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ADHERENCE IS A COMPLEX BEHAVIOR

The challenge and causes of non-adherence

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Professor Rob Horne is Founding Director of a UCL-Business company (Spoonful of Sugar Ltd) providing consultancy on treatment engagement and patient support programms to healthcare policy makers, providers and pharmaceutical industry

Medicines adherence

A serious public health problem across both high- and low-income countries

- **50%** of medicines are not taken as prescribed[1]

- The increased likelihood of people dying as a result of 'poor adherence' compared with those with 'good adherence' is **2-3 fold**[2,3]

  In Simpson's publication[2], the analysis of mortality risk according to adherence group was based on 2779 (5.9%) deaths in 46 847 participants:
  - 1462 (4.7%) deaths occurred in 31 439 participants with good adherence to drug therapy,
  - 1317 (8.5%) deaths in 15 408 participants considered to have poor adherence.

Cost to EU
125 billion Euros/year

Series of Cochrane Systematic Reviews show that only about half of intervention work [4]
A comprehensive review commissioned by NHS (NIHR) identified *why* and what we should do about it[5]

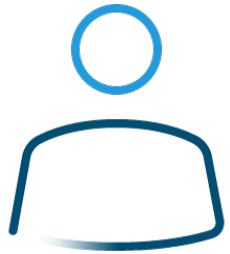
1. Sabaté E, editor. Adherence to long-term therapies: evidence for action. World Health Organization; 2003.
2. Simpson SH, Eurich DT, Majumdar SR, Padwal RS, Tsuyuki RT, Varney J, et al. BMJ. 2006;333(7557):15.
3. DiMatteo MR, Giordani PJ, Lepper HS, Croghan TW. Med Care. 2002;40:794-811.
4. Kripalani S, Yao X, Haynes RB. Interventions to Enhance Medication Adherence in Chronic Medical Conditions: A Systematic Review. Arch Intern Med. 167(6):540-549.
5. Horne R et al. Concordance, adherence and compliance in medicine taking. NIHR SDO 2005.

Non-adherence – A variable behavior not a trait characteristic

Adherence rates vary…

Between patients

Within the same patient over time & across treatments



Most of us are non-adherent some of the time

Non-adherence may be the NORM not the exception!

Horne R, Weinman J, Barber N, Elliott RA, Morgan M. Concordance, Adherence and Compliance in Medicine Taking: A conceptual map and research priorities (2005). National Co-ordinating Centre for NHS Service Delivery and Organisation R&D, London [Accessed October 2021]

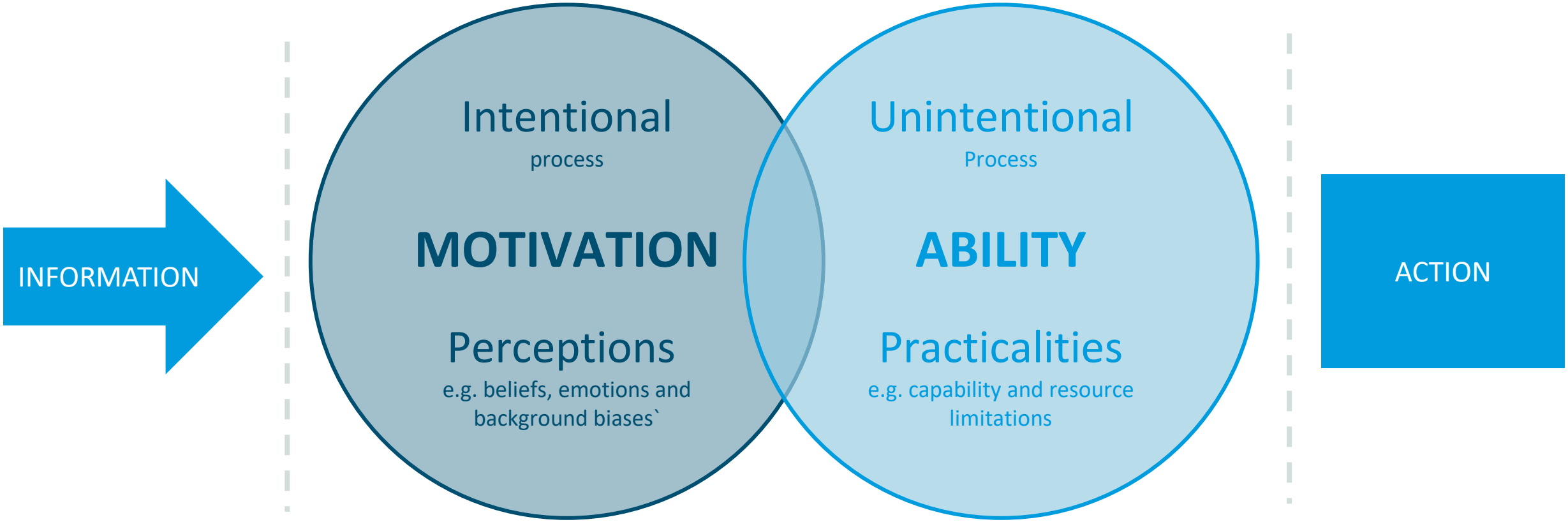
The Information – Action Gap

For information to change behavior it needs to bridge the information-action gap

Horne, R., Cooper, V., Wileman, V., & Chan, A. (2019). Supporting adherence to medicines for long-term conditions: A perceptions and practicalities approach based on an extended common-sense model. European Psychologist, 24(1), 82–96.

The Perceptions & Practicalities Approach (PaPA)[1-2]

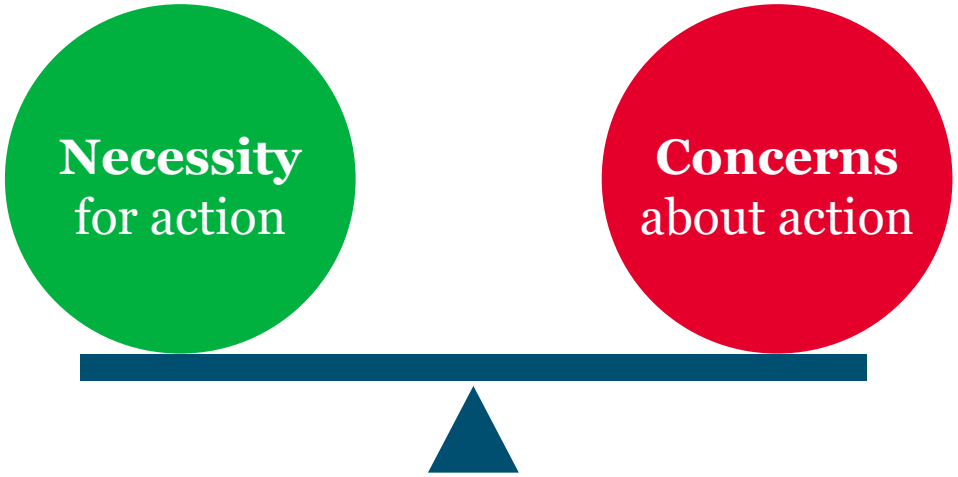
A framework for developing adherence support– applied in NICE Medicines Adherence Guidelines



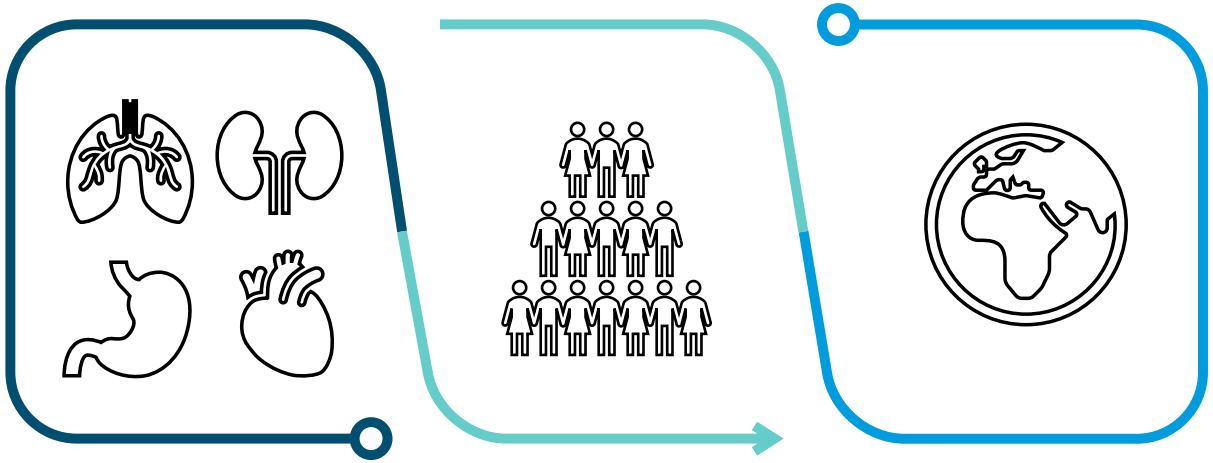
1. Horne R. In Pharmacy Practice, 2001. Ed. by KMG Taylor & G Harding. London: Taylor & Francis [Accessed October 2021]; 2. Horne, R., Cooper, V., Wileman, V., & Chan, A. (2019). Supporting adherence to medicines for long-term conditions: A perceptions and practicalities approach based on an extended common-sense model. European Psychologist, 24(1), 82–96.

What are the key beliefs influencing adherence?

Understanding treatment beliefs: The necessity-concerns framework (NCF)[1,2]



Disease-agnostic framework



> 23 different therapy areas

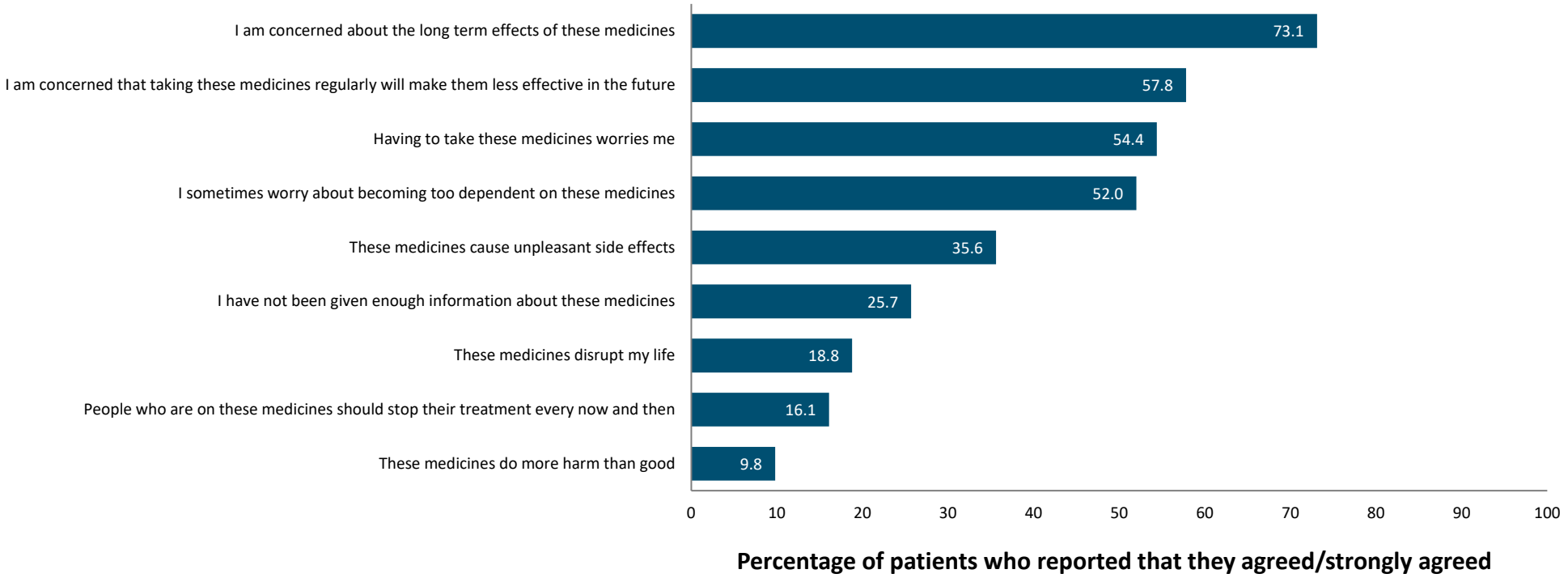
> 27,000 patients

>18 countries & healthcare systems

1. Foot H, La Caze A, Gujral G, Cottrell N. The necessity-concerns framework predicts adherence to medication in multiple illness conditions: A meta-analysis. Patient Educ Couns. 2016;99(5):706-17; 2. Horne R, Chapman SC, Parham R, Freemantle N, Forbes A, Cooper V. Understanding patients' adherence-related beliefs about medicines prescribed for long-term conditions: a meta-analytic review of the Necessity-Concerns Framework. PLoS One. 2013;8(12): e80633

Specific concerns about medicines: Beyond side-effects

N = 1871 (a survey of 1 in 10 members of crohn's and colitis uk)[1,4]



Other concerns

- Personal meaning of medication: Impact on sense of self[2]
- Symbol of lack of faith[3]

1. Horne R, Parham R, Driscoll R, Robinson A. Patients' attitudes to medicines and adherence to maintenance treatment in IBD Inflamm Bowel Dis. 2009;15:837–44;
2. Cooper, V. et al. Perceptions of HAART among gay men who declined a treatment offer: AIDS Care 14, 319-328, (2002); 3. Sherr L, Lampe FC, Clucas C, et al. Self-reported non-adherence to ART and virological outcome in a multiclinic UK study. AIDS Care 2010;22(8):939-45; 4. Speaker data.

There may be disconnects between patient and HCP concerns

Mismatch between patient and clinician ratings of ‘problems’?

Patients rank ‘tolerability’ side effects as severe e.g., effect on family or partner, loss of hair, fatigue and nausea and vomiting[1,2]

Experience of subjective side effects reduces adherence[3]

1. Sun CC, Bodurka DC, Weaver CB, Rasu R, Wolf JK, Bevers MW, Smith JA, Wharton JT, Rubenstein EB. Rankings and symptom assessments of side effects from chemotherapy: insights from experienced patients with ovarian cancer. Support Care Cancer. 2005 Apr;13(4):219-27; 2. Bernard M, Brignone M, Adehossi A, Pefoura S, Briquet C, Chouaid C, Tilleul P. Perception of alopecia by patients requiring chemotherapy for non-small-cell lung cancer: a willingness to pay study. Lung Cancer. 2011 Apr;72(1):114-8; 3. Fontein DB, Nortier JW, Liefers GJ, Putter H, Meershoek-Klein Kranenbarg E, van den Bosch J, Maartense E, Rutgers EJ, van de Velde CJ. High non-compliance in the use of letrozole after 2.5 years of extended adjuvant endocrine therapy. Results from the IDEAL randomized trial. Eur J Surg Oncol. 2012 Feb;38(2):110-7

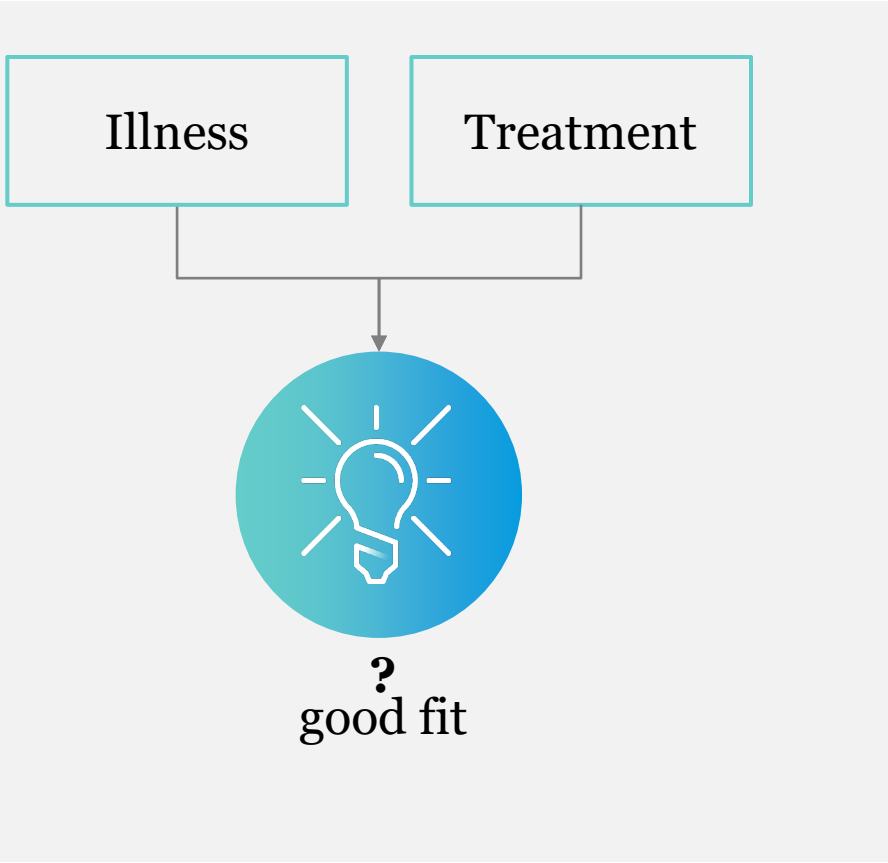
Origins of treatment necessity beliefs and concerns

Common-sense fit and common-sense defaults

Patients need to see a common-sense **fit** between their understanding of the problem (the illness) and the proposed solution (the treatment)[1-3]

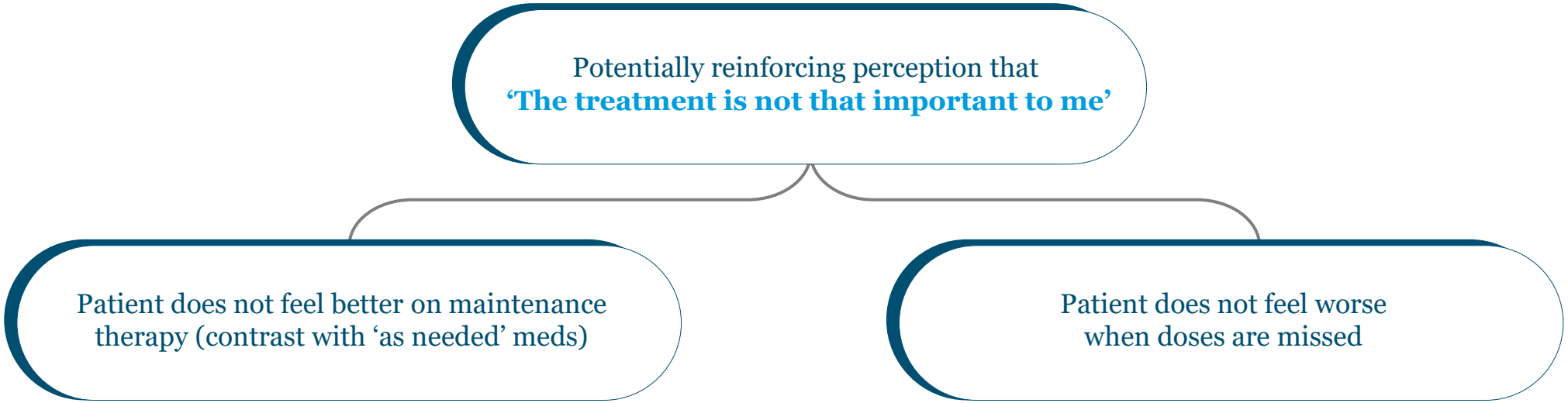
For many patients that fit is not clear

Just telling patients how the medicine works or how to take it is not enough- we need to tell 'the story' in a way that overcomes 'common-sense defaults' in the way that many people think about medicines



1. 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(1), 17–32. 2. Halm EA, Mora P, Leventhal H. No symptoms, no asthma: the acute episodic disease belief is associated with poor self-management among inner-city adults with persistent asthma. Chest. 2006 Mar;129(3):573-80. 3. Hall S, Weinman J, Marteau TM. The motivating impact of informing women smokers of a link between smoking and cervical cancer: the role of coherence. Health Psychol. 2004 Jul;23(4):419-24.

Necessity beliefs common-sense default: No symptoms, no problem![1-2]



Many patients are not convinced of personal need for daily medication treatment … 'no symptoms, no problem'

Expectations of treatment linked to symptom experiences, e.g. 'I feel better now, I don't need it' OR 'I still feel ill; it's not working'

1. 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(1), 17–32; 2. Halm EA, Mora P, Leventhal H. No symptoms, no asthma: the acute episodic disease belief is associated with poor self-management among inner-city adults with persistent asthma. Chest. 2006 Mar;129(3):573-80

Other common – sense defaults

- Chemical bad, natural good
- Medicines accumulate in the body over time
- More powerful medicines are more harmful
- Suspicion of the pharmaceutical industry
- If I express a doubt or concern about the treatment the doctor will interpret it as a doubt in them

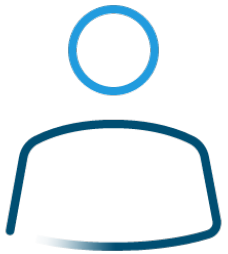
Horne Invited paper https://acmedsci.ac.uk/policy/policy-projects/how-can-we-all-best-use-evidence [Accessed October 2021]

Disconnects drive the behavioral gap

The fundamental cause of non-adherence is often a disconnect between beliefs and expectations of prescriber and patient[1,2]

HCPs :
Knowledge, beliefs and expectations about illness and treatment

Match?
Disconnects?



Patient:
Knowledge, beliefs and expectations about illness and treatment

1. Horne R, et al. PloS one 2013; 8(12): e80633; 2. Horne R, et al Patient Preference and Adherence 2018; 12: 1099.

3-step perceptions and practicalities approach (PAPA)[1]

A ‘no-blame’ approach to facilitate an honest and open discussion to address

Perceptions

Communicate a ‘common-sense rationale’ for why the treatment is needed – Taking account of the patients perceptions of the illness and symptom expectations. e.g. ‘Why should I take this stuff when I feel well and/or my illness is controlled’

Elicit and address CONCERNS about potential adverse consequences of the treatment – including support with side-effect management

Practicalities

Tailor a convenient regimen and address practical barriers – Make it as easy as possible

NECESSITY

CONCERNS

PRACTICALITIES

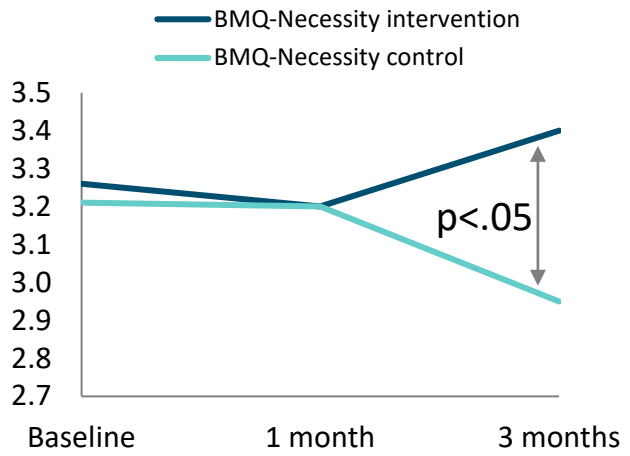
1. Horne, R., Cooper, V., Wileman, V., & Chan, A. (2019). Supporting adherence to medicines for long-term conditions: A perceptions and practicalities approach based on an extended common-sense model. European Psychologist, 24(1), 82–96

Changing necessity beliefs and concerns

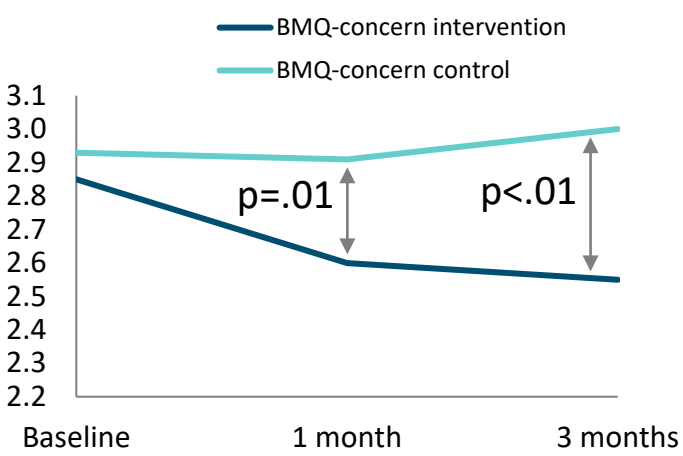
Tailoring support to address the patient's belief barriers can improve adherence[1]

In a study with inflammatory bowel disease, digital adherence support **PERSIGNIA™** reduced adherence barriers ($p<0.01$) and reported nonadherence ($p<0.05$)[2]

BMQ-necessity



BMQ-concerns



As demonstrated in the graphs

Without PERSIGNIA™, and left unchecked, necessity beliefs REDUCE over time and concerns stay the same, leading to non-adherence

With PERSIGNIA™ necessity beliefs INCREASE over time, and concerns are REDUCED – safe-guarding adherence

1. Petrie KJ, Perry K, Broadbent E, Weinman J. A text message programme designed to modify patients' illness and treatment beliefs improves self-reported adherence to asthma preventer medication. British journal of health psychology 2012; 17(1): 74-84; 2. Chapman S, Sibelli A, St-Clair Jones A, Forbes A, Chater A, Horne R. Personalised adherence support for maintenance treatment of inflammatory bowel disease: A tailored digital intervention to change adherence-related beliefs and barriers. Journal of Crohn's and Colitis. 2020;14(10):1394-404

Intervention components: Practicalities

Forgetting

- Pillbox organizer
- Text reminders
- Provide feedback on adherence

Environmental/ contextual barriers

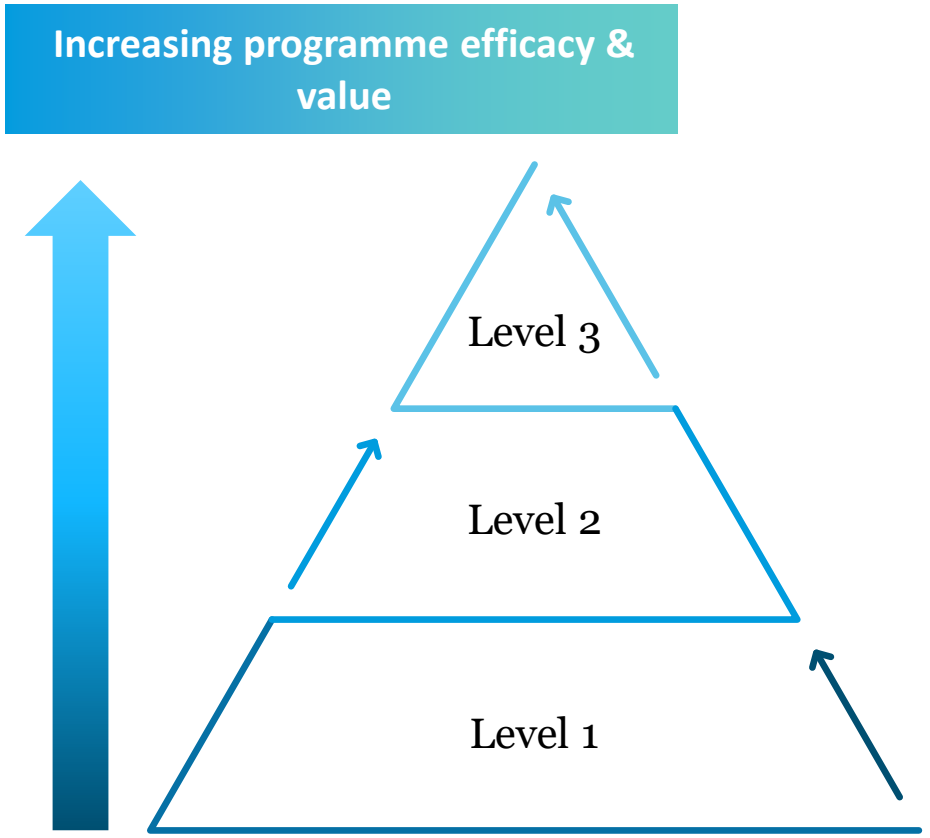
- Identify environmental/ contextual barriers
- Develop and review action plans (when, where and how to take treatment)
- Link behavior with prompts and cues

Lack of social support

- Identify potential sources of support
- Encourage use of support

1. Horne R. Compliance adherence & concordance In: Taylor K & Harding G, editors. Pharmacy Practice 2nd ed: Routledge; 2015; 2. NICE. Clinical guideline 76: Medicine adherence: involving patients in decisions about prescribed medicines and supporting adherence. London: National Institute for Health and Clinical Excellence; 2009. [Accessed October 2021]; 3. Horne R, et al . Supporting Adherence to Medicines for Long-Term Conditions: A Perceptions and Practicalities Approach Based on an Extended Common-Sense Model. European Psychologist 2019 24: 82-96

PaPA-based interventions[1] can improve adherence and be cost effective[2-4]



Tailored PaPA
Support tailored to address individual perceptions and practicalities

Perceptions
Take account of key beliefs influencing
Motivation

Practicalities
Simplify regimen packaging
Monitoring
Text reminders
Ability

1.Horne R, Cooper V, Wileman V, Chan A. European Psychologist 2019; 24(1): 82-96; 2.Clifford S, Barber N, Elliott R, Hartley E, Horne R.. Pharm World Sci. 2006;28(3):165-70; 3.Elliott RA, Barber N, Clifford S, Horne R, Hartley E.. Pharm World Sci. 2008;30(1):17-23; 4.Odeh M, Scullin C, Fleming G, Scott MG, Horne R, McElnay JC.. Br J Clin Pharmacol. 2019;85(3):616-25

Take home messages

Recognise that the patient does not come as a 'blank sheet' that we can write the prescription instructions on	These are usually logical, common-sense interpretations of the condition and treatment; they make sense from the patient's perspective, but are often mistaken from a medical perspective
Patients come with pre-existing ideas about their condition and with beliefs and expectations of treatment	Beliefs and expectations drive adherence/non-adherence