

21 | BREATHING GAMES – FREE/LIBRE AND OPEN SOURCE GAMES FOR RESPIRATORY HEALTH

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ABSTRACT

Breathing Games brings together and share resources to make knowledge and technology in respiratory health playful, accessible, and customizable.

KEYWORDS

Breathing games; Respiratory health; Free/libre and open source; FLOSS; Cystic fibrosis; Respiratory disease; Children; Creative commons; Therapy; Breathing exercises; Community-based health research; Game jam; Hackathon.

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2. Freely adaptable games and hardware




education
eg. airway function



self-screening
lung capacity test · asthma



treatment
therapy · cystic fibrosis



1. Collective creation,
participatory research

3. Data commons
to inform policies



CONTEXT

Around the world today, 9/10 people are breathing polluted air and 2/10 live with a chronic respiratory disease, such as Asthma or Cystic Fibrosis (CF). According to the Lung Association [1], in Switzerland, 1/2700 newborn is affected with CF. The consequences of this disease go from everyday life adverse effects, lethal body function deterioration, passing by life-threatening crisis.

CF is known as the most frequent genetic disease in Caucasian population [2]. Since 2011 in Switzerland, systematic CF screening is done on every newborn [3]. This is a progressive lethal disease that, in addition to other symptoms, causes a mucus thickening leading to chronic inflammation in the airways and permanent damages to the lungs. Thanks to daily respiratory therapy, medication and transplantation in the worst cases, the lifespan of the people affected increased from 20 years old in the 1980s to 50 years old nowadays [2].

TARGETED ISSUES

Early in life, children must understand their disease. CF progressively deteriorates many body functions, but these can also suddenly decrease or improve depending on external factors. Children should learn how to evaluate their own body functions to understand their capacities, and how they are impacted by the environment.

Current therapy consists of home-based respiratory exercises done twice a day including airway clearance techniques (ACTs). The goal is to help detach the mucus stuck in the airways, so it can be coughed up, reducing the risk of obstruction, inflammation, or infection. These exercises are the most time-consuming treatment-related activity, and almost half of the affected children poorly adhere to them [4].

Finally, CF is a rare disease, and each person is differently affected. People who live with CF generally avoid meeting each other, in order to avoid germs or bacteria transmission. CF does not attract many researchers, and investments remain often focused on genetic research in the private sector. Educational contents regarding this disease are often country specific and limited. Efforts are needed to encourage the affected ones to transmit their knowledge to others and communities and groups to contribute to the well-being of CF sufferers.

PROPOSED SOLUTION

We developed a connected breath-through controller, while aiming at the same benefit as currently-used therapy device and measuring the same respiratory variables, that can be used with a computer or a smartphone. Among other benefits, this device can be interfaced to SGs aiming to create lasting interest and enjoyment during physiotherapy exercises. This would address one of the major issues in therapy: adherence.

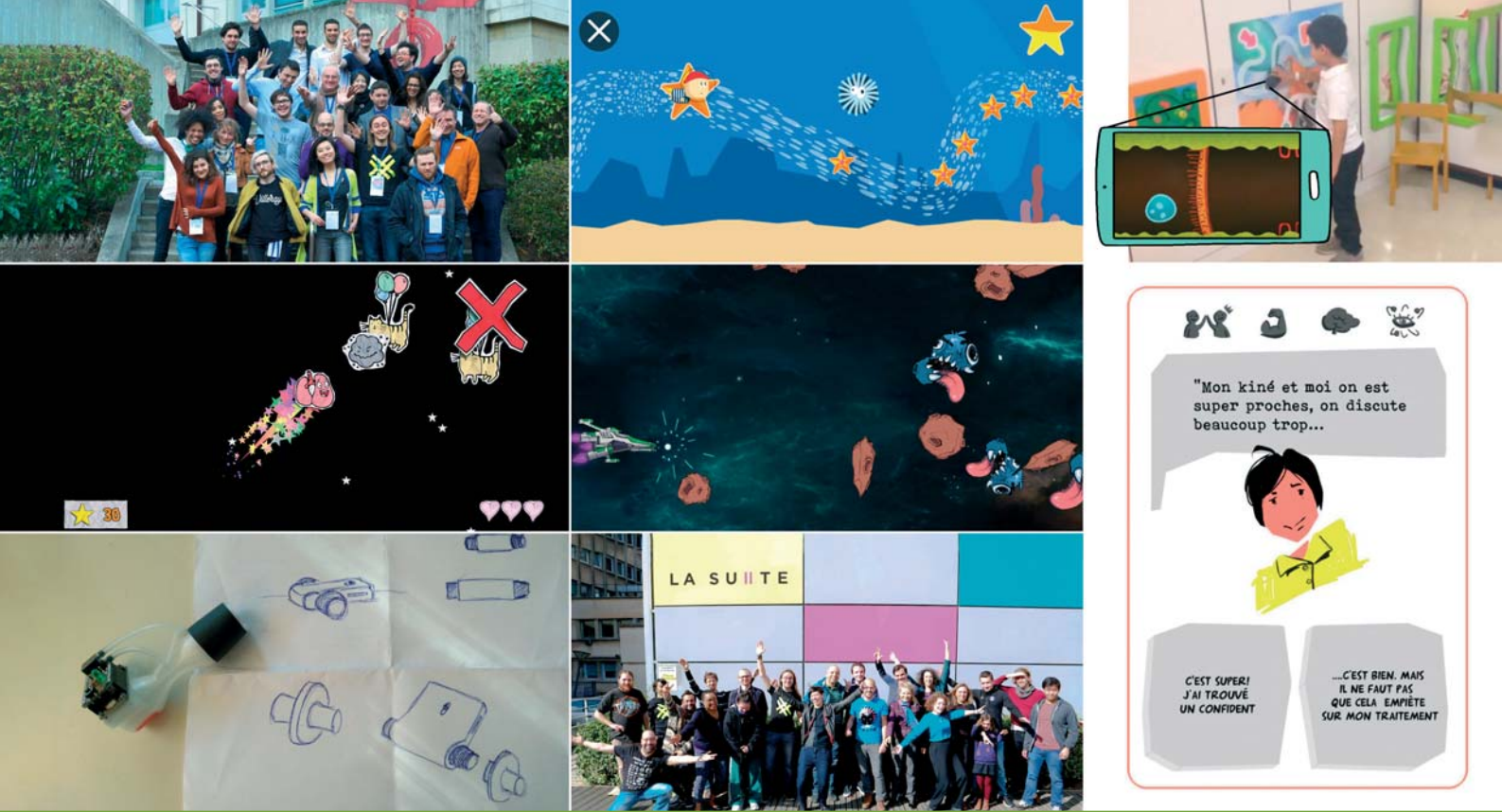
[...] the latest want to build richer, playful contents that potentially deviate from strict patterns but favor adherence and time spent in caring about themselves.



Launched in 2014, “Breathing Games” “mutualizes resources to make respiratory health knowledge and technologies enjoyable, accessible and freely adaptable.” [5] It is a global initiative collaborating with researchers spread in Switzerland, Canada, France, and Italy.

Our goal is to bring together and share resources to make knowledge and technology in respiratory health playful, accessible and customizable. By means of participative events (game jams or hackathons), we bring professionals from various fields together, such as clinicians, designers, programmers, graphic designers, musicians, and also people suffering from respiratory diseases. We create in common SGs and other therapeutic and educational materials.

By creating open material in a participative manner, we aim to sensitize everyone on the respiratory diseases public health challenge. By producing free, open, accessible and customizable content we hope to fill the gap regarding respiratory health material within and between countries.



Picture credits: breathinggames.net

RELEVANT INNOVATION

The project innovates at different levels:

First, transforming the treatment into a game, so that the affected ones can give a new meaning to the exercises they have to do.

Second, encouraging the affected ones, their parents, caregivers, and other interested people in developing the games collectively, so that the different stakeholders' needs are taken into consideration.

Third, documenting and sharing the games and their source code under free/libre and open source licenses to encourage communities to further develop the games, adapt them to their specific needs, and get an understanding on how such technologies can be developed.

PROJECT OUTCOMES & RESULTS

Since 2014, more than 250 people have contributed, 4 research articles published, 3 student projects realized, and 19 game jams or hackathons held to produce free/libre and open-source contents. Today, 19 games have been prototyped, 13 of which are in development. Different SGs use a dedicated device or an API. A pilot study is planned to test three SGs in Switzerland. The most recent game jams were held in Paris and Geneva in March 2019, during the Open Geneva festival.

The developed SGs have different purposes. Eight of them target education, to discover or rehearse knowledge about the diseases, for young people with a disease or their surroundings (e.g., family, friends). Five of them target specific CF ACT exercises [6]. The challenge was to develop a playful experience for precise respiratory therapeutic exercises.

Based on the received feedback on these five exercise-based SGs, four more have been developed aiming at more generic breathing exercises. They put the priority on the playful aspect rather than the strict reproduction of the therapeutic exercise patterns (without ignoring all their medical basis). This allowed expanding the initiative to other diseases, such as asthma for future studies in Italy and Canada. The last two SGs created in Paris with young adults suffering from CF focus on fostering a positive mindset, attractive storytelling around self-care despite new autonomy (leaving family, college...), and share the skills they developed through living with CF.



CONCLUSION

In the last five years, “Breathing Games” has involved more than 250 people and produced 17 SGs addressed to children with respiratory diseases. These SGs aim at sharing knowledge or increasing adherence to therapeutic exercises. While the first SGs focused on translating strict physiotherapy exercises in SGs, the latest want to build richer, playful contents that potentially deviate from strict patterns but favor adherence and time spent in caring about themselves.

PERSPECTIVES & NEEDS

Most of the developed devices and SGs are still in development by voluntary contributors. Some educational SGs have triggered interest in other external parties and are on their way to their first use in clinics. And many more are still to come, like three game jams and hackathons planned in the coming months.

We are always looking for passionate game designers, developers, artists, or clinicians to join this initiative and become new ambassadors for respiratory health.

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