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INTRODUCTION – BEHAVIORS AND BELIEFS: THE FOUNDATIONS OF ADHERENCE

Behaviors and beliefs: The foundations of 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 programmes to healthcare policy makers, providers and pharmaceutical industry.

The Information – Action Gap

FOR INFORMATION TO CHANGE BEHAVIOR IT NEEDS TO BRIDGE THE INFORMATION-ACTION GAP

INFORMATION → **ACTION**

Information is **essential** to enable adherence

BUT…

Giving more information **does not guarantee engagement**

Beliefs

To result in action, information must either:

Agree with our existing **beliefs**

OR

Change them

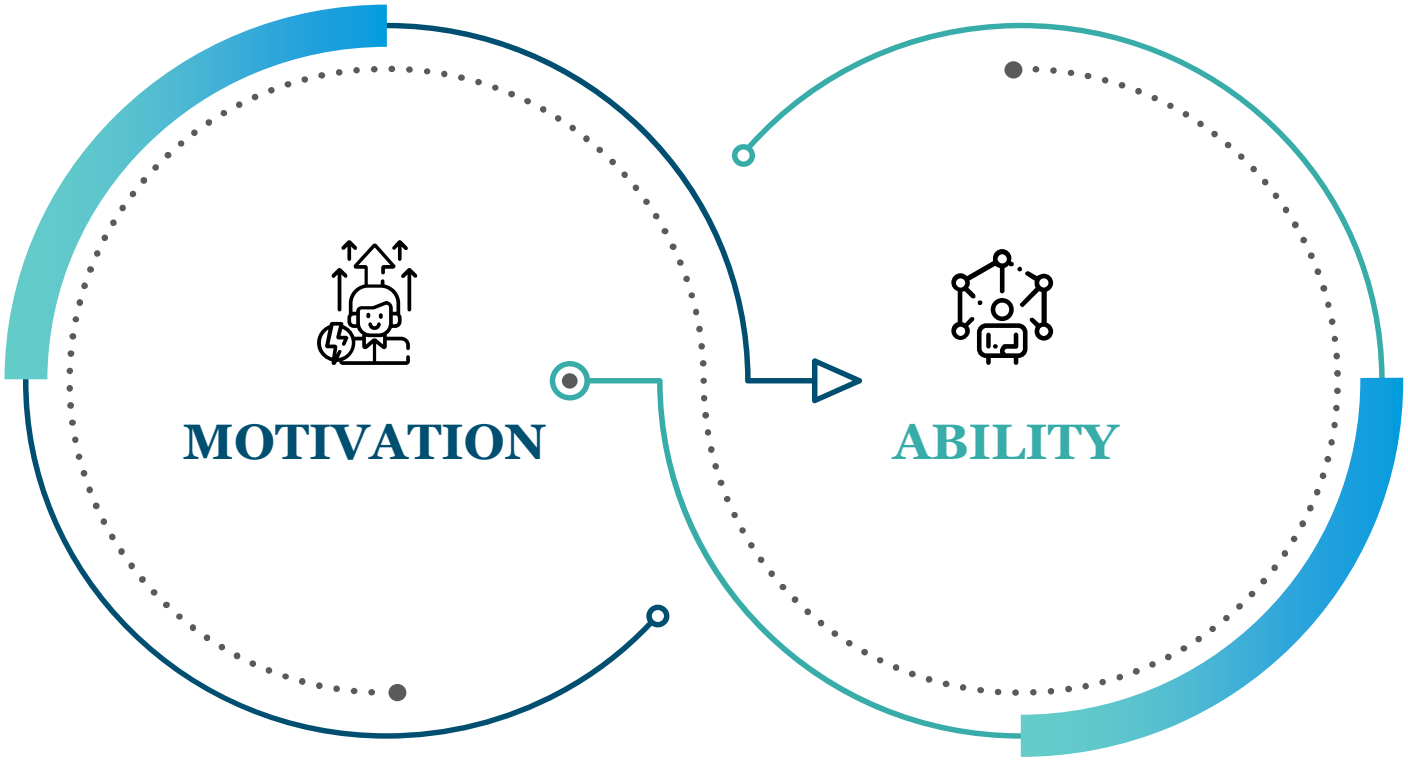
Horne, R., Cooper, V., Wileman, V., & Chan, A. (2019). Supporting adherence to medicines for long-term conditions: A perceptions and practicalities approach based on an extended common-sense model. *European Psychologist*, 24(1), 82–96.

The Perceptions & Practicalities Approach (PaPA) [1-3]

A FRAMEWORK FOR DEVELOPING ADHERENCE SUPPORT– APPLIED IN NICE MEDICINES ADHERENCE GUIDELINES

Intentional
process

Perceptions
e.g., beliefs, emotions & background baises

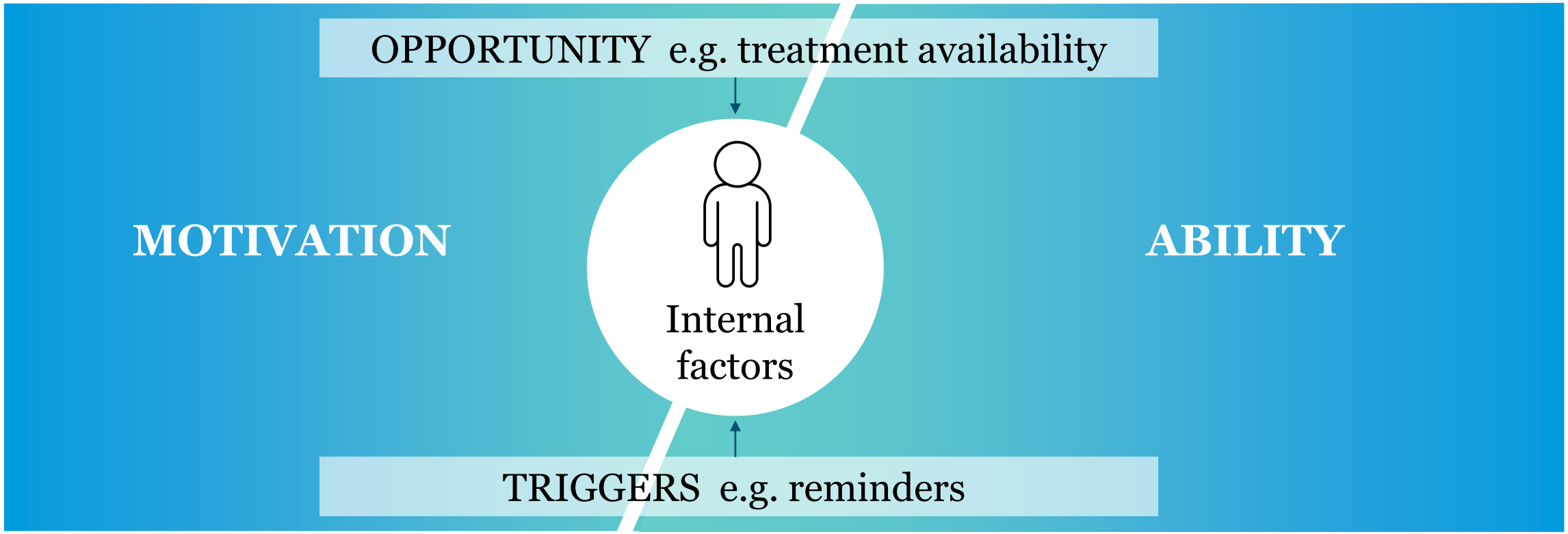


Unintentional
process

Practicalities
e.g., capability and resource limitations

1. Horne R. In Pharmacy Practice, 2001. Ed. by KMG Taylor & G Harding. *London: Taylor & Francis;* 2. Horne R *et al* (2005). Concordance, Adherence and Compliance in Medicine Taking, *London: National Co-ordinating Centre for NHS Service Delivery and Organisation;* 3.Horne R *et al*. Supporting Adherence to Medicines for Long-Term Conditions, European *Psychologist* 2019; 24(1): 82-96.

Motivation and ability influenced by opportunity and triggers



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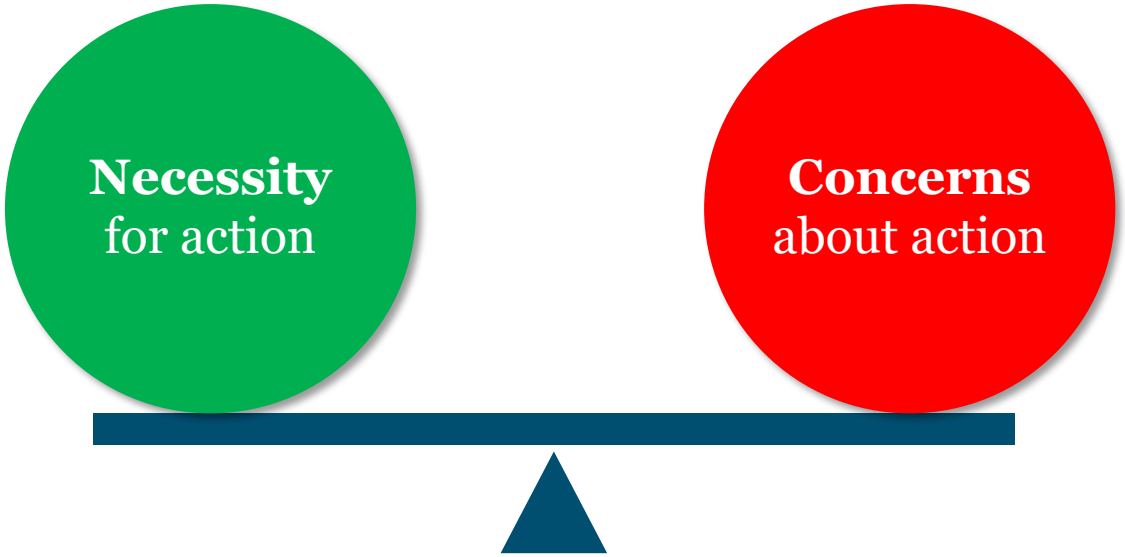
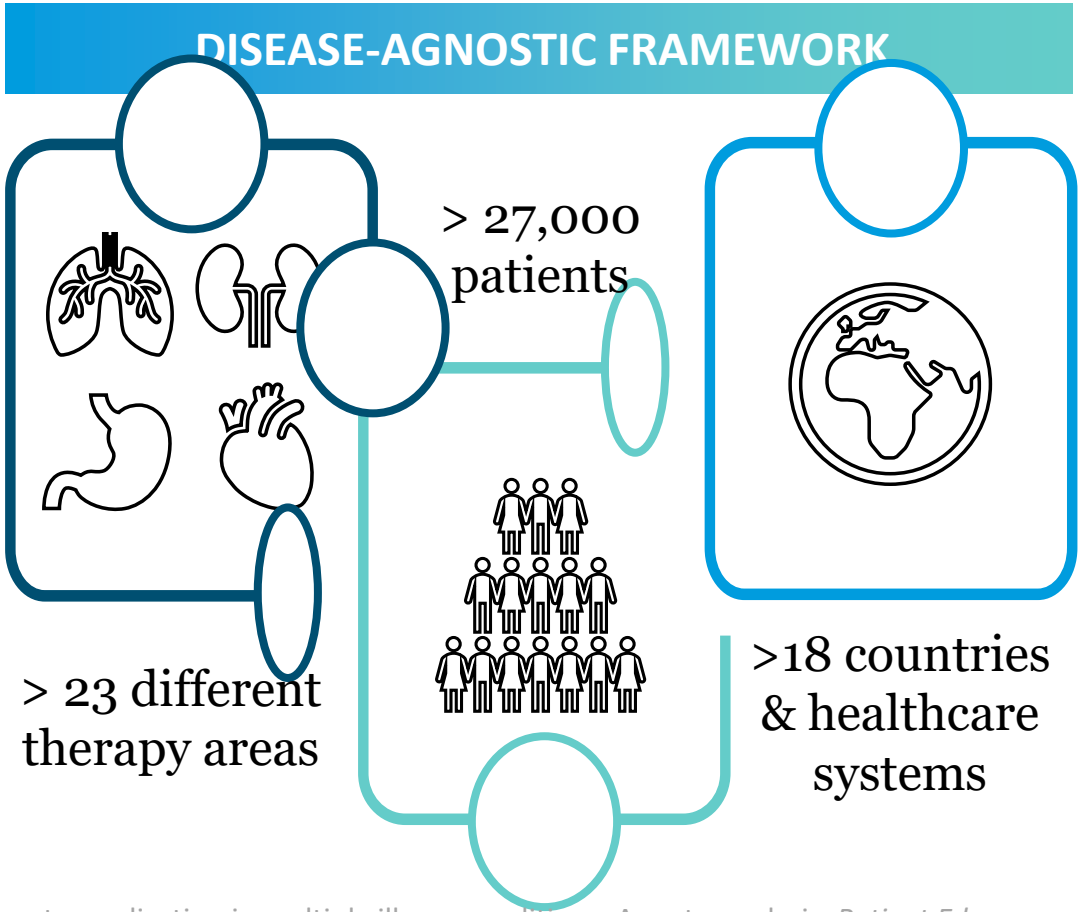
What are the key beliefs influencing adherence?

Understanding treatment beliefs: The Necessity-Concerns Framework (NCF)[1,2]

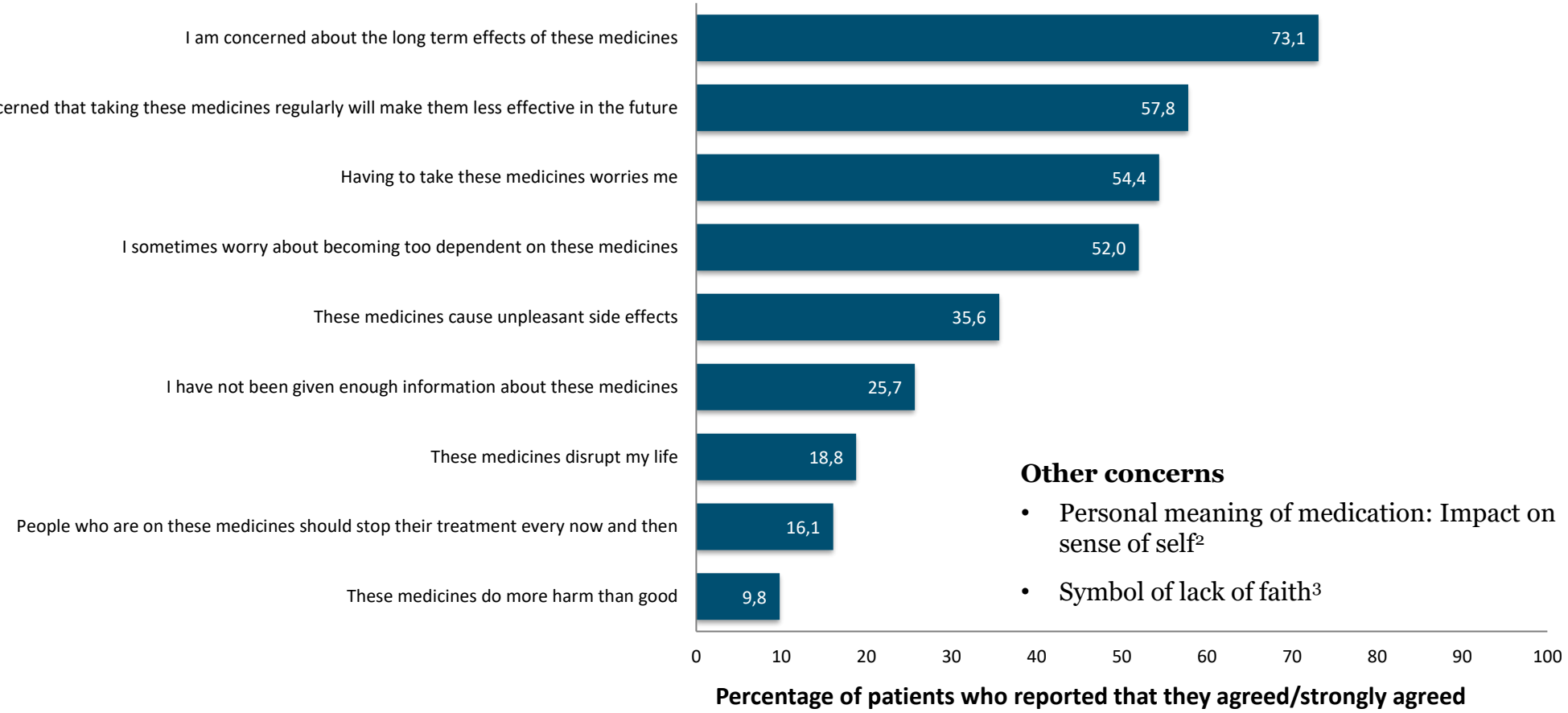




1. Foot H, La Caze A, Gujral G, Cottrell N. The necessity-concerns framework predicts adherence to medication in multiple illness conditions: A meta-analysis. *Patient Educ Couns.* 2016;99(5):706-17; 2. Horne R, Chapman SC, Parham R, Freemantle N, Forbes A, Cooper V. Understanding patients' adherence-related 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. Data on file.

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]

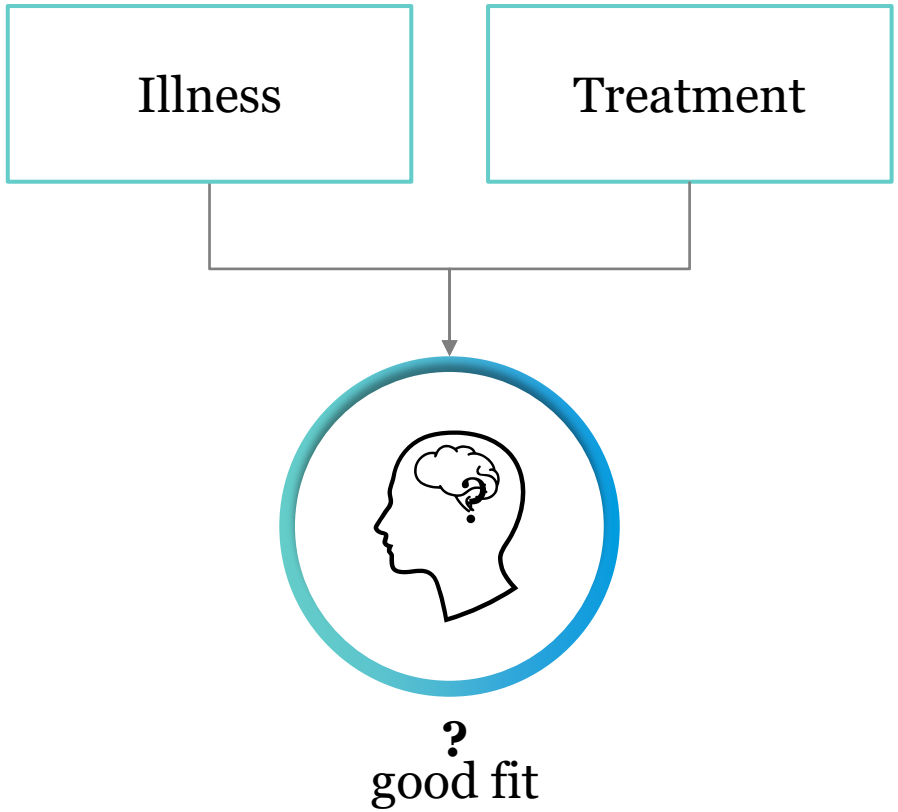
Experience of subjective side effects reduces adherence[3]

1. Sun CC, *et al.* 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, *et al.* 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, *et al.* 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.

Leventhal's common-sense model: Illness perceptions

Health threat e.g. Symptoms or Diagnosis

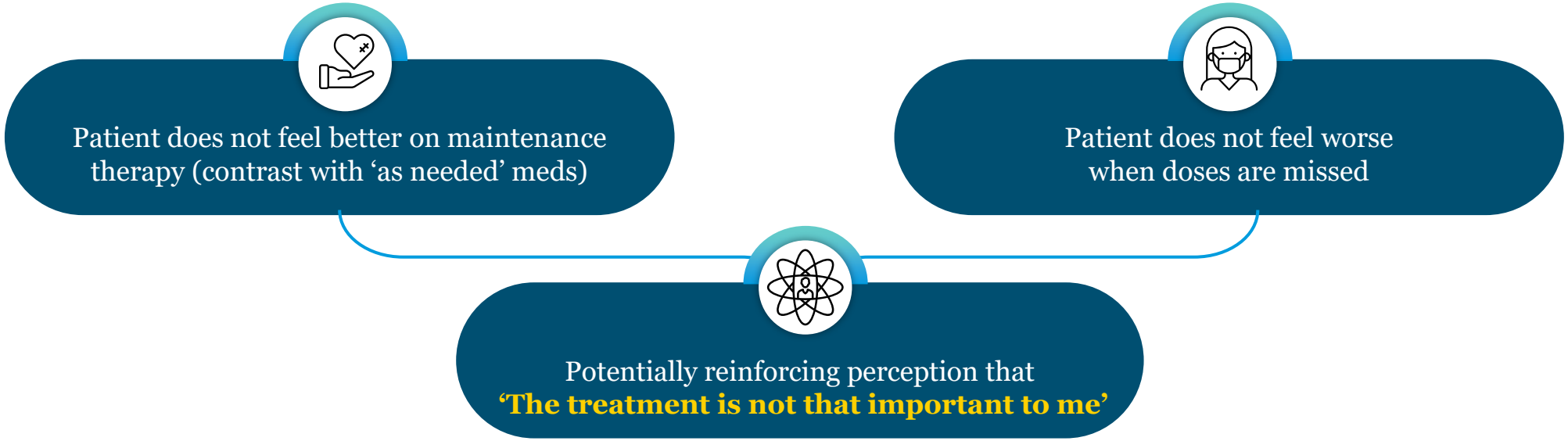
ILLNESS REPRESENTATIONS: MENTAL MAP/MODEL

Identity	What is it? Symptoms and labels
Cause	What caused this?
Timeline	How long will it last?
Consequences	What will happen as a result of this?
Cure/control	What will make it better?

Illness behavior (coping response)

Hagger, M. S., & Orbell, S. (2003). The Common-Sense Model of Self-Regulation (CSM): A Dynamic Framework for Understanding Illness Self-Management. *Psychology & Health,* 18 (2), 141-184; Leventhal H, Phillips LA, Burns E. Journal of Behavioral Medicine 2016; 39(6): 935-46; Petrie K, Weinman J, Sharpe N, Buckley J. *Brit Med J* 1996; 312: 1191-4

Necessity beliefs common-sense default: No symptoms, no problem![1-3]



- 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

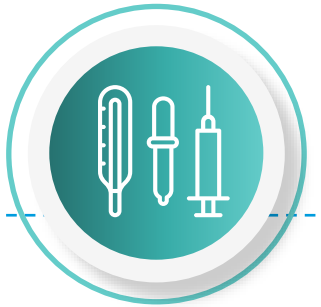
Horne Invited paper https://acmedsci.ac.uk/policy/policy-projects/how-can-we-all-best-use-evidence [Accessed October 2021]

Non-adherence – A variable behavior not a trait

ADHERENCE RATES VARY…

Between patients

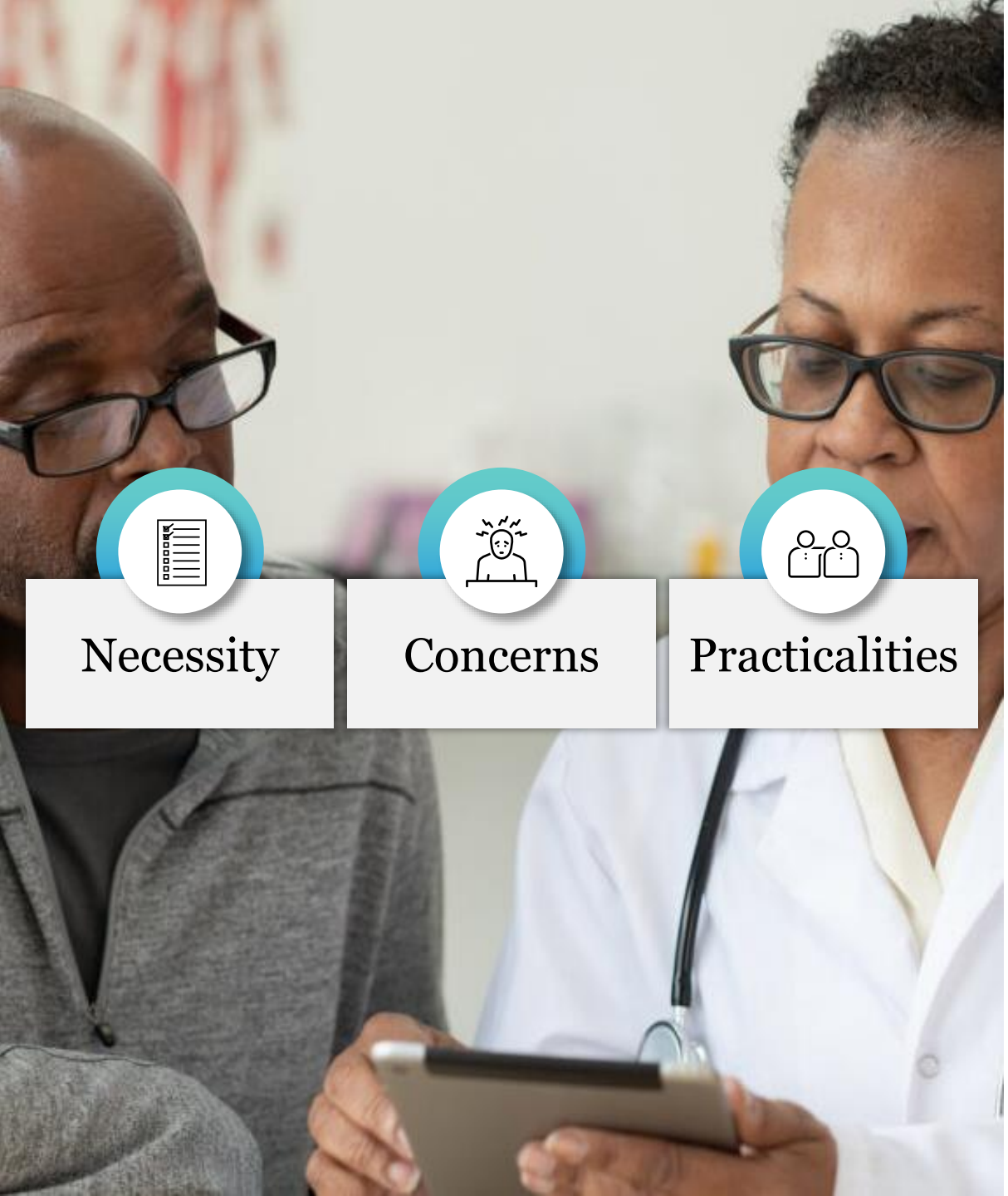
Within the same patient over time & across treatments



Most of us are non-adherent some of the time

Non-adherence may be the NORM not the exception and is best understood in terms of the individual interaction with a particular illness and treatment!

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*



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

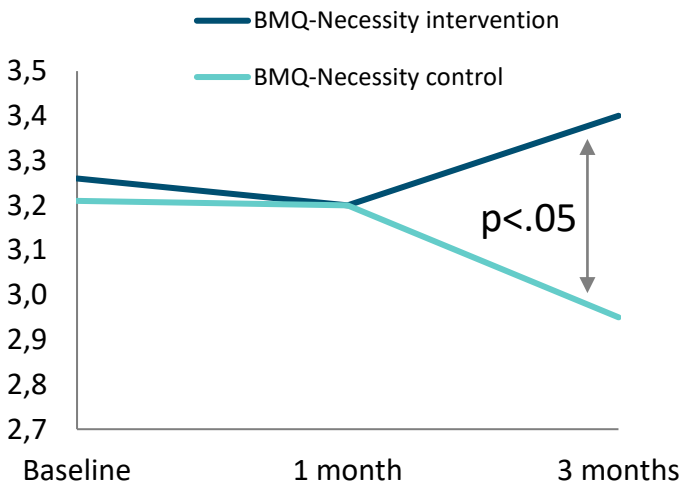
1. Horne, R., Cooper, V., Wileman, V., & Chan, A. (2019). Supporting adherence to medicines for long-term conditions: A perceptions and practicalities approach based on an extended common-sense model. *European Psychologist*, 24(1), 82–96

Changing necessity beliefs and concerns

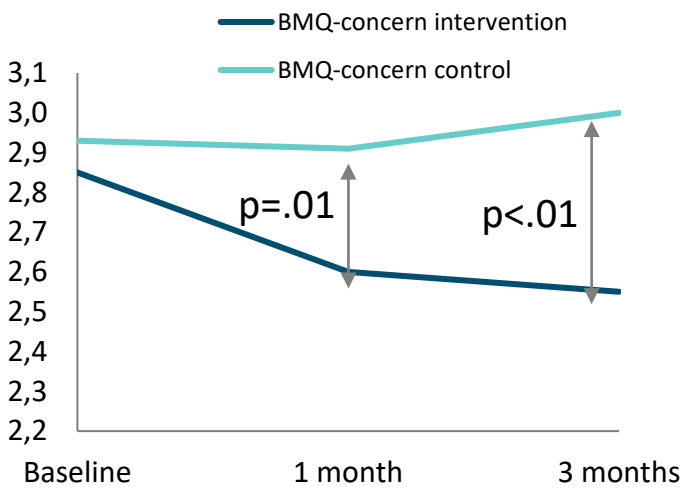
Tailoring support to address the patient's belief barriers can improve adherence[1]

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

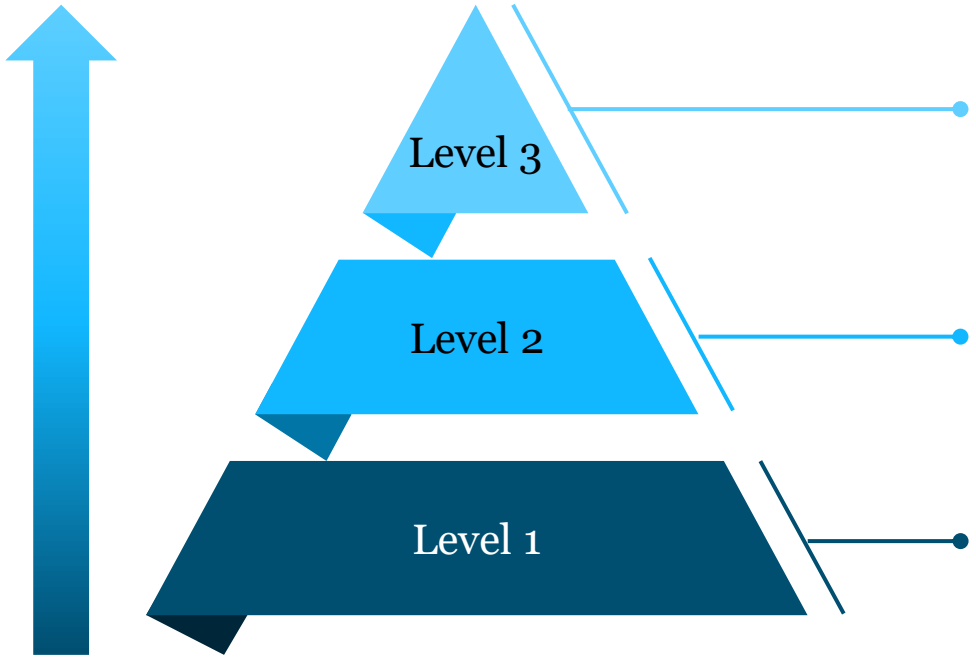
Intervention components: Practicalities

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]

Increasing programme efficacy & value



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. Supporting Adherence to Medicines for Long-Term Conditions, *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

Patients come with pre-existing ideas about their condition and with beliefs and expectations of treatment

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

Beliefs and expectations drive adherence/non-adherence