When populations care about their respiratory health: a scalable bottom-up model to foster self-care for all

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breathinggames.net

1 Health for all by 2030: wishful thinking or ethical duty?

One in five individuals worldwide are affected by a chronic respiratory disease, mainly chronic obstructive pulmonary diseases (COPD) and asthma.

Major preventable risks include exposure to tobacco smoke, air pollution, allergens, irritants, as well as a lack of proper nutrition and physical activity.

However, investment in health promotion and primary prevention remains scarce in comparison to disease management, even if prevention is more cost effective – 1 to 3 dollars investment per person yearly can already have significant impact.

When it comes to disease management, the medical care system has also reached its limits: one person in two does not follow the treatment as agreed with their caregiver. In addition, many affected individuals remain undiagnosed. [1-5]

Given this situation, how can we move towards the United Nations Global Goal agreed by 193 countries to ensure healthy lives for all by 2030? [6]

2 Digital health enters into habits, transforming access to health

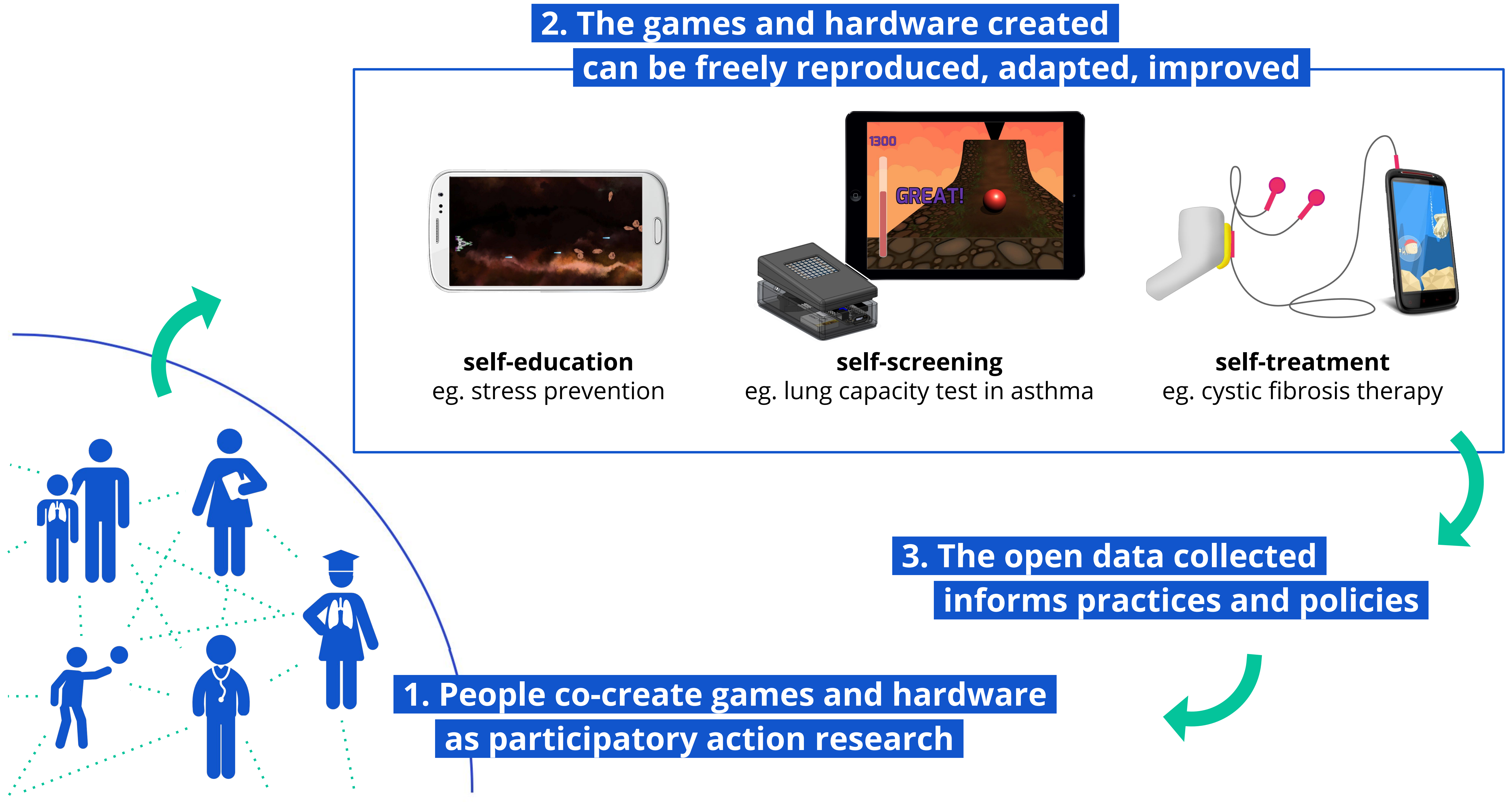
While the burden of respiratory diseases grows, many individuals around the globe adopt mobile apps and devices that collect health data – a market that will be nine times bigger in 2018 than it was in 2013. [7]

However, the mainstream approach for developing and distributing these technologies inherently limits their impact on the health of a population. [8-10]

First, in most cases, development is done in closed organizations, which do not involve end-users throughout the process. Second, the distribution is often realized in a proprietary mindset, prohibiting others from reproducing, adapting, improving, or repairing the products. Moreover, the data collected are generally not accessible to researchers and communities.

breathinggames.net proposes a new framework – one that builds on collective intelligence, and makes health education and technologies accessible to all. [11-12]

3 BreathingGames.net



2. The games and hardware created can be freely reproduced, adapted, improved

self-education
eg. stress prevention

self-screening
eg. lung capacity test in asthma

self-treatment
eg. cystic fibrosis therapy

3. The open data collected informs practices and policies

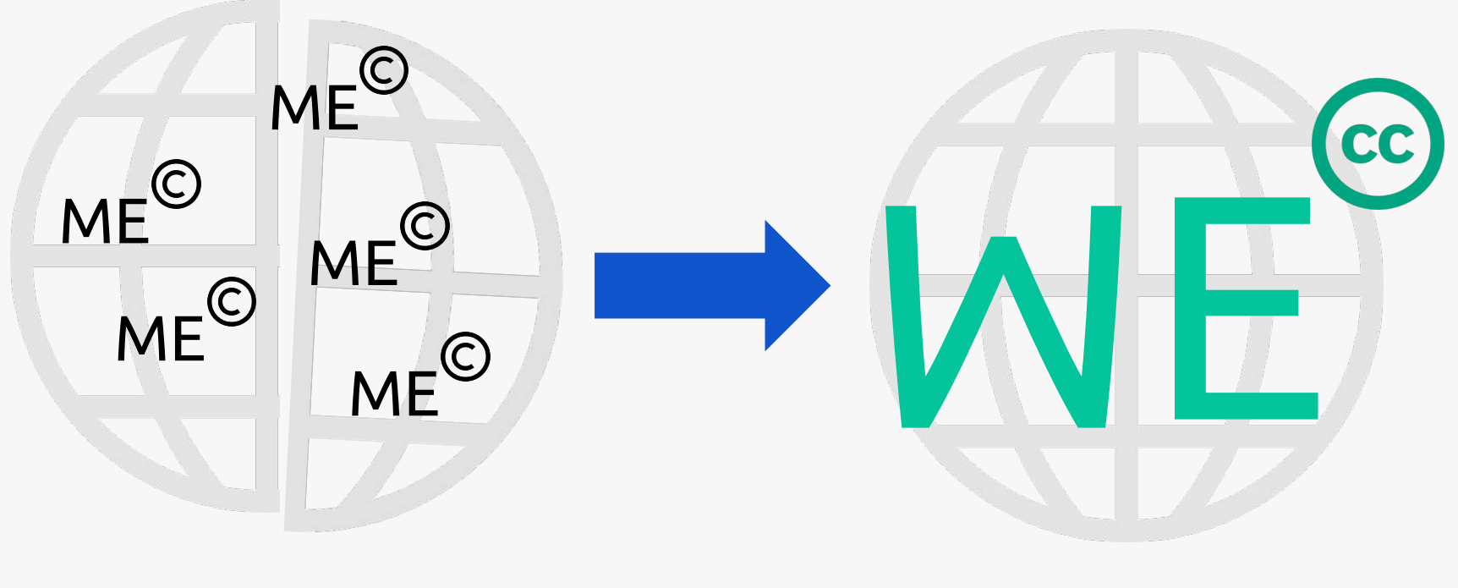
1. People co-create games and hardware as participatory action research

4 Do-it-yourself health tech: taking the lead on one's health

This framework combines five elements to encourage the appropriation of respiratory health knowledge and technologies by the broadest population – unlike traditional processes, which generally excludes the use, reproduction, improvement, and repair of potentially lifesaving innovation. These elements are:

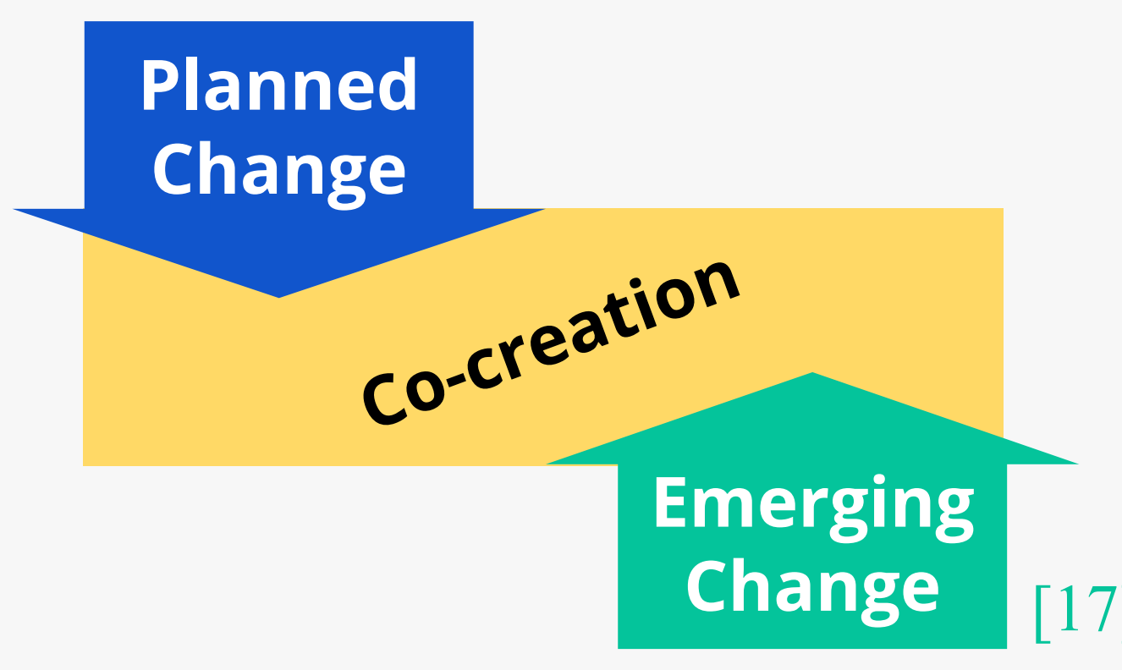
- **Free software and open-source hardware**
  We use tools which respect the users' freedoms to use and share them, and modify their code or design. Examples: OpenOffice documents, Arduino electronics. [13]
- **Copyfair licences**
  Instead of copyright, we use licences that preserve the right to reuse knowledge if reciprocity is provided. Examples: GNU AGPL, Creative Commons BY-SA. [14]
- **Accessible documentation**
  We document the co-creation process, the source code of software and designs of hardware created, and make this documentation freely accessible on our website, GitLab, or in full open access publications to facilitate knowledge appropriation.
- **Participatory action research**
  We do research with the participants rather than on or for them. This engagement in knowledge co-production aims social transformation. In such approach, not to have a positive impact when being privileged is considered unethical. [15]
- **Distributed data system and open governance**
  We log contributions in time, money and kind to acknowledge individual efforts towards the collective. This also provides a basis for transparency and traceability. A system of distributed data and token (cryptocurrencies) is also being created to ease participatory decision-making, encourage communities and makerspaces to develop local projects, as well as raise awareness on data privacy challenges.

These elements build a whole, coherent system: an **open access commons**. [16] This commons is increasingly capable of sustaining communities in appropriating and developing health technologies, fostering social inclusion, social justice, equity, access to healthcare, and reducing inequalities. In addition, the knowledge and technologies created remain freely available, even if core contributors leave the collective. The work realized transcends individuals, institutions, and countries, for the benefit of the collective.



5 A model for population-driven, Open Science interventions

This open access health commons offers an alternative to private/public structures. It presents how populations can produce their own health technologies, and actively contribute, with the support of experts, to fun health education, which is accessible at anytime in one's pocket. This bottom-up model complements top-down regulations, and allows individuals and local communities to join forces and emerge in a constructive, win-win dialogue, towards health for all.



Planned Change

Co-creation

Emerging Change

[17]

Since 2014, breathinggames.net has mobilized over 200 individuals. Co-creation events have been regularly held to develop prototypes, with the support of universities, patient associations, hospitals, and development networks.

Twelve games and three devices to transform breath into digital data were created. Results were presented in 13 scientific communications, and 23 media interviews, including the documentary "A new Economy." Research is ongoing to evaluate the experience and health knowledge acquired through the games and the co-creation.

The commons received funds from Canadian, French and Swiss research funds.
It participates in the Open Source Initiative, and United Nations GlobalCompact.

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