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A:CARE CONGRESS

Individual adherence strategies and their impact on patient experience in women's health

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Director of the Diploma of Advanced Studies in Sexual Medicine at the Advanced Study Center of the University of Basel, and Emeritus Professor at the Department of Obstetrics and Gynecology at the University Hospitals of the University of Basel, Switzerland

Prof. Rossella Nappi
Full Professor of Obstetrics and Gynecology, Chief of the Research Center for Reproductive Medicine and Gynecological Endocrinology-Menopause Unit, IRCCS San Matteo Foundation, University of Pavia, Italy

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INDIVIDUAL ADHERENCE STRATEGIES AND THEIR IMPACT ON PATIENT EXPERIENCE IN WOMEN'S HEALTH

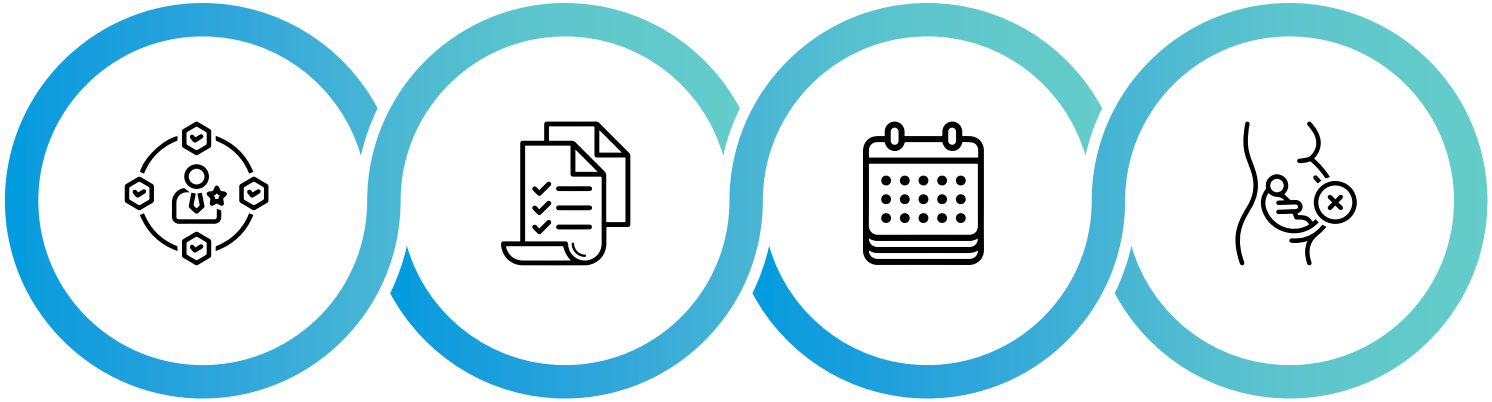
The impact of non-adherence in women´s health unintended pregnancies

Prof. Johannes Bitzer
Advanced Study Center of the University of Basel
Department of Obstetrics and Gynecology at the University Hospitals of the University of Basel, Switzerland

The pandemic of unintended pregnancies

These reproductive health outcomes occur irrespective of country income level, region or the legal status of abortion.

Of these unintended pregnancies, 61% ended in abortion. This translates to 73 million abortions per year.[2]



Unintended pregnancy and abortion are experiences shared by people around the world.[1]

Roughly 121 million unintended pregnancies occurred each year between 2015 and 2019.[2]

- Unintended pregnancies have a higher risk of obstetrical complications[3]
- Negative psychosocial consequences for the woman and the newborn especially in adolescents[3]

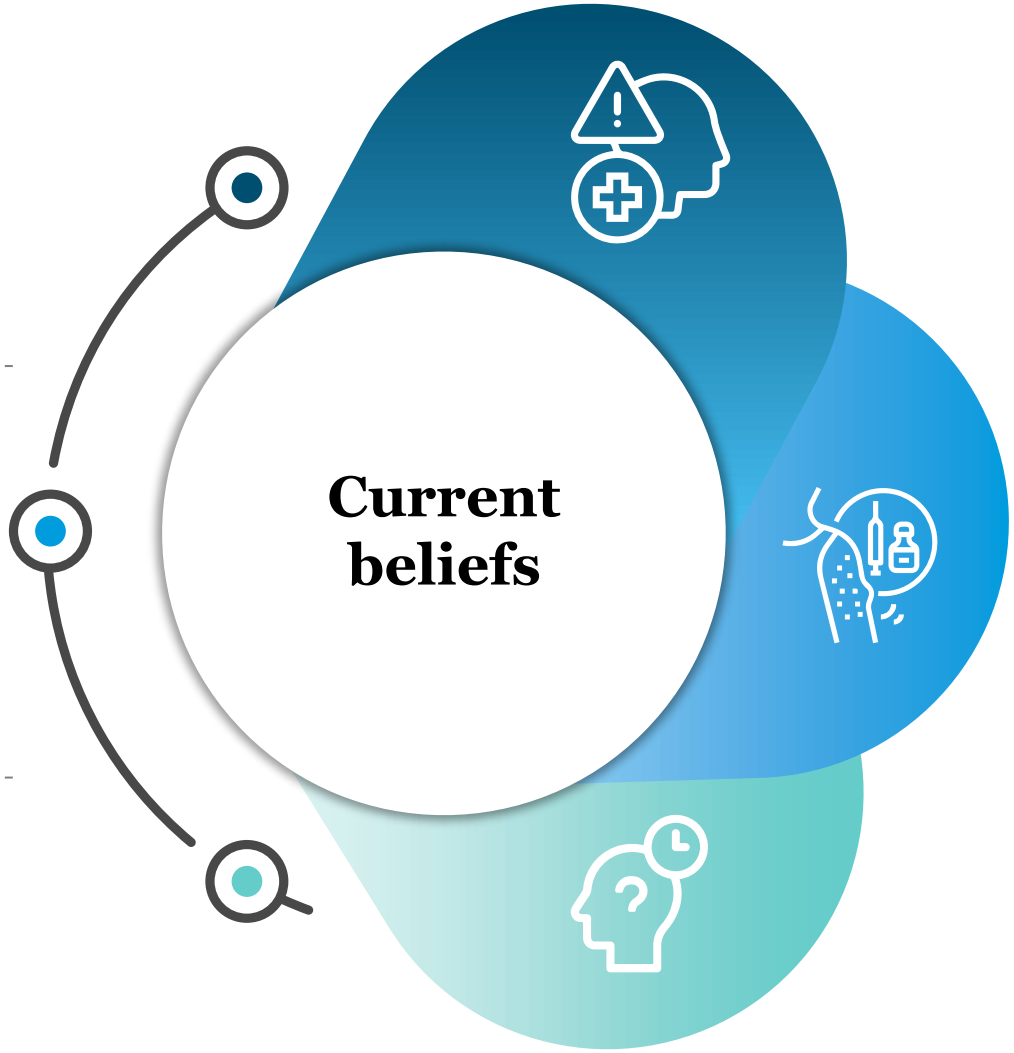
1.RCOG and FSRH key messages on safe abortion. https://www.rcog.org.uk/globalassets/documents/global-network/projects-and-partnerships/making-abortion-safe/rcog-and-fsrh-key-messages-on-safe-abortion.pdf [Accessed October 2021]; 2. Bearak J *et al*, Unintended pregnancy and abortion by income, region, and the legal status of abortion estimates from a comprehensive model for 1990–2019, *Lancet 2020*;8:e1152-61; 3. Brown S and Eisenberg L (1995), The Best Intentions: Unintended Pregnancy and the Well-Being of Children and Families. *National Academy Press*.

Why Does It Happen?

No contraception
- Lack of motivation
- Fear of health risks and side effects

Discontinuation of contraception
- Side effects
- Bad image

Forgetting or non-adherence to proper use of the method

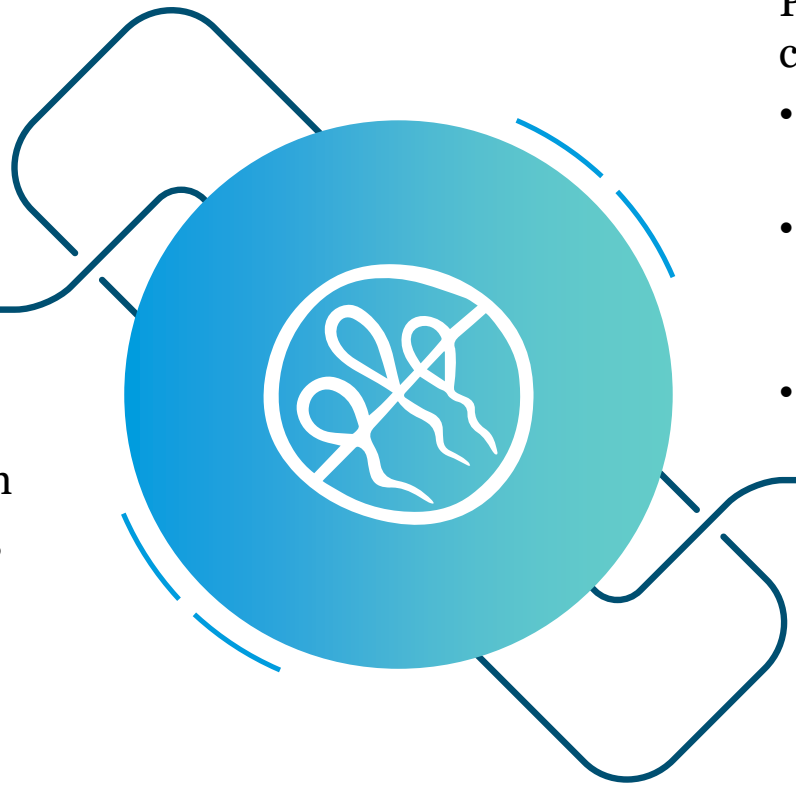


How to improve adherence in Contraception

The medical strategy

User independent methods

- Long-acting methods
- Intrauterine contraception
- Progestogen based LARCs
- Future methods



Patient centered, shared decision-making based counselling and care

- Increase and maintain motivation by providing knowledge (empowerment) to the user
- Help the user to come to a self-determined, individual benefit/risk evaluation (this is my method)
- Be a partner in the follow up to evaluate the satisfaction, inform and give advice

The individualization method

The right contraception for the right woman

1. Mack N, *et al*. Strategies to improve adherence and continuation of shorter-term hormonal methods of contraception. *Cochrane Database Syst Rev*. 2019 Apr 23;4(4):CD004317.pub5.; 2. Bitzer J. Kontrazeptive Compliance - warum kommt es immer wieder zum Versagen der kontrazeptiven Therapie? [Contraceptive compliance - why is contraceptive failure still so frequent?]. *Ther Umsch*. 2009 Feb;66(2):137-43. German.

The right method

COMBINED ORAL CONTRACEPTIVES

EE dose
15 µg
20 µg
25 µg
30 µg
35 µg
≥ 50 µg

Progestogen type
Norethisterone
Levonorgestrel
Gestodene
Chlormadinonacetate
Desogestrel
Drospirenone
Cyproterone acetate
Dienogest
NOMAC

Regimen
21/7
24/4 or 26/2
Continuous

Estradiol 1.5
E2V 2,0

Mono, Bi, Triphasic

LONG ACTING REVERSIBLE CONTRACEPTIVES



HORMONAL CONTRACEPTIVES

Non-daily (non-oral) Contraceptives


Progesterone only pills

Progestogen type
Norethisterone
Ethynodiol diacetate
Levonorgestrel
Desogestrel

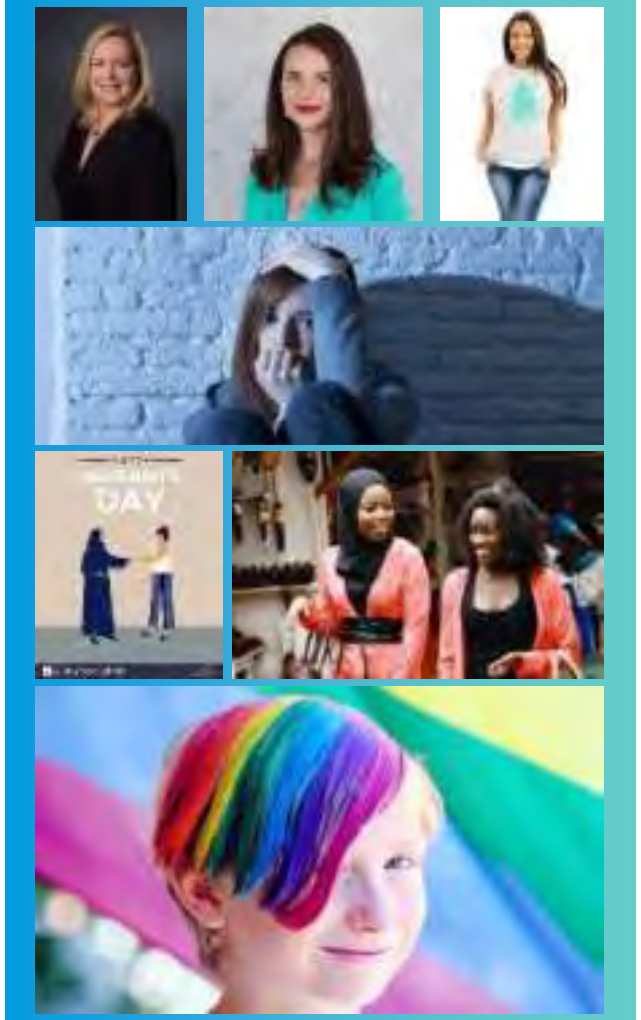
NONHORMONAL CONTRACEPTIVES

Clinician dependent



Not clinician dependent





The right woman

What do doctors want, what do women want?

THE HEALTH CARE PROFESSIONAL

Maximize efficacy

Realize additional health benefits

Medical Counselling

Optimize tolerability

Minimize health risks

Cost effectiveness

THE PATIENT, CLIENT, USER

Maximal efficacy

Independent of partner		Easy to use
Under the control of the woman		Linked/ not linked to sexual activity
Additional health benefits	**Individualized Counselling**	**Optimal tolerability**
Discrete		On demand
Low Cost		Forgettable

Minimal health risks

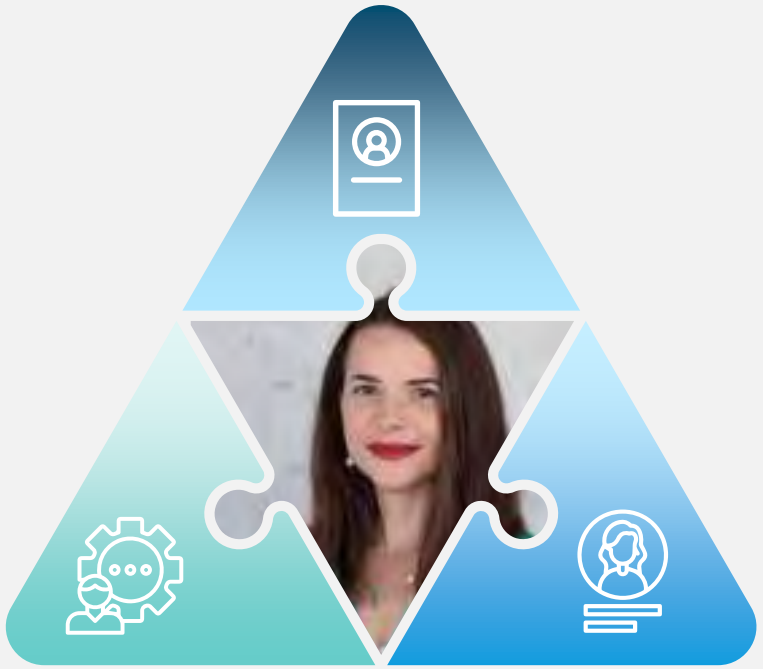
1. Merki-Feld GS, Caetano C, Porz TC, Bitzer J. Are there unmet needs in contraceptive counselling and choice? Findings of the European TANCO Study. *Eur J Contracept Reprod Health Care*. 2018 Jun;23(3):183-193. 2. Bitzer J, Oppelt PG, Deten A. Evaluation of a patient-centred, needs-based approach to support shared decision making in contraceptive counselling: the COCO study. *Eur J Contracept Reprod Health Care.* 2021 Aug;26(4):326-333.

Make the best fit between the woman, the context and the method

Professional Competence

Communication Competence

Method Profile



Context

Woman Profile

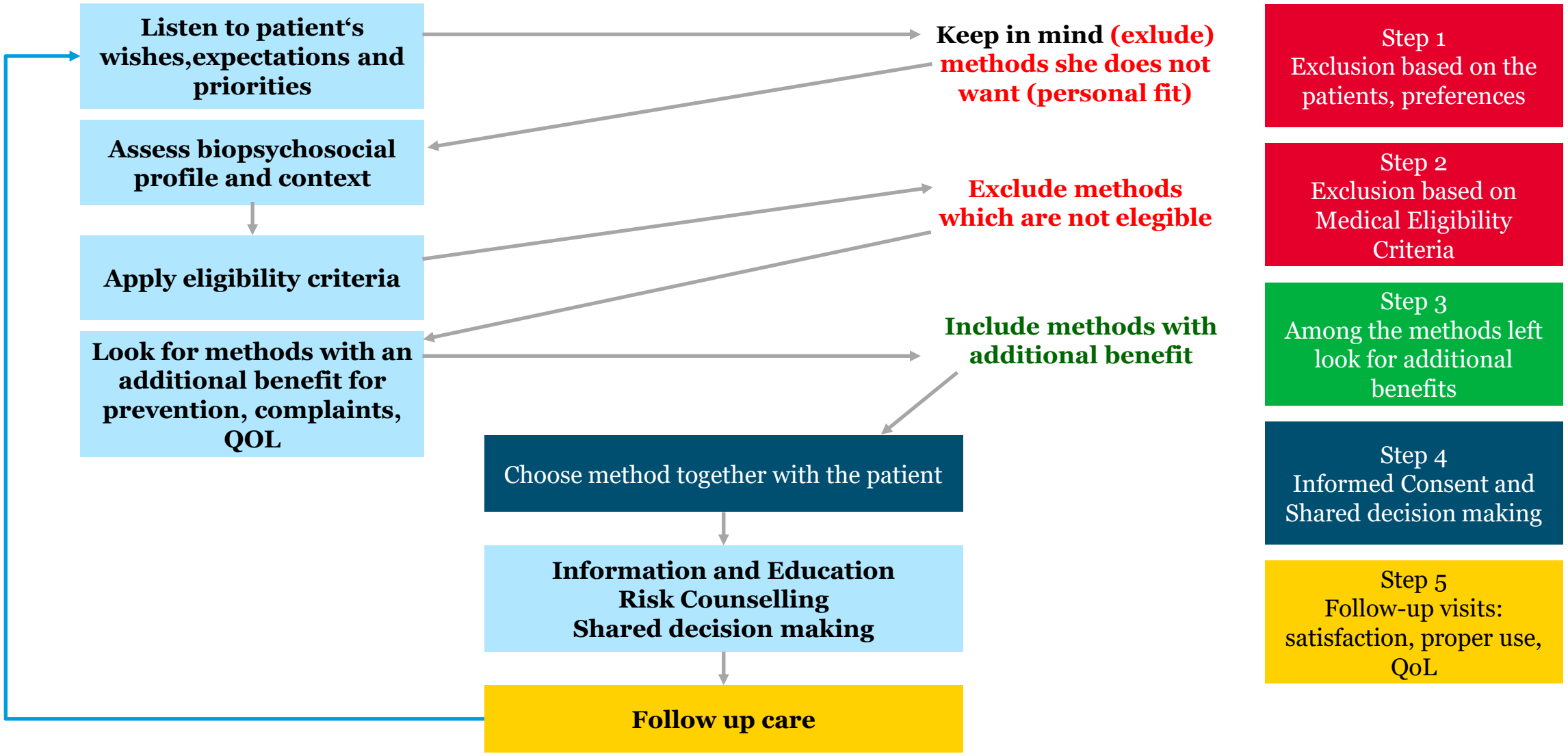
Bitzer J, Oppelt PG, Deten A. Evaluation of a patient-centred, needs-based approach to support shared decision making in contraceptive counselling: the COCO study. *Eur J Contracept Reprod Health Care*. 2021 Aug;26(4):326-333.

The Science and Art of Contraceptive Counselling

- Patient centered communication
- Information and Education
- Shared decision making

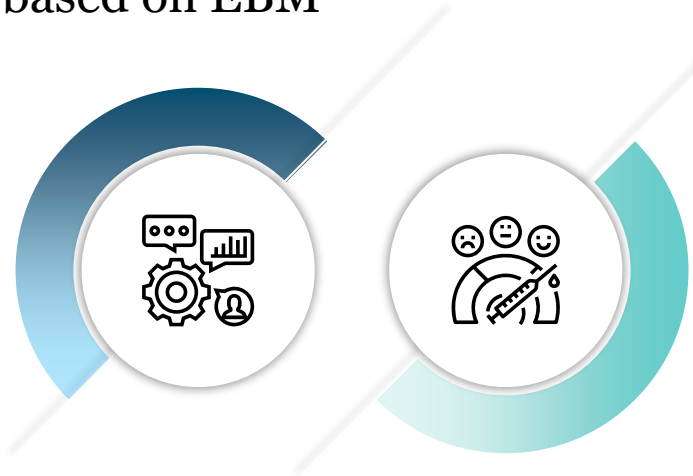
Bitzer J, Marin V, Lira J. Contraceptive counselling and care: a personalized interactive approach. *Eur J Contracept Reprod Health Care*. 2017 Dec;22(6):418-423.

The Contraceptive Dialogue

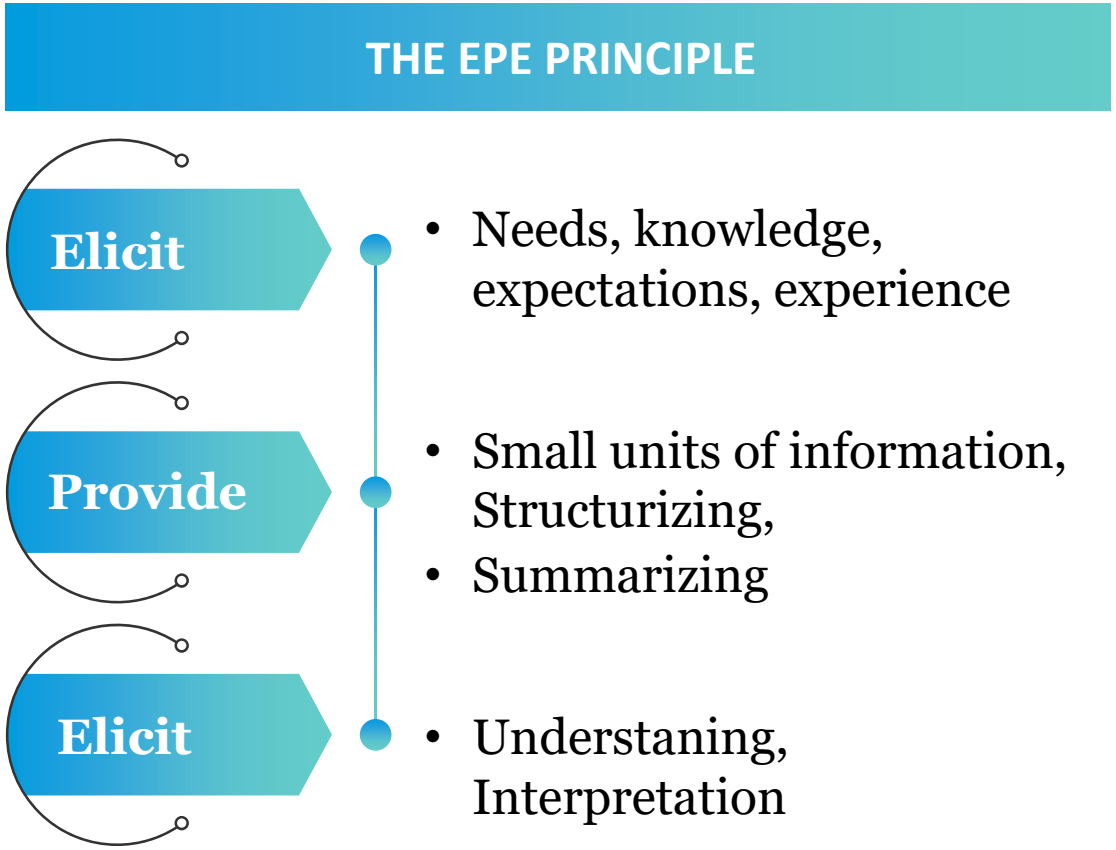


Give evidence based information in a patient centered way

- Inform and educate about methods in understandable way based on EBM

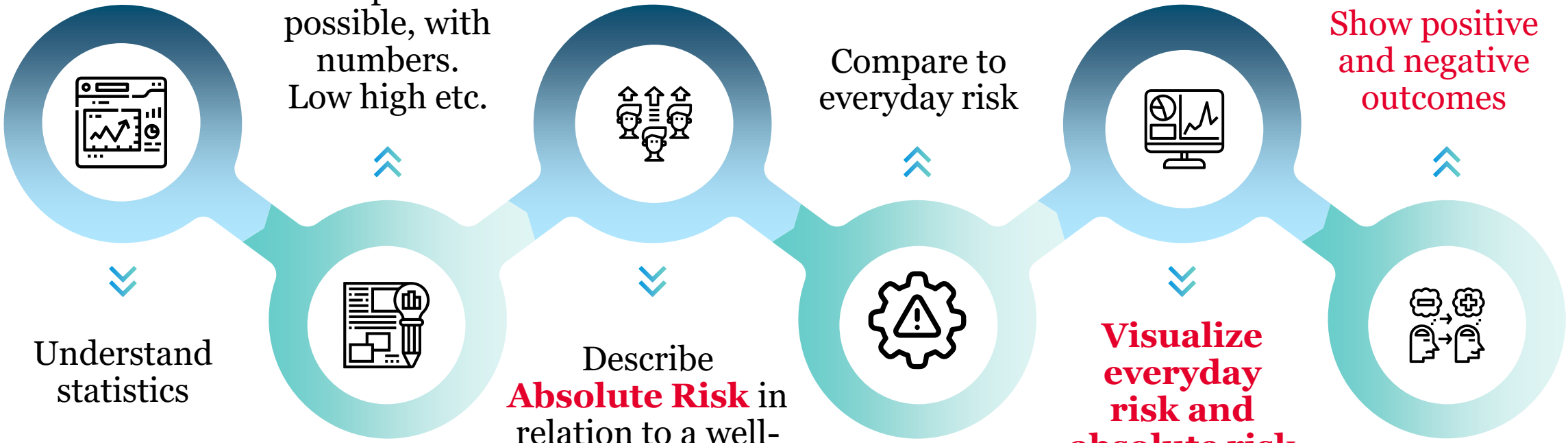


- Efficacy
- Health Risks
- Tolerability
- Benefits



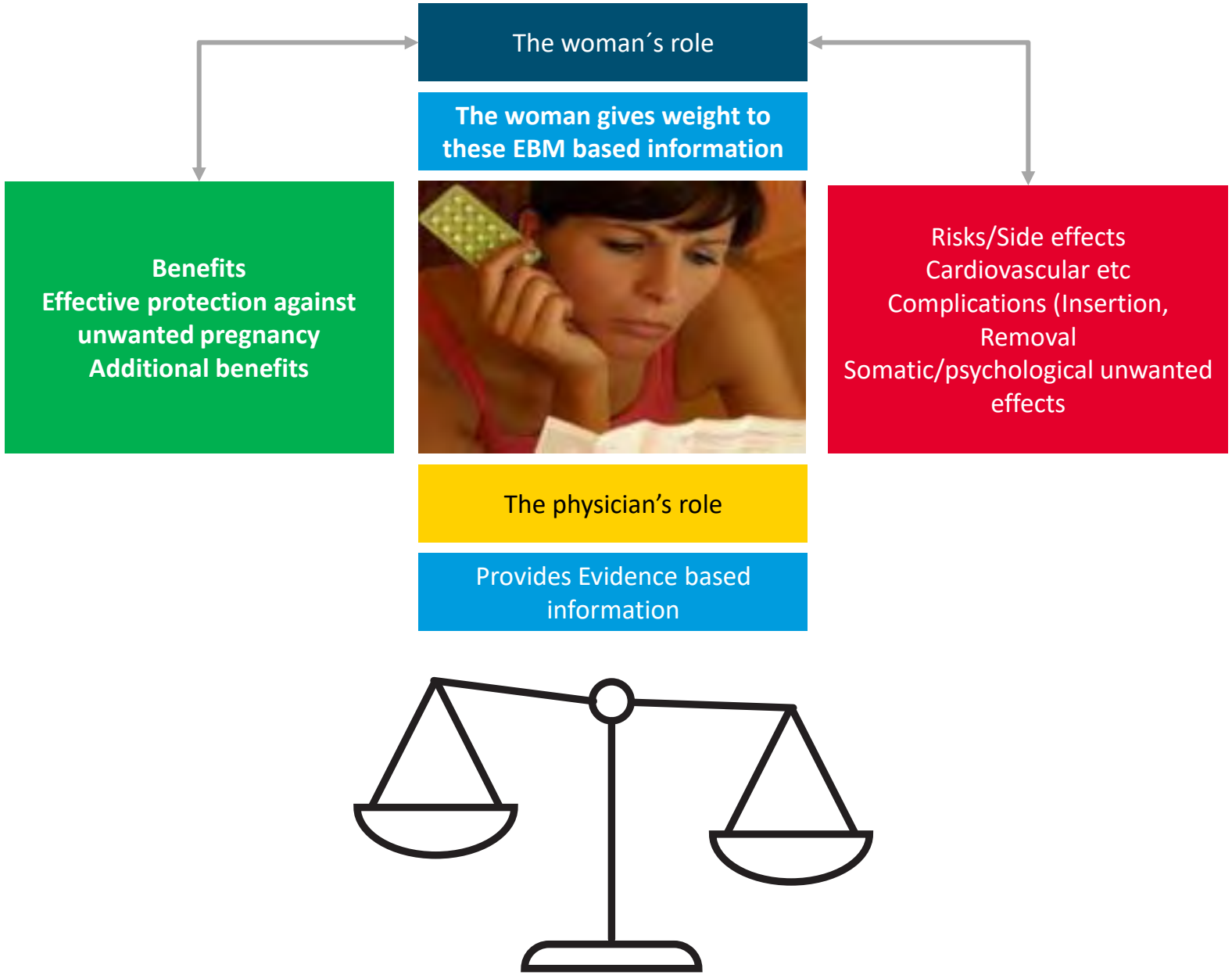
Bitzer J, Marin V, Lira J. Contraceptive counselling and care: a personalized interactive approach. *Eur J Contracept Reprod Health Care.* 2017 Dec;22(6):418-423

Recommendations and guidelines for risk counselling



Bitzer J, Marin V, Lira J. Contraceptive counselling and care: a personalized interactive approach. *Eur J Contracept Reprod Health Care.* 2017 Dec;22(6):418-423

Contraceptive counselling and care is a continuous benefit/risk evaluation-trade off



Bitzer J, Marin V, Lira J. Contraceptive counselling and care: a personalized interactive approach. *Eur J Contracept Reprod Health Care*. 2017 Dec;22(6):418-423

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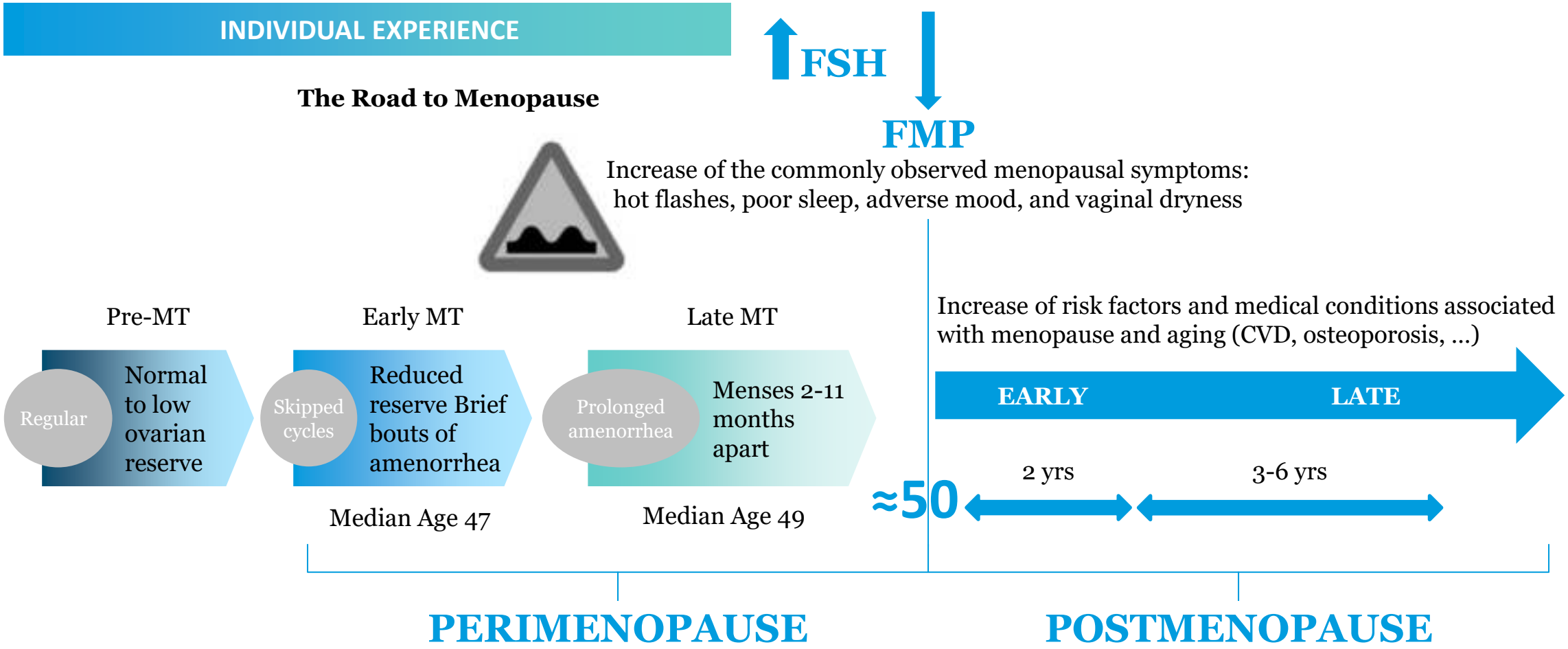
INDIVIDUAL ADHERENCE STRATEGIES AND THEIR IMPACT ON PATIENT EXPERIENCE IN WOMEN'S HEALTH

Navigating menopause with your patients

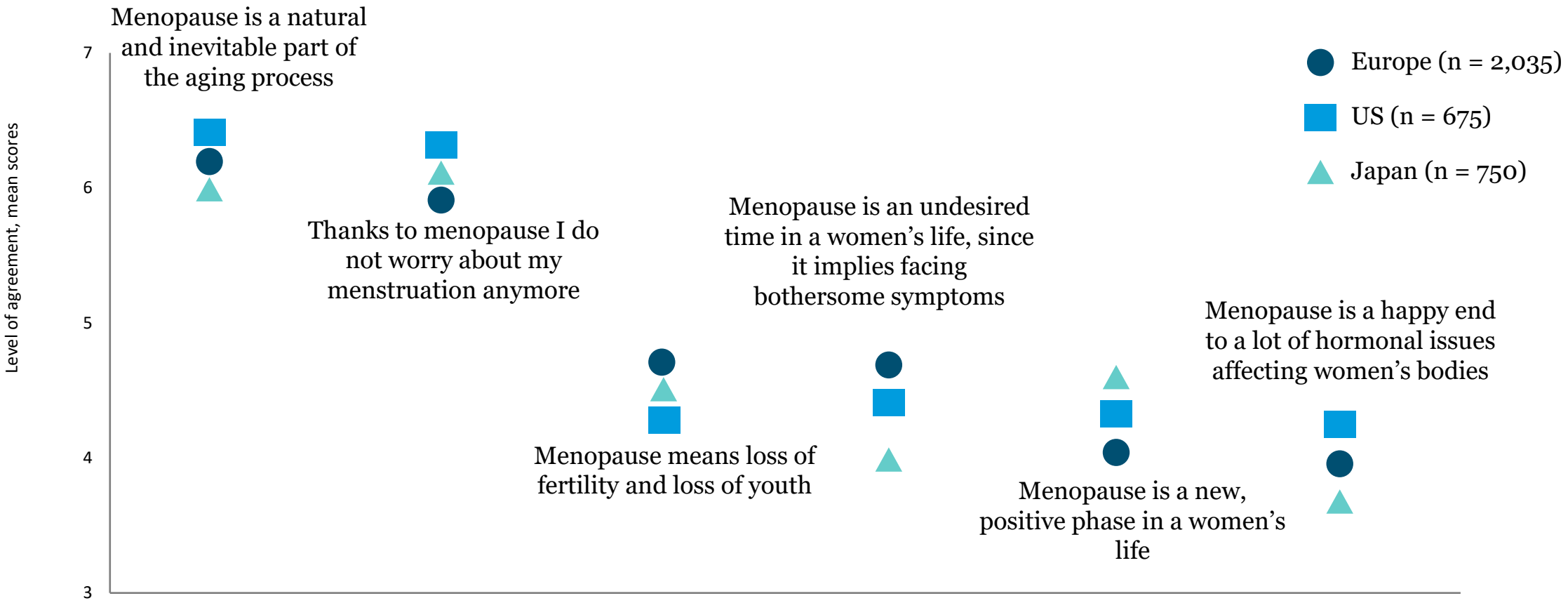
Prof. Rossella Nappi MD, PhD
Research Center for Reproductive Medicine and Unit of Gynecological Endocrinology & Menopause – Dept Ob/Gyn, IRCCS "S. Matteo Foundation", University of Pavia
General Secretary of International Menopause Society (IMS)
Italy

Menopause is a long journey



Santoro N. Perimenopause: From Research to Practice. *J Womens Health (Larchmt)*. 2016 Apr;25(4):332-9. Epub 2015 Dec 10.; Harlow Sd et al.; STRAW 10 Collaborative Group. Executive summary of the Stages of Reproductive Aging Workshop + 10: addressing the unfinished agenda of staging reproductive aging. *Menopause*. 2012 Apr;19(4):387-95; The NAMS. Keeping your heart healthy at menopause https://www.menopause.org/for-women/menopauseflashes/bone-health-and-heart-health/keeping-your-heart-healthy-at-menopause [Accessed October2021]

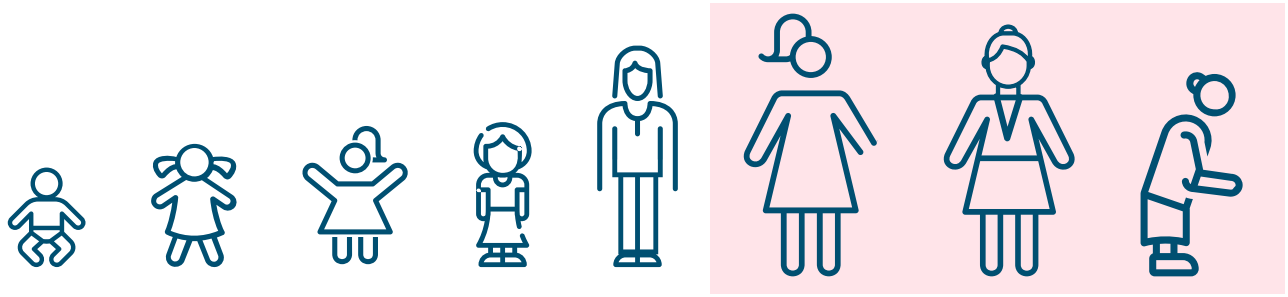
The nature-nurture issue of Menopause beliefs



1 means "I strongly disagree" & 7 means "I strongly agree"

Nappi RE, Kroll R, Siddiqui E, Stoykova B, Rea C, Gemmen E, Schultz NM. Global cross-sectional survey of women with vasomotor symptoms associated with menopause: prevalence and quality of life burden. *Menopause*. 2021 May 24;28(8):875-882.

The burden of menopause is significant



The average woman is postmenopausal for more than 1/3 of her life

~50%–75% of women in midlife experience VMS

~30%–50% experience GSM in midlife and beyond

The median duration of VMS over the menopause transition is 7.4 years

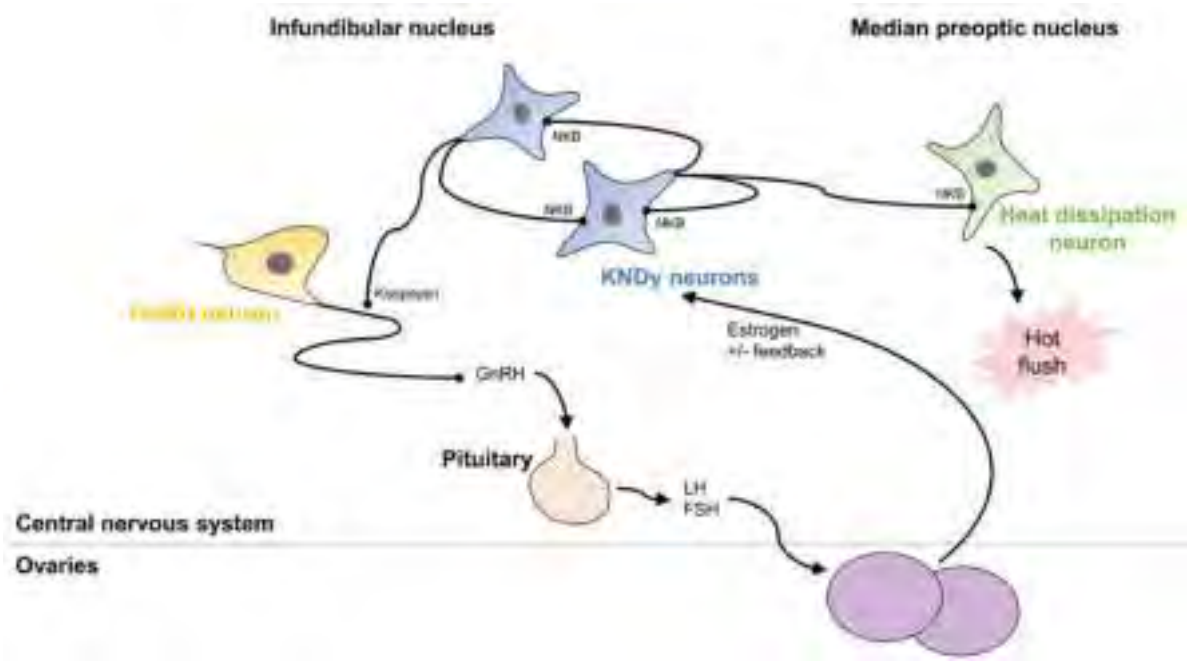
VMS = Vasomotor Symptoms

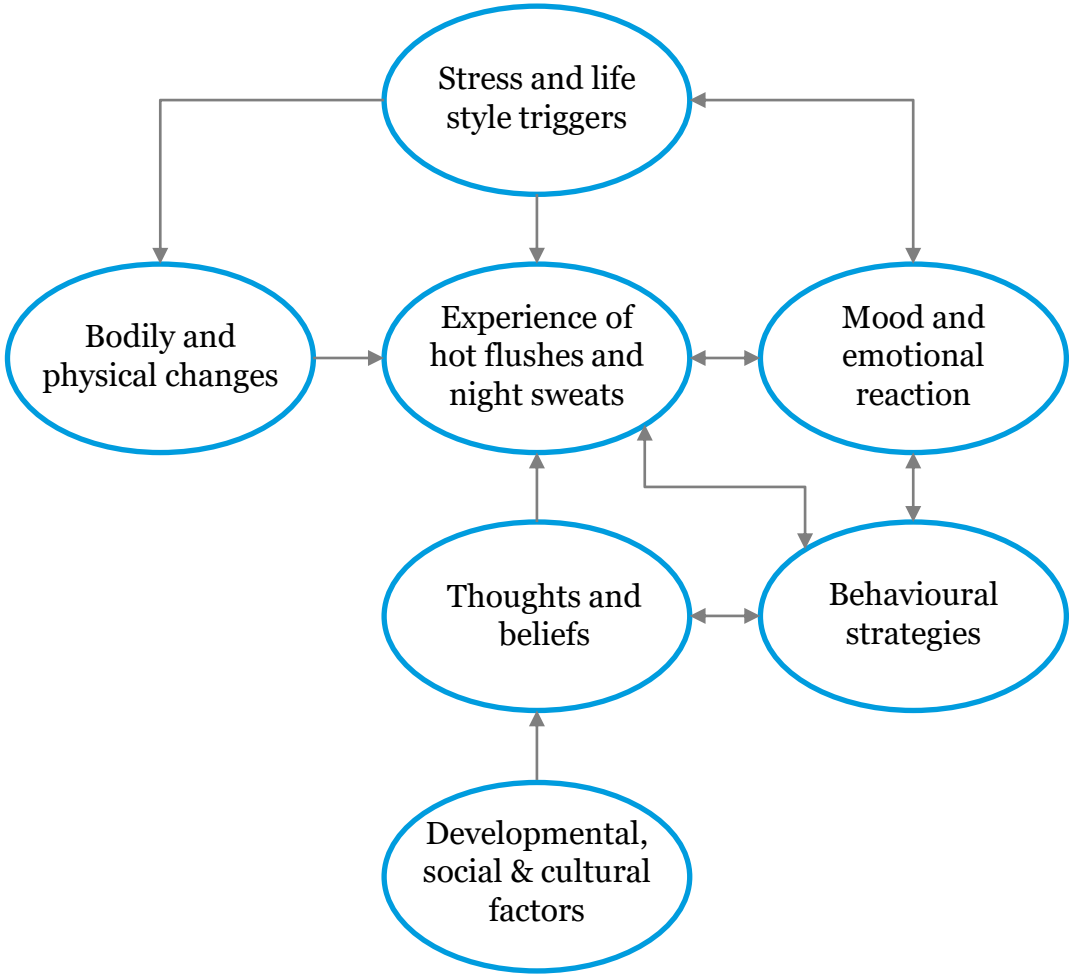
GSM= Genitourinary Syndrome of Menopause

Soules MR, Bremner WJ. The menopause and climacteric: endocrinologic basis and associated symptomatology. *J Am Geriatr Soc.* 1982 Sep;30(9):547-61. 2. Portman DJ, Gass ML; Vulvovaginal Atrophy Terminology Consensus Conference Panel. Genitourinary syndrome of menopause: new terminology for vulvovaginal atrophy from the International Society for the Study of Women's Sexual Health and the North American Menopause Society. *Menopause*. 2014 Oct;21(10):1063-8. 3. Avis NE, et al.; Study of Women's Health Across the Nation. Duration of menopausal vasomotor symptoms over the menopause transition. *JAMA Intern Med*. 2015 Apr;175(4):531-9. 4. Stuenkel CA, et al. RJ. Treatment of Symptoms of the Menopause: An Endocrine Society Clinical Practice Guideline. *J Clin Endocrinol Metab.* 2015 Nov;100(11):3975-4011.

Menopause is a bio-psycho-socio-cultural process

THE "HOT-FLUSHES" EXAMPLE

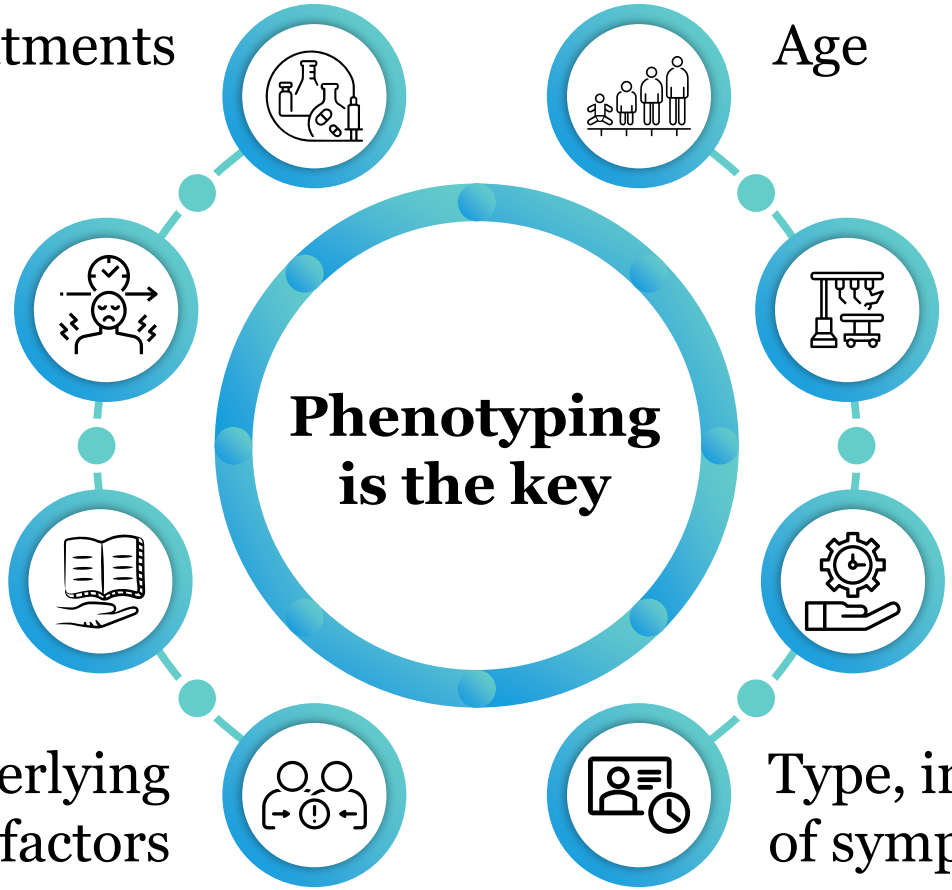




Neuroendocrine mechanisms interact with other dimensions

Hunter M, Rendall M. Bio-psycho-socio-cultural perspectives on menopause. *Best Pract Res Clin Obstet Gynaecol*. 2007 Apr;21(2):261-74. Santoro N, Roeca C, Peters BA, Neal-Perry G. The Menopause Transition: Signs, Symptoms, and Management Options. *J Clin Endocrinol Metab*. 2021 Jan 1;106(1):1-15.

There is not only one menopause!



Duration of treatments

Age

Attitudes to chronic medical interventions

Type of menopause (natural, surgical, chemo-/radio-therapy)

Level of general health literacy

Time since menopause onset

Presence of underlying conditions and/or risk-factors

Type, intensity and duration of symptoms

1. Genazzani AR et al. Hormone therapy in the postmenopausal years: considering benefits and risks in clinical practice. *Hum Reprod Update.* 2021 Aug 25:dmab026; 2. The 2017 Hormone therapy position statement of The *NAMS. Menopause.* 2017 Nov;24(7):728-753; 3. Baber RJ, Panay N, Fenton A; IMS Writing Group. 2016 IMS Recommendations on women's midlife health and menopause hormone therapy. *Climacteric*. 2016 Apr;19(2):109-50. Epub 2016 Feb 12.; 4. Stuenkel et al. Treatment of Symptoms of the Menopause: An Endocrine Society Clinical Practice Guideline. *J Clin Endocrinol Metab.* 2015 Nov;100(11):3975-4011. Epub 2015 Oct 7.; 5. Berkman ND, Davis TC, McCormack L. Health literacy: what is it? *J Health Commun.* 2010;15 Suppl 2:9-19.

Specific challenges at menopause

Menopause should be treated like any other medical condition, especially if distressing symptoms and/or specific risk factors are present

- Collect history
- Share information
- Take decisions
- Make appropriate follow-up

Benefit-risk evaluation may be difficult

- Lack of awareness
- Sensitive topics
- Goals and Concerns
- Complex data environment

Training and competence of HCPs are fundamental to empower women

Parish SJ, Nappi RE, Kingsberg S. Perspectives on counseling patients about menopausal hormone therapy: strategies in a complex data environment. *Menopause*. 2018 Aug;25(8):937-949.

Successful communication at menopause

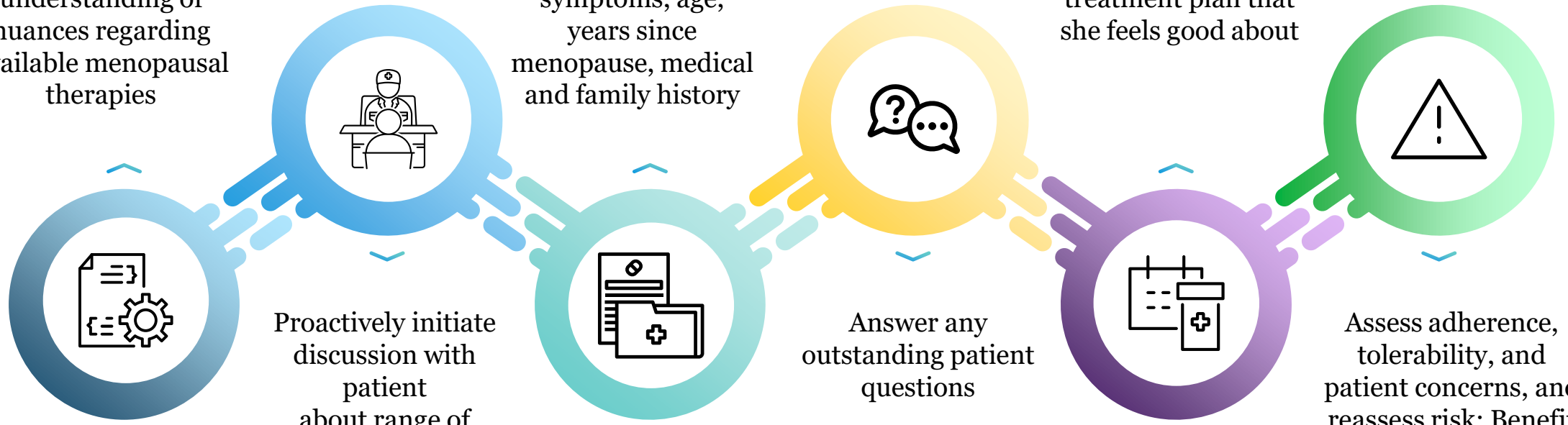
OARS

O **Open questions**	A **Affirmations**	R **Reflections**	S **Summaries**
Open questions that encourage further elaboration and consideration	Affirmations that foster positive feelings during the consultation	Reflections that indicate the clinician has heard and accurately understood the patient	Summaries that extend the basic reflections to include additional information
"What do you know about the symptoms of menopause?" "What do you know about taking hormones at the time of menopause?"	"Those hot flushes must be very uncomfortable."	"I understand that you would like to consider treatment options for your symptoms but have some questions."	"Every woman's experience with menopause is her own. We can tailor HT to your specific needs and work to maximize the potential benefits and minimize the potential risks."

OARS, open questions, affirmation, reflective listening, and summary reflections.

Tuccero D, Railey K, Briggs M, Hull SK. Behavioral Health in Prevention and Chronic Illness Management: Motivational Interviewing. *Prim Care*. 2016 Jun;43(2):191-202.; Parish SJ, *et al.* Perspectives on counseling patients about menopausal hormone therapy: strategies in a complex data environment. *Menopause*. 2018 Aug;25(8):937-949.

Individualizing discussions with women about treatment of menopausal symptoms

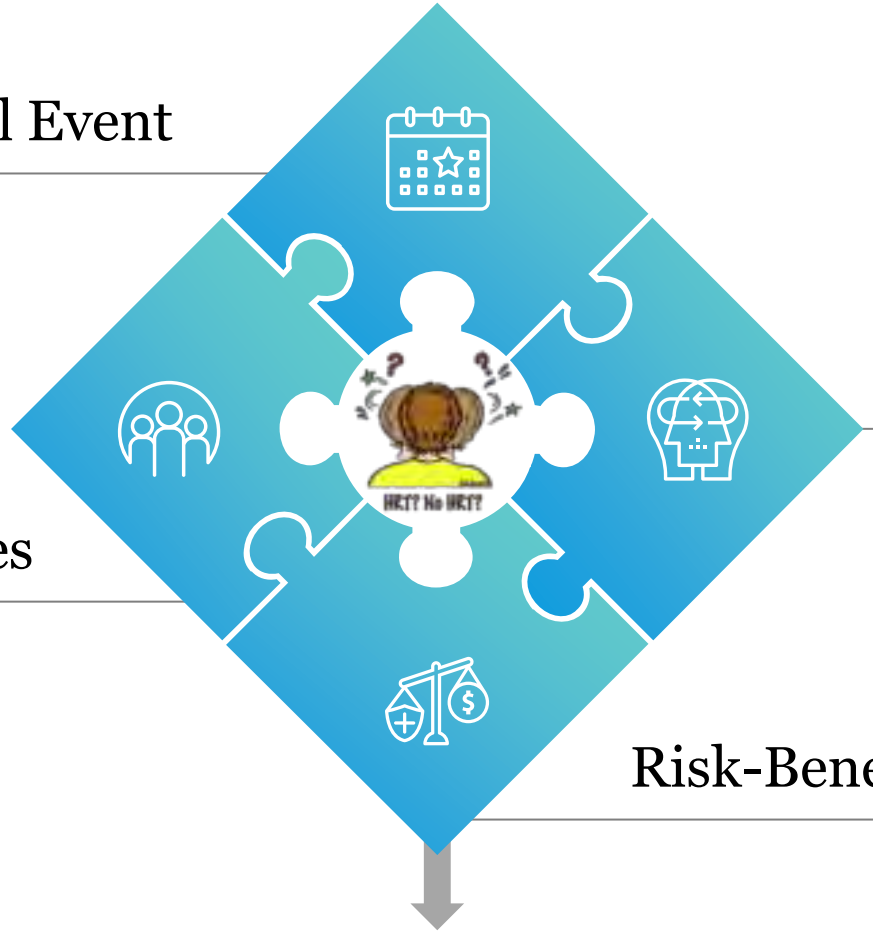


Parish SJ, Nappi RE, Kingsberg S. Perspectives on counseling patients about menopausal hormone therapy: strategies in a complex data environment. *Menopause*. 2018 Aug;25(8):937-949

Shared decision making at menopause is complex

Menopause as a Natural Event

Multitude of Phenotypes



Communication Skills

Risk-Benefit Balance

Individualized Management

Parish SJ, Nappi RE, Kingsberg S. Perspectives on counseling patients about menopausal hormone therapy: strategies in a complex data environment. *Menopause*. 2018 Aug;25(8):937-949.

Aiming at precision therapy in menopausal women

- Consider Guidelines on Menopausal Therapy and on other Conditions in the context of Menopausal Medicine to manage symptoms and prevent chronic conditions
- Promote Primary Prevention and a healthy Diet and Life-Style
- Control Blood Pressure and other CVD Risk Factors
- Supplement with Vitamin D, when needed
- Type, Route, Dose, Duration of MHT should be tailored on the individual woman taking into account goals, efficacy, tolerability, adherence, and any other relevant aspects

1. Baber RJ, Panay N, Fenton A; *IMS Writing Group.* 2016 IMS Recommendations on women's midlife health and menopause hormone therapy. *Climacteric*. 2016 Apr;19(2):109-50; 2. Stuenkel CA, Davis SR, Gompel A, Lumsden MA, Murad MH, Pinkerton JV, Santen RJ. Treatment of Symptoms of the Menopause: An Endocrine Society Clinical Practice Guideline. *J Clin Endocrinol* Metab. 2015 Nov;100(11):3975-4011.; 3. Lobo RA, Davis SR, De Villiers TJ, Gompel A, Henderson VW, Hodis HN, Lumsden MA, Mack WJ, Shapiro S, Baber RJ. Prevention of diseases after menopause. *Climacteric*. 2014 Oct;17(5):540-56.

Successful communication and shared decision-making lead to better health outcomes

TAKE THE TIME TO CLEARLY PRESENT EVIDENCE IN ORDER TO ENGAGE YOUR PATIENTS IN THEIR OWN MEDICAL DECISION

Improve knowledge of options

Allow choices better aligned with patient values

Put risks and benefits into perspective

Enhance adherence to treatment

Increase patient satisfaction

Parish SJ, Nappi RE, Kingsberg S. Perspectives on counseling patients about menopausal hormone therapy: strategies in a complex data environment. *Menopause*. 2018 Aug;25(8):937-949.

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INDIVIDUAL ADHERENCE STRATEGIES AND THEIR IMPACT ON PATIENT EXPERIENCE IN WOMEN'S HEALTH

Individual adherence strategies and their impact on patient experience in women's health

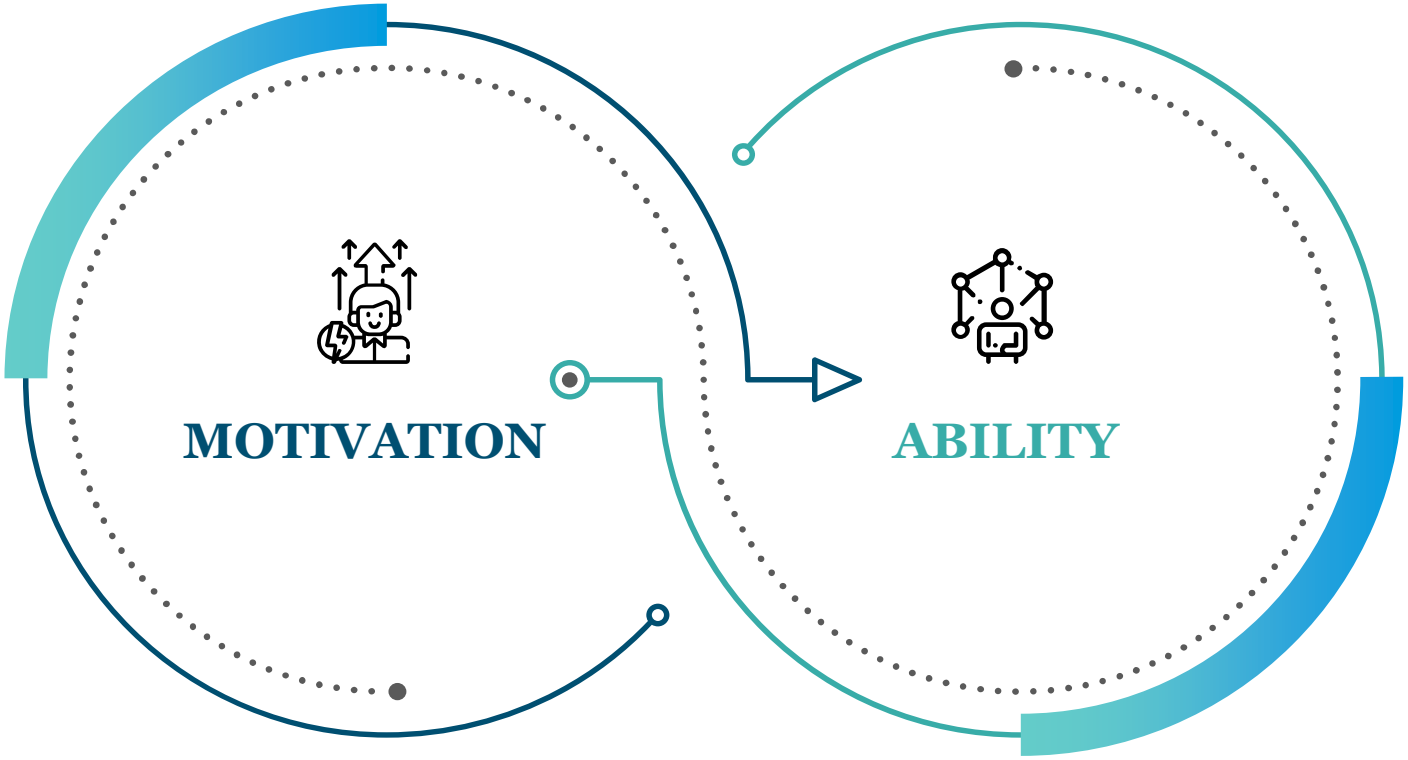
Prof. Rob Horne
University College London, UK

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



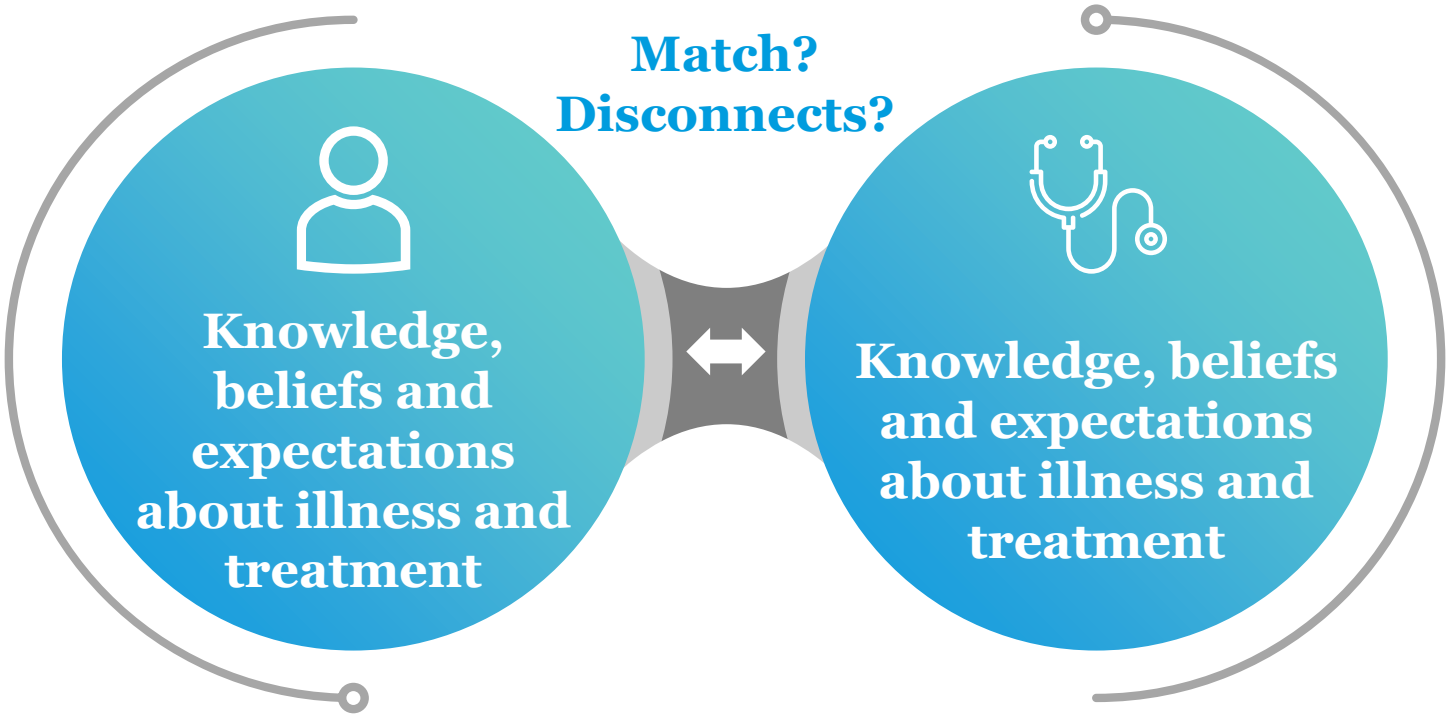
Unintentional
process

Practicalities
e.g. capability & resource limitations

1. Horne R. In Pharmacy Practice, 2001. Ed. by KMG Taylor & G Harding. *London: Taylor & Francis* [Accessed October 2021] 2. Horne R *et al* (2005). Concordance, Adherence and Compliance in Medicine Taking Publisher: *London: National Co-ordinating Centre for NHS Service Delivery and Organisation*, January 2005; 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* 24(1):82-96

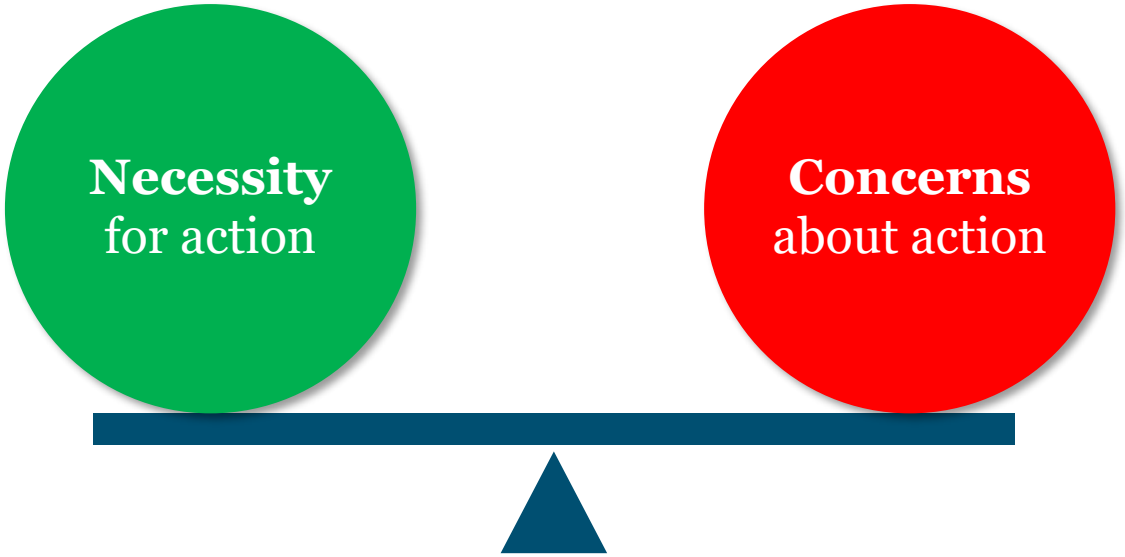
Disconnects drive the behavioral gap

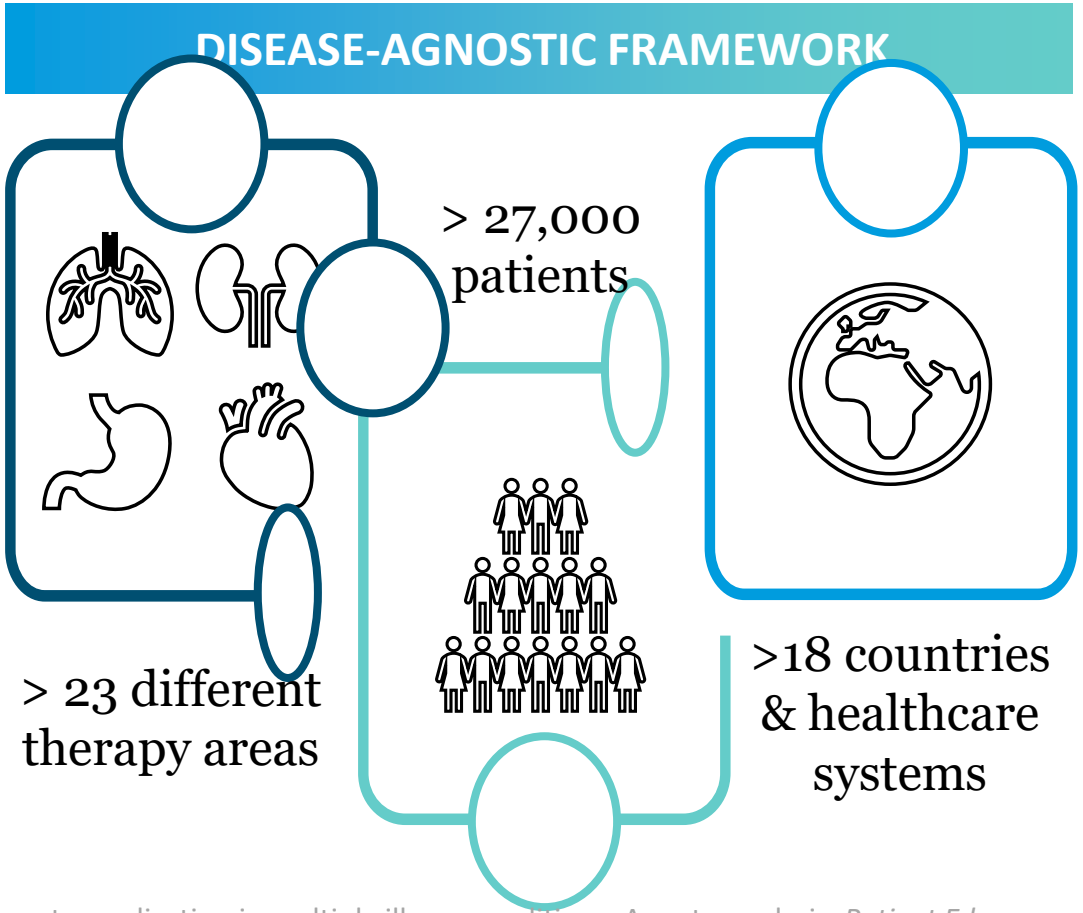
THE FUNDAMENTAL CAUSE OF NON-ADHERENCE IS OFTEN A DISCONNECT BETWEEN BELIEFS AND EXPECTATIONS OF PRESCRIBER AND PATIENT[1,2]



1. Horne R, *et al*. Understanding patients' adherence-related beliefs about medicines prescribed for long-term conditions: a meta-analytic review of the Necessity-Concerns Framework. *PLoS One*. 2013 Dec 2;8(12):e80633. 2. Horne R, Albert A, Boone C. Relationship between beliefs about medicines, adherence to treatment, and disease activity in patients with rheumatoid arthritis under subcutaneous anti-TNFα therapy. *Patient Prefer Adherence*. 2018 Jun 22;12:1099-1111.

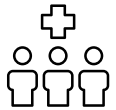
Understanding treatment beliefs: The Necessity-Concerns Framework (NCF)[1,2]





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, *et al.* 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.

Perceptions & practicalities driving non-adherence to osteoporosis treatment

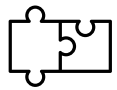


DOUBTS ABOUT TREATMENT NECESSITY/ EFFICACY

- I'm not at risk
- Osteoporosis is normal part of ageing
- Osteoporosis is not worth treating
- Treatment is not effective

HIGH CONCERNS ABOUT MEDICINES

- Perceptions of high risk of side-effects
- Fear of future harm



PRACTICAL DIFFICULTIES

- Understanding and health literacy
- Comorbidity/ polypharmacy/ treatment burden

Raybould G, Babatunde O, Evans AL, Jordan JL, Paskins Z. Expressed information needs of patients with osteoporosis and/or fragility fractures: a systematic review. *Arch Osteoporos*. 2018 May 8;13(1):55.

The Necessity-Concerns Framework (NCF) in women with breast cancer prescribed endocrine therapy

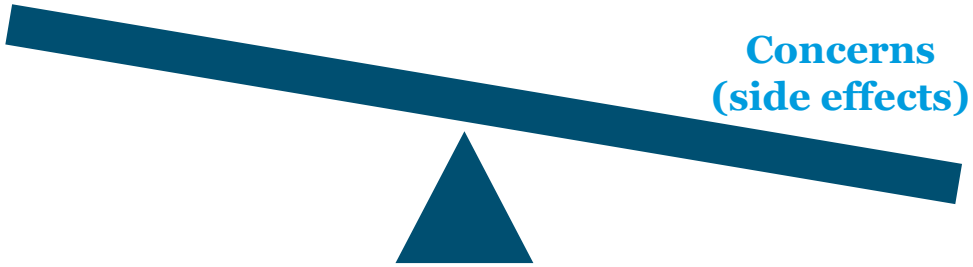
QUALITATIVE RESEARCH WITH 30 WOMEN PRESCRIBED ENDOCRINE THERAPY[1]

"Well since the option is keep taking it or be dead, it's not much of a choice for me."
Vanessa, 63, adherent

Necessity beliefs (tamoxifen is keeping me alive)

"I absolutely hate taking this tablet. It's a very powerful drug. It's not just the side effects. It's a reminder of what I had."
Anita, 52, discontinued

Concerns (side effects)



"When I don't take it I think oh, god, I should be taking it. I just feel so guilty when I don't take it, but I do feel better when I'm not on it."
Kate, 52, non-adherent

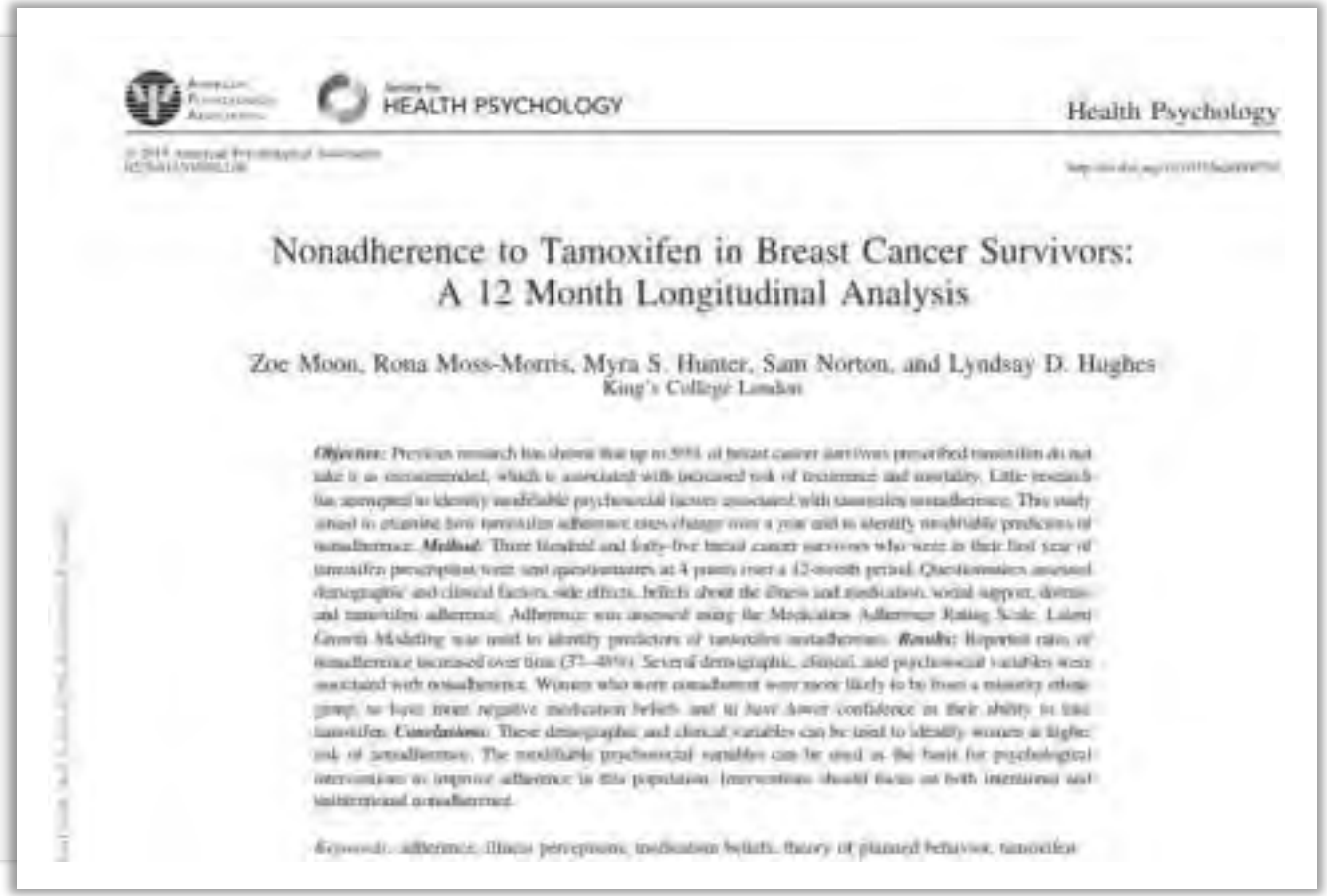
Conflicting beliefs

Moon Z, Moss-Morris R, Hunter MS, Hughes LD. Understanding tamoxifen adherence in women with breast cancer: A qualitative study. *Br J Health Psychol*. 2017 Nov;22(4):978-997.

The Necessity-Concerns Framework (NCF) in women with breast cancer prescribed endocrine therapy

MOST CONSISTENT PREDICTORS OF ADHERENCE WERE

- Having more **positive medication beliefs (necessity-concerns differential)**
- Higher perceived behavioral control over medication taking
- Being from a white ethnic background



HEALTH PSYCHOLOGY

Health Psychology

Nonadherence to Tamoxifen in Breast Cancer Survivors: A 12 Month Longitudinal Analysis

Zoe Moon, Rona Moss-Morris, Myra S. Hunter, Sam Norton, and Lyndsay D. Hughes

King's College London

Moon Z, *et al*. Nonadherence to tamoxifen in breast cancer survivors: A 12-month longitudinal analysis. *Health Psychol*. 2019 Oct;38(10):888-899.

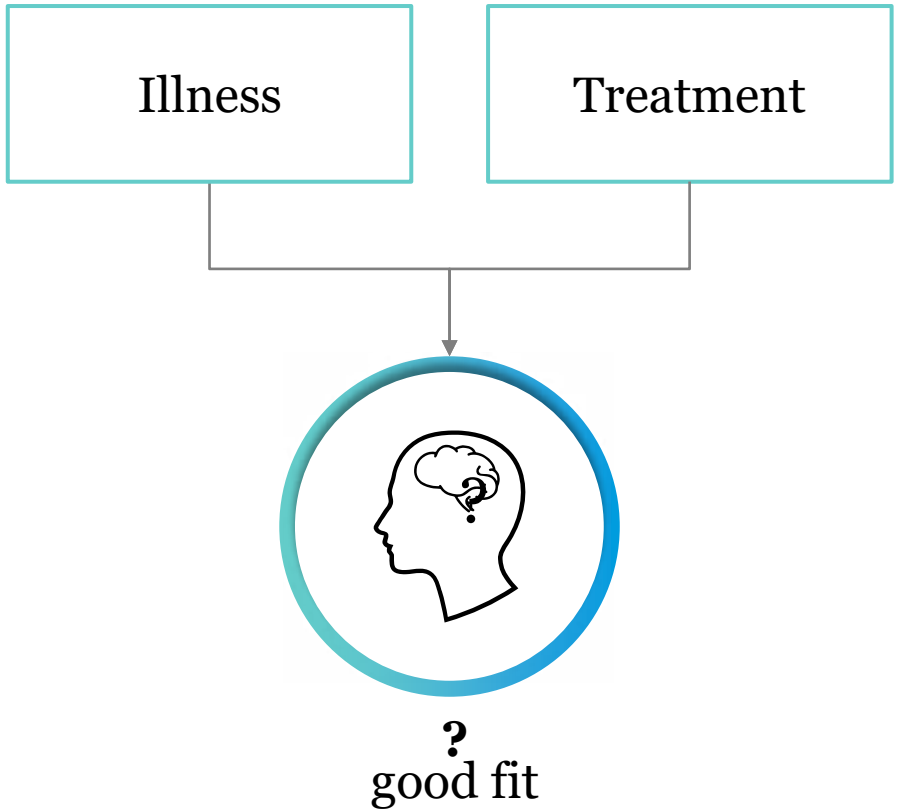
There may be disconnects between patient and HCP concerns

- 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.

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.

Illness prototypes and stereotypes and negative impact on sense of self[1-3]

DISEASE PROTOTYPES

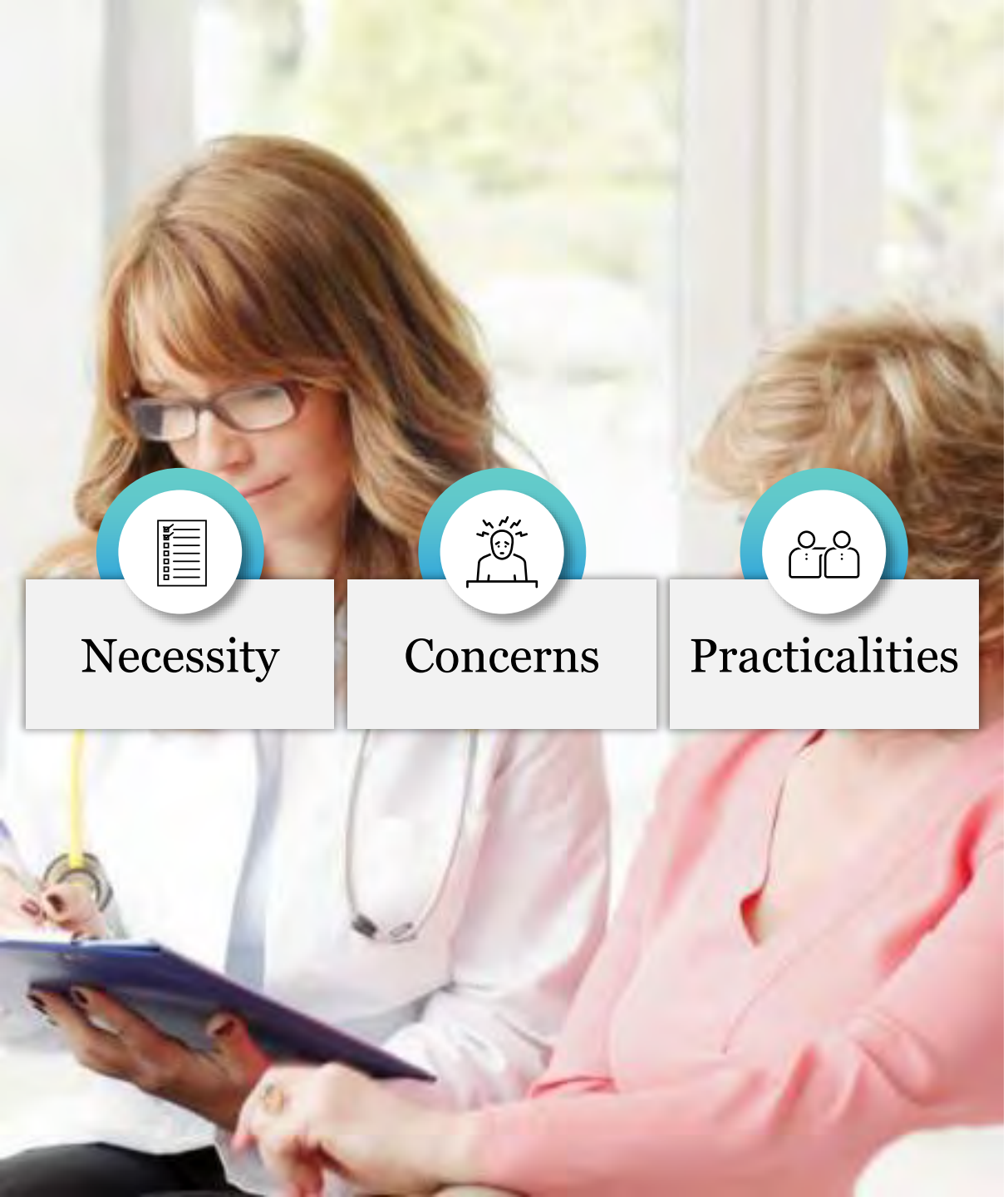
- People have pre-existing models of common illnesses
- Influence **how** and **when** we act if experiencing symptoms or receiving health advice

DISEASE STEREOTYPES

- What sort of person gets this disease?
- How much do I resemble them?

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.Kumar K, et al. Determinants of adherence to disease modifying anti-rheumatic drugs in White British and South Asian patients with rheumatoid arthritis : a cross sectional study. *BMC Musculoskelet Disord*. 2015 Dec 29;16:396. 3.Stack RJ, et al. Delays in help seeking at the onset of the symptoms of rheumatoid arthritis: a systematic synthesis of qualitative literature. *Ann Rheum Dis*. 2012 Apr;71(4):493-7.

Solutions



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

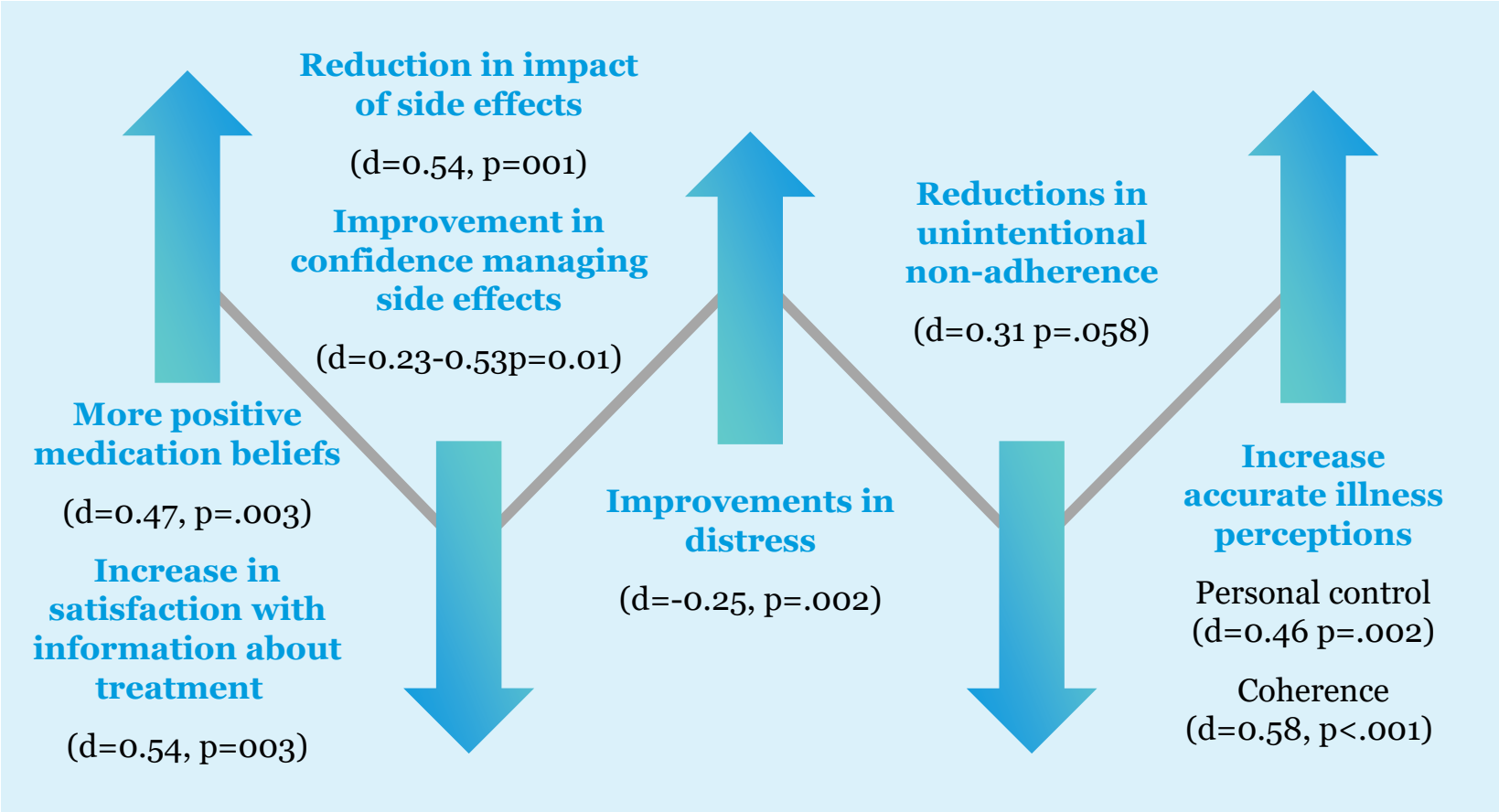
Practicalities

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.

PaPA based intervention in breast cancer survivors[1]

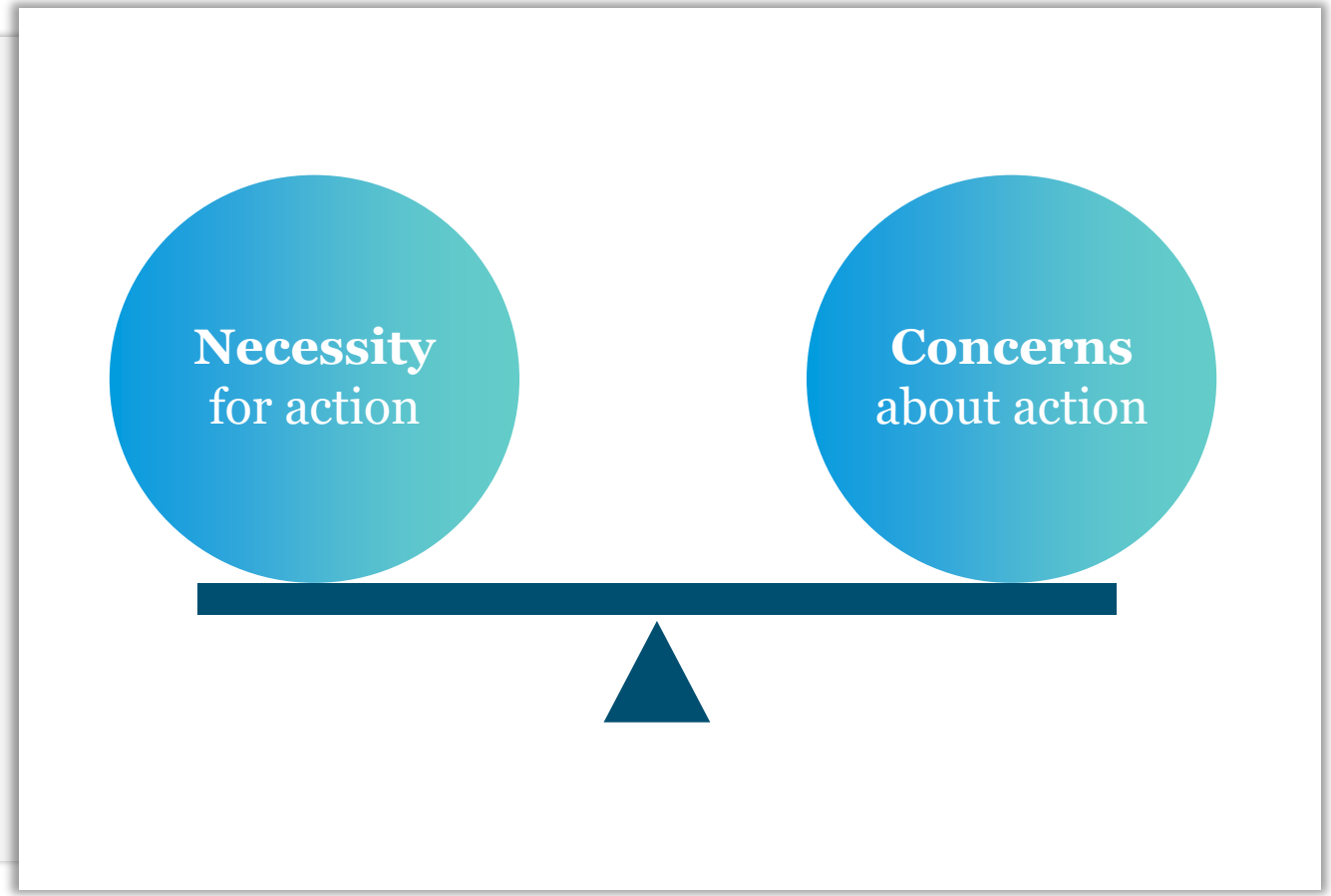
- Self-directed psycho-educational booklet (based on PaPA)
- Feasibility and acceptability study showed intervention to be feasible & acceptable, and to improve adherence and medication beliefs.
- Pre-post study, n=30



1. Moon, Z., *et al*. (2019). Acceptability and feasibility of a self-management intervention for women prescribed tamoxifen. *Health Education Journal*, 78(8), 901-915.

Supporting informed choice

- Tools to communicate uncertainties and probabilities in an accessible form[1]
- Support to help patients translate information about the relative risk and benefits into common-sense necessity beliefs and avoiding misplaced concerns[2]



1.Spiegelhalter D, Pearson M, Short I. Visualizing uncertainty about the future. *Science*. 2011 Sep 9;333(6048):1393-400. 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 Dec 2;8(12):e80633.

Examples

Communicating uncertainty, benefits, and risks

EXAMPLE 1 DRUG BENEFITS IN OSTEOPOROSIS

YOUR CHANCE OF BREAKING A BONE OVER THE NEXT 10 YEARS

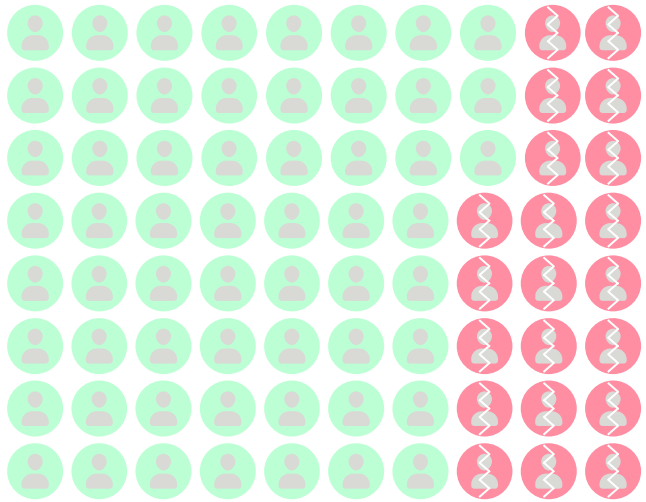
Communication of PERSONAL Necessity e.g.,

1. Bone is strengthened
2. Reduces risk of fracture (not inevitable due to ageing)
3. Mobile for longer – more active life e.g. able to play with grandchildren etc

Improving Fracture Prevention

National Institute for Health Research

WITHOUT OSTEOPOROSIS MEDICINE



For 100 people like you

75	25
Will not break a bone	Will break a bone

WITH OSTEOPOROSIS MEDICINE

Royal Osteoporosis Society

Keele University

Communicating uncertainty, benefits, and risks

EXAMPLE 2 PLACING RISK IN CONTEXT WITH BENEFIT[1]

Pros of taking mesalazine

+ The gut tissue becomes less inflamed
+ Regular symptoms, such as diarrhoea and abdominal pain, become less common and occur only now and then
+ It can protect against colon cancer
+ There is less risk of developing complications, such as fistulas (tissues break down forming tunnels into healthy tissue)
+ Available in rectal treatment, such as enemas and suppositories

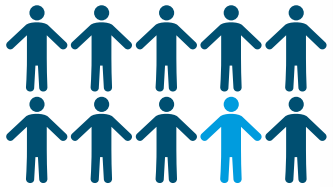
Cons of taking mesalazine

– Some people experience side effects such as headaches and diarrhoea. However, these can go away with time, once the dose is reduced or another medicine is prescribed by their doctor

1. 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. *J Crohns Colitis.* 2020 Oct 5;14(10):1394-1404.

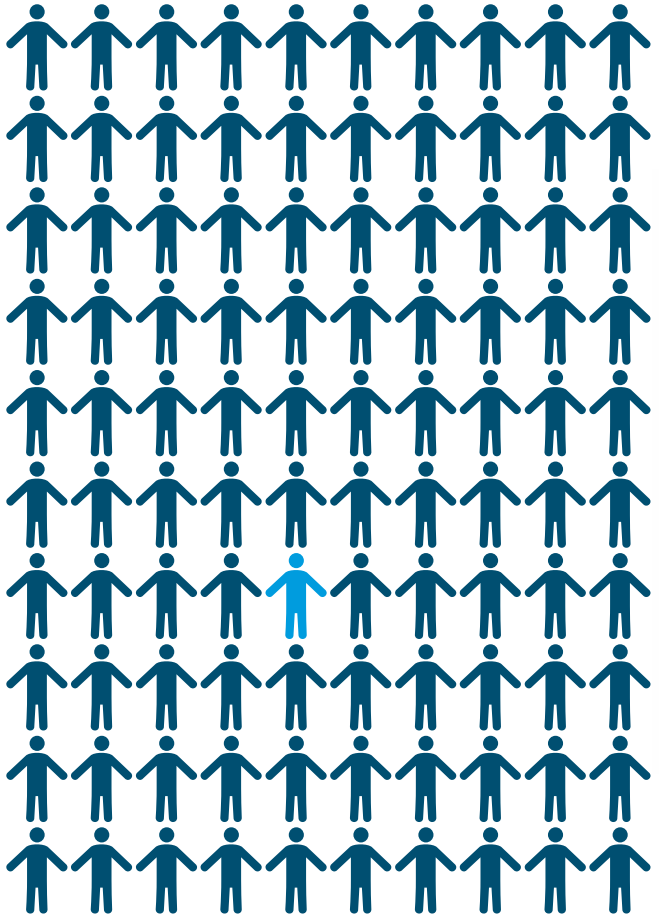
Communicating uncertainty, benefits, and risks

EXAMPLE 3 POSITIVE FRAMING OF SIDE-EFFECTS RISK



This is what looks like, if a side-effect is labelled as occurring in 1 in 10 people

A very common side-effects means that often **9 in 10 people won't get it**



This is what looks like, if a side-effect is labelled as occurring in 1 in 100 people

A common side-effects means that often **99 in 100 people won't get it**

Conclusions

APPLY GOOD COMMUNICATION/CONSULTATION SKILLS COMBINED WITH PAPA TO ADDRESS NECESSITY BELIEFS AND CONCERNS TO IDENTIFY AND ADDRESS ADHERENCE DISCONNECTS

- Patient is not 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 engagement/adherence/ non-adherence
- Taking account of them is essential to support informed choice and adherence