breathing games.net ™

Festival 'taking care together'

Dossier of intent: we are building this project in an agile way, integrating feedback from the community over the weeks. We also want to establish this dialogue with you to refine the proposal according to your expectations and experiences.

First edition 2020
Concept for 2022
Inspirations

Spaces
Process of commoning
Didactics and dissemination
Examples of activities

Team
Partners
Impact and reporting

Annexes and addenda

the texts in purple
are web links

the coloured circles
have different meanings
throughout the pages

2019. Following the health game jams organised by Breathing Games (19:30, A new Economy), the Geneva Health Forum and Open Geneva invite our association to design and organise a citizen event of open innovation in health.

2020. The GHF Open Village opened, offering 20 participatory activities on health commons. The summary poster, distributed in nine languages, was seen 2200 times. Today, we propose a revisited edition of the Village.

HEALTH TECHNOLOGY AS COMMONS: TRUSTABLE, AFFORDABLE, ADAPTABLE

Geneva Health Forum 2020 · Open Village · www.openvillage.ch

6 in 10 humans still have no access to care, or do not adhere to it, despite rising investments.[1-3]

Alcohol-based hand rub[4] and WikiMed[5] illustrate how creating freely reproducible equipment and software with communities can: save millions of lives, increase integrity, cut costs by 90%.

Cooperation-driven care is the only way to realize the 2030 agenda in time: health for everyone.[6]

We present nine alternatives to the dominant proprietary excluding innovation model, to drive development towards a responsible, solidar society.

Hand prosthesis to ease one's daily life
A prosthetic hand usually costs 6-10 K€. Enable brings together over 30000 volunteers who design and distribute 3D-printed prostheses to vulnerable people. www.enablingthefuture.org + www.gre-nable.fr + www.enablenepal.org

Drugs produced with integrity
India has a pioneer approach in pharmaceutics. Open Source Drug Discovery brings together 7900 people who collectively develop open-source, low-cost therapies for neglected diseases such as tuberculosis, malaria, leishmaniasis. www.osdd.net

Open-sourcing MRI could save the German healthcare over 200 M€ yearly[7]
Medical imaging is crucial in diagnosing, understanding and treating a number of diseases. The Open Source Imaging initiative gathers experts to create MRI scanners that can be built and maintained for a fraction of the cost of current MRIs. www.opensourceimaging.org

Ultrasound scanner in the pocket
One in three persons have access to medical imaging. A portable ultrasound device usually costs 8-22 K€. EchOpen develops a probe to visualise organs on a smartphone. It helps guide the diagnosis and make patient management more fluid. www.echopen.org

Detecting seizures with wearables
50 million people have epilepsy, 1/3 are drug resistant. Epileptic seizures lead to daily stress and social exclusion. We develop wearables and software to log and analyse biological data. www.aura.healthcare + www.openhumans.org + www.cri-paris.org

Making air pollution a visible matter
In Switzerland, one in seven premature deaths is linked to air pollution. LogAir helps everyone to map the air quality (fine particles) using cheap devices. Generating data can help avoid bad air quality, but can also motivate policy changes for healthier cities. www.logair.io

Collecting and visualizing data
MindLogger makes it easy for anyone to collect, analyze, and visualize data using mobile devices. Users are able to build their own activities, such as surveys, quizzes, digital diaries, or cognitive tasks. www.mindlogger.org

Transforming gesture into sound
Fuga explores the potential of emerging technologies for preventing, diagnosing, monitoring, and rehabilitating mental health disorders in line with recent advances in psychiatry and neuroscience. www.hoosh.space/fuga

Taking care of our breathing through play
Worldwide, one child in ten has asthma, one senior in twenty has COPD, a disease caused by pollution and smoking. Breathing Games is developing a multiplayer game and a breath sensor to promote respiratory health. www.breathinggames.net

We also discuss ageing, public policies, quality systems, and cryptocurrencies.

Videos and more: www.openvillage.ch · Cite: www.doi.org/10.5281/zenodo.4327587

Fabio Balli[A] Mathilde Matringe[B] Clement le Couedic[C] Jon Schull[D] Shikshya Gautam[D] Patrick Jandard[D] Emmanuel Kellner[E] Afroditi Anastasaki[F] Katerina Serada[G] Samir K Brahmachari[H] Lukas Winter[I] Pierre Lonchampt[J] Felix Schoeller[K] Anirudh Krishnakumar[L] Bastian Greshake[M] Kevin Lhoste[N] Christophe Parot[O] Guillaume Jeanmaire[A]

[A]Breathing Games [B]EchOpen [C]Aura [D]Enable [E]LogAir [F]Open Geneva [G]SDGHub [H]Open Source Drug Discovery [I]Open Source Imaging [J]Helpful Engineering [K]Fuga [L]MindLogger [M]Open Humans [N]CRI Paris [O]Join Seeds

1. WHO and World Bank. Half the world lacks access to essential health services... 2018.
2. WHO. Adherence to long-term therapies: evidence for action. 2003.
3. World Bank. Current health expenditure (% of GDP). 2020.
4. WHO. Guide to Local Production: WHO-recommended Handrub Formulations.
5. WikiMedia. Wiki Project Med/App. 2020.
6. United Nations. #Envision2030 Goal 3: Good Health and Well-being.
7. Winter et al. Open Source Medical Devices for Innovation, Education and Global Health. 2018.

open GENEVA · GENEVA HEALTH FORUM

Current issues

After two years of restraint, "the population as a whole is showing signs of fatigue; the passive endurance mode in the face of the crisis has sapped strength" (Federal Office of Public Health 2021). Mental health problems are on the rise, especially among the most vulnerable (KOF 2021, Swiss Re 2020), and Swiss democracy is in decline (EIU 2021, Freedom House 2020).
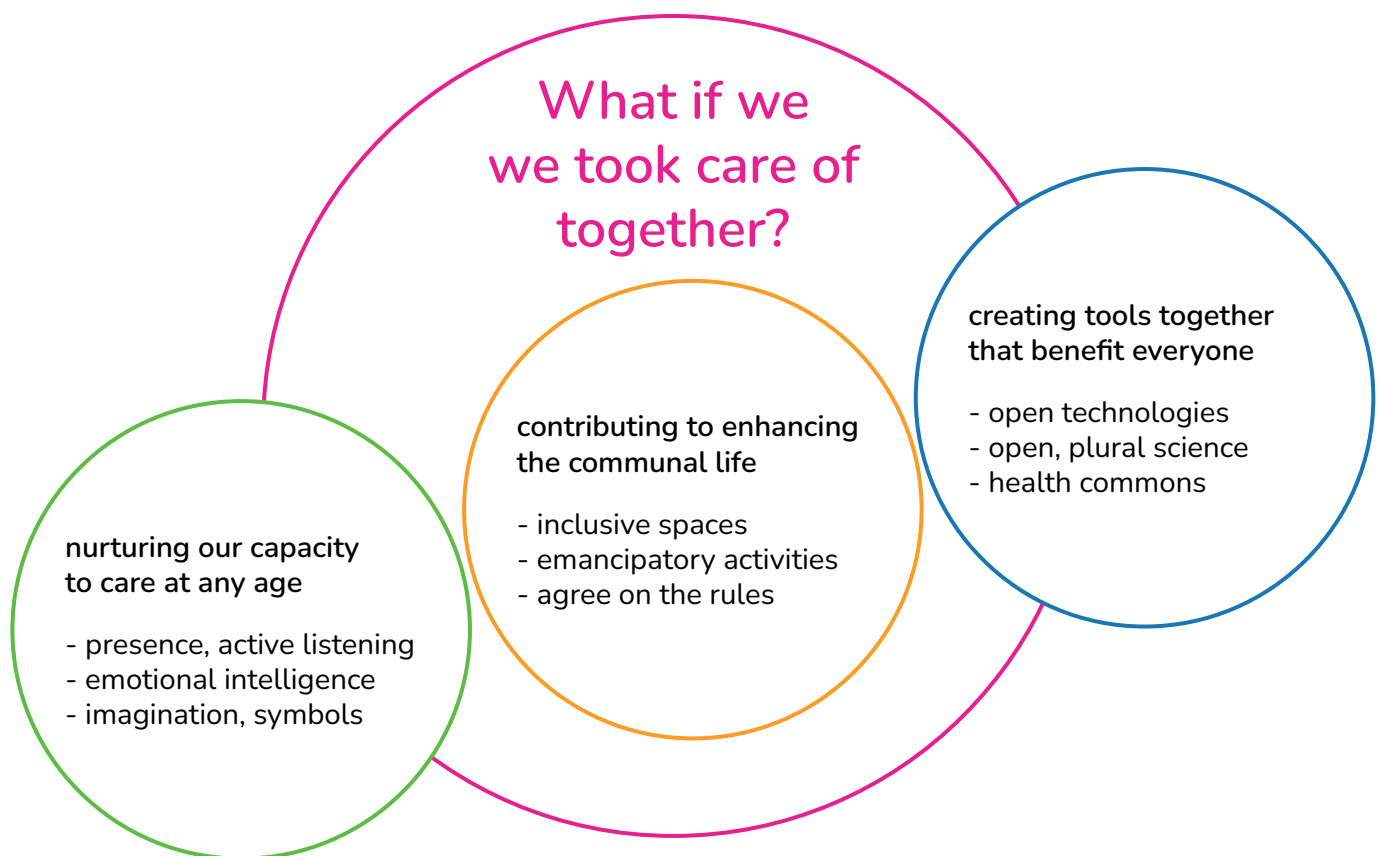
But while our health declines when measures are imposed on us, it improves when we are the protagonists of our lives (Ng et al '12).

Our vision

A festival co-created with and for the Romands, to heal the wounds resulting from the crisis.

A festival that values collective intelligence, creativity, subjectivity, and strengthens citizens' capacities for self-determination and shared governance. Balm to the heart to create together a future we no longer dream of.

A citizen festival in addition to and near the Geneva Health Forum, from 3 to 5 May 2022, with an international reach.

What if we we took care of together?

contributing to enhancing the communal life

- inclusive spaces
- emancipatory activities
- agree on the rules

creating tools together that benefit everyone

- open technologies
- open, plural science
- health commons

nurturing our capacity to care at any age

- presence, active listening
- emotional intelligence
- imagination, symbols

Logo

The festival logo represents a plural circle of people gathered around a fire, the emergence of a common project, the appeased snake of Aesculapius' staff that returns to the heart of the four elements or, more symbolically, the fertilisation source of life.

Organisers

A project led by the Breathing Games Association under the patronage of the Geneva Health Forum and the Open Geneva association.

The Geneva Health Forum 2022 will focus on global and environmental health. The Mekong Delta will be the guest of honour.

With this in mind, we imagine a festival that celebrates social connection and nature. Here are some of our inspirations.

rooted, embodied

The heart of the festival is to reconnect and nurture the connection to nature. We are therefore planning a Mamajah tent near the CICG (IUC park or Place des Nations garden), including activities by the local Vietnamese (Mekong) community.

festive, creative

After two years of constraints, we want to celebrate the joy of living, and heal damaged relationships, like the Indian festival Holi. We will promote creativity and art therapy, in collaboration with the Art hives, a community art network.

communal, scalable

To invite citizens to reclaim common spaces, we will encourage the emergence of ephemeral spaces for listening and sharing gestures of kindness, such as the sanctuary presented in the film *The Square*, or the *Life Vest Inside* movement.

plural, documented

We will adopt a create-as-research methodology (Chapman and Sawchuk 2015) so that activities are documented (abstract, videos, images, etc) in our wiki, and freely adaptable through copyleft licenses.

Images: sites mentioned

Spaces

The heart of the festival will be three zones, open from 9 am to 5 pm and into the evening:
- meeting space open to the public, dedicated to exploring the health commons (sporadic activities)
- manufacturing lab-bus open to the public, dedicated to welding and 3D printing (sporadic activities)
- federating space dedicated to cooperation between actors engaged in the health commons (activities from 0.5 to 3 days: resource sharing, development of good practices, advocacy, ...)

We will also help a plurality of carers to facilitate one hundred ephemeral listening activities across the city over the three days. These activities will be recorded and documented on our wiki.

Identified ambassadors will announce our activities to the participants of the Geneva Health Forum.

1m²

table available by the hour

bar

high tables

large screen
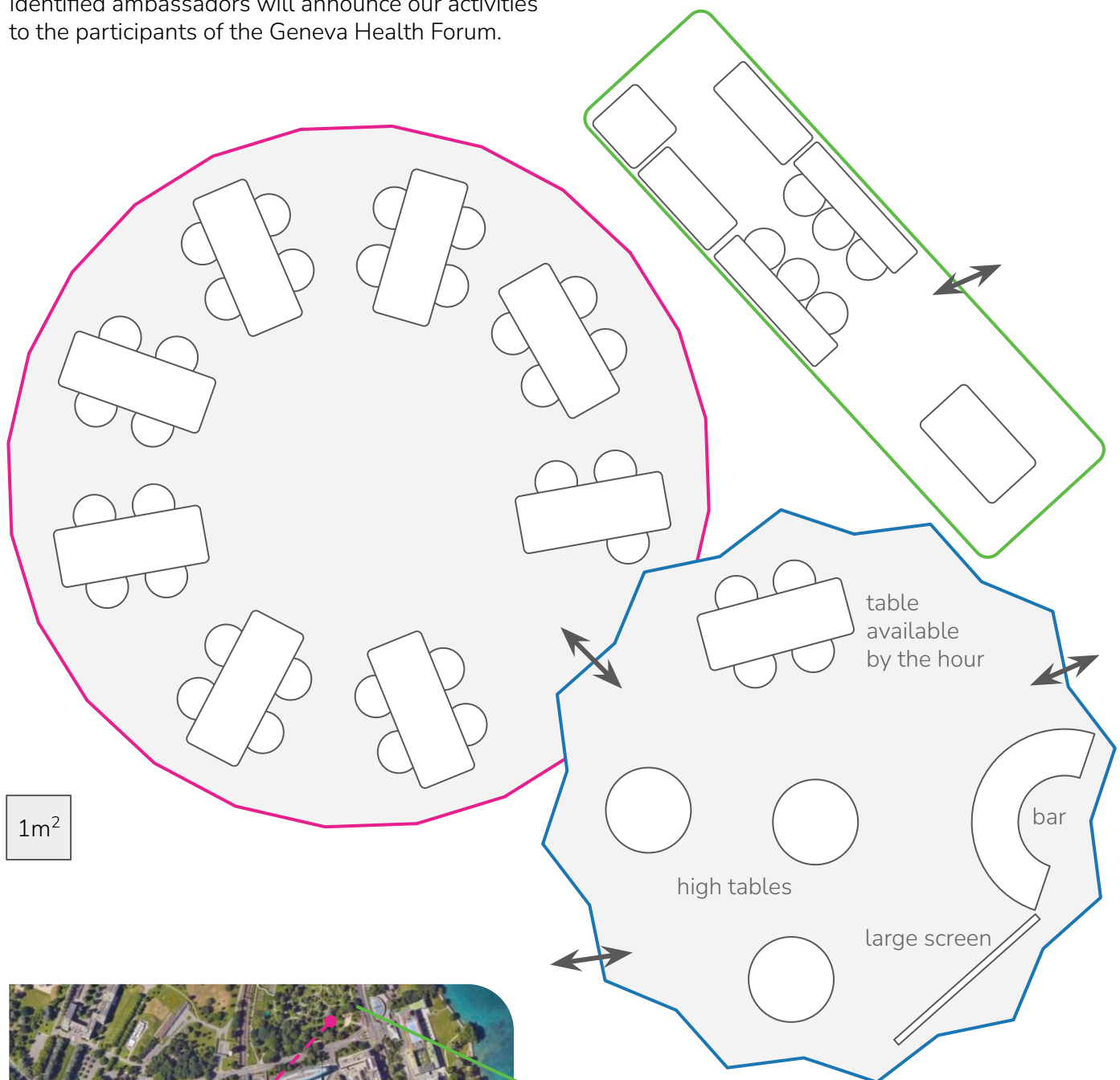
Botanical garden

Place des Nations

Geneva-Sécheron station

Core of the festival (venues considered)

Geneva Health Forum (CICG)

Map: Google

Creating a shared heritage...

The majority of the resources should be used to build and preserve an information heritage under a legal regime of copyfair or copyleft, or a normative framework of equivalent effect.

In concrete terms, this means that all activities and projects carried out during the festival will be documented and disseminated in such a way that they can be used, reproduced and enriched freely (BY-SA license).

In order to do this, project holders will need to ensure that the proposed activities are

· aligned with the three objectives of the festival
· not for profit
· supported by 3+ people involved
· based on active participation
· documented in detail on our wiki according to the creation-as-research approach

... of citizen knowledge

This pooling process is in line with the UNESCO recommendation on open science adopted at the end of November 2021 by 193 countries. The principle is that

"More open, transparent, collaborative and inclusive scientific practices, combined with more accessible and verifiable scientific knowledge subject to scrutiny and criticism, improve the efficiency, quality, replicability and impact of the scientific enterprise and hence the reliability of the evidence needed to make sound decisions and policies and to increase trust in science"

The visual below shows the key elements of open science. The festival (pink) thus aims to foster inclusive (blue) co-creation (orange) of diverse open scientific knowledge (green) in health.

Visual from UNESCO adapted by Fabio Balli, CC BY-SA licence

Ethics principles

The festival opens a space for the emergence of a culture of health that increases our individual and collective capacities for self-determination and shared governance.

We therefore ensure that the design of the event reduces barriers to knowledge and to the recognition of our own capacities (individuation process, CG Jung).

With epistemic humility (J. Medina 2013) and a will for empowerment, we opt for an ethic of active participation:

"The simple act of doing no harm [...] overlooks the privileges that allow researchers to observe but choose not to be involved. [Participatory action research encourages] participants to generate benefits for themselves" (LC Manzo, N Brightbell 2007)

Festival dynamics

The festival itself aims to foster the *emergence* of citizen initiatives, methods, open knowledge (bottom-up), in response to *planned* policies such as the recommendation on open science addressed to public authorities (top down).

Andragogical approach

All festival activities should be in line with ethical principles, and allow for an active contribution from participants over 2/3 of the time.

Some compatible methods:

· dialogic sessions (N. Cornett)
· education for critical consciousness (P. Freire)
· experiential learning (D. Kolb)
· problem-based learning (McMaster)

Dissemination

The dissemination and improvement of the project is based on an iterative (agile) co-creation practice. Unlike a company whose activity is carried out by a defined number of employees, we value the contributions of all interested people (crowdsourcing).

By opting for libre/open collaborative tools, we minimise barriers to participation, and encourage interested people to become part of the project, for example by taking the concept to organise a festival in another city. The choice of MediaWiki to document our actions thus aims to provide a fertile ground for the emergence of an inclusive and plural culture of our health.

Planned public policies
State / Institutions

Democratic dialogue

Emerging popular consensus
Population / Commons (Co-organized festival)

Visual from M. Laugeri, adapted by F. Balli,
santé 2030 from FOPH, circle from UNESCO
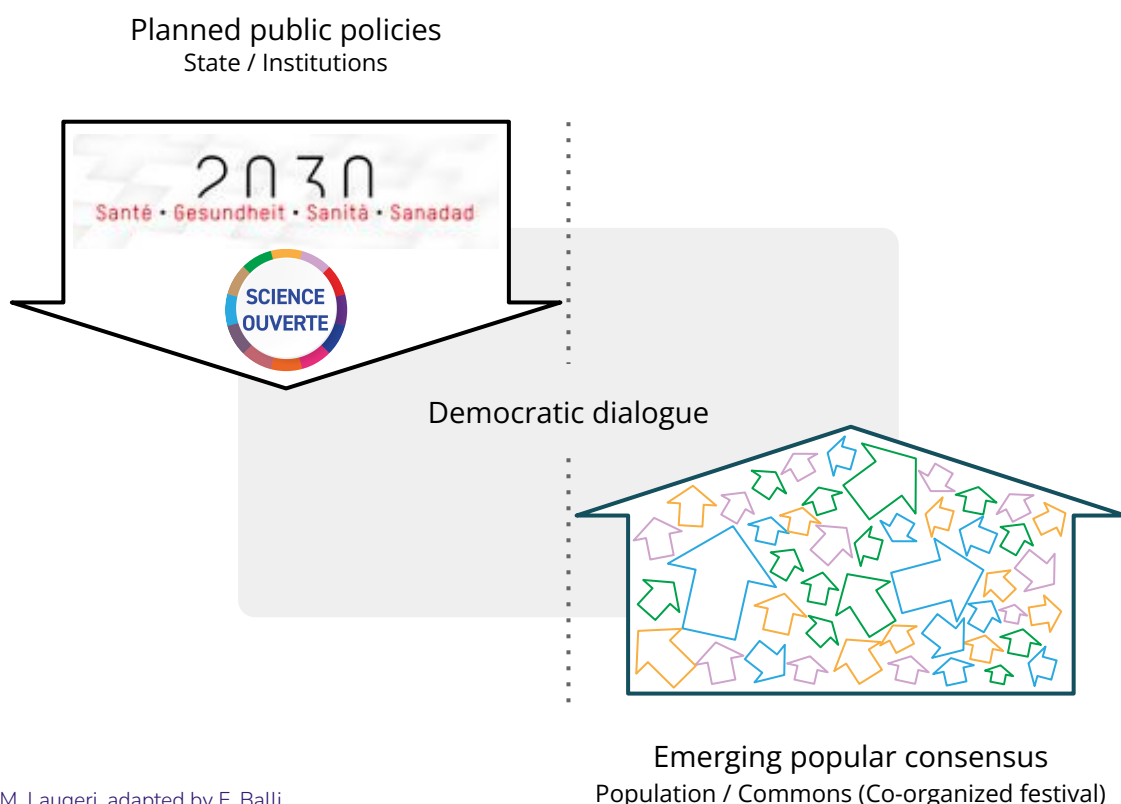
Some activities that may take place in French or English, and known or potential partners*.

disease management and prevention

Transdisciplinarity
Sharing perspectives on asthma: patients, doctors, psychoanalysts, naturopaths, ...
Partner: WHO Lung Alliance

Methodological pluralism
List relevant protocols to document, analyse and compare the impact of alternative medicines
Partner: Leenaards santeintegra*.

Regulation
Drafting a guidance note on the regulation of medtechs created by liberal communities
Partners: Polyvent, CERN

Digital data
Reflect on the risks and benefits of quantification / objectification such as patient records, chatbots, watches
Partners: Heka, InterHop, HippoAI

health promotion and well-being

Somatic art therapy (J. Hamel)
Explore and visually represent various physical sensations experienced and their possible meaning
Partner: Ruches d'art

Manufacturing workshop
Reproduce and adapt open hand prostheses to the needs of vulnerable people
Partners: HackaHealth, E-nable

Self-hypnosis (M. Erickson)
Understanding the principles of self-hypnosis
Partner: Institut Erickson Québec*.

Health Commons
Sharing good practices to mobilise and enhance a healthy community
Partners: Maker's Asylum, OSMS

critical public health

Legislative Theatre (A. Boal)
Co-create a legislative proposal in response to emergency laws, with the support of lawyers, parliamentarians
Partner: Le caméléon*

Health / my health
Encourage collective reflection on the social construction of illness (ableism, care), on evils vs words
Partner: CREACC-Diversités

Patients' rights
Bringing together good practice and challenges in the patient-hospital relationship, incl. coping with error
Partner: Féd. suisse des patients*

Narrative medicine (R. Charon)
Lifting the veil on the suffering of the medical profession, internalised oppression and collective narratives
Partner: Aura Association

Rights to quality air and water
Addressing water decolonisation and air preservation using the example of the Italian referendum of 2011
Partner: IUC Turin

Science fiction
Imagining a future desired by the greatest number, which values social links rather than technology
Partner: Darkmatterlabs*

The festival is co-organised by a group of people active in the health commons.

Mathilde Matringe, MDes
community manager, EchOpen
ultrasound scanner for emergency physicians

Clément le Couedic, MEng
Co-founder, Aura Association
patch to better manage epilepsy

Emmanuel Kellner, PhD student
Co-founder, LogAir
pollution mapping

Pascal Carpentier, PhD(c)
Director of Information Systems, DNDi
treatments for rare diseases

The vision and coordination is provided by Breathing Games Association.

Fabio Balli, PhD(c)
President, Breathing Games
co-creation of playful care

It includes people who have a chronic disease, caregivers, researchers, makers...

David-Zacharie Issom, PhD
Patient researcher, HUG
chatbot on sickle cell disease

David Risse, PhD
Researcher, CREACC-Diversities
community health activities

Katerina Serada, LLM
Director, SDG hub
public policy analysis

Charly Pache, MSc
Independent computer scientist
citizen democracy initiatives

The festival is organised under the patronage of the Geneva Health Forum and Open Geneva.

Eric Comte, MD
Director, Geneva Health Forum

Thomas Maillart, PhD
President, Open Geneva

To ensure the festival impact, we integrate a full time equivalent, divided into three roles. The coordination will be done by F. Balli, the other two roles by experienced people.

We also plan funds to ensure that those active in the health commons and those organising the ephemeral activities have the resources (time and materials) to do so.

Roles and distribution over the year	Apr	May	June	July	Aug	Sep	Oct	Nov	Dec	Jan
Coordination (ø 45%)	100	100	100	60	30	30	30	30	30	30
Public relations (ø 30%)	80	100	40	20	20	20	20	20	20	20
Community (ø 25%)	60	80	20	20	20	20	20	20	20	20
Total FTE	240	280	160	100	70	70	70	70	70	70

The preparation activity (from January to March) is funded separately to meet the deadlines and conditions of various funders.

The fund will be distributed transparently, via a cobudget.co type system, to coherent and community supported proposals.

The festival is the result of a cooperation between several Geneva-based non-profit organisations, as well as several communities active in the development of the health commons.

Breathing Games Association - Vision and Coordination

Promoting the playful co-creation of freely reproducible health knowledge (common). 22 research-creation events (Canada, Switzerland, France)
Member: WHO Respiratory Alliance, Open Source Initiative, CAGI, Après GE.
Website · Global report 2014-2022 · Contact: Fabio Balli, President

Geneva Health Forum - Patronage

The Forum that brings together the key players in global health. A biennial congress that brings together 1800 people from 80 countries (medcare, policy makers, academics, patients). Theme 2022: Global Health and the Environment.
Website · Contact: Eric Comte, Executive Director

Open Geneva Association - Patronage

Stimulating open innovation in Greater Geneva and international organisations. Annual festival that brings together some 1500 people from the region in 40 hackathons organised by civil society actors.
Website · Annual report 2021 · Contact: Thomas Maillart, President

Mamajah Association - Infrastructure (under discussion)

Working for a solidarity ecology, for more conviviality and mutual aid between generations. Tree year co-hosts of 'Healing Heart' festival. Place of integration and garden production at Jardins de Loëx. Rental of temporary structures.
Website · Contact: Philippe Rohner, co-director

Various health commons - Content creation and facilitation

Contents of the GHF Open Village 2020 have been created by a plurality of actors of the health commons: EchOpen, Aura, LogAir, E-nable (co-hosts), Open Humans, Learning Planet Institute, Open Source Imaging, Open Source Drug Discovery, Fuga, MindLogger, etc.

New organisations will join us for this new festival edition: Drugs for Neglected Diseases initiative, Hackahealth, Brainhack, Ruches d'art, CREACC-Diversités, Heka.coop, Maker's Asylum, Polyvent, GNU Health, etc.

A successful festival will have

Romand population

strengthened people's capacity to take care of themselves through active listening, setting common priorities, pooling resources, exploring open technologies created by and for communities

Caregivers

nurtured a dialogue valuing a range of care approaches, from disease management and prevention to critical public health, health promotion and wellbeing (Greenhalgh 2008)

Actors of common in health

enabled different communities to discover open science and contribute to the creation of open scientific knowledge (UNESCO 2021) with a creation-as-research approach (Chapman and Sawchuk 2015)

created a freely usable and reproducible common heritage in health, through more than one hundred activities and projects documented on a Wiki platform that can be easily edited, enriched and translated during the festival and afterwards

Community GHF / OG

positioned Geneva as a world leader in the health commons, bringing together recognized pioneers of the field, in an event that emerges from the community (bottom-up) outside of institutional planning (top-down)

Several aspects of the project remain to be defined, such as reporting indicators to be designed with funders and partners.

The potential impact of the festival in terms of participants and projects that will emerge is difficult to assess given the novelty of the format and the field (health commons, open science, ...).

However, we will, over the weeks, validate the interest of the different communities, by quickly launching a call for proposals and by building links with the actors of the civil society in Geneva and in Romandie.

To put the budget in perspective, the state spent 98 billion of public funds to the management of the covid, or an average of 12000.- per capita (Federal Finance Administration 2021).

Our budget then corresponds to valuing listening and active cooperation between 33 people, who will dedicate their energy to realizing a collective project that any romand will be able to freely use and enrich - such as a visual guide to provide young and elders with tools to preserve their mental health.

We sincerely hope that this project will inspire you, and that we are going to have your support to refine this proposal and make it a success.

For Breathing Games Association

F. Balli

Fabio Balli, President

Former civil society project leader of the European Union vs Virus hackathon which brought together 20'900 participants over three days. See interview with Prof. Pittet

We welcome your feedback to adjust this project.

Thank you for your support

Fabio Balli, balli@breathinggames.net

Annexes

Association in charge
Versioning

Addenda to download

Activity report Breathing Games Association 2021
Breathing Games Global Report 2014-2022
Auditor's report 2020 (audit 2021 ongoing)
Curriculum vitae Fabio Balli

Other links

MediaWiki GHF Open Village
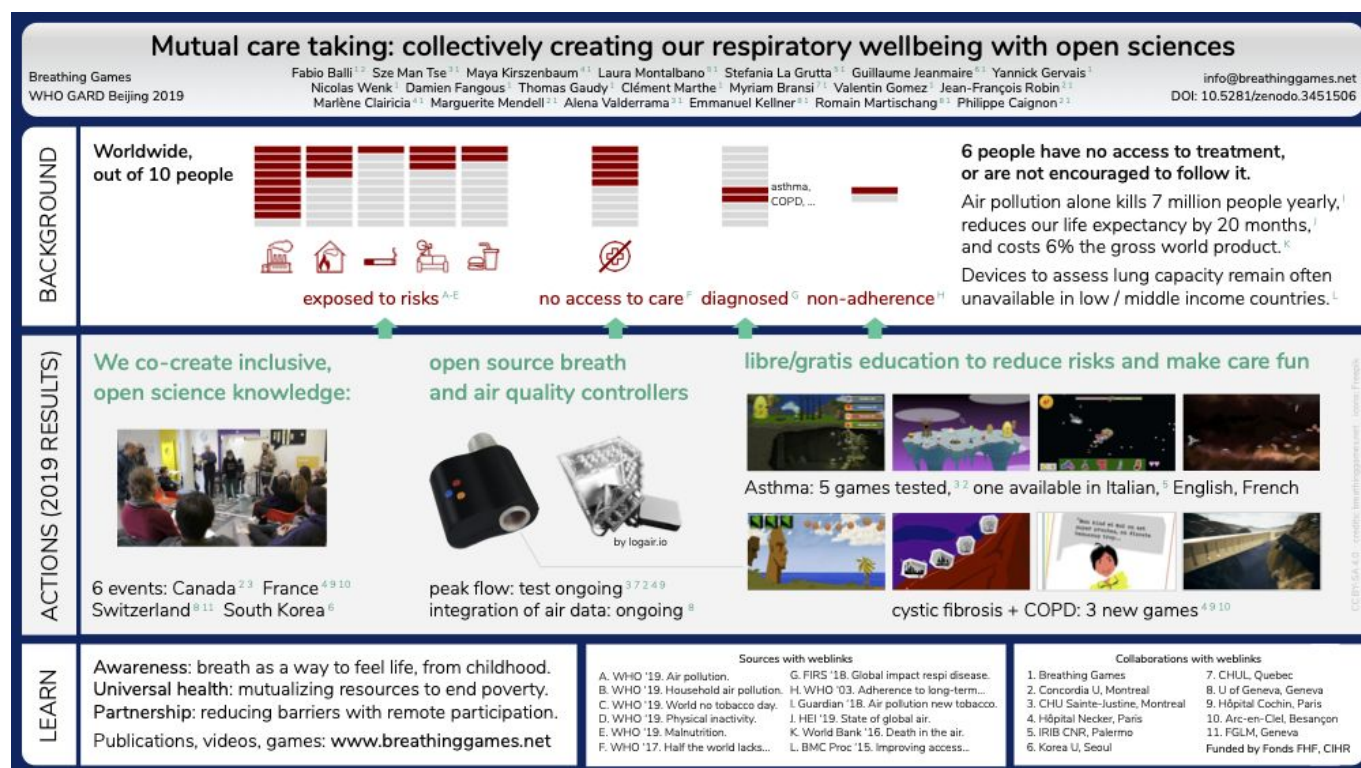
Association in charge

Festival 'taking care together'

Since 2014, the Breathing Games community has been organising events to co-create health games. The goal: making health accessible and participatory through play, a natural way to experiment, socialise, learn.

Today, we have two games translated into twelve languages, and a multiplayer where players·se·s can create levels and tell their stories.

Breathing Games is

· 23 co-creation events in health
· 470 contributors across five countries
· 320K of funds received (CIHR, FHF, HE Arc, ...)
· 75 scientific papers
· 23 sets and 8 prototyped breath catchers
· 450K viewers reached

Mutual care taking: collectively creating our respiratory wellbeing with open sciences

Breathing Games
WHO GARD Beijing 2019

Fabio Balli [1 2] Sze Man Tse [3 1] Maya Kirszenbaum [4 1] Laura Montalbano [5 1] Stefania La Grutta [5 1] Guillaume Jeanmaire [5 1] Yannick Gervais [1]
Nicolas Wenk [1] Damien Fangous [1] Thomas Gaudy [1] Clément Marthe [1] Myriam Bransi [1] Valentin Gomez [1] Jean-François Robin [2 1]
Marlène Clairicia [4 1] Marguerite Mendell [2 1] Alena Valderrama [3 1] Emmanuel Kellner [8 1] Romain Martischang [8 1] Philippe Caignon [2 1]

info@breathinggames.net
DOI: 10.5281/zenodo.3451506

In 2021, we facilitated four workshops in which the content emerged from the participants.

· 24.04, Open Education Day, CH-Open
  From discipline(s) to cooperation
· 24.08, Swiss Public Health Conference
  Envisioning the future of public health
· 12.10, IASC Commons General Conference
  The Great Renaissance: Healing Commons
· 26.11, Geneva hub for Global Digital Health
  Health Democracy

We shared our work to various networks (WSIS, FOSDEM, Réseau mère-enfant, Mixed Methods Symposium, Geneva-Tsinghua, GDHub, etc), A highlight was presenting 15 respiratory health commons at the WHO Global Alliance against Chronic Respiratory Diseases, of which we have been a member since 2018.

For 2022, beyond the festival, we intend to launch a multinational study to assess the games in various contexts, and enrich them on this basis.

This page documents the evolution of the content.

- 1.0   Jan 05   Initial version submitted
- 1.1   Jan 10   Financial part updated to ledger format, Versioning page added, distribution of the team budget carried over from April to January, clarification on team and association in charge parts, various titles revised, explanatory links and partners added, typos corrected
- 1.2   13.01   PPL licence added, Didactics and dissemination page added