ORION
open science

Deliverable D3.10
Multi-stakeholders Citizen Science projects

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 741527 and runs from May 2017 to September 2021.

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Contents

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Executive summary

Two Citizens Science proposals were granted 50.000 Eur within the remit of ORION WP3 on open experiments to develop life sciences research projects involving public participants' expertise. Science that makes me move (MDC, Berlin) is an epidemiological study involving school students' in assessing physical activity and sedentary behaviour in order to identify related lifestyle and environmental factors. Genigma (CRG, Barcelona) is a smartphone game for assembling 3D cancer genomes in a crowdsourced manner.

Disruptions caused by the COVID-19 pandemic resulted in the decision of the ORION Steering Committee to extend the timelines of Genigma and SMOVE. This extension was necessary to adapt to remote working, organize virtual events and also allowed for a better integration of participants' expertise into the research projects.

The projects have provided an opportunity for all involved to learn more about Citizens Science. The scientific teams have been confronted with an innovative and unfamiliar methodology, which once professionally coordinated, has been acknowledged as enriching the scientific projects. The hosting organisations agreed on the need to resource and equip researchers adequately, due to the innovative the research methodology. Public participants, school students in SMOVE and varied audiences in Genigma, have praised the opportunity to get involved with scientific research and stated further interest in collaborating. Other ORION organisations are designing strategic activities to encourage wider uptake of Citizens Science projects.

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Introduction

The challenge the ORION consortium set in this task was to incentivize scientists from ORION partner organisations to look at their research through Citizen Science lenses and to co-design and implement real CS projects in the life science and biomedical fields. For this purpose, the ORION consortium ruled out the involvement of citizens as mere "research subjects" or "data sources" (e.g. as simple providers of samples or data, survey respondents, etc.) and called for making use of participants' expertise throughout the projects.

Two proposals were awarded funds after an evaluation against the call criteria of excellence, implementation and impact (as reported in D3.4).

"Science that makes me move" (SMOVE), MDC (Berlin)

The aim of SMOVE is to work together with school students (8th grade or higher, in the German education system that corresponds to 14 years old or higher) from Berlin and Brandenburg on an epidemiological study assessing students' physical activity and sedentary behaviour to identify related lifestyle and environmental factors based on the students' critical input. The students were introduced in class to the importance of an active lifestyle for health based on the current scientific evidence and together with SMOVE scientists they developed a questionnaire to assess potential factors that could influence physical activity and sedentary behaviour. The students then wore an activPAL accelerometer over a week for data collection. The activPAL is a small device that the students attach to their upper thigh to record movement; due to the position on the thigh it is especially sensitive to detect sedentary behaviour such as lying or sitting. After the data collection, the data was prepared for in-class analysis and interactive interpretation. Thus, the design of SMOVE allowed the students to actively contribute to the success of the project by providing original ideas and expertise at the beginning, during and at the end of the project.

Despite difficulties due to school closures during the course of the COVID-19 pandemic, the SMOVE project could include in the study 152 students from 12 classes from 9 schools in Berlin and 3 schools in Brandenburg (10 classes from 7 schools in Berlin, 2 classes from 2 schools in Potsdam, and 3 classes from schools in Brandenburg) between February 2020 and June 2021.

GENIGMA, CRG (Barcelona)

The main goal of Genigma is to develop a game for smartphones to engage citizens in genomic research. The game is conceived as an innovative approach for *assembling 3D cancer genomes* in a crowdsourced manner, helping to build a large dataset for the benefit of science and society as a whole. From the scientific point of view, this is a challenging goal. Genetics is what makes a cell behave and respond the way it does to treatments and stimuli. Everything is coded into their DNA: when to replicate, when to die, when to activate gene programs, and react to an external cue, etc. When researchers work with cancer cell lines, they interpret their discoveries at the light of a "genomic map", which tells them, among

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other things, where their study genes are located in the DNA of the cell. This map is what is known as a *genome reference sequence*. For most studies, researchers use a canonical human genome reference sequence to navigate through the genomic landscapes of the cells and interpret their results. These maps, in principle, should be free of these aforementioned errors, however, using these canonical maps would be like navigating the streets of a city using a 150-year-old map: the sea and the mountain delimit the city, but many neighbourhoods or streets have been created, expanded, or even removed. That map is not useful anymore! So, Genigma aims to use citizen science to build a tailored, and precise genomic map of the most used cancer cell lines, reflecting all these changes in their genetic landscape, using three-dimensional genomics.

Genigma will use citizen brain computing power to solve some of the most complex and exciting problems in biology and will be launched by the end of September 2021. If it succeeds, the specific reference genomes for the different types of cancer will be a valuable tool to better characterize how the genome works and to advance new treatments.

Fortunately, the Covid-pandemic did not deeply affect the project, because the lockdown measures were introduced when the co-created events had already been held. The pandemic did impact Genigma timeline as in person play test and a workshop originally planned to be held in Italy in collaboration with ANT could not take place and had to be adapted to on-line. COVID19-related human resources shortages also impacted the development of the project, yet the extra time offered to mitigate the impact of the pandemic had an overall positive effect in the project.

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Genigma

1. Project activities

The project officially started in January 2019 and until June 2021, Genigma performed many interesting activities in different areas: citizen participation, scientific knowledge, game development, and communication & networking.

Citizen participation

From the beginning of the project, ***more than 500 people*** have participated in several events, collaborating in the brainstorming for the design and in the testing of the beta versions.

- The project started with 3 co-creation events with teachers, artists, cancer patients, medical doctors, storytellers and gamers to incorporate the knowledge of people outside the Academy and add value to the project. Around 120 people participated in these events between January and April 2019. The results of these events were the basis for designing the Genigma game.
- In May 2019 there was a special event with gamers to test a first analogic prototype playtest during a CS Festival in Barcelona. 23 people participated in this session.

After that, many other playtests were organized to test the game in its different stages of development.

- In October 2019 the first digital prototype of the game was tested during the Open Day of the Biomedical Research Park (PRBB) in Barcelona (the building that hosts the CRG), with more than 150 people of all ages and professions participating. On this occasion, we filmed how players interacted with the screen to observe the movements of the players on the tablets and to understand the different strategies used to obtain the best score.

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- In November 2019 there was an event with genome researchers (12 people). The objective of this session was two-fold: on the one hand, to align the game dynamics with the needs of the research that will benefit from these results, and on the other hand, to start analysing the results of the games to work on the format and the information received. This data is stored in a CRG server and will become available once it has been analyzed after the public launch of the game.

- Between December 2019 and January 2020 the beta version of the game was presented to a group of participants of the co-creation sessions to collect their inputs about the game dynamics (30 people).

It took almost one year to improve the first beta version, which took into account all the feedback of the players.

- In January 2021 a new set of playtests were organized (4) with people of different profiles, ages and countries that contacted us through social networks to collaborate with the project. On this occasion, the new version of the game was tested. Among the participants there were teachers and high school students that showed a great interest in running the project in their class. Also, representatives of associations against cancer from Catalonia and Italy, as the Fondazione ANT Italia, ONLUS in Bologna, and the FERO Foundation in Barcelona, were interested in disseminating the project among cancer patients and their families.

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After those playtests, feedback from the players was collected and their suggestions were included in the game. In parallel, while the programmers were concluding the app development, the scientists analysed the data resulting from the games played. These tests were run on the non-cancerous GM12878 lymphoblastoid cell line. These cells have a genome with a normal set of chromosomes that does not divert from the reference genome. These tests were planned to check that the data obtained actually decipher the position of the different genes on the chromosomes as those are known.

The analysis revealed that players were able to rearrange DNA pieces correctly and that the game mechanism was working. However, scientists realised that more tests were needed to ensure the quality of the data because, as explained before, we need at least 40 players returning the same solution for each game to reach a consensus solution that we will take as valid, hence we decided to build larger test experiments with schools for this purpose.

- In April 2021, an on-line participation session was organized with more than 150 secondary school students from Catalonia and Italy. Those students were the first players to test cancer genomes (T47D line of breast cancer). In particular, they analysed chromosome 9, which is known to present re-arranged regions in this cancer cell type. Following the suggestion of the teachers, who wanted the students to spend an average of 20 hours on the project, it was decided to commission them proposals for a Genigma communication campaign, aimed at young people of the same age. The suggetions were so spectacular that they surprised the whole team. The students' proposals are now being considered for implementation in the next phase, the communication campain for the game launch (planned for September 2021).

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The scientific team decided to carry out two final tests to make decisions on the level of resolution of the DNA data to be provided to the players.

- In June 2021 Genigma was tested with 11 PhD and Postdoc volunteers of the Faculties of Physics and Genomics of the University of Bologna. This test continued with the analysis of the T47D cancer cells, this time focussing on reordering the fragments of chromosome 15 and found 4 regions, which may be implicated in translocations with other chromosomes, in particular chromosome 9.
  The opportunity to participate in these tests also attracted a group of Chilean university students who were supposed to participate in this event. Unfortunately, they were unable to make it because the University was closed due to the pandemic situation at that time in Chile.

- In July 2021, the last play test was run with a group of 90 international students that participated in the Barcelona International Youth Science Challenge, a two-week international excellence program that has been designed and developed with the aim of offering the participants a world-class experience by working in research projects. Unfortunatley, this event was cancelled after the first day because some students tested positive for Covid and the organisers, The Pedrera Fundation, rejected the possibility of doing it online. The Genigma team is hopefull that a new play test would be organized in September.

Dissemination activities

Twitter and Facebook accounts (both Genigma3D) have been created and they have 500 and 240 followers respectively by the end of June 2021.

Two promotional videos have been produced for the project. One, focused on the game, aimed at a general public potentially interested in participating in the project (https://vimeo.com/529259717). The other (in preparation), will aim at explaining the research aspects of the project, motivating the players and making the work team visible.

El·lipse magazine, from the Barcelona Biomedical Research Park, published an article on the development of the 3 co-creation sessions in May 2019. The publication of this article in

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the early stages of the project contributed to disseminate the project among the scientific community of the PRBB and also to increase external visibility.

The team also presented Genigma at:

- November 2019. Jornadas #Dmasi2019 in Zaragoza (E. Broglio and Oriol Bartomeu, gamer who participated in the 3rd co-creation event. Talk, in person)
- September 2020. "ECSA 2020 conference" in Trieste (E. Broglio. E-poster)
- October 2020. "Knowledge for Change: A decade of Citizen Science 2020-2030 in support of the SDGs" Conference in Berlin (E. Broglio. Online Talk)
- November 2020 European Research Night in Barcelona (M. Martí Renom, J. Rodríguez, Talk)
- November 2020. European Research Night in Barcelona. "Round table: what is an effective scientific communication" (M. Di Stefano. Talk)
- December 2020. "Making Citizen Science - drivers, challenges and benefits?" organised by the Karolinska Institute in Stockholm (M. Di Stefano. Online Talk)
- December 2020. Genigma: a challenging project on genome research. Presentation for the CS community of the Barcelona Citizen Science Office in Barcelona (E. Broglio. Online Talk)
- March 2021. "Genigma. A citizen science project". Curs for students at the Curie Institute in Paris (M. Martí-Renom. Online talk)
- June 2021. "Future of Science Communication" Conference. Session Engaging the public in #science through dialogue & #co-creation (G.Lligadas. Online round table)
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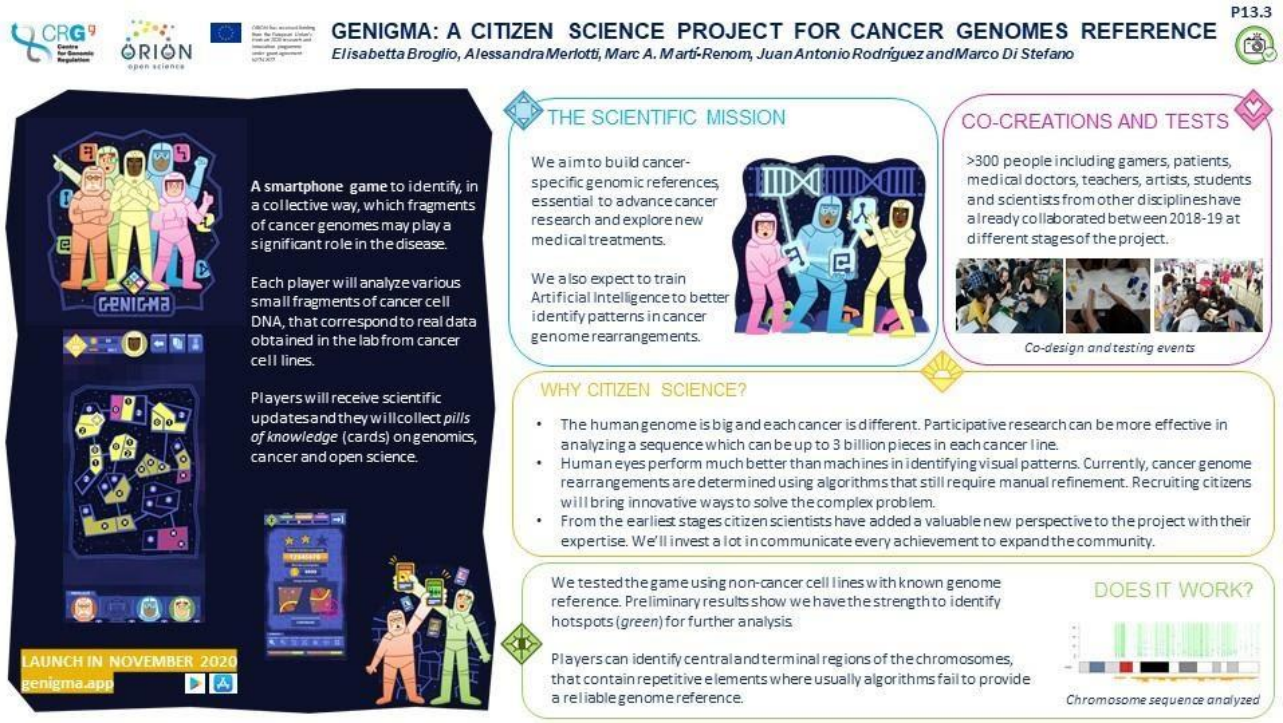

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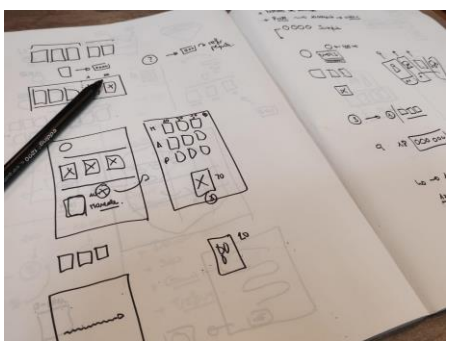
Two inspiring stories were published in the ORION website to disseminate Genigma co-creation experiences. One story is about the effect of co-creation events on scientists and how getting out of their comfort zone has brought them new perspectives and ideas for their project. The second one is about the impact on the citizens who have participated with ideas and suggestions in the project. In the case of students, it highlights the potential of the project with this group and how their ideas about communication with other young people have been a lever to think of an engagement strategy based on Instagram (in preparation, not yet published on the ORION website).

2. Main results achieved

Five cancer cell lines have been analysed: breast cancer (T47D), ovarian cancer (TOV21G), bone cancer (U2OS), leukaemia (KBM7), and cervical cancer (HeLa) by a wet lab team who also prepared the DNA. The selection of cell lines was based on the results of a survey conducted among CRG researchers to assess the most used cell lines in cancer research laboratories world-wide. The preliminary results include the chromosome contact maps of the 5 cancer cell lines in mitosis, which were analysed by the TADbit software to obtain contact maps. These results *per se* are already relevant to cancer research as such maps were not available so far. The open data will be shared in online repositories.

Before the final version, the game has gone through several beta versions. All of them were produced both for Iphone and Android, in 4 languages (Spanish, Catalan, English and Italian) and included most of the suggestions from players that participated in the playtests.

The game is a cyberspace adventure: the player is invited to join the team to decipher the cancer genome. Once it starts, the Captain of the mission assigns to every player one of the 4 teams (clans) that have to compete in the genome analysis trying to organise/order the pieces. Each piece of the game represents a real DNA fragment. The goal is to rearrange the pieces to get the highest score possible to identify how the genome has been rearranged in cancer cells after undergoing different mutations. There is no need for any previous knowledge to play: everybody can collaborate in finding those fragments that are not in the correct position in relation to healthy cells. The Tutorial the gamers find at the beginning of the game, explains that Gengima works collaboratively to find solutions arising from the consensus. The solution will arrive at achieving the maximum score in the same game played by many people.



The game offers the possibility to learn about open science, genomics, and cancer, and offers information and curiosities related to these branches of knowledge. Any time that

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players pass the record, they win a “card”. Genigma contains more than 200 “pills of science” to stimulate the interest in science and reward players for their time and dedication.

A messaging system has also been designed through which players are notified of the winning clan of the week and of the main scientific results obtained on the cell line under investigation (important regions discovered, analysis of one chromosome completed, etc). The player is redirected to the website of the game (genigmagame.app/resultados) to discover the scientific figure that illustrates the main results of the week.
A website was created to explain the project and disseminate the events: http://genigma.app. This website, in 4 languages, includes a blog with more than 30 posts, used to describe the development of the project step by step (*https://genigma.app/en/blog/).*

A special website focussing exclusively on the game has also been developed, which includes a space for displaying the results obtained by the players. Results will be uploaded on a weekly basis by the scientists, so that participants get feedback. (http://genigmagame.app/)

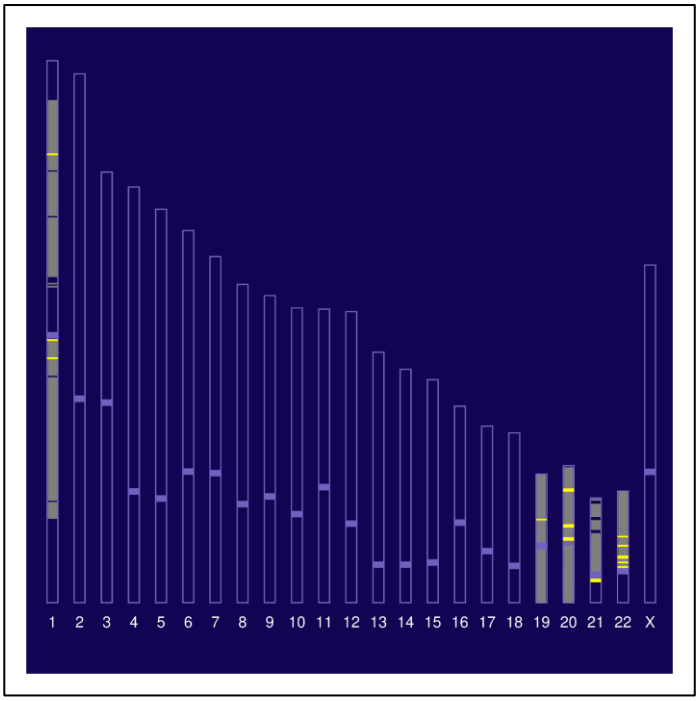

Figure 1: A karyogram showing the regions that were used to play in the first playtests, using a non-cancer cell line (GM12878). Chromosomes are represented schematically as rectangles, including all autosomes from 1 to 22 and the sexual chromosome X. For chromosome Y, the Hi-C technique doesn’t provide enough information to be used for our project. Chromosomes used for the playtests are (partially) filled with colors: the reddish (bluish) the filling the closer (farther) is the represented chromosome region to be solved. Yellow lines mark *Eureka* regions in which the score provided by the players exceeds the one one expects from the reference genome known using bioinformatics algorithms and currently used in the scientific labs. Identifying *Eureka* regions is one of the result we obtain from the Genigma App.

The analysis on GM12878 cells revealed that players were able to rearrange DNA pieces correctly and that the game mechanism was working. In Figure 1 above, we have the representation of real Genigma results, derived from the test we ran on GM12878 cells between January 2020 and January 2021. The figure depicts a schematic representation of the 23 chromosomes of the human genome (excluding chromosome Y which is usually poor in data), aligned vertically and numerically ordered. Those that are filled with horizontal bars show the chromosomes that have been used for the playtest (chromosome 1, 19, 20, 21, and 22), with the yellow horizontal bars indicating a genomic region where players have achieved a higher score than expected, what we have named as “*Eureka regions*”. Identifying these regions is one of the objective of Genigma, as it will tell the researchers where are the particular variations (cancer translocations) that our citizen players are finding

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for us. The *Eureka* regions found in the GM12878 cell line may be due to the presence of repetitive regions, which lead to bad definition of the reference sequence.

The tests of the Genigma app also revealed the presence of several regions of the T47D cells genome whose sequence differs from the reference genome of healthy cells. Interestingly, these regions, which have been identified by the players with a consensus of at least 3 participants, include pericentromeric and telomeric regions of chromosomes 9, 7, 15, and 17. These results are promising because they may relate to the mechanism of chromosome break and repair of centromeric regions which has been reported (*Barra, V. & Fachinetti, D., Nat. Comms. (2018)*) to be at the origin of several diseases, including cancer. Therefore, properly annotating these regions will already be useful for the scientific community. As shown in Figure 2, players from the latest test have identified *Eureka* regions in 4/4 of the chromosomes from the T47D cancer cell line that was used for the test.

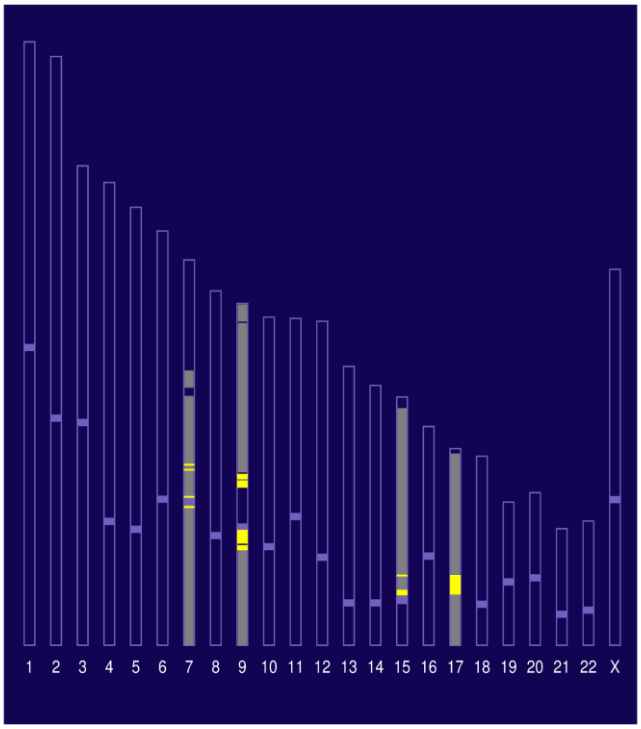

Figure 2: The karyogram depicting the results of playtests using T47D cancer cell lines. The color scheme is the same as in Figure 1.

Data produced so far in Genigma includes the following:

- Hi-C experiments on 5 cancer cell lines and the in-house scripts for bioinformatics analysis (5Tb of raw and processed data) are stored in the CNAG/CRG cluster. At completion of the scientific project, raw (.FASTQ files) and processed files will be uploaded in the public repository Gene Expression Omnibus (GEO).
- The preliminary results obtained from the playtests (200Mb of data) are stored in the computers of the Marti-Renom group at CNAG/CRG. All data will be shared with the scientific community in later stages of the project via the CRG server.
- The scripts for bioinformatics analysis developed in the project are stored in the private Github repository (https://github.com/MarcoDiS/Genigma/). This page will open to the public at completion of the project.

3. Deviations

A few months after the start of the project, the company originally consulted to develop the game closed down. This unforeseen and unfortunate event did not affect the project, as the Genigma team decided to keep the principles on consensus and scoring mechanisms into the game to tackle the scientific questions.

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Originally, the project plan was to finish in November 2020. However, due to the COVID-19 pandemic, it could be extended until September 2021.This extension allowed the Genigma team to adjust the game much more to the comments and suggestions of all the stakeholders involved in the co-creations and playtests.

The face-to-face playtests events had to be reorganised due to the pandemic. However, the online version allowed same results - to collect suggestions from participants and identify bugs in the app for the team to correct.

4. Use of resources

The ORION Citizen Science fund (50.000 €) covered all the costs of the co-creation events; the game design, development, illustration and merchandising; website design and domain, video, text corrections and Genigma Trademark registration. Costs covered by other means beyond the ORION ORION CS fund were: CS facilitator wage (CRG); sequencing services (10.000 €), the scientists' salary (part-time), and access to computational nodes to prepare the data for the game and to analyze the results (CRG Structural Genomics Lab)

The planned expenses were mostly in line with reality. Costs associated with travelling, which were not used due to COVID-19, were repurposed to cover other needs of Genigma project. The budget made it possible to meet all the objectives and even more.

5. Interactions with ORION and beyond

Along this ORION task and the development of the Genigma project, the ORION team at CRG collaborated with all ORION partners, and more intensively with some of them in very specific Genigma actions.

Together with all ORION partners, CRG was involved in the design the CS call for proposals, defining the evaluation criteria and comissioning the evaluation of the projects. With VA the collaboration revolved around communication activities, such as newsletters and the inspiring stories. Genigma team collaborated with CRECIM to prepare the evaluation tools (questionnaires for participants) and coordinate the interviews to the scientists and the CS facilitator. The collaboration with ANT was focussed on creating bridges with patients. They were invited to participate in the 2nd co-creation event, and an event was jointly organised in Italy to raise citizens' interet in the project. This collaboration also included the review of the dissemination content of the game cards, the Italian version of the app, and the co-organisation of a big play test with Italian secondary schools.

Collaboration with other EU Projects:

- Genigma along with seven other citizen science projects from Spain, Portugal and Italy were selected to take part in the "NEWSERA Academic Scientists Lab". The Lab is held digitally and consists of co-creation workshops which were designed to help expand the uptake of the projects within academic communities.

  The workshop held in March 2021 highlighted several important opportunities for clarifying the benefits of Genigma to academic research by using examples of data

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that have been collected through the app's development. The participants also raised the need to use specific strategies to help researchers understand the value of this new approach to data analysis, as citizen science is currently not very widespread in the biomedical field. Link to the news in the ORION page.

- Collaboration with IIIA (Institute of Research in Artificial Intelligence) of Barcelona and the UE Project Decidim4CS, a digital platform for participatory citizen science. It allows citizen scientists to propose ideas, comment and vote on them. This platform constitutes the deliberation technology used for the Crowd4SDG project that aims to use citizen science to track progress towards sustainable development goals. Genima was uploaded there in July 2021 and will receive the feedback of the citizens to improve further versions of the game.
- We established a collaboration to dig deeper into the scientific branch of Genigma with the Department of Physics and Astronomy from University of Bologna (Italy). A PhD student (Alessandra Merlotti) came to visit the Structural Genomics lab and developed some of the key mathematical algorithms behind the Genigma game. Eventually, the outputs of this research internship were incorporated into her PhD thesis as a chapter. As stated earlier in the present document, she became a part of the Genigma team.

Once ORION is over, there are plans to continue collaborating with project partners in the dissemination of the game and eventual organisation of events in their respective countries.

6. Impact

The project has had a high impact in different areas.

Impact on the scientific team

The scientific team has been confronted with an innovative and unfamiliar methodology. For the first time, they have worked collaboratively with people outside the academic world and have been impacted by the ideas and proposals that have come from the public. The words of one of the inspiring stories published by ORION are very informative about this aspect:

"*By assembling people with different interests and expertise during co-creation events, it was possible to see the Genigma project from a completely different point of view which was incredibly valuable to our scientific team. I was also invited as a speaker in two international events to explain my experience in Genigma. In both events, I discussed my role in the project and had the opportunity to inspire young scientists towards a Citizen Science experience. Finally, the playtests with schools and young researchers have also been a source of inspiration for me. The enthusiasm of the students for Genigma and their idea of communicating and promoting the project were really unexpected for us. We are extremely happy with how enthusiastically they received the project and science behind it and how creatively they responded to Genigma", says Marco Di Stefano, co-Principal Investigator of the project*."

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The other co-Principal Investigator of the project, Juan Antonio Rodríguez says: "*I have the feeling that we should popularise this way of doing science to the rest of the scientific community. By co-creation workshops and active participation of a varied audience it is possible to get a unique perspective on scientific problems that otherwise is not possible*".

Finally, Marc A. Marti-Renom (head of the Structural Genomics Lab at CNAG-CRG) adds: *"Genigma has been special for many reasons. However, I would highlight one aspect: it forced us to think out-of-the-box and accept input that we would have never sought otherwise. This is clearly a learning process I will take with me."*

Impact on the public participants

Citizens have participated in different phases of the project, from co-creation sessions to playtests. Together with the CRECIM team we elaborated a post-event questionnaire to collect some impressions from the public. In general, there was a high level of satisfaction among all participants and many of them expressed their willingness to continue collaborating with Genigma after its launch.

Some sentences from the questionnaires with students and general public:

"It was great to be able to actively participate in scientific research as an ordinary citizen." Student

"The students responded to Genigma's proposal with incredible enthusiasm at the idea of doing something really useful and, even those who usually lack motivation, gave their best." Teacher

"The groups of students competed to amaze us and really tried to imagine how best to promote the project among their peers." Teacher

"The CRG should invite everyone to devote even just a small part of their free time to Genigma" . Participant

Impact on the Institution (CRG)

The project has helped to raise awareness about Citizens Science among CRG stakeholders. As such, Genigma successfully secured support by ARIMA Genomics, which offered a laboratory kit to perform Hi-C experiments in the laboratory. Additionally, the Structural Genomics Lab at CNAG-CRG provided funds for sequencing parts of the experiments, to make the genomes of five different cancer lines available to players, and pay for the salary of the researchers while working for the GENIGMA project.

Genigma has brought further insights on the citizen science methodology to the CRG. Our experience in CS (with Genigma and before with Stick out your Tongue) made us realise that there were further changes that needed to be carried out to adopt CS as a new research methodology at institutional level. In this sense, we had the opportunity to enrol in the H2020 project TIME4CS - Supporting sustainable institutional changes to promote citizen science in science and technology, which will allow us to implement institutional

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guidelines on CS, involve CRG's governance, offer general CS training to our researchers and raise awareness among our community.

Genigma has also brought new ideas for research. Co-creation has proved to be a good way to get fresh ideas for the project and, for our scientists, it was an amazing opportunity to get a unique perspective on the scientific problems posed.

The project has also contributed to increase the CRG visibility and reputation in the field of citizen science. Genigma has been presented at several national/international meetings, and co-creation events and playtests that have contributed to raise our profile in CS. Once the game is launched, the visibility will notably increase, as we are planning different dissemination actions to get as many players as possible, so that we can reach the scientific objectives of the project.

For more in-depth analysis of the starting point; insights and impact from the viewpoint of the participating Public Engagement Experts and researchers, and limitations of these Citizen Science initiatives, please go to Deliverable 5.4 Final Evaluation Report on Co-creation Initiatives.

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SMOVE

1. Project activities

During the preparatory phase, the SMOVE team developed questionnaires for students, their parents and teachers to capture established factors potentially associated with physical activity and sedentary behavior based on the questionnaires from the pilot study "[DEDIPAC Studie: Sitzendes Verhalten erforschen]" ("DEDIPAC study: Investigating sedentary behavior", https://www.frontiersin.org/articles/10.3389/fspor.2020.00093/full) within the Joint Programming Innitiative "A Healthy Diet for a Healthy Life" (JPI-HDHL) project Determinants of Diet and Physcial Activity Knowledge Hub (DEDIPAC KH). During the following field phase, the questionnaires for students were supplemented by additional questions developed by students in class in interaction with the scientists, i.e., questions ascertaining factors students deem valuable with respect to the analysis of the generated data on physical activity and sedentary behavior. In order to supplement and optimize the data output of the activPAL device, a diary was given to the students to record periods they did not wear the accelerometer as well as sleeping phases.

Standard operation procedures (SOPs) for conducting the field phase were developed, i.e., to define a study protocol with respect to the preparation of documents and accelerometers, data collection, data storage, data entry, etc.

A data management plan was developed and shared within ORION (available in ORION drive). To prepare the data collection with questionnaires and the accelerometers, a computer has been set up to prepare the documents (paper version) as well as to initialize the accelerometers and to download the collected measurement data. Servers in the MDC research network were set up for data entry and storage. An internal data infrastructure platform for study documentation, programmed using PEARL and MySQL, was developed for SMOVE to facilitate the planning and monitoring of the practical field phase as well as for data entry. Different tests regarding the accelerometer measurement and data processing were carried out.

The data protection plan was developed and submitted to the MDC data protection office on June 4th 2019. The documents for the ethical approval by the Charité – Universitätsmedizin Berlin, including a detailed study description, data protection measures and information documents for students and parents, were submitted on May 21st 2019 and the final approval was obtained on October 17th 2019.

The SMOVE project developed the following resources to raise the profile of the project in Berlin and Brandenburg and recruit schools to participate:

- A flyer to inform and engage students, teachers and parents
- An enquiries email address (smove@mdc-berlin.de)
- An article published on the MDC homepage (https://www.mdc-berlin.de/news/news/smove-brings-research-classroom)
- A website for the project (https://www.mdc-berlin.de/content/combining-school-education-scientific-practice) with its content updated regularly

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- Mailing campaign in August 2019 and December 2020 for schools in Berlin and Brandenburg in MDC's network (more than 440 addresses) containing a cover letter, study description, and SMOVE flyer
- Teachers information workshops (24/09/2019 & 09/02/2021)
- A participation agreement form, which required the formal permission of their respective school principals, sent to teachers who expressed interest to participate in SMOVE with one of their school classes

These communication activities were supported by in-kind contributions of MDC communications department as well as external experts. The costs of the flyer were covered by SMOVE funds.

Overall, 7 schools in Berlin (10 school classes, grade 8th and higher) and 2schools in Potsdam, Brandenburg (2 school classes, grade 8th and higher) returned the signed forms to the MDC and participated in the SMOVE project between February 2020 and June 2021. The 12 school classes comprised overall 223 students of whom 152 participated in SMOVE. The average response rate in the school classes was 74% and ranged between 50% and 89%.

During the field phase data collection occurred. For this purpose, participating schools' teachers received the informed consent forms for students and their parents, and also for teachers in Brandenburg, and the dates for the school visits were agreed. The practical field phase consisted of up to three school visits (Figure 1).

Figure 1. Practical field phase of SMOVE

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Between the first and the second school visit, students wore the accelerometers for seven full days and questionnaires were filled out by parents and teachers. Between the second and the third school visit, the students received an individual feedback on their personal results of the accelerometer measurement (Figure 2).

During the third visit to the school classes, the SMOVE team presented the class results including aggregated results on physical activity parameters and of the class questionnaire and discussed with the students about data analysis, interpretation and generalizability of the data and gave an outlook on the further SMOVE-related activities, i.e., on the joint data analysis on the total sample as well as on publication of the (anonymized) study data and results. The students and teachers had also the opportunity to provide feedback about their participation in SMOVE, which was overall very positive.

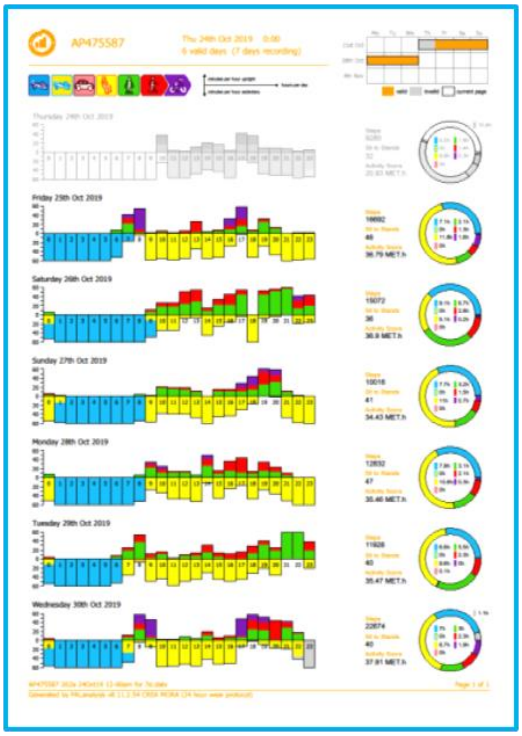

Figure 2. Example of individual results of accelerometer measurement (no actual results output)

2. Results

Due to the COVID-19 pandemic, the schooling situation changed throughout the field phase. From the 12 school classes, 2 school classes were visited before the pandemic, 7 school classes during the pandemic, but in full attendance (all students in class), 1 school class during lockdown (all schools closed, only homeschooling) and 2 school classes during the pandemic with partial attendance (students partially in class, partially in homeschooling) (Table 1).

COVID-19 pandemic phase	**School classes (N=12)**	
	n	%
Pre-pandemic	2	16.7
Pandemic: Full attendance	7	58.3
Pandemic: Second Lockdown	1	8.3
Pandemic: Partial attendance	2	16.7

Table 1. School situation during the field phase (February 2020-June 2021) according to the COVID-19 pandemic

During the first visit to the school classes, students were engaged in an interactive discussion in small groups to identify factors they consider as influence factors of their physical activity and sedentary behaviour. The collected influence factors were then

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discussed with the whole class and rated by the students regarding their importance (Figure 3, green dots).

Figure 3. Example of the result of the interactive discussion between students and MDC scientists on factors students considered as influence factors of their physical activity and sedentary behaviour.

The factors considered most important were then included in a class-specific questionnaire by the scientists if they were not already covered by the generic students' questionnaires. The question items developed by the students were often related to school (e.g. "time spent with homework", "bothered by amount of sitting in school", "feel exhausted after school") and social media (Table 2). Their friends' physical activity and sedentary behaviour was considered as potential influence factor for their own behaviour in five school classes. Other items considered as potential influence factors of physical activity and sedentary behaviour by the students comprise subjective factors such as motivation to be physically active, physical fitness and satisfaction with one's own body.

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Question items developed by students	N*
Time spent with homework (weekday/weekend-day)	9
Time spent with social media (weekday/weekend-day)	8
Bothered by the amount of sitting in school	7
Feel exhausted after school and homework	6
Feel physically active	6
My friends' sports and activity behaviour influences my own	5
Time constraint	4
Motivated to be physically active	4
Time spent with learning outside school	3
My hobbies result in me being more physically active	3
I can do the sport I want to do	3
Time spent with sports in the past 12 months (summer/winter)	2
Pet	2
More active during vacation than during school times	2
Satisfied with my body	1
Go to fitness center regularly	1
Attitude towards physical activity	1

Table 2. Question items ascertaining factors related to physical activity and sedentary behaviour developed by students. N* refers to the number of school classes where these items were included in the class-specific questionnaire (out of 12).

SMOVE scientists prepared a preliminary dataset (SMOVE 2020 dataset) with the data collected with the activPAL accelerometer devices from students from the first 8 school classes from 5 high schools in Berlin who participated in SMOVE between February and December 2020 (9th to 13th grade, n=107 students). From this dataset, data of 15 students were excluded due to incomplete activPAL records. The median age of participants in the SMOVE 2020 dataset was 16 years, with an age range from 14 to 19 years. An overview on the participants' sex distribution in the SMOVE 2020 dataset is shown in Table 3.

	Total (N=92)	
	n	%
Sex		
Boys	31	33.7
Girls	60	65.2
Diverse	1	1.1

Table 3. Study population of SMOVE database

Analysis of the aggregated data (Table 4) revealed long sitting hours of the students, with a median of 19.4 hours per day, while a limited time of standing (median 3.0 hours per day) and stepping (median 1.5 hours per day) was observed. The average step count per day ranged from 3,013 to 16,036 with a median step count of 7,707 steps per day. The median

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number of sit-to-stand-transitions per day was 56.4 (range 31.7 to 106.0). The median energy expenditure was 33.4 MET-hours per day (range 31.5 to 36.6).

	Total (N=92)
Sitting or lying, hours/day	
Min, Max	16.5, 21.5
Median (25th-75th percentile)	19.4 (18.5, 20.0)
Standing, hours/day	
Min, Max	1.7, 5.4
Median (25th-75th percentile)	3.0 (2.5, 3.7)
Stepping, hours/day	
Min, Max	0.6, 3.3
Median (25th-75th percentile)	1.5 (1.4, 2.0)
Step count/day	
Min, Max	3,013, 16,036
Median (25th-75th percentile)	7,707 (6,819, 9,500)
Sit-to-stand transitions/day	
Min, Max	31.7, 106.0
Median (25th-75th percentile)	56.4 (49.5, 67.1)
Energy expenditure, METh/day	
Min, Max	31.5, 36.6
Median (25th-75th percentile)	33.4 (33.1, 34.3)

Table 4. Parameters of physical activity and sedentary behavior in the SMOVE 2020 dataset

The time spent sitting or lying, on average, was highest on Sundays as compared to the rest of the week (Figure 4).

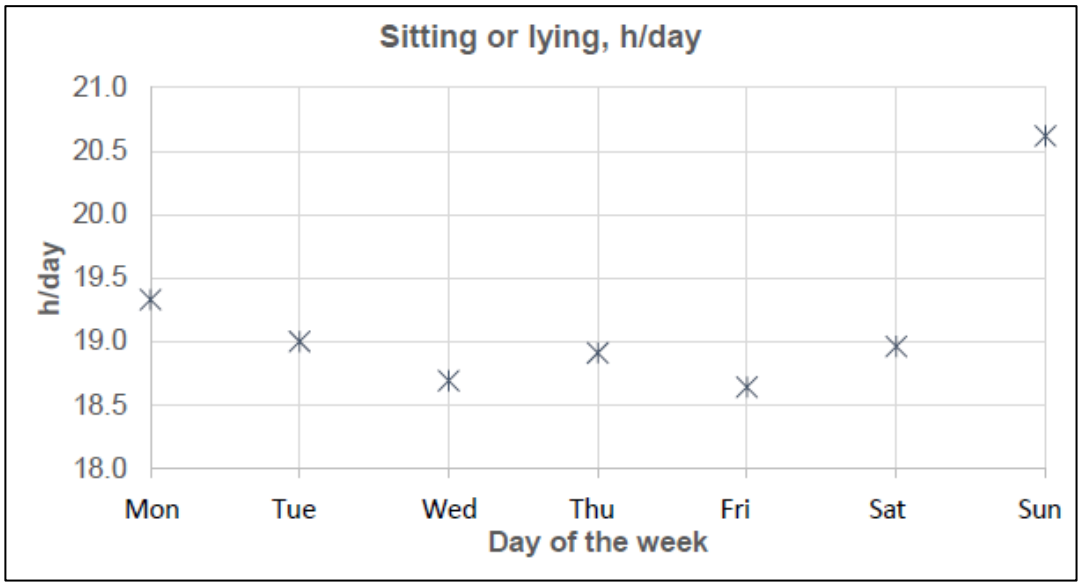

Figure 4. Average time spent sitting or lying, by weekdays in preliminary SMOVE 2020 dataset (n=92 students from 8 school classes)

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In the generic students' questionnaire, school and leisure time factors potentially related to physical activity and sedentary behaviour were ascertained. A descriptive analysis of the distribution of a selection of these factors, which have been investigated also in the pilot study (DEDIPAC study, https://www.frontiersin.org/articles/10.3389/fspor.2020.00093/full), are displayed in table 5.

	Total (n=92)	
	n	%
School-related factors		
Traffic safety around school, n (%)		
high	83	90.2
low	0	0.0
Missing	8	8.7
Allowed to use media devices, n (%)		
yes	29	31.5
no	54	58.7
Missing	8	8.7
Availability of play equipment, unrestricted, n (%)		
yes	50	54.3
no	33	35.9
Missing	8	8.7
Leisure time-related factors		
Neighborhood quality, n (%)		
high	47	51.1
middle	41	44.6
low	3	3.3
Presence of media device for personal use, n (%)		
yes	86	93.5
no	5	5.4
Rules concerning media use at home, n (%)		
yes	19	20.7
no	72	78.3
Encouragement for non-sedentary activity, n (%)		
yes	27	29.3
no	62	67.4
Missing	2	2.2

Table 5. School-related and leisure time-related factors in the SMOVE 2020 dataset

Of the 5 school classes in the SMOVE 2020 dataset, social media use was included as item in the questionnaire developed by the students in 4 school classes. The results from these questionnaires revealed high use of social media (median 2 hours) on weekdays and even higher on weekend days (median 3 hours, Table 6).

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Time spent for social media (min/day)	n=54 (from 4 classes)
School day	
Min, Max	10, 360
Median (25th-75th percentile)	120 (60, 180)
Weekend day	
Min, Max	10; 540
Median (25th-75th percentile)	180 (60, 240)

Table 6. Time spent with social media on weekdays and weekend days

Time constraints was raised as potential influence factor of physical activity and sedentary behaviour by students of 2 school classes (out of 5 classes in the SMOVE 2020 dataset). The distribution of answers in these 2 school classes (23 students) are shown in Figure 5.

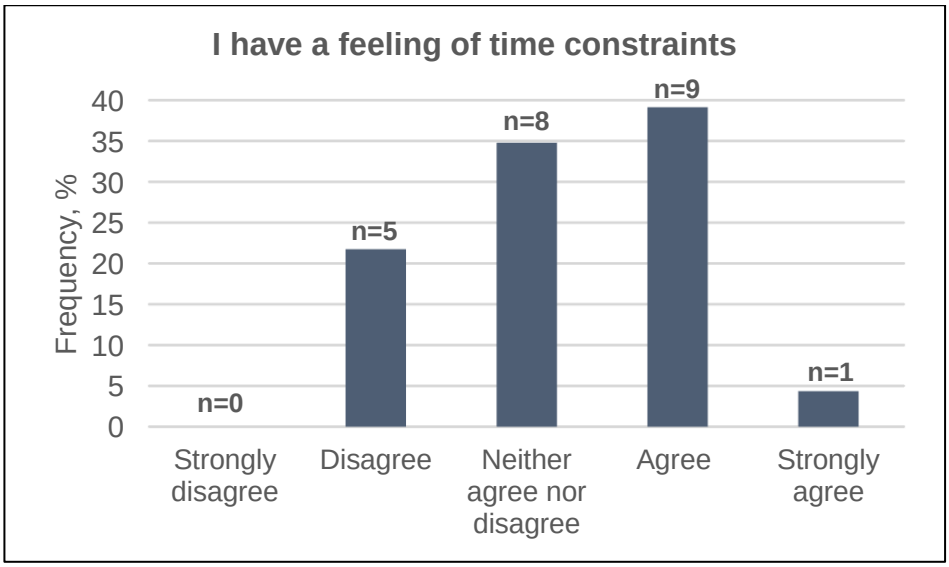

Figure 5. Distribution of answers to the question "I have a feeling of time constraints" from 2 school classes (23 students) of the SMOVE 2020 dataset.

The data entry of the total data gathered in all questionnaires (students', parents' and teachers' questionnaires) is currently ongoing (for quality assurance, the data entry is performed individually by two student assistants and disagreements are resolved before the preparation of the final dataset) and will be finalized in August 2021. After data cleaning and quality control procedures, we will then conduct the scientific analysis based on the final dataset, aiming at the investigation of determinants of physical activity and sedentary behavior of students in Berlin and Brandenburg. In addition, we will investigate the students' self-reported behavior changes during the COVID-19 pandemic. The aggregated results will be published on the SMOVE website https://www.mdc-berlin.de/content/combining-school-education-scientific-practice as well as in scientific journals. On the SMOVE website, we refer to the toolbox/instruction manual that is available upon request to support teachers as future citizen scientists to independently set up the SMOVE project with their school classes.

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3. Deviations

Due to the COVID-19 pandemic there were several school closures, which interrupted several times the practical field phase of SMOVE. The SMOVE team used these interruptions to update the questionnaires and logistics to be able to continue the practical field phase during the pandemic and include other scientifically meaningful results. Nevertheless, during 2021 the team encountered the problem that teachers were less willing to participate in the study and lost some school classes that already had signed the participation agreement. Therefore, despite the extension of the field phase, they could not include n=300 students in the study as originally planned, but only n=152 students.

The study documents (study exposé indicating name of participating schools; signed participation agreement forms; study information for parents and students; and the consent forms for parents and students) were submitted for approval to the Berlin school authority in November 2019 and the approval was received on December 18th 2019, in good accordance with the project plan. However, no scientific studies were permitted at schools in Brandenburg between March 2020 and December 2020 due to the COVID-19 pandemic, and hence the submission of all study documents to the Brandenburg school authority was delayed to early 2021 and approval to start with the study was received on May 4th 2021.

The practical field phase started in February 2020 with data collection completed in 2 school classes (33 students) before interruption due to school closures during the first COVID-19 lockdown in March 2020. During the time of this first lockdown, the SMOVE researchers updated the questionnaires and logistics (including a hygiene concept) to match the pandemic situation and to obtain scientifically meaningful results during the COVID-19 pandemic. In the updated version of the students', parents', and teachers' questionnaire, behavioural as well as socio-cultural and socio-economic changes due to the pandemic situation as well as the home-schooling situation are included as questionnaire items. The practical field phase re-started in September 2020 (after re-opening of schools in Berlin) with data collection in 6 school classes from September to December 2020 (77 students). A second interruption of the practical field phase occurred due to school closures during the second COVID-19 lockdown in December 2020. During the second lockdown, a fully contact-free (digital) solution (with accelerometers and all study documents mailed to students by the teacher and all physical visits replaced by videoconferences) was developed to continue the practical field phase of SMOVE and this solution was tested in one school class in January 2021. The practical field phase continued in Berlin and Brandenburg digitally or in presence (after May 2021) with further inclusion of 4 school classes (42 students). In total, 152 students in Berlin and Brandenburg participated in SMOVE.

4. Use of resources

From April 2019 till July 2021 we employed a study manager on the SMOVE budget. The exact personnel expenses are 59,107.78 Euros. In addition, we used the 1100 Euros allocated for communication (flyers) for the first year. Additional costs for communication (e.g. catering for the teachers' information event) were covered by MDC. Furthermore, the costs of 2 student assistants for the double data entry of the SMOVE questionnaires were covered by MDC.

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5. Interactions with ORION and beyond

The concept of SMOVE and the status of the preparatory phase was presented at the ORION 2nd Annual Meeting in Brno on May 6-7 2019. Later on, we presented SMOVE and preliminary results during the ORION 3rd Annual (online) Meeting on April 28th 2020 as well as during the ORION general assembly meeting on February 9th 2021 and the ORION community meeting on July 13th 2021. In addition, we presented SMOVE and preliminary results during the "Open Science Café" of the "Berlin Science Week" on November 4th 2020, which was also recorded and published (https://www.youtube.com/watch?v=Ce_ZHTaFds0). After the scientific analysis of the collected data, aiming at the investigation of determinants of physical activity and sedentary behavior in students in Berlin and Brandenburg, we will share these results and our experiences with the Citizen Science project SMOVE with the EU-LIFE community.

6. Impact

The project has had a high impact in different areas.

Impact on the scientific team

The questionnaire items developed by the students are of special interest because they were not part of the generic students' questionnaires and enrich the way SMOVE scientist at MDC investigate determinants of physical activity and sedentary behaviour. Whether these factors are indeed associated with the collected activity data will be analysed in the final dataset. For most of the school classes, the class-specific questionnaires co-developed together with the students covered items related to school and social media, as well as subjective factors such as motivation to be physically active, physical fitness and satisfaction with one's own body were named by the students as potential influence factors. SMOVE can also be considered as a proof-of-principle study to involve citizens directly in the questionnaire development. This concept will be integrated in future epidemiologic studies involving questionnaire design at MDC.

Impact on the public participants

SMOVE has broadened MDC's network of schools and teachers who may be open for further citizen science projects in the future.

Impact on the Institution (MDC)

Conducting the SMOVE project has helped raise awareness of citizen science in the MDC as well as more widely in the Helmholtz Association. The SMOVE project has been presented at the Citizen Science @Helmholtz meeting on March 25th 2019 and the "Wissenstransfer-Tagung" of the Helmholtz Association on December 9-10 2019 in Berlin. The SMOVE project together with the idea of citizen science was part of several presentations at MDC, including one given in May 2021 to the MDC executive board.

For more in-depth analysis of the starting point; insights and impact from the viewpoint of the participating Public Engagement Experts and researchers, and limitations of these Citizen Science initiatives, please go to Deliverable 5.4 Final Evaluation Report on Co-creation Initiatives.

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Conclusions

This ORION task sought to improve engagement in life science and biomedical research by encouraging scientists at ORION participating organisations to experience the value of involving citizens in scientific research. This objective has been achieved among the SMOVE and Genigma teams, the host organisations and their stakeholders, as explained in the impact sections in this report. In the case of MDC, the assembly of questionnaire items developed by the students showcases one of the benefits of this CS approach. In the case of CRG, participation in Genigma and another CS project in the past has brought about the realisation that developing institutional guidelines on CS, involving higher management and providing general CS training to CRG researchers is needed to support further CS projects.

Furthermore, this ORION task has reassured both host organisations that conducting citizen science projects where study participants are involved beyond data collection in the design and interpretation of the study requires more time and resources. As such, both CRG and MDC teams agreed that, since scientists are not familiar with the CS approach, having a CS facilitator is not only beneficial but necessary.

Lastly, ORION Citizens Science funding call has also helped benchmark CS awareness and practices at partner organisations. Accordingly, and in line with ORION project overarching goal of embedding open science at participating organisations, the Babraham Institute plans to include CS as a strategic ambition for their next strategy round as a result of this ORION task.

For more detailed conclusions regarding these Citizen Science projects and other co-creation initiatives undertaken at ORION, please consult ORION Deliverable 5.4 Final Evaluation Report on Co-creation Initiatives.

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