

# The Wellness Thermometer: the experiences of patients with human immunodeficiency virus using a new wellbeing monitoring tool

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## HIV care has changed



*Modified diagram with thanks to Chu C, J Urban Health. 2011 June; 88(3): 556–566*

## Quality of life issues

Psychological , interpersonal, spiritual , environmental concerns

- Care paradigm has changed
- Challenges patients face living with a chronic condition
- Challenges to mental well being
- Adhering to treatment
- Impact on sexual relationships
- Housing concerns
- Benefits
- Side effects to treatment

## Barriers to communication are many...

Patient

HCP

- “Doctor knows best”
- Fear and anxiety (e.g. side effects)
- Embarrassment
- Hopelessness; depression?
- Social difficulties
- Disempowerment; inequality
- Lack of trust in medical system
- Perception of feeling judged
- Complex medical information
- Expectations
- Previous experience
- Resistant to change
- Linguistic ability
- Lack of time
- Illness and cognitive difficulties
- Societal norms

- “Opening the can of worms”
- Fear and anxiety
- Assuming patient will communicate their problems
- Focus on bio-medical concerns only
- Burden of work
- Lack of time
- Lack of support-supervision
- ‘Burn-out’
- Avoidance behaviour
- Lack of confidence in ability to respond
- Fear of undermining hope
- Telling people what to do
- Medical threats
- Judging
- Poor communication skills
- Over-rating own communication skills

## Benefits of patient empowerment and good communication are well recognised

*"Physician-patient relationships and communication quality are related to outcomes in HIV care" <sup>1,2</sup>*

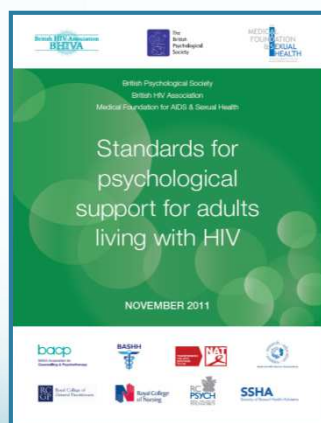
*"Higher quality communication and relationships are associated with improved patient engagement in HIV care" <sup>3</sup>*

*"Recognising symptoms that patients attribute to ART side effects might avoid loss of adherence and deterioration of trust in the patient-provider relationship" <sup>4</sup>*

*"Supporting patients requires good communication not just between clinician and patient but also between all healthcare staff involved with their care...including their GP" <sup>4</sup>*

1. Schneider J et al. J Gen Intern Med. 2004;19(11):1096–1103.
2. Laws MB et al. Patient Prefer Adherence. 2012;6:893–903.
3. Tabor E. et al. J Acquir Immune Defic Syndr. 2013;63(3):362–366.
4. BHIVA Guidelines. HIV Medicine. 2014;15(Suppl. 1):1–85.

## Psychological guidelines



- Patients are offered routine screening
- Screening at particular trigger points, change in disease progression, treatment failure, bereavement, relationship problems

## Psychological care, self-management and patient participation are Standards of Care<sup>1</sup>



### ■ Standard 6:

#### Psychological care

People living with HIV should receive care and support which promotes their mental, emotional and cognitive well-being and is sensitive to the unique aspects of living with HIV.



### ■ Standard 9:

#### Self-management

People living with HIV should be enabled to maximise self-management of their physical and mental health, their social and economic well-being, and to optimise peer-support opportunities.



### ■ Standard 10:

#### Participation of people with HIV in their care

People living with HIV should have opportunities to be actively involved in decisions about their health care. People who use HIV clinical services should have opportunities to be involved in the design, planning and delivery of these services.



1. British HIV Association Standards of Care for People Living with HIV, 2013. Available online at: <http://www.bhiva.org/documents/Standards-of-care/BHIVStandardsA4.pdf> Accessed March 2014

## What did we want in a tool?

- ✓ Easy to interpret
- ✓ Simple to use
- ✓ Need to take into consideration a variety of different literacy skills
- ✓ Contain key information to assist communication

## What was already out there?

- The distress thermometer has been found to be an economical and useful screening tool in cancer care and facilitates the identification of practical , family , emotional and physical difficulties in patients
- The distress thermometer was design for active disease burdens and not a chronic disease area where the burdens can be different

1. V2.Iskandarsyah et al 2013
2. Loquai et al 2013
3. iteket et al 2007

## The Wellness Thermometer

## WELLNESS THERMOMETER

**1** Circle the number from 1 to 10 that the thermometer scale best describes how well you feel in the past 7 to 10 weeks.

I am not feeling well
I am feeling okay
I am feeling well

12345678910

Think about your feelings:  
mood, worries, health.

**2** Is there anything that affects your well-being?

Circle all of the relevant points below:

<ul style="list-style-type: none"> <li>Problems with sleeping</li> <li>Fatigue/low energy</li> <li>Feeling sick</li> <li>Exhaustion</li> <li>Changes in weight</li> <li>Stress or other stressors</li> <li>Feeling lonely</li> </ul>	<ul style="list-style-type: none"> <li>Pain and medical issues</li> <li>Adverse workplace</li> <li>Power</li> <li>Exp. problems</li> <li>Appearance</li> <li>Sexual problems</li> <li>Feeling out of control</li> <li>Taking medication</li> </ul>	<ul style="list-style-type: none"> <li>Sleeping</li> <li>Verbal/sexual</li> <li>Feeling dirty</li> <li>Sexual abuse</li> <li>Fragrances</li> <li>Sexual violence</li> <li>Feeling unsafe</li> <li>Facing oppression</li> </ul>
<ul style="list-style-type: none"> <li>Facing war/inst</li> <li>Minorities</li> <li>Personal inadequacy</li> <li>Smell/sight</li> <li>Drugs and alcohol use</li> <li>Have someone to talk to</li> <li>Feeling lonely</li> </ul>		

Something else \_\_\_\_\_

**3** What would you like to discuss during your appointment today?

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 TEL: 415.863.2200 FAX: 415.863.2201  
 WWW.POSITIVECONNECTIONS.ORG

[illegible]

## Aim of the project

- To establish if the Wellness Thermometer improves conversations between healthcare professionals and patients
- To establish patients experiences of using the Wellness Thermometer
- To explore how the Wellness Thermometer could be used in clinical practice to improve whole person care

## Practical issues

- Ethical approval

Full ethical approval was sort but not required. Project was registered with the NMGH R&D department ( 14RECNA16)

- Methodology

Service evaluation

- Funding

Good will and an unrestricted educational grant from Gilead

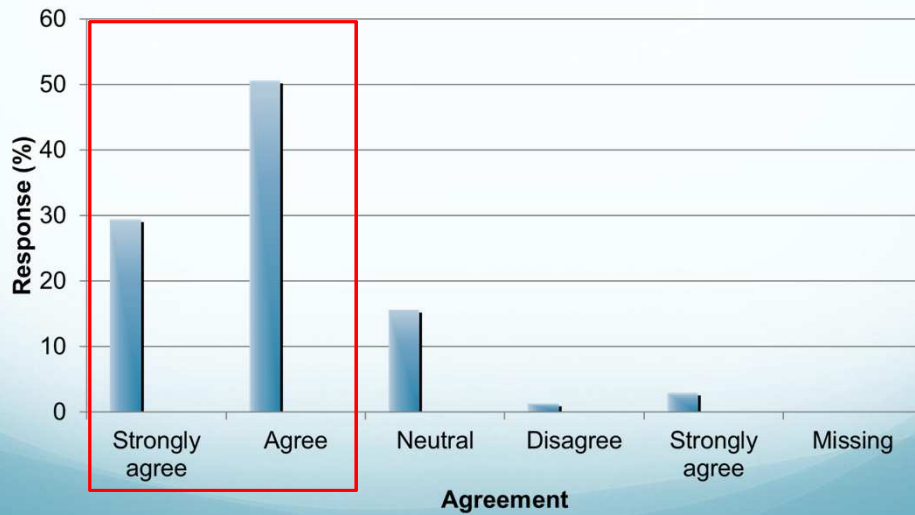
## Data collection

- North Manchester General Hospital, East Sussex NHS Healthcare Clinics and Milton Keynes were the sites that explored if the WT worked in practice
- For 1 month all patients attending HIV clinic were given the WT
- Total number of patients who took part in the project and completed a survey n=231
- Patients were given the information and tool prior to their consultation and asked to fill in the tool .
- Patients would then hand over the WT to the HCP , this was reviewed and used as a discussion point
- After the consultation a "survey card" was given to the patient to capture their views on the WT and consultation in real time

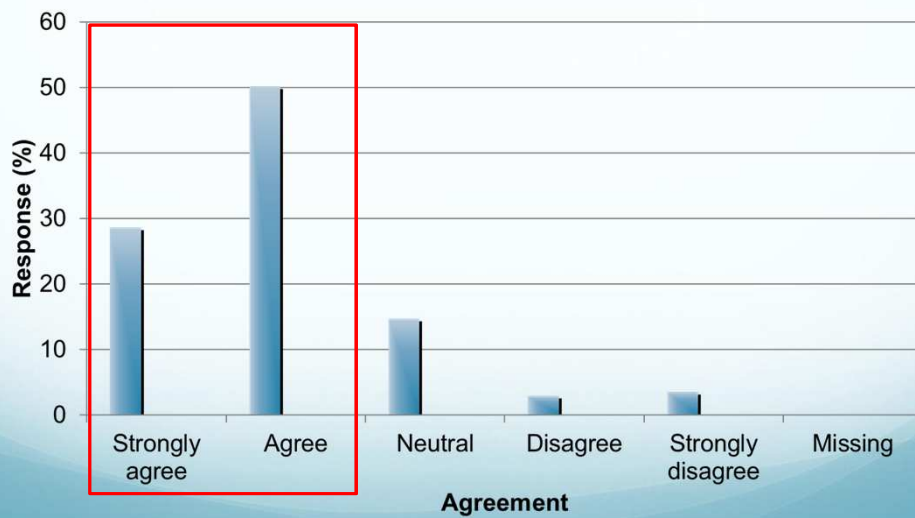
## Findings



## The Wellness Thermometer helped me identify my concerns

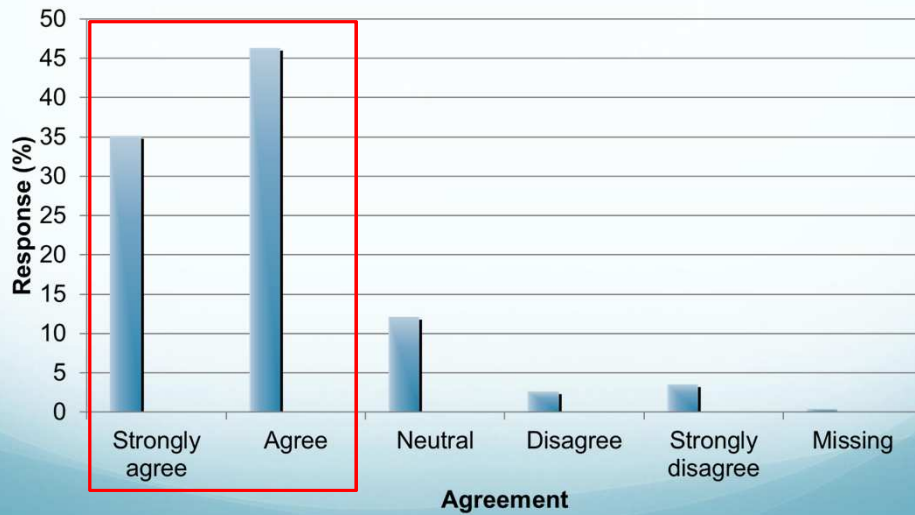


## The Wellness Thermometer improved my conversation with my doctor/nurse

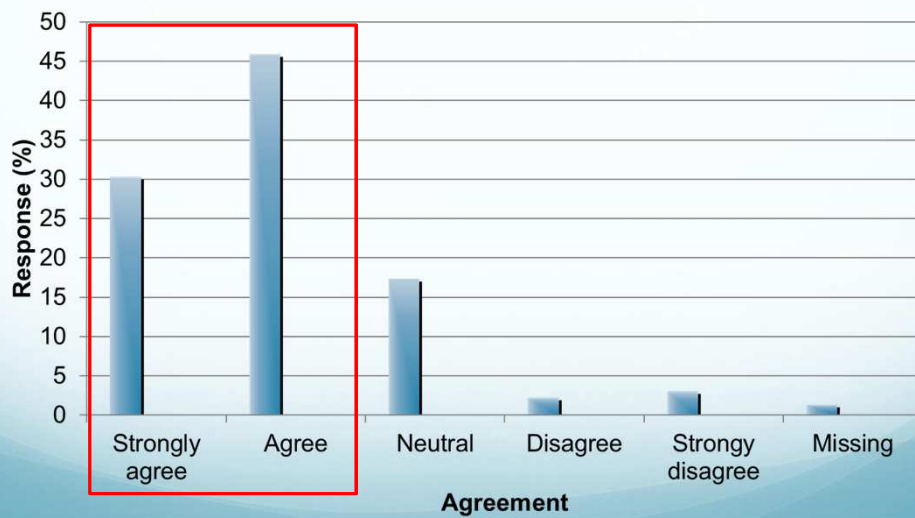




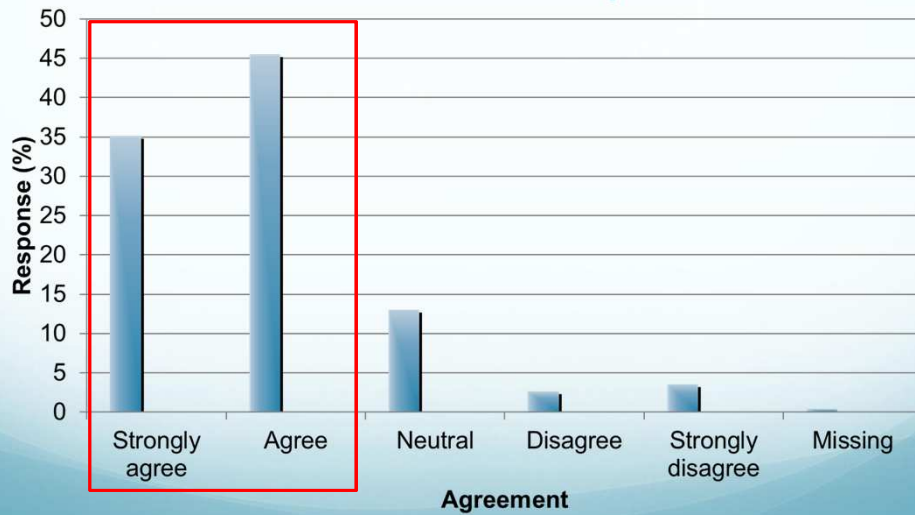
### The Wellness Thermometer helped me bring up my concerns with my doctor/nurse



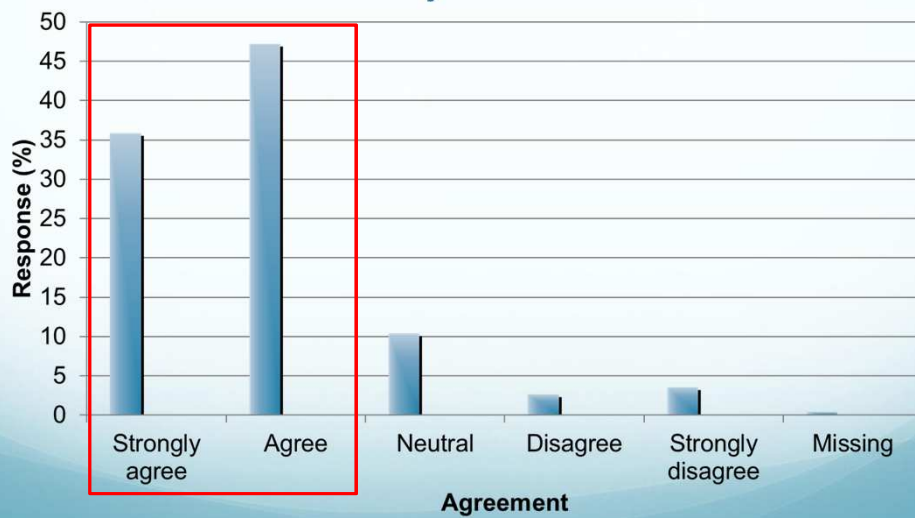
### The Wellness Thermometer will help me record my concerns between appointments



**I would recommend the  
Wellness Thermometer to a friend or family  
member with a health problem**



**I would recommend the  
Wellness Thermometer to other people  
with my condition**



## Summary

- Patients well being is related to clinic outcomes
- Patients value being assessed holistically
- Patients must feel empowered to alert their care team about all the concerns they have in relation to living with HIV
- WT acts as a tool to facilitate holistic disclosure of concerns
- WT has demonstrated an improvement in conversations between HCP and patients



“We need to learn to  
measure what we value,  
not value what we  
can easily measure”

Marcus Aurelius, Roman Emperor and  
Philosopher, AD 120

# Thank you

- **All the patients that took part**
- Dr Andrew Ustianowski, North Manchester
- Dr Jenny Petrak, Homerton Hospital
- Mr. Martin Jones, East Sussex
- Ms. Shan Walker, Milton Keynes hospital
- Ms. Dee Sheedy, Milton Keynes hospital
- Mr Terry Whitehead, Gilead Sciences
- Mr David Lindsay, Gilead Sciences
- Dr Paul Benn, Gilead Sciences
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- Gilead Sciences Ltd