

# **Empowerment through self-testing apps: both goal and process**

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## Self-testing apps

[included screenshots of different self-testing app companies' websites]

Self-testing apps offer users information about their current health status by providing them with the means to test themselves for having a disease without the help of a healthcare professional.

[included screenshots of taking BrainTest, an app to detect cognitive impairments]

[included pictures of Tweets and advertisements of self-testing apps  
being advertised with claims of empowerment]

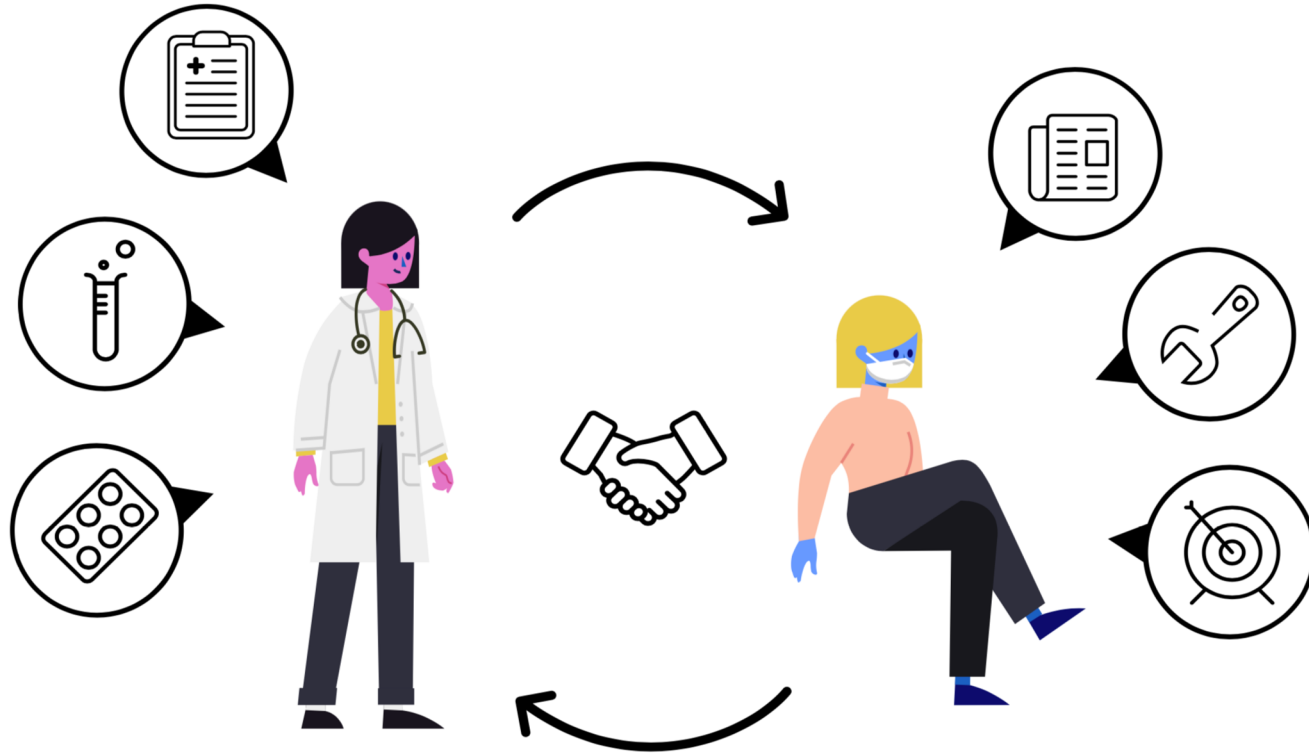
# Health empowerment

“Patient empowerment is defined as a process to help patients develop knowledge, skills and a heightened awareness of values and needs. In turn, this enables them to define their goals, take responsibility for their medical treatment and increase their autonomy. This definition implies improved problem solving abilities, better communication with healthcare professionals, and often an awareness of health-promoting behaviors” (Varekamp et al. 2009)

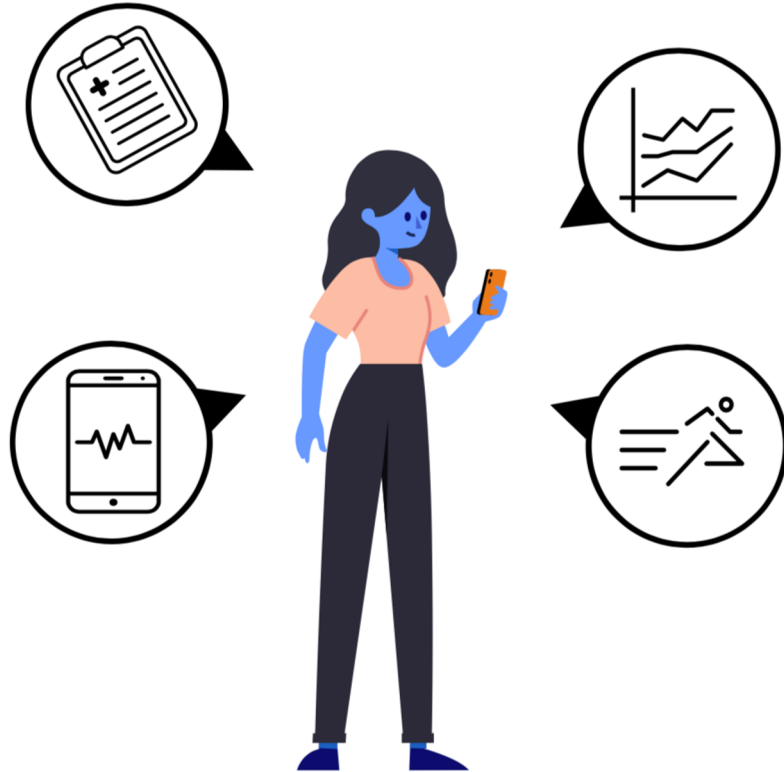
Or....

“A process in which patients understand their role, are given the knowledge and skills by their health-care provider to perform a task in an environment that recognizes community and cultural differences and encourages patient participation” (WHO 2009)

# Health empowerment



# Mobile health empowerment?



# Empowerment through self-testing?

- “Empower and control your health” (SkinVision)
- “Envisioning a world where data empowers mental wellness” (Medibio)

Parallels with mHealth (e.g. self-tracking): “order and control over what might otherwise be an unpredictable (because unknowable or mysterious) body may be instituted via digital and metric knowledges” (Lupton 2013)

We agree that self-testing apps:

- Provide a *particular kind* of knowledge, previously only attainable through health professionals
- Control over the way this knowledge is received

However: to what *extent* can knowledge and control be achieved through self-testing apps? What do you need to be in control over? Is that empowering?



# Knowledge of what?

- Positive result: and now?
- Uncertainty
- “Paradoxically, the conditions of uncertainty in which early diagnosis is promoted produces, rather than sorts, a number of uncertainties, particularly around patient futures” (Swallow, 2016)
- Status of the result

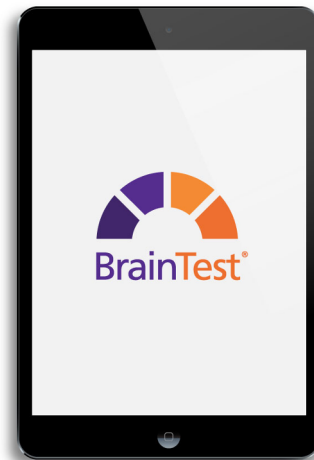
→ knowledge *that* something is or might (not) be the case, but not necessarily to knowledge of what this actually means for the user and *how* to proceed



# Control over what?

## Control over test circumstances vs over health

- Contextual control
  - control over environmental factors that affect one's health-related well-being or abilities
  - BUT taking the test precedes the actual health decision
- Internal control
  - control over oneself, i.e., over desires and actions which have effects on health
  - BUT extra motivation to make “better” choices does not automatically mean these choices have an influence on the development of the disease they tested positive for

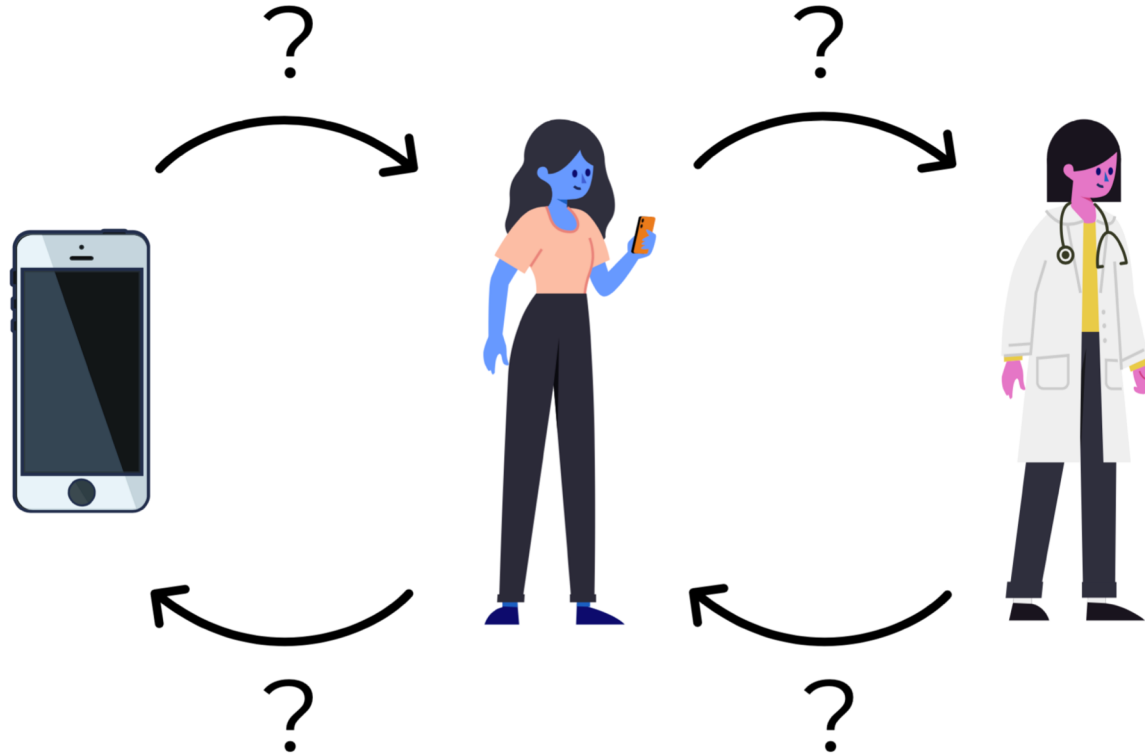


# Controlling health?

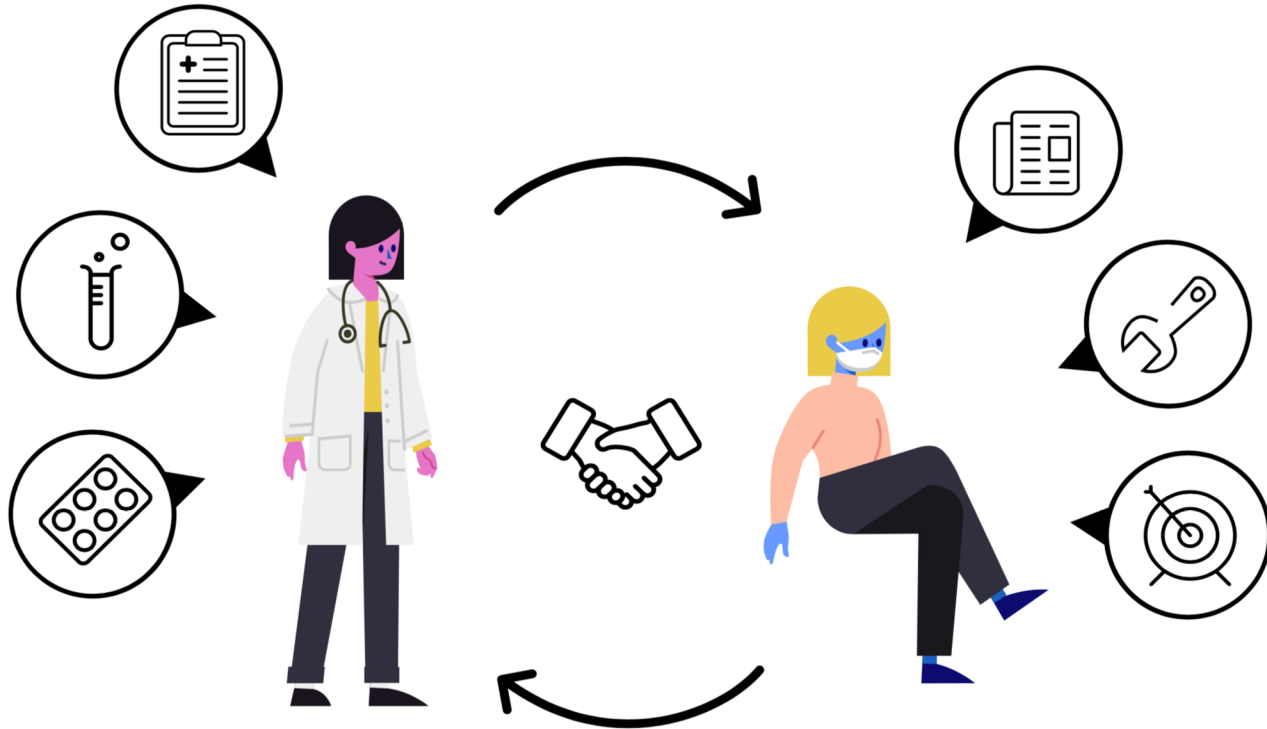
- Health as something that always can and should be controlled
- Responsibility
- Blame
- Different “starting points” or “pre-existing empowerment”



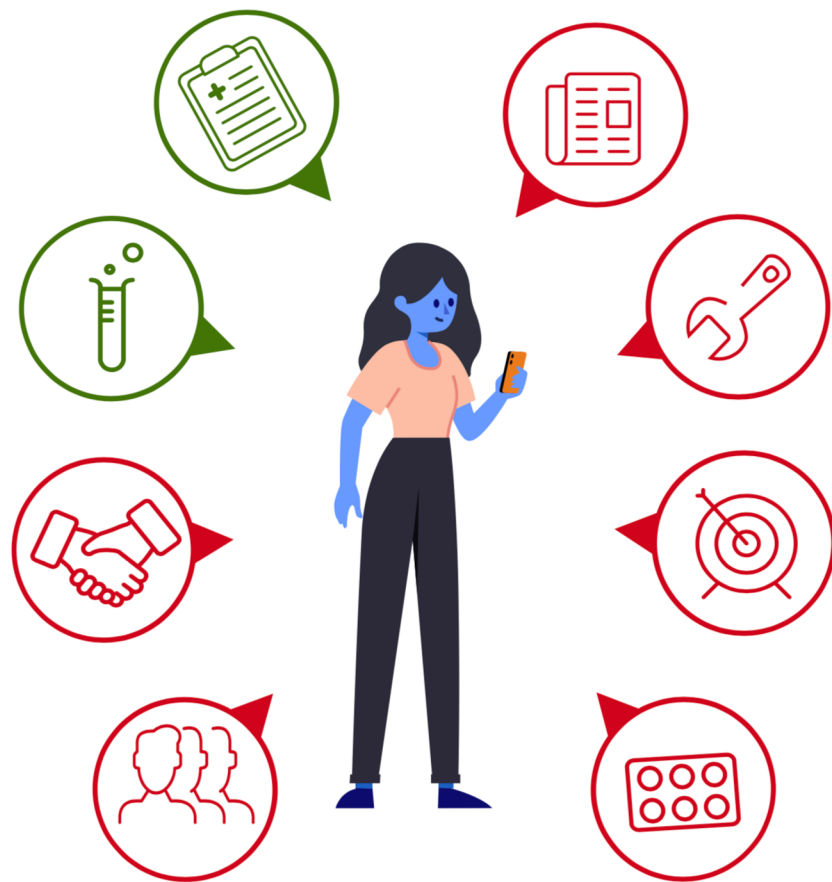
# Empowerment through self-testing?



We observe a shift in focus from...



To...



# Empowerment as goal and process (Tengland)

	Goal	Process
Refers to	the envisioned <i>state</i> of an individual or group	the <i>means</i> required to attain the goals sought
Means	to have control over the determinants of (i.e. those factors that contribute to) one's (quality of) life. The more control one has, the more empowered one is	attending to professional practice on the 'local' level, i.e. working together with the people involved

# Different empowerment ideas

Self-testing apps:

[included advertisement mentioning empowerment again]

→ Although using a self-testing app is a result of the user's own efforts, how empowering this ultimately is depends on factors beyond the individual user.

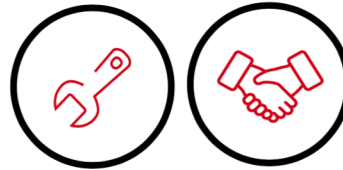
Health empowerment: "A process in which patients understand their role, are given the knowledge and skills by their health-care provider to perform a task in an environment that recognizes community and cultural differences and encourages patient participation" (WHO 2009, emphasis added).



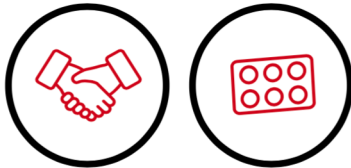
# Introducing process-considerations



Provide users, as well as others in their social circle, with additional resources to interpret and act upon their test results



Promote education and support for care providers: what do they need to know about these technologies?



Support users in their 'next steps': which care providers are nearby? If none, what alternatives are there?



Include care providers and users in development, to ensure technology meets needs and goals

Thank you!

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