Health & Play – Addressing together the challenges of creating an open source standard for breathing games

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ABSTRACT

This proposed workshop invites us to discover an initiative – the Breathing Games – that aims to mobilize citizens around respiratory health by creating a free/libre and open source standard for health games – a common.

After being presented the two years journey of the initiative, participants will use their skills and talents to meet the current challenges of an open collaboration projet.

CCS Concepts

•Human-centered computing \rightarrow Collaborative and social computing design and evaluation methods; Collaborative and social computing devices; Open source software; •Applied computing \rightarrow Sociology; Health informatics; Education; •Software and its engineering \rightarrow Software creation and management; Open source model; •General and reference \rightarrow Computing standards, RFCs and guidelines; •Hardware \rightarrow Analysis and design of emerging devices and systems;

Keywords

Health; Games; Standard; Breathing; Chronic Disease; Respiratory; Adherence; Asthma; Cystic Fibrosis; MPOC; Commons; Open Science; Open Collaboration; Open Source; Open Hardware; Free Software; Libre

1. GOALS

At the end of the workshop, participants will have:

- acquired knowledge about the ins and outs of the challenges related to an interdisciplinary project based on open collaboration
- applied their skills and creativity on a meaninful project promoting health
- experimented a collaborative process that values the group as a whole

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2. THE INITIATIVE

Breathing is our first act in life.

Each day, we breath in and out 10,000 to 15,000 liter air. When unfolded, our airways cover 60 to 90 square meters – versus 1.7 for our skin.

But what does happen when breathing becomes a challenge? What would we feel if we breath through a straw, or had water in the lungs?

2.1 A public health challenge

Breathing is a challenge for one person out of twenty. Each year, over four million people die from chronic respiratory diseases, and hundreds of millions more suffer from respiratory failure. [3]

According to the World Health Organization [8], one patient in two is not doing their therapy according to the recommendations agreed with their caregiver. This increasing problem results in more frequent hospitalizations and costs billions to the healthcare system each year.

In chronic illnesses such as cystic fibrosis, patients have to do one hour daily therapy to prevent a lung transplant. This lifelong, tedious routine starts when children are three to seven years old.

Now, imagine that lung specialists, children affected with cystic fibrosis, elders with asthma, designers, yoga practitioners, anthropologists and professionals of all fields collaborate to foster breathing health.

What if we created games that stimulate the inclusion and autonomy of people with chronic diseases, but that also learn us how to breath well?

This is the mission of the Breathing Games initiative.

2.2 Democratizing health innovation

Health games have shown promising results in increasing the adherence to therapy [2, 5, 6]. Games enable the patients to improve the quality of their care without supervision, but also provide a window into the real time behaviors of patients, which advances research.

Through storytelling, games can also address the psychosocial risks resulting from illness, and transform the feeling of loneliness, shame, unfairness lived by some patients into a feeling of belonging, pride, inner peace.

However, creating immersive games that are attractive on the long run requires all actors to share their information.

Releasing the Breathing Games' work under public licences – GNU AGPL, OHL and CC BY SA – was therefore a logical choice.

2.3 Current situation and vision

Today, the initiative has involved more than 120 contributors from 18 countries. Five game prototypes and two hardware device prototypes have been produced. A preliminary study was done at Sainte Justine hospital (Canada), and a clinical research is being prepared at the University of Applied Sciences Western Switzerland. [1, 4]

A system to log contributions and redistribute the raised funds – Sensorica / Mikorizal Value Network Software – as well as a tool to foster collaborative and transparent decision-making – Enspiral Loomio – were set up to establish a collaborative governance.

Based on the experience gathered, the initiative's mission evolved to: Promoting respiratory health through the creation of an open source standard for health games.

To this end, the Breathing Games aims to generate:

- a community to build and share the commons resources freely accessible to everyone
- a process to help stakeholders from different organizations build on collective intelligence
- a software development kit with examples and specifications to create plug-and-play game modules
- blockchain data management that preserves users' privacy and fosters research
- a marketplace with processes to call contributors, validate the work achieved, redistribute the raised funds

Goal of the workshop is to move forward in the creation of this standard.

3. TIME SEQUENCE

While the general framework is given, the content will be co-created according to the participants' skill and interests in order to foster pro-activity and autonomy.

3.1 Opening

Objectives: Participants feel welcome, have an idea of the project as well as an overview of how the workshop unfolds.

Process: Presentation of the facilitator, workshop's goals, program and collaboration rules (active listening, constructive feedbacks), video on Breathing Games.

3.2 Meeting peers

Objectives: Participants get to know each other and build a shared identity. They connect to their Inner Child through their creativity.

Process: In groups of three, participants present themselves by choosing a living being as a methaphor. They explain why they chose this being, and describe how it presently feels. For example: I can choose a horse for its authenticity and its strength. This horse feels good because it lives outside under the sun and eats fresh grass.

In a second round, they select an organ of their chosen being. They explain the role of the organ and its relation to breathing. For example: I am the horse's liver. My role is to filter, to get rid of all toxines I find. Breathing is one of my favorite activities as it nurtures me.

This six minutes process is done three times, so that every participant meets six peers.

3.3 Belonging

Objectives: Participants get recognized as part of the whole group.

Process: In a group discussion, all participants give their name and, in one sentence, present the proeminent element of the previous discussion.

3.4 Presentation of the initiative

Objectives: Participants know the history of the Breathing Games, the challenges faced during the last two years and the solutions found. They also learn about the current problematic issues they will address.

Process: Presentation of slides. Main stages of the initiative (inception, collaboration with hospitals and universities, software and hardware development, events and community). Challenges faced (fun experience vs therapy pattern, clinical research vs agile development, traditional fundraising vs crowdfunding). Solutions implemented regarding governance (value accounting system, collaborative decisionmaking). Current challenges to be addressed (contribution and validation process, financial sustainability, development of the community).

3.5 Creating groups

Objectives: Participants create 3 to 7 people groups according to their skills and the current challenge that matters most to them.

Process: Open Space Technology. Participants join and agree on a common, simple, but significant outcome to be realized in 60 minutes.

3.6 Collaborative work

Objectives: Every group uses their collective intelligence to come up with a pragmatic solution to the selected challenge and thus realizing their outcome.

Process: Group work. The facilitator is available as a ressource.

3.7 Sharing outcomes

Objectives: Participants share their results.

Process: In a group discussion, every group presents their chosen goal and their realized outcome in one minute.

3.8 Reflexive learning

Objectives: Value the individual and group commitment. Process: In a group discussion, all participants explain in a few words about what they retained from the activity.

3.9 Feedback + wrap up

Objectives: Enable everyone to give their impression about the activity and to release energy for the next one.

Process: In a group discussion, each participant says a few words about what they liked or what they see could be improved. The facilitator does closing remarks.

Table 1: Schedule for a morning

1	Opening	$5 \min$
2	Meeting peers	$20 \min$
3	Belonging	$10 \min$
4	Presentation of the initiative	15 min
5	Creating groups	10 min
	– break –	$10 \min$
6	Collaborative work	$60 \min$
7	Sharing outcomes	$20 \min$
8	Reflexive learning	20 min
9	Feedback + wrap up	$10 \min$

4. FURTHER INFORMATION

For general information and for a list of all contributors and partners, please visit www.breathinggames.net.

A wikipedia page is also available: www.respi.wiki.

Videos of previous events and prototypes can be found on youtube.com/channel/UC2bK-LCBKF3SeFATwgg3U6g

The process used to structure the workshop is inspired by the Three Contracts Methodology. [7]

5. BIOGRAPHY

Passionate about the capacities of teams to self-organize and about inner transformation, Fabio has been exploring practices that favour collective wisdom. After working for ten years with multinationals and networks that are at the forefront of social change, he is developing an open source standard for health games. Fabio holds a Master of Advanced Studies in Human Systems Engineering and a Graduate Diploma in Adult Training. He is continuing his education at the doctoral level on "Mobilizing citizens around Health Autonomy: play and open collaboration as keys to inner transformation" at Concordia University.

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