



ORION INSPIRING STORIES

Ideas & examples



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Introducing co-creation in fundamental life sciences?

Genigma is one of the two citizen science projects that has received funding from ORION. The project, managed by CNAG-CRG, is developing a game to explore the genomic alterations in cancer cells. The idea of the game is the result of a collaboration between the scientific team and a group of citizens who have participated in co-creation events previous to the game development.

Genigma will be a game for smartphones to investigate 3D genomic structures in cancer cells. The experiment was conceived as a project of extreme citizen science, and its purpose was to count on the collaboration of society in as many phases as possible and from the beginning through co-creation with key stakeholders. These stakeholders were all involved and have taken part in co-creation events to work out what was needed to produce a successful game. At its core, the game is a way to do participatory research to answer a scientific question rigorously. The aim of the participatory process was to incorporate the knowledge of people outside science and add value to the project from the very beginning.

At the start of the Genigma project, the scientists involved were very sceptical about how valid the contribution of outsiders to the field would be. To them, this was a research project and they were the researchers, it was hard to see how outside input could have been useful. This was not an unreasonable concern, research funding and time is a scarce resource, not to mention the whole purpose of this project was to help generate useful information for research into various forms of cancer. It didn't make sense to waste time or dilute their efforts.

Despite these initial concerns, the scientist involved in the Genigma project attended three co-creation workshops of Genigma together with citizen science experts to guide the process. The purpose was to

explain the project to different stakeholders and to get input for how it should be improved and developed further. Teachers, artists, patients, storytellers, communication experts, developers, gamers and researchers from different disciplines were invited to attend the co-creation workshops and were talking among them and present ideas in groups made up of people with different profiles.

The workshops were a resounding success, with 120 people involved. *"By assembling people with different interests and expertise, it was possible to see the Genigma project from a completely different point of view which was incredibly valuable to the scientific team"* says Marco Di Stefano, the co-PI of the project.

Citizens helped scientists to understand where some of their explanations were too complex or contained too much jargon. After the first workshop the researchers reformulate their presentation using their feedback and start using metaphors that come out from the brainstorming with artists. Gamers contributed to the project with fresh ideas and suggested essential elements to be taken into account for a compelling game.

The other co-PI 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”.

Oriol Bartumeu, physic, sound technician and gamer, one of the participants of the co-creation workshops said: *“It was great to be invited to participate in the initial brainstorming. That connect me again with science and I enjoyed a lot. It was a pleasure*

to contribute with my personal knowledge to such interesting project and now I feel like I’m part of this project too.”

Generating institutional change is one of the goals of the ORION project and to positively affect the opinions of researchers like this is a step on the road to creating real institutional change.

Introducing co-creation in fundamental life sciences?

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Encouraging co-creation through a funding call

A major goal of the ORION project was to open a funding call that encouraged different stakeholders to come together and present new and innovate ways to make science more accessible and participatory. The overall aim of this funding call was to support long-term collaboration between unusual/different stakeholders.

Designing a call in a co-creative manner incorporating the input of different stakeholders was a challenge. It was important to decide how to allocate funds as well as determine specific criteria for the kinds of projects that would be eligible. The key criteria for successful projects placed high demands on collaborative teams that included voices and expertise from different areas of society to produce knowledge and new ideas in a co-creative manner. This meant that the ORION partners had to place the same high demands on their approach to designing the call. By putting time and energy into assembling many different stakeholders to design the co-creation call, the ORION team thought that they would give the funding applications the best possible chance of creating a unique project with real potential for impact.

It was decided that the call would be designed in a multi-stakeholder workshop where a multidisciplinary group would meet and outline the objectives and parameters for the co-creation call. It was important that this group was diverse and included stakeholders from scientific research, policy, communications, public health and governance. Assembling this group was a challenge in itself, but coming to a consensus would be even harder.

During the workshop it was clear that the group had different opinions such as how to allocate the fund-

ing whether as a lump sum to one project or as a smaller grant to several projects. During the workshop the decision was to leave this open to applicants to decide how much funding they would need and award the funds based on the reviewers evaluation (scores). While differing opinions can lead to disagreement and argument, the tone of this stakeholder workshop was always collaborative and there was a strong sense that individuals were looking for common ground.

Ultimately, it was clear that the diversity of experience and perspective really enriched the discussion, for example the suggestion of allowing early career researchers to be able to apply rather than their supervisors. There were many different and varied suggestions of the types of projects that should be funded. However, there was a surprising level of consensus for what the co-creation call should not fund. The stakeholders expressed that typical public engagement projects, workshops and whitepapers should be avoided and that more than two groups should collaborate which is unusual for these types of projects. This was an important realisation and helped to truly lay the ground for novel ideas.

The co-creation workshop led to a successful call that received many excellent applications making it difficult to choose one to fund. Ultimately, two projects



received money. MELTIC, which stands for Ideas MELting pot for ITC and Health Science for Citizens in Small Communities. This project aims to improve the quality of life for EU citizens in the small communities of: La Palma del Condado Municipality in Huelva, Spain, Mirabello Municipality in Italy, Deta in Romania and Reguengos de Monsaraz in Portugal. By developing ICT health services with many different stakeholders including local residents, it was hoped that the solutions presented would provide real

improvements to the quality of life for residents. The MELTIC project produced a co-creation dossier for health and wellbeing related solutions for small and isolated communities, which have been compiled in a 100-ideas handbook. The second project to receive funding was VACCINE project, which aimed to educate young people about vaccination using a digital game. This was a collaboration between researchers, school children and a game developer and was launched in the summer of 2021.

Encouraging co-creation through a funding call

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Aligning an entire country to develop an Open Science action plan

Taking Open Science ideas and putting them into practice is a challenge. Even at institutional level there are many different stakeholders with different motivations and challenges who need to support Open Science initiatives. At a national level, these challenges are even greater with many institutions and governing bodies needing to find common ground. This is a challenge that has been taken up by the ORION project and the Czech partner CEITEC - Central European Institute of Technology, set about changing the way that their institution engaged in Open Science.

As CEITEC began to look at their own Open Science policies, they noticed that there was very little guidance from a national level. As an institution, this made it more difficult for them to produce a coherent Open Science strategy as there was always a question mark over how it would align on a national level, as well as with other institutions within the Czech Republic. The CEITEC team realised that other institutions within the Czech Republic would face the same issues trying to implement Open Science so they decided to tackle the problem head on.

They knew that there needed to be a Czech action plan for Open Science that could help to provide practical guidance for institutions within the country to implement Open Science by following an agreed upon set of guidelines. This had been actively discussed by the Research and Innovation Council for many years and a decision had been taken to make an action plan, although nothing had been agreed upon. The CEITEC team, together with the Open Access Initiative of the Association of Academy Libraries (AKVŠ) and Horizon 2020 Information Desk from Technology Centre of Academy of Science saw that the key stakeholders were waiting for the opportunity to communicate about the topic openly together. There were many reasons for this action, such as time commitments and differing levels of commitment to

Open Science in general. It seemed important that everyone who was impacted by Open Science or who could have an influence on a National Action Plan needed to meet and be allowed to speak about the topic.

The ORION National Stakeholder Workshop organized by CEITEC took place in 2018 in Prague. The workshop was attended by almost 50 participants representing funders, companies, scientists, policy makers, students, journalists and Open Science enthusiasts. It was a unique meeting to address selected topics of Open Science – Open Access, Open Research Data, Open Infrastructure, Citizen Science and Policies and Institutions.

The diversity of attendees from different stakeholder groups made this workshop logistically difficult to organize. Despite this difficulty, the workshop it was a resounding success. Thanks to the perseverance and organization from the CEITEC team, it was possible to use the national workshop to consolidate the views and needs of a wide variety of stakeholders and to draw a consensus. This consensus was then compiled and ultimately became the Action Plan for the Implementation of the National Strategy of the Czech Republic's Open Access to Scientific Information for 2017–2020.



The Czech Republic had these Action National Plan from 2019 till 2020, which helped drive changes on the national and institutional levels. From 2021, the next steps of Open Science actions in the Czech Republic have a place in the newly developed Strategy of Research and Innovation 2021+. The CEITEC team,

through the ORION project, helped develop these principles for the Czech Republic and is taking the recommendations to draft and implement them, including archiving data and defining the responsibilities for Open Science within the institution.

Aligning an entire country to develop an Open Science action plan

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Thinking differently through dialogue

To help open science up to a wider audience, ORION organised a number of Public Dialogues in the UK, Sweden, Germany and the Czech Republic. One purpose of the dialogues was to explore public attitudes to genome editing technology, which has revolutionized scientific research in the past decade and has the potential for broad societal impact.

The dialogues also aimed to understand how to engage the public on disruptive technologies and how public engagement strategies could vary between countries. Information about the potential use of the technology has led to a wide variety of different opinions and reactions from the public, which are not always based on scientific fact and gather empirical evidence to provide the basis communications strategies in the future. The purpose of the public dialogues was to bring researchers close to the public for an extended period of time where they could have structured conversations about genome editing in life sciences. It was crucial that these events were not lectures or seminars, but earnest two-way discussions where experts were able to understand the perspectives of the participants and vice versa.

The format of the public dialogues was first decided by consulting expert panels in different countries. These panels represented experts in various fields related to genome editing such as scientific research, ethics, research, law, medicine and patient groups. They helped to decide some of the national differences in the workshops while maintaining a recognisable core so that each workshop would generate results and insights that could be compared.

This consultative approach to open science and communication represents a departure from the way that science is normally communicated. There was a risk going into the dialogues that communication would not be two-way as intended, with people unable to take on board different perspectives. Therefore, the success of the entire project relied on overcoming

any barriers there might be to two-way communication and monitoring if people changed their perception over the course of the public dialogue.

After the dialogue the feedback was overwhelmingly positive. It was especially rewarding to hear that the experts that took part felt like they gained as much from the experience as the participants. Many expressed how they were surprised how interested people were in the topic and their research. They also explained how the experience encouraged them to look at their research in a different way and thoroughly consider aspects of genome editing that they were not exposed to on a daily basis.

"It does feedback into how I view my research portfolio... So, it does have a long-lasting effect on making you think and maybe change your longer-term research ambitions a little bit. As academics you can get a bit focused on the nitty-gritty of stuff that's only relevant to twelve people around the world but actually you need these events to remind you of some of the more important things that you are researching but maybe you should make more of a priority for research." – Participating scientist.

Similarly the participants of the public dialogue had a positive experience. The national groups, who were chosen to represent a cross-section of society, all came into the process with very different opinions and ideas of what genome editing meant. The public dialogues did not unify what the participants thought, and this was definitely not the purpose. However, most people expressed that their understanding had



shifted considerably in light of a better understanding of the scientific and societal implications. Most people agreed that genome editing had great potential to address issues related to health wellbeing and food production. However, many voiced caution over the use of genetic engineering for cosmetic heritable traits and in medicine for non-life-limiting conditions.

Overall, the public dialogues set out to achieve a two-way conversation between experts and the public and this was achieved. Whether or not such labour intensive projects can be done on a regular basis is hard to say. However, what is clear is that engagement methods that encourage dialogue and reflection should form a greater part of any scientific organization.

Thinking differently through dialogue

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Using Art as a way to level the playing field when discussing science

Can art help to explain scientific concepts? During the course of the ORION project, artist Emilia Tikka designed an art piece to represent a possible future scenario where it was possible to prevent aging using genome editing. The art piece was produced by Tikka while she was on a residency with the ORION partner, the Max Delbrück Center for Molecular Medicine in Berlin. There she spent time in a molecular biology lab and developed the concept for her art piece titled “ÆON – Trajectories of Longevity and CRISPR.”

The ÆON art piece illustrates a couple, who in the past as young adults, had made opposite choices to use the rejuvenating technology which was based on genome editing, and now 60 years later has to face the consequences of this decision. The poetic story indicates how the possibility of so-called eternal life challenges us to face our own fears about loss and the threshold of death. By illustrating these two opposite worldviews, ÆON addresses societal dimensions of the idea of a prolonged lifespan, underlying significant philosophical questions about human life, death and afterlife.

The ÆON art has been used in several different ways, one of which was during public dialogues held by various ORION partners in four different countries in Europe; Czech republic, Germany, Sweden and the UK. The idea of the public dialogues was to understand attitudes of the public towards genome editing. The ÆON artwork was used as a “stimulus” to promote thinking and discussion of how genome editing could be used.

Fredrik Wermeling is an Assistant Professor at the Karolinska Institute in Stockholm. He is using CRISPR to develop a screening platform in his lab to help rapidly study areas such as inflammation, autoimmune disease and cancer immunotherapy. He was invit-

ed to attend as an expert to help answer questions and guide the discussion around genome editing and CRISPR.

In the beginning, Fredrik was sceptical about how useful an art piece could be when discussing complex scientific topics such as CRISPR. While he is a fan of art, he felt like the use of the ÆON art piece would have been more of a distraction than a helpful tool during the dialogue. He just didn't see how it could have been useful, after all, art can be very abstract and open to interpretation whereas the science of genome editing is detailed and well defined.

However, during the public dialogue in Stockholm, there was a moment when Fredrik changed his mind. He realised that during the discussions, the ÆON art piece served as a useful point of reference. *“It was really useful because it meant that as the expert on the table, I didn't feel like I was talking down to anyone. It really made it feel like we were all equal in the discussion by using the art piece as a reference to bring forward questions, ideas and explanations.”* - Fredrik Wermeling.

The ÆON art piece was new to everyone at the public dialogue meaning that nobody had any prior knowl-



edge making it easier for people to discuss the complex subject of genome editing on a more equal level. When talking about the science behind genome editing on its own, Fredrik would always have the upper

hand as this was his area of expertise. However, when discussing a novel art installation, it becomes easier to discuss features of the art piece and introduce elements of science in a less obvious way.

Using Art as a way to level the playing field when discussing science

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Pollution project captures the imagination of primary school children

Talking about pollution on a global level is important, but for communities, it is equally important to understand and discuss how pollution is affecting their local environment. Protecting areas of local natural beauty is crucial in local communities, but this is difficult to achieve if people don't know about the environmental threats that their local area faces. Klára Vaculíková from Brno University technology designed a project to engage school classes who helped to monitor levels of the water pollutant phosphorus in the Moravský kras which is a spectacular natural limestone feature to the north of Brno. This project was funded as part of a co-creation call from the ORION partner South Moravian Centre for International Mobility, JCMM.

Two primary schools were engaged as part of their environmental protection classes. Although much of the Moravský kras is underground, the children traveled 2 different surface streams that fed into the karst so that they could collect data from different locations to be able to compare their results. The school classes went and performed simple colorimetric tests for phosphates which gave them a quantitative readout of the levels of pollution. The data collected not only helped the children learn but was useful for the researchers to see which of the streams was more polluted.

These results themselves would not have been as important to the children had they not been put into the proper context. Therefore, in their classes, they learned about where phosphorus and phosphates come from and how they influence the environment. This was then linked to their own well-being in terms of their local environment and food-chains.

Both the practical work and the appropriate supporting information were essential. The information that the children received allowed them to understand the data that they collected in terms affected them

personally. By sampling the streams in person, the information they learned in class took on a whole new significance and became something real and tangible rather than just another fact to remember.

The data collected by the children was extremely valuable as a teaching resource, however the project was planned so that the results could be used and interpreted by researchers. In fact, they appear in Klára Vaculíková's master's thesis. Engaging school children in research in this way adds an extra layer to the educational value of the project. There are not many school age children that can say they have been a part of a real scientific study.

The novelty and value of this project caught the attention of the national media and led to Klára Vaculíková and her thesis supervisor Assistant Professor Jitka Malá being interviewed on the prime-time news of Czech TV. The combination of several different stakeholders coming together for a project that benefits both academia and the local residents of Brno was a resounding success and it was important for the public to hear about it.



Pollution project captures the imagination of primary school children

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Engaging at every level for deep institutional change

Embedding institutional change is a challenging process that requires the buy-in from diverse groups of stakeholders. The Instituto de Salud Carlos III in Spain (Madrid) had the ambitious goal of embedding RRI right at the heart of the institution so that it would filter through into all of their research practices and projects.

The team at ISCIII realised that to implement real institutional change, they would need a founding set of guidelines and rules for how researchers were expected to implement RRI in the daily activities. The set about producing an RRI accreditation guide which clearly outlined all of the practical considerations to implement a strong and comparable RRI strategy.

ISCIII has associations with many institutions especially around Spain where ISCIII is the Flagship Institution for the Health Research Institutes. By including RRI principles in their accreditation guide, ISCIII wanted to promote and encourage the RRI practices in all of the accredited institutions. For this reason, the team included RRI themes in the official accreditation guide designed to maintain high standards across all of their collaborations.

The update of the accreditation guide came at the perfect moment as the ISCIII director expressed strong ambitions to align with the RRI strategy from the EU. It was a clear institutional alignment of the ISCIII with European RRI policy in order to make a fundamental, institutional change and include RRI at the heart of their institution.

However, there was a big challenge. RRI strategies and alignment with mandates from the EU can be quite a dry and political topic to communicate. This became a challenge as successful RRI requires lots of different stakeholder to be engaged, especially researchers. The ISCIII team realised that communication and lan-

guage used to talk about RRI needed to be adapted to give it broader appeal and ensure that it would be more widely adopted.

Within the scope of the ORION project, the team came up with the idea to host nationwide RRI Health Awards where members of all the researcher institutions could submit their entries to show how they were implementing RRI in their research. Participants were asked to submit video entries for the RRI Health Awards and the winner received funding to continue their work on RRI.

The competition received entries from all around Spain and the video entries provided the perfect vehicle to communicate about RRI. The videos were published and shared on social media helping to generate awareness about the RRI initiative.

The campaign by ISCIII ultimately led to widespread awareness of RRI in Spain. On the institutional level for ISCIII, the objectives for RRI were clearly outlined in the letter from the director in the annual report. This showed that not only were RRI goals widely accepted, but that there were concrete steps being taken at an institutional level to ensure that RRI was adopted at every level at ISCIII.

The RRI Prize was originally designed to be a one-off event. However, the success means that new editions of the prize are now being considered in the future, to continue growing the awareness of RRI and the accreditation offered by ISCIII.



The three winning projects were: *“Co-creation and citizen participation in the design of the PEN-SA Study of Prevention of Cognitive Impairment in People with Subjective Memory Complaints”* by the [Hospital del Mar Medical Research Institute](#) in Barcelona which stands out for its application of citizen participation in the design of a clinical trial. The initiative *“What really matters”* by the [Maimonides Bio-medical Research Institute of Cordoba](#), an innovative approach in the area of science education. The third winning project *“Promoting Responsible Conduct in*

Research: Development of Scientific Integrity Policies” by the [Fundación Jiménez Díaz University Hospital Health Research Institute](#) in Madrid which promotes responsible conduct in research and development of Scientific Integrity policies.

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Engaging at every level for deep institutional change

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What are the advantages of a podcast for communicating about Open Science?

The ORION Open Science Podcast started as a way to communicate with new audiences. For science to be open, information has to be accessible, and taking advantage of this unique audio medium was too good an opportunity to pass up. The podcast officially launched with episode one in 2019 and is now in its second season with the podcast hosts Luiza Bengtsson and Zoe Ingram who have deep dive discussions with experts on a wide variety of topics related to Open Science.

For being a relatively unexplored medium, podcasting brings a host of benefits for sharing information from experts. It is possible to use this format to deliver education and training material in a conversational way. The flexibility of being able to record from almost anywhere is especially useful and the format lends itself to discussion that brings out passion in speakers that is rarely seen in classical lectures.

However, the journey of starting and maintaining a high-quality podcast was not always smooth. From the very beginning, it was hard to know if anyone would listen and if people did listen, would they be researchers who were the target audience? Even when the podcast was launched, this was still unclear as the arduous process of building an audience was underway. At some points, the pressure to come up with episode ideas was also difficult.

One day the podcast team were sitting round a table trying to decide who they should interview for the next episode when an email landed in their inbox. It was from a researcher who wrote to let the team know that they listened to the podcast all the time and that they wanted to be a guest. It was the first piece of

fan mail for the podcast and a moment of realisation that their message was actually reaching people and that their hard work was paying off. The podcast has now been downloaded over 6400 times and the team now regularly receive suggestions for who they should interview. This demonstrates a healthy audience engagement and guarantees a steady stream of exciting episodes.

When the team looked back at their back catalogue of episodes, they noticed that their work could also tell us about current research in Open Science. They mapped the content of each podcast episode onto the Foster Open Science Taxonomy. They quickly got an interesting snapshot of the different subjects that they have covered, with a particular emphasis on Public Engagement and Science Communication. Interestingly, by comparing the podcast topics to the taxonomic chart, they realised that some of the episodes could not be characterised at all. They discovered that Preprints, Public Engagement and Open Science Training were not represented in the taxonomy which can now be updated. Open Science is such a fast-moving field that it's easy to fall behind. That is why it is crucial to take inspiration from the



work that we do in Open Science and take the effort to communicate it well to the research community.

The podcast has really emerged as much more than just a communication channel. The conversational style made up of many interviews has made it possible for

the team to grow an engaged network of experts who are sharing their deep knowledge on Open Science. The conversational style and the engagement from listeners means that they were also able to quickly become a part of this newly emerging network and connecting in many different ways.

What are the advantages of a podcast for communicating about Open Science?

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Online education tool helped researcher apply for funding

Online education is now more popular and essential than ever. Students are supplementing, and during the pandemic even replacing, their in-person education with online lectures and professionals are taking advantage of the convenience to learn new skills online. One example of an online course format is the MOOC which stands for Massive Open Online Course and has become popular among universities who put courses online for anyone to take, free of charge.

The ORION partner MDC, Max-Delbrück-Centre for Molecular Medicine in Berlin set up a MOOC to engage students on the topics of Open Access, Open Data, Science Communication and Public Engagement. The course is 6 modules long and was initially run over a 6-week period before being converted to a self-paced format. The goal behind the ORION MOOC for Open Science in the Life Sciences was to produce a mixed media course that would truly engage participants and teach them about Open Science in a practical way. At the end of the course, participants should have been able to think differently about their work and apply the facets of Open Science directly in their professional life.

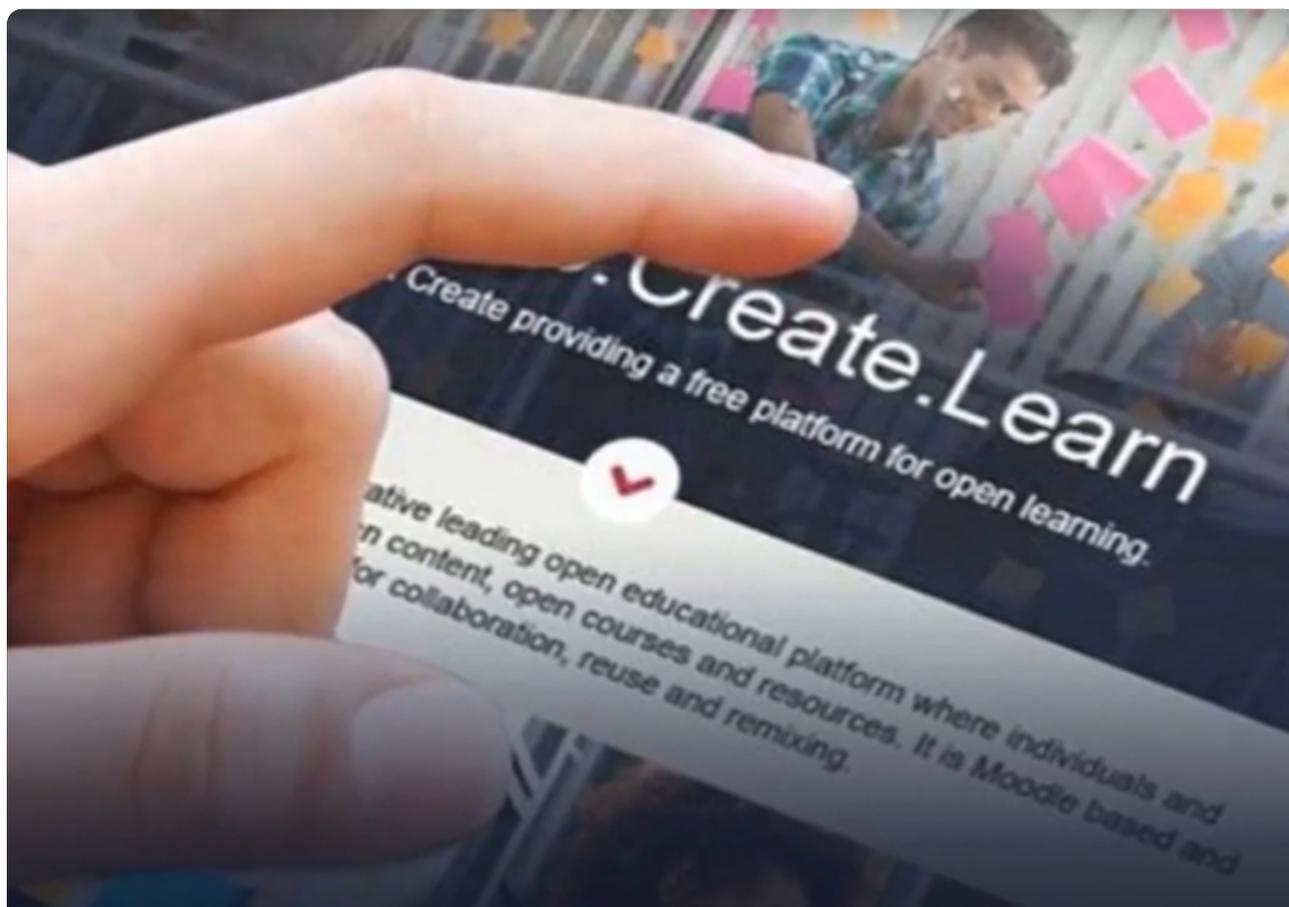
One of the participants on the MOOC was Deirdre Winrow who is a Researcher studying prostate cancer at Dublin City University. She originally signed up to participate in the hope of improving how she communicated about her research. *"I'm quite a young researcher and I don't have a lot of experience with communicating science to others so I just felt that the course might help me do that a bit better,"* explained Deirdre.

During her participation, she realised that there were ways in which the course content could immediately

impact her research. *"It seemed like every time there was a lesson in the course it was something I was trying to do at work,"* Deirdre remarked. However, there was one aspect of the course that was especially well timed for her. *"I did find it very useful because we were writing an application for a patient engagement initiative to bring our research out into the public, and to make it more accessible to patients and to people in general. So, I found the course really instructive for navigating my way through that."*

She also used the MOOC to help work out a Data Management plan for her current project, which was to develop a urine-based test for the detection of prostate cancer. With the data plan, she then finished writing the application for the Irish Research Council, IRC New Foundations award.

When Deirdre finally heard back from the Irish Research Council, IRC it was good news and her application had been successful. With that she was able to start the project and really put into practice what she had learned in the MOOC. Receiving the funding provided external validation for the content in the course and helped Deirdre to improve her skills and realise her vision of bringing her research to the public.



Course

ORION MOOC for Open Science in the Life Sciences



Online education tool helped researcher apply for funding

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MOOC website:

www.open.edu/openlearncreate/course/view.php?id=4633





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