, 402-421.

recommended.<sup>38</sup> A recent meta-analysis of 94 studies covering 23 long-term conditions in 18 countries showed that adherence to medication prescribed for long-term conditions is often related to necessity beliefs and concerns.<sup>39</sup>

### ***Common sense evaluations of treatment necessity***

Necessity beliefs might be thought of as the answer to two questions: 'How much do I need this treatment to achieve a goal that's important to me?' and 'How much can I get away with without it?' Perceived necessity is not a form of efficacy belief: people might believe that a treatment will be effective but not that they need it. They might have a low necessity belief even if they understand the scientific evidence for the potential benefits of treatment. This might occur because people do not 'value' that particular benefit or perceive it be important enough to overcome concerns about taking the medicine.

Perceptions of illness influence beliefs about the necessity of medication. To be convinced of a personal need for ongoing medication, people must first perceive a good fit between the problem (the illness or condition) and the solution (the medicine).<sup>40</sup> Here, symptom perceptions relative to expectations are key.<sup>41</sup> Until they experience a chronic condition, most people's experience of illness is symptomatic and acute. However, for many long-term conditions the medical rationale for maintenance treatment is based on a prophylaxis model where the benefits of treatment are often silent and long-term. This may be in stark contrast to the intuitive model of 'no symptoms; no problem'.<sup>42</sup> Similarly, missing doses may not lead to an immediate deterioration in symptoms, reinforcing the erroneous perception that high adherence to the medication may not be necessary. Related to this is the fact that people often stop taking treatment when they judge that the condition has improved. These judgments are often based on potentially misleading symptom perceptions rather than on objective clinical indicators of disease severity.<sup>43</sup>

This can be illustrated by considering two patients with asthma. The first shares the 'medical view' of asthma as an 'acute on chronic' condition (i.e. it is a chronic disease which manifests as acute symptomatic flair up or asthma attacks) with potentially serious consequences. This patient understands that asthma remains a problem even when there are no overt symptoms of breathlessness. In this scenario, the rationale for the regular use of inhaled steroid to prevent or at least lower the frequency of attacks is easy to accept. This can be contrasted with a second patient whose model of asthma is closely linked to symptom experience. This patient does not think that their asthma has serious consequences because their attacks happen fairly infrequently. Although they feel very ill during the asthma attack, at other times they have no symptoms. They doubt their personal need for preventive medication because the notion of asthma as a chronic condition, needing continuous treatment, is at odds with their experience of it as an *episodic* problem. The first patient is more likely to agree with the *necessity* of regular prophylactic medication than the second patient, who perceives their asthma to be an acute problem (short timeline) with few personal consequences.<sup>44,45</sup>

Abstract scientific evidence for the potential benefits of treatment derived from clinical trials may be less persuasive than 'concrete' symptom experiences. This is illustrated by a study exploring the reasons why people decided not to take a clinically indicated offer of antiretroviral treatment (ART) for human immunodeficiency virus (HIV) infection. Evidence-based guidelines for the optimum time to initiate ART stipulate CD4 count (an indicator of immune status) and viral load (a marker for disease activity) as key indicators for when ART is clinically indicated. However, receiving 'abstract' information about personal CD4 and viral load lab results was less persuasive than more 'concrete' symptom experiences. A common reason given by interviewees for refusing ART was that they were experiencing few, if any, of the symptoms that they associated with HIV infection.<sup>46</sup> Their common-sense interpretation of their experiences (i.e. feeling fine) seemed to convince them that they did not need treatment yet and could afford to delay starting ART, despite the scientific evidence supporting an

<sup>38</sup> Horne R, et al. (2007). *Patients' perceptions of highly active antiretroviral therapy in relation to treatment uptake and adherence: the utility of the necessity-concerns framework*. Journal of Acquired Immune Deficiency Virus **45**, 334-341.

<sup>39</sup> Horne R, et al. (2013). *Understanding patients' adherence-related beliefs about medicines prescribed for long-term conditions: a meta-analytic review of the Necessity-Concerns Framework*. PLoS One **8**, e80633.

<sup>40</sup> Horne R & Weinman J (2002). *Self-regulation and self-management in asthma: exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication*. Psychology & health **17**, 17 - 32.

<sup>41</sup> *Ibid.*

<sup>42</sup> Halm EA, et al. (2006). *No symptoms, no asthma: the acute episodic disease belief is associated with poor self-management among inner-city adults with persistent asthma*. Chest **129**, 573-580.

<sup>43</sup> Cooper V, et al. (2009). *The influence of symptom experiences and attributions on adherence to highly active anti-retroviral therapy (HAART): a six-month prospective, follow-up study*. AIDS Care **21**, 520-528.

<sup>44</sup> Horne R & Weinman J (2002). *Self-regulation and self-management in asthma: exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication*. Psychology & health **17**, 17 - 32.

<sup>45</sup> Halm EA, et al. (2006). *No symptoms, no asthma: the acute episodic disease belief is associated with poor self-management among inner-city adults with persistent asthma*. Chest **129**, 573-580.

<sup>46</sup> Cooper V, et al. (2002). *Perceptions of HAART among gay men who declined a treatment offer: preliminary results from an interview-based study*. AIDS Care **14**, 319-328.

immediate start.<sup>47</sup>

### **Concerns about medicines**

There is a striking similarity in the type of concerns that patients report about medicines. One obvious source of concern is the experience of symptoms as medication 'side-effects' and the disruptive effects of medication on daily living; but this is not the whole picture.<sup>48</sup> Many patients receiving regular medication who have not experienced adverse effects are still worried about possible problems in the future. These concerns often arise from the belief that regular use can lead to dependence or that the medication will accumulate within the body and lead to long-term effects. These concerns are related to the social representations of medicines as harmful and overused, as discussed above.<sup>49</sup> Other concerns are specific to particular classes of medicine.<sup>50</sup> For example, worries that corticosteroid inhalers prescribed for asthma will result in weight gain<sup>51</sup> or that regular use of analgesic medication will make it less effective in the future.<sup>52</sup>

The 'case for' taking a medicine regularly for the long-term may need to overcome a fundamental aversion to taking medicines and suspicion of pharmaceuticals and the pharmaceutical industry, as was evident from the Academy of Medical Sciences' public dialogue and surveys of general practitioners and the general public.<sup>53,54</sup> More research is needed to fully understand how communication of the scientific evidence of probabilities of potential benefits and harms impacts on these concerns.<sup>55</sup> In practice, patients are often reluctant to express concerns or doubts about their medication to the prescriber, possibly because they fear that the clinician will interpret doubts, concerns and non-adherence as a 'lack of faith' in the doctor. Patients' fundamental questions about the value and safety of their medication may remain answered by healthcare professionals, leaving patients dissatisfied with the quality of information they have received.<sup>56</sup>

### **Meaning of medication and sense of self**

Concerns also relate to the meaning that being on regular medication has for the individual and their sense of self. Taking a daily treatment may be an unwelcome reminder of an illness that has a negative impact on how people see themselves or perceive they are seen by others. In these circumstances non-adherence might be seen as an implicit strategy for minimising the impact on their sense of self.<sup>57,58</sup> Determining the necessity of a treatment may also be influenced by notions of self. There has been disappointingly little research in this area, but perceptions that one can resist the progress of disease by drawing on sources of 'inner strength', 'hardiness' or by keeping a 'positive outlook' emerged as reasons for deciding not to start clinically indicated ART in interviews with over 100 HIV-positive men.<sup>59</sup>

## **Other contextual factors affecting the interpretation of scientific evidence**

### **Media reports**

Perceptions of specific treatments can also be influenced by exaggerated claims about the potential of early stage research, with recent research showing that many examples of exaggerated, distorted or misleading claims are not the result of

<sup>47</sup> Horne R, et al. (2007). *Patients' perceptions of highly active antiretroviral therapy in relation to treatment uptake and adherence: the utility of the necessity-concerns framework*. Journal of Acquired Immune Deficiency Virus **45**, 334-341

<sup>48</sup> Cooper V, et al. (2015). *Patient-reported side effects, concerns and adherence to corticosteroid treatment for asthma, and comparison with physician estimates of side-effect prevalence: a UK-wide, cross-sectional study*. npj Primary Care Respiratory Medicine **25**, 15026.

<sup>49</sup> Chater AM, et al. (2014). *Profiling patient attitudes to phosphate binding medication: a route to personalising treatment and adherence support*. Psychology & Health **29**, 1407-1420.

<sup>50</sup> Horne R & Weinman J (2002). *Self-regulation and self-management in asthma: Exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication*. Psychology and Health **17**, 17-32.

<sup>51</sup> Cooper V, et al. (2015). *Patient-reported side effects, concerns and adherence to corticosteroid treatment for asthma, and comparison with physician estimates of side-effect prevalence: a UK-wide, cross-sectional study*. npj Primary Care Respiratory Medicine **25**, 15026.

<sup>52</sup> Gill A & Williams AC (2001). *Preliminary study of chronic pain patients' concerns about cannabinoids as analgesics*. Clinical Journal of Pain **17**, 245-248.

<sup>53</sup> <http://www.acmedsci.ac.uk/evidence/public-dialogue>

<sup>54</sup> <http://www.acmedsci.ac.uk/evidence/survey>

<sup>55</sup> Cooper V, et al. (2015). *Patient-reported side effects, concerns and adherence to corticosteroid treatment for asthma, and comparison with physician estimates of side-effect prevalence: a UK-wide, cross-sectional study*. npj Primary Care Respiratory Medicine **25**, 15026

<sup>56</sup> Bowskill R, et al. (2007). *Patients' perceptions of information received about medication prescribed for bipolar disorder: Implications for informed choice*. Journal of Affective Disorders **100**, 253-257.

<sup>57</sup> Horne R (2003). *Treatment perceptions and self-regulation*. In Cameron LD & Leventhal H eds. (2003) *The Self-Regulation of Health and Illness Behaviour*. Routledge. London, UK

<sup>58</sup> Cooper V, et al. (2002). *Perceptions of HAART among gay men who declined a treatment offer: preliminary results from an interview-based study*. AIDS Care **14**, 319-328.

<sup>59</sup> *Ibid.*



journalistic misreporting but reflect statements made in original press releases.<sup>60</sup> Likewise, concerns about medication, and even symptom/side-effects can be influenced by inaccurate media reports.<sup>61,62,63</sup>

### Perceptions of information sources

Basic psychological factors and interpersonal interactions affect how information is perceived – including information regarding medical decisions – often unknowingly to the individual concerned. Various models identify different dimensions that can influence how people form opinions of other people or sources of information. These dimensions include competence, warmth and moral character.<sup>64,65</sup> In a medical context, this might refer to the competence, warmth and moral character of the healthcare professional. These factors can shape opinions and perceptions very quickly and often subconsciously, and they can be deep-seated with long-lasting impact.<sup>66</sup>

There are many specific examples of how broader factors affect how evidence is perceived in the context of health. Perhaps most famously, Amos Tversky and Daniel Kahneman showed in classic studies how the way information is framed can affect people's decisions. They found that people were generally more risk-taking when the outcome of a treatment was expressed in terms of losses, yet were generally more risk-averse when the very same treatment was framed in terms of health gains.<sup>67</sup>

### Over-medication and medicalisation

As discussed in the 'Enhancing the use of scientific evidence to judge the potential benefits and harms of medicines' report, making decisions about medicines is increasingly difficult in view of the complexity of illnesses, as presented, for example, by multiple co-occurring illnesses (multimorbidity). There is paucity of support structures and evidence-based decision-aids to help patients and healthcare professionals make decisions in the face of this complexity. We heard that healthcare professionals are often only guided by disease-specific guidelines produced by NICE, leading to prescription of a suite of medicines, with no guidance as to which should be prioritised. Further, patients, healthcare professionals and governments often resort to therapeutic interventions rather than others, such as lifestyle changes, which may be more difficult. This has led to concerns about over-medication and medicalisation. In that regard, the Academy of Medical Royal Colleges has compiled a list of commonly used treatments and procedures which are of questionable value and whose use should therefore be carefully discussed with patients.<sup>68</sup> The Academy of Medical Sciences has also recently launched a project addressing the global challenge of multimorbidity to explore the gaps in the existing evidence and the associated research priorities in this area.<sup>69</sup>

## Conclusions

Myriad factors influence decisions about medicines. The available evidence suggests that the communication of the potential benefits and harms derived from scientific evidence may be much less influential than other factors, from beliefs about illness and treatment to past and present experiences. Subjective experience and interpretation of symptoms may be more influential than scientific evidence of likely benefits and harms gleaned from populations. People may rate others sources, such as experiences from family and friends, as more influential than scientific evidence. Methods of communicating scientific evidence therefore need to help people translate information from population studies into an understanding of the potential personal benefit. Crucially, when communicating scientific evidence, for example about the potential benefits and harms of medicines, consideration should be given as to how to create a common-sense rationale for personal necessity or value and how to address personal concerns.

<sup>60</sup> Sumner P, et al. (2014). *The association between exaggeration in health related science news and academic press releases: retrospective observational study*. *BMJ* **349**, g7015.

<sup>61</sup> Faasse K, et al. (2015). *High perceived sensitivity to medicines is associated with higher medical care utilisation, increased symptom reporting and greater information-seeking about medication*. *Pharmacoepidemiology and Drug Safety* **24**, 592-599.

<sup>62</sup> Horne R, et al. (2004). *Medicine in a multi-cultural society: the effect of cultural background on beliefs about medications*. *Social Science & Medicine* **59**, 1307-1313.

<sup>63</sup> Petrie KJ, et al. (2005). *Worries about modernity predict symptom complaints after environmental pesticide spraying*. *Psychosomatic Medicine* **67**, 778-782.

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Despite this, it is important that, as the most reliable source of information about the potential benefits and harms of medicines, scientific evidence plays a greater role in the process of better-informed decision-making about their use. Although reliable scientific evidence is only one of the factors influencing decisions about treatments, a better understanding of the factors – such as beliefs, personal preferences and cognitive biases – that drive decisions and influence how evidence is interpreted and acted upon is needed. The outcomes of such research should subsequently be used to better equip healthcare professionals to understand, listen to and respond to patient concerns, and communicate evidence in a way that people can meaningfully use to avoid decisions based on misunderstandings or misconceptions.

[info@acmedsci.ac.uk](mailto:info@acmedsci.ac.uk)  
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