

# **Deliverable 3.7**

Implementation of the public dialogue to inform CRG's research strategy



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### **Executive summary**

As part of the Horizon 2020 funded ORION (Open Responsible research and Innovation to further Outstanding kNowledge) project, the Centre for Genomic Regulation (CRG) conducted a public dialogue exercise to gather opinions from civil society and strategic stakeholders to explore how to take them into account for the development of the next CRG strategic plan for the period 2021-2024, so to align the plan with society's views, values and expectations. Internally, the aim of this exercise was also to promote a cultural change in the perception of open science throughout the CRG community. The public dialogue took place during the months of October and November 2020 and was held online due to the COVID-19 pandemic.

This dialogue, corresponding to ORION project task 3.2.2, has served as an instrument to support and encourage ORION overarching goal: embedding Open Science and Responsible Research and Innovation (RRI) principles in research funding and performing organisations (RFPOs). Ipsos MORI, a global market research organisation, was commissioned to implement the full dialogue project, which developed as three main steps: first, a 11-days online community with 30 citizens and 6 CRG scientists; then, a 3-hour workshop with 21 stakeholders and 10 CRG scientists; and finally, a 2,5-hours workshop, with a representation of both the citizens (13 participants) and the stakeholders (9 participants), and 5 scientists. During the debates, 6 research projects from the CRG were presented to the citizens and the stakeholders to show them more widely and deeply the science of the centre. These also served as the basis for debate.

An internal Advisory Group provided further oversight and governance. The project was originally designed by the task organisers in 2018 considering all the inputs from previous workshops with stakeholders and CRG staff conducted in the same year (reported in the second periodic technical report (Part B)), and was refined by Ipsos MORI in 2019. Materials shared with the participants during the events were co-designed together with the Advisory Group and CRG scientists, and were validated by the Advisory Group. An internal evaluation on this public dialogue is being carried out by ORION partner CRECIM. CRECIM's evaluation of this task is aligned with the overall evaluation strategy for the ORION project, which aims to provide evidence about its expected impact in terms of facilitating the behavioural, cultural and institutional changes required to embed Open Science and providing insight for improving ORION actions for promoting these changes. This evaluation is part of the deliverables of the ORION project (D5.4, Final evaluation report on co-experiences), which will be submitted separately. A brief summary of the most relevant results from this evaluation is included in the Section 3 of this report.

Ipsos MORI produced a full report gathering the process, observations, recommendations and conclusions of all the workshops conducted. A brief report was elaborated in order to make the reading more accessible. Moreover, a guideline to organise a public dialogue in a science research centre was also produced to ensure this exercise is reproducible at other centres, facilitating the process and disseminating the learnings to more beneficiaries. All these documents are available on the <u>ORION Open Science website</u>.

The key aims for this project were:





- 1. Understanding how the citizens and stakeholders value CRG's research, how they rate basic research vs applied research and pinpoint reasons for increasing investment in fundamental research.
- 2. Exploring how basic science should be funded considering public and private investments.
- 3. Identifying participants' concerns about CRG's research ethical and social implications.
- 4. Exploring insights for science communication and outreach activity design, while also finding an optimal CRG positioning.
- 5. Promoting a cultural change in the perception of open science throughout the CRG community.

Main conclusions and results:

**Conclusion 1 (Aim 1)**. Findings of this public dialogue reveal strong support among the citizens and the stakeholders towards the CRG, its values, the 6 research projects shared with them, its way of working and its commitment to Open Science. Research areas related to medical advances and health are particularly valued. The CRG covers different, complementary areas relevant for health, thereby eliciting strong public support. This information and other contextual data conclude that when science is related to health, it is of great interest to citizens. With regards to basic research, it can be concluded that the citizens not only perfectly understood the 6 research projects shared with them, but also consider it interesting, necessary and are in favour of funding it.

**Conclusion 2 (Aim 2).** The debates with the participants about funding bodies and strategies conclude that, when the project viability depends on finding funding, both the public and the private bodies are valid options. The citizens and the stakeholders support collaborations with private companies and the creation of start-ups under the CRG umbrella, but pointed out that transparency is needed, and that the profits from CRG patents and new companies should be reinvested in research. Participants also approve the idea of the CRG devoting efforts to patronage and philanthropy to fund its research.

**Conclusion 3 (Aim 3).** Citizens who participated in this public dialogue consider that scientists are trustworthy professionals. The citizens take for granted that codes of ethics with technical requirements are already in place and applied to ensure that neither morally nor ethically questionable actions are carried out. However, the citizens' trust in scientists does not prevent them from demanding an internal debate among the research community for the creation of action guidelines that go beyond the current regulations on ethics. During this public dialogue, it also came out from the citizens and stakeholders that scientists need to move beyond their professional persona and become more humanised.

**Conclusion 4 (Aim 4).** Over the course of this public dialogue, it has become clear that the citizens are interested in and open to debate on science. There is a key need to bring the two worlds –citizens and scientists– closer to each other and overcome prejudices on both sides. It is a responsibility of research institutions and researchers to disseminate science





and its findings. Some stakeholders go even further and claim it is an ethical duty to spread science. The citizens and stakeholders advocate for more presence of research topics in social and mass media, a clear communication from scientists and one-to-one conversations with them. Researchers need to talk to the public and engage in research not only as "experts" but also as "citizens" who are part of society.

**Conclusion 5 (Aim 5).** The researchers who participated in the dialogue were highly satisfied with the experience, pointing out that they found it very enriching and helpful in changing their perception of how the public sees them. They would recommend to other scientists to take part in events like this. They were surprised of the great interest of the people about very basic science topics and the science ecosystem. They also realised that citizens had fresh and different ways of looking at scientific problems, including a social point of view that the scientists must also consider. All these aspects contribute to make scientists the change in scientists' perceptions on how open research priorities should be to the citizens, after participating in the public dialogue. They now think that they have to be almost totally open to citizens and that citizens need to be involved in research decisions, whereas this openness was not that evident before taking part in the public dialogue.

As a final and additional success of this project, after an internal evaluation from the organisers and the Advisory Group, two key actions have been implemented in the new CRG strategy for the period 2021-2024 as a consequence of the recommendations resulted from this public dialogue: a series of regular talks about ethics for scientists and two more public dialogues about specific research topics of the centre. In addition to these new actions, a more humanised, personal and impactful public engagement strategy, with a strong focus in social media, has been also implemented. Definitely, the project has had an influence in the centre's higher management and governance, becoming more aligned with citizens' needs and demands.





## **1. Introduction**

As part of the Horizon 2020 funded ORION (Open Responsible research and Innovation to further Outstanding kNowledge) project, the Centre for Genomic Regulation (CRG) conducted a public dialogue to gather opinions from civil society and strategic stakeholders to explore how to take them into account for the development of the next CRG strategy for the period 2021-2024 better aligned with society's views, values and expectations. Internally, the aim of this exercise has also been to promote a cultural change in the perception of open science throughout the CRG community. The public dialogue took place during the months of October and November 2020 and was held online due to the COVID-19 pandemic.

The expected benefits of this dialogue project linked back to the overarching aims of the ORION project, which are:

- 1. Increasing the general knowledge of RRI and Open Science practices.
- 2. Contributing to changes in RFPOs governance settings that are consistent with Open Science and RRI.
- 3. Enriching and improving the quality of existing training on RRI and Open Science.

The public dialogues have contributed towards aim (1) by involving multiple actors, from the citizens to CRG scientists and higher management, as well as stakeholders such as ethics experts, journalists and science communicators, clinicians, representatives from the private industry, and so on. As a result of the bilateral dialogs and of having actively listened to all the voices of all the participants, the CRG has included two key actions its new CRG strategy for the period 2021-2024: a series of regular talks about ethics for scientists and two more public dialogues about specific research topics of the centre. In addition to these new actions, a more humanised, personal and impactful public engagement strategy, with a strong focus in social media, has been also implemented. Definitely, the project has had an influence in the centre's higher management and governance, becoming more aligned with citizens' needs and demands, contributing this way to the ORION aim (2).

The public dialogue methodology and lessons learnt have been shared in a guide to organise a public dialogue in a science research centre. This document was produced to ensure this exercise is reproducible at other centres, facilitating the process and disseminating the learnings to more beneficiaries, contributing thereby to the ORION aim (3). The guide is attached as appendix to this report.

The CRG's public dialogue helped to realise that external views can enrich the centre's strategy in a way that is more align with society needs by strongly engaging the citizens to basic science. On the other hand, it has been proved that scientists become more open to listen and to be involved and incorporate citizens and stakeholders' views and demands in their work after participating in this public dialogue, so this ORION project has been key in detecting and implementing this need.





# 2. Dialogue Objectives, Design and Delivery Method

### 2.1 Overview and timings

The table below outlines the key stages in this public dialogue project and the deviations to the estimated timeline, reported in D3.3 and reframed in the second periodic technical report (Part B), where they existed.

	Public dialogue stages	Estimated timeline	Actual timeline
1	Recruitment of Advisory Group members	Q1 2019	Q1 2019
2	Commission public dialogue facilitating organisation	Q1 2019	Q2 2019
3	Workshop with the Advisory Group to help design and scope the dialogue	Q3 2019	Q3 2019
4	Development of public dialogue stimulus material and other required resources	Q1 2020	Q2 2020
5	CRG scientists' engagement	Q1 2020	Q2 2020
6	Stakeholders' engagement and recruitment	Q1 2020	Q3 2020
7	Selection and recruitment of citizens	Q1 2020	Q3 2020
8	Preparing researchers	Q1 2020	Q3 2020
9	Public dialogue delivery – Citizens' workshop	Q1 2020	Q3 2020
10	Public dialogue delivery – Stakeholders' workshop	Q1 2020	Q3 2020
11	Public dialogue delivery – Final workshop	Q1 2020	Q3 2020
12	Reporting	Q2 2020	Q3 2020-Q1 2021
13	Elaboration of a guideline to organise a public dialogue on a research centre strategy	Q2 2020	Q3 2020-Q1 2021

### 2.2 Governance

An internal Advisory Group provided further oversight and governance. The project was originally designed by the task organisers in 2018 considering all the inputs from previous workshops with stakeholders and CRG staff conducted in the same year (reported in the second periodic technical report (Part B)), and was refined by Ipsos MORI in 2019. Materials shared with the public during the events were co-designed together with the Advisory Group and CRG scientists and were validated by the Advisory Group.

### 2.3 Objectives

The broad objectives throughout the public dialogue workshops have been to:





- Explore the different research areas conducted, the strategic decision-making processes of prioritising this research, and generate a dialogue on ethical and societal considerations around the CRG's research.
- Identify priorities, concerns, hopes and fears relating to fundamental research in general and in the CRG's work in particular.
- Identify options and explore opinions on CRG funding.
- Identify the content and messages for communications and outreach which will enable the public to engage further with all subjects.

The following specific aspects were covered:

- Observation of the public and stakeholders' reactions to the CRG research.
- Understanding how public and stakeholders rate basic research and pinpoint reasons for increasing investment in it: basic vs translational research.
- Identifying their interests in the CRG's research and concerns about its ethical and social implications.
- Exploration of insights for communication and activity design, while also finding an optimal CRG positioning.

### 2.4 Methodology

The initial approach considered in this public dialogue was:

- Stimulus development, scoping and framing. Together with the Advisory Group, 6 research projects were selected to present to the citizens and stakeholders. These also served as the basis for debate around the aspects at the heart of this public dialogue.
- **The Dialogue**. The initial plan was to conduct two substantive full-day workshops, one with stakeholders and one with the citizens (30 participants at each), followed by a half-day reconvened workshop involving 30 representatives, 15 from each of the previous workshops. All three workshops were to take place in Barcelona, Spain.
- Analysis and final summary report. A report was to be prepared incorporating all elements of the project that the CRG can use to convene and prompt wider discussion on how basic science and genomics can be open to public debate.

The eruption of the coronavirus pandemic made it necessary to modify the Dialogue methodology. The health and safety measures prevented groups of 30 people meeting, meaning the objectives had to be adapted to an online format.

Thus, the 3 face-to-face workshops of the public dialogue were replaced with a three-phase design, combining the following methodologies.

• **Stage 1**: 11-day online community with the citizens running from September 28th to October 13th, with 30 participants. Using the Ipsos-owned platform Ipsos Live, participants were able to analyse the materials designed and answer the questions put to them.





Additionally, three online sessions were held on October 1st, 5th and 7th in which the citizens, divided into groups of 5-6 people, interacted with the 6 researchers responsible for the case studies shown.

• **Stage 2**: 1 online workshop lasting 3h with stakeholders selected by the CRG held on October 20th, 2020.

With 21 stakeholders and 10 CRG researchers, debate groups on 4 main topics were established: basic research, funding, ethical debates and science communication.

• **Stage 3**: 1 online workshop lasting 2.5h with 13 citizens (stage 1), 9 participants from the stakeholders' workshop (stage 2) and 5 CRG researchers.

This workshop took place on November 4th, 2020 with the goal of obtaining feedback from the analysis of the information collected in the two previous stages, and gathering all ideas to be incorporated into the CRG's strategy.

#### 2.5 Selection and recruitment of participants

The design of the general public sample was as follows:

Variables	32 people were recruited and a total of 31 took part		
Location	Barcelona Madrid Seville Bilbao	8 8 8	
Sex	Men Women	16 16	
Age Groups	18 to 30 31 to 45 46 to 60 61 to 75	8 8 8 8	
Work Situation	Working Not working	20 12 (students, unemployed people, housewives and pensioners)	
Activity	Services Industry Agriculture and livestock Public administration	12 5 2 1	
Social Class (education level, occupation and income)	Upper class Middle class Upper middle class	8 16 8	
Nationality	Spanish Other	29 3	

#### Table 1. Sample profiles

In relation to this sample, it is important to observe that:





- It reflects the Spanish population but is not a statistically representative sample as occurs with the quantitative study samples.
- The switch to an online format allowed for the geographic scope of the sample to be broader than initially planned, previously including people residing in Barcelona only.

The stakeholders invited to the public dialogue were people with a professional relationship with the centre. Ultimately, a total of 22 took part with very diverse profiles:

- 4 journalists and science communicators
- 4 representatives from private companies
- 2 funders
- 3 bioethics' experts
- 3 clinicians
- 1 representative from a patients' association
- 3 researchers from different disciplines to biomedicine
- 2 experts in formal and informal science education

A total of 15 CRG researchers took part in the 3 stages online:

- 3 PhD students
- 2 Postdocs
- 3 Staff scientists
- 1 Group Leader
- 3 Programme Coordinators
- 2 Heads of Unit / Department
- 1 Director

#### 2.6 Case studies

The materials designed for the presentation of the projects (case studies) that shown some of the science carried out at the CRG consisted of a brief descriptive text along with an explanatory video presented by one of the researchers involved in the project.

The case studies chosen were:

- The discovery of something unexpected. Fundamental research revealed something unexpected: some genes became more active after death. CRG scientists developed a model / algorithm to predict the time since death from the analysis of the transcriptome of a few readily accessible tissues. This model could lead to potential application in forensic pathology, although it was not the initial aim of the study. Larger datasets more balanced across a wider post-mortem time interval will be required to assess the full potential of the approach.
- **Mucin and cystic fibrosis.** Mucin, the protein forming mucus, which is lining for example the respiratory and gastrointestinal tract, protects us from pathogens, chemicals, etc. CRG scientists have been studying these processes since several years. Now they're finding interesting molecular mechanisms that could be relevant to tackle important diseases related to mucin, such as cystic fibrosis, etc.





- Can any cell type be generated in the laboratory? In this project, together with Eugin, an assisted reproduction clinic, scientists aim to develop an in vitro system of human oogenesis. Such a system will allow to better understand human egg generation. This is in general a quite hard process to study, since in humans takes place at early stages of development, and obtaining samples is both ethically and legally controversial. Therefore, an in vitro system will be of great help to understand how human reproductive cells are generated. The availability of such systems could eventually lead to the in vitro generation of gametes for reproductive purposes.
- The super synthetic vaccine. The main goal of the project is to develop a chassis to produce vaccines and treat respiratory diseases specifically in lung tissue. Within the project, the scientists have followed two different approaches. First, the group has worked in the development of synthetic vaccines to decrease the incidence of mycoplasma related diseases in farm animals. In the second approach, the group is working in the development of an attenuated mycoplasma to deliver specific treatments against lung infectious diseases, in particular to ventilator-associated pneumonias.
- The what and the how matter in the genome. In this project, scientists aim to identify acquired epigenetic vulnerabilities in the DIPGs, a particularly aggressive brain tumour in children, for selective targeting of tumour cells. To directly transfer our results to clinics, scientists have teamed up with oncologist experts from the Sant Joan de Déu Barcelona Children's Hospital.
- The CRG and the coronavirus pandemic: on the CRG's contribution to the mass detection of coronavirus thanks to the PCR test. The CRG contributed to the mass detection of the SARS-CoV-2 during the COVID-19 pandemic thanks to the PCR, a widely used technique in biomedical research. On the other hand, basic research projects which aim to deeply know viruses similar to SARS-CoV-2 can lead to the development of a vaccine against these kind of viruses in a fast, efficient and safe way due to all the knowledge acquired before the emergence and expansion of an eventual disease.

As an introduction to the dialogue, a short introductory video about the CRG was also made.

All these materials are outputs that can be used in wider communications and public engagement actions, as well as in future public dialogues or similar projects.

The case studies are included in the Appendix 2 of the full Ipsos MORI report, which is attached to this report in the Appendix section.

#### 2.7 Reports and other outputs

Ipsos MORI produced a full report gathering the process, observations, recommendations and conclusions of all the workshops conducted. A brief report was elaborated in order to make the reading more accessible. Moreover, a guide to organise a public dialogue in a science research centre was also produced to ensure this exercise is reproducible at other centres, facilitating the process and disseminating the learnings to more beneficiaries. In addition, the case studies' materials can be used in wider public engagement activities. All these documents are attached and linked in the Appendix section of this report.





### 3. Evaluation

An internal evaluation on this public dialogue is being carried out by ORION partner CRECIM. CRECIM's evaluation of this task is aligned with the overall evaluation strategy for the ORION project, which aims to provide evidence about its expected impact in terms of facilitating the behavioural, cultural and institutional changes required to embed Open Science and providing insight for improving ORION actions for promoting these changes. This evaluation, which includes both a qualitative and a quantitative study, is part of the deliverables of the ORION project (D5.4, Final evaluation report on co-experiences), and its main results will be submitted separately.

In order to assess the impact of the public dialogue on participant CRG scientists, qualitative data was collected through interviews to three CRG researchers, and quantitative data was gathered by distributing online questionnaires to participants before and after the event. The sample of CRG researchers who responded both the questionnaire previous and the one after the event (n=4) is too small to consider it statistically representative, but some trends can be observed.

When asked about their experience as participants in the public dialogue, the three researchers interviewed valued it positively, highlighting the interaction with the general public and the interesting discussions:

"... it was a very good experience, especially because of the questions that people asked (...) for me it was very cool, especially for that, for the questions that were asked and to be able to explain how science really works, at the end (...) they only see the final part and don't know how it was to reach that point." (Researcher 1)

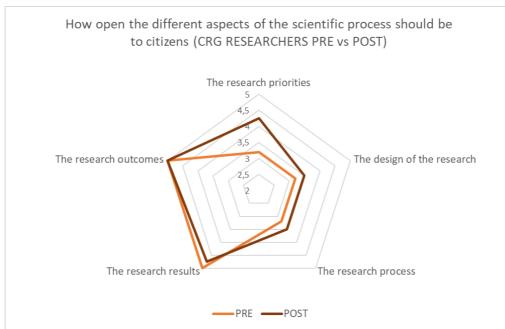
"... they were very interesting discussions for anyone. In fact, I would have open it to the entire scientific community, this discussion." (Researcher 2)

"... I think it is an opportunity to contact with people (...) and especially at the end, when we had the general discussion (...) they have very different ideas than we think, or they think of super different things, I mean, as a scientist I wouldn't have thought of (...) I think it is very enriching, and it has changed my perception of how others see us and how I feel about others..." (Researcher 3)

The quantitative study also points to a change of CRG researchers' perceptions, after participating in the public dialogue, about how open the different aspects of the scientific process should be to citizens (see *Figure 1*). Particularly, after the event they show a more positive view towards opening the research priorities, the design of the research and the research process.







*Figure 1.* Spider chart showing the opinions of CRG scientists before (PRE) and after (POST) having participated to the public dialogue about how open the different aspects of the scientific process should be to citizens (n=4). Extracted from a summary of the evaluation results of this public dialogue, elaborated by ORION partner CRECIM.

When asked specifically about the main things they gained or learnt from participating in the public dialogue, the interviewed CRG researchers mentioned several aspects, such as the realization that more communication with the citizens is necessary and the possibility of reflecting about their research by sharing different perspectives:

"... I learnt there is a lot of lack of knowledge and that much more intercommunication with the general public is lacking (...). Things that you already take for granted (...) then you see that people don't know" (Researcher 1)

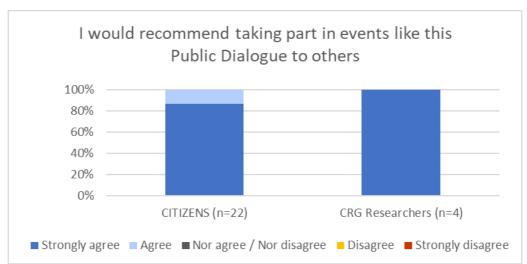
"... what I gained is asking myself questions that in my day-to-day I would never ask myself, and having the opportunity to see a problem from different perspectives (...) a little bit of reflection from a social point of view of the scientific community" (Researcher 2)

"... the final discussion, when we talked all of us, all these possibilities to do outreach (...) the brainstorming was awesome" (Researcher 3)

In terms of satisfaction, it is worth mentioning that both citizens and CRG researchers would mostly recommend taking part in exercises like this public dialogue (see *Figure 2*).







*Figure 2.* Bar diagram showing the level of agreement for participants to the public dialogue with the statement "I would recommend taking part in events like this public dialogue to others". Extracted from a summary of the evaluation results of this public dialogue, elaborated by ORION partner CRECIM.

The above mentioned are relevant and important results of this project and ORION itself, as they clearly show an impact of this public dialogue in RRI perceptions of CRG scientists towards a more open governance.

As a more qualitative evaluation by the organisers' team, we observed that, initially, the higher management of the CRG was guite closed to open the science of the centre to a lay audience. They considered their opinions in some topics would not be relevant or would not be appropriated due to the lack of expertise of the citizens participating to this exercise. However, little by little, after several detailed explanations and, mostly, after the Advisory Group workshop, their openness towards the project was raising and their scepticism diminishing. The crucial factor was their participation to the workshops of the public dialogue, in which the CRG director had an outstanding attitude towards the participants, both the citizens and the stakeholders, actively listening to them and valuing and validating their views and opinions. A face-to-face interview is planned by the ORION partner CRECIM to go more into detail on the impact that this exercise has had on CRG director' particular views on open science. The results of this interview will be included in the D5.4, Final evaluation report on co-experiences, elaborated by ORION partner CRECIM. For the moment, two new Open Science and RRI actions have been implemented in the upcoming CRG strategy, possibly meaning a significant impact of this public dialogue on the centre's higher management opinions about Open Science.





## 4. Conclusions

# Part I: Reflection on the findings of ORION public dialogue on CRG's research strategy

Findings of this Public Dialogue reveal strong support among the citizens and the stakeholders for the CRG, its values, the 6 research projects shared with them, its way of working and its commitment to Open Science.

The analysis of reactions to the CRG research areas and the case studies shown have effectively covered the objectives and allowed for more general conclusions to be drawn from this public dialogue. As previously indicated in this report, research areas related to medical advances and health are particularly valued. The CRG covers different, complementary areas relating to health, thereby eliciting strong public support. This information and other contextual data conclude that when science is related to health, it is of far greater interest to citizens.

In addition, participants particularly highlighted the CRG's contribution to the massive detection of coronavirus during the first wave of the virus and *The super synthetic vaccine*, as these are the projects most closely related to the current pandemic situation. Analysis of these two cases clearly shows that not only is it time to generate interest in science, but also in basic research. The synthetic vaccine is seen as a scientific breakthrough, an example of the importance of basic research.

With regards to basic research, it can be concluded that the citizens not only perfectly understood the 6 research projects shared with them, but also consider it necessary and are in favour of funding it. They ask for the communication of examples of potential future applications or even successful past examples of other research projects. Internal obstacles and fears among scientists themselves about communicating their basic research projects to the public were also observed. Fears and concerns about possible reactions of a public that, in a way, has been "excluded from" this dialogue.

This brings us to the general citizens' perception of the figure of the scientist. This public considers scientists to be trustworthy professionals. This public trust in scientists is clearly evident in the discussion of the case studies *Can any cell type be generated in the laboratory*?, and *The discovery of something unexpected*. Despite the ethical debate generated around the first case in particular (the topic is both contemporary and close to the people), the citizens made one thing very clear: their trust in scientists. The participants take for granted that codes of ethics with technical requirements are already in place and applied to ensure that neither morally nor ethically questionable actions are carried out.

However, the citizens' trust in scientists does not prevent them from demanding an internal debate for the creation of action guidelines that go beyond the current regulations (on ethics). It was also found that scientists need to move beyond their professional persona and become more humanised. Scientists need to talk to the public and engage in research not only from their scientific perspective but also as human beings who form part of society.

The citizens and stakeholders believe it is essential to obtain funding for science, including basic research, and that resources need to be allocated to it and all possible channels explored. When a project's viability depends on finding sources of funding, the citizens and





stakeholders consider both the public and the private initiative valid options. And, of course, they should not be mutually exclusive. When it comes to funding, the CRG still has many options available to explore and invest in.

In short, it can be concluded that the time for science is now. The citizens are more interested in science than ever, they are open to support basic research and are capable of understanding science when explained by a scientist in a one-to-one conversation. All the scientific research shown to the participants was accepted and awakened interest. This would suggest that whatever the centre's main line of research may be in the future, if it is properly explained, it will be well received.

To keep advancing in science, it is essential to generate awareness and interest in society. The basic premise is that funding is a must if scientific advances are to be made; and the more interest awoken in a specific area, the more funding will be obtained. It will be fundamental to hold an ongoing open dialogue with the citizens and stakeholders and to be present in their channels. Society must become our main ally.

# Part II: Reflection on the impact of the perception of open science throughout the CRG community

The CRG scientists that participated in the public dialogue were very satisfied with the experience, manifesting they found it very enriching and helpful in changing their perception of how the citizens see them. On the other hand, they were surprised about the interest the citizens had in their research topics and the interesting questions and ideas they made. Scientists realised that people had fresh and different ways of looking to scientific problems from a social point of view (especially regarding ethical issues) that the scientists must also consider and are not considering. Also, after the experience, they feel more encouraged to talk to the people about basic science, so it will be easier to engage them in future public engagement activities.

It is also relevant to mention that the senior scientists that took part in the public dialogue claimed that this exercise should have been open to all the CRG community. Beyond the logistic and technical difficulties of this suggestion, it is very significant the value they saw in this exercise to all the scientists. More specific opinions and quotes from the CRG scientists that participated in the public dialogue can be found in the full Ipsos MORI report attached to this document and also in the D5.4, Final evaluation report on co-experiences when submitted.

From the evaluation results, as shown in the previous section, it is very satisfactory and significant to see how CRG scientists changed their perception on how open should be the research priorities to the citizens after participating to the public dialogue. They now think that the research priorities' decisions have to be almost totally open to citizens, whereas before taking part in this exercise this openness was not that evident.

Finally, it is very relevant to mention that two key actions derived from this public dialogue will be included in the CRG next strategy: regular talks about ethics and two more public dialogues about specific research topics of the CRG. In addition to these new actions, a more humanised, personal and impactful public engagement strategy, with a strong focus





in social media, has been also implemented. Definitely, the project has had an influence in the centre's higher management and governance, becoming more aligned with citizens' needs and demands.

Considering the experiences learnt with this exercise and the results exposed in this document, it can be concluded that the public dialogue is a very appropriate and efficient tool to inform a research centre's strategy by embedding Open Science and Responsible Research and Innovation (RRI) principles and to make a strong impact on scientists about the need to listen to citizens' and stakeholders' opinions about their research.

### Annexes: Ipsos MORI full report, executive summary and guide

The executive summary of the full report and the guide to organise a public dialogue in a science research centre prepared by the company Ipsos MORI are included here. The full report by Ipsos MORI is available on the <u>ORION website on this page</u>.



# A PUBLIC DIALOGUE ON THE RESEARCH STRATEGY AT CRG: PERCEPTIONS FROM THE CITIZENS AND STAKEHOLDERS

# **Executive Summary**

January 2021



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The new CRG strategy will have your genes. A big thanks to you all.

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# 1. Introduction, Objectives and Methodology

This public dialogue (PD hereinafter) is positioned within the framework of the EUfunded ORION project (**O**pen **R**esponsible research and **I**nnovation to further **O**utstanding k**N**owledge). Its fundamental goals are:

- Firstly, to take the opinions of civil society and strategic stakeholders into account for the development of a CRG research and public engagement strategy better aligned with society's views, values and expectations.
- Internally, the aim of this exercise has also been to promote a cultural change in the perception of open science throughout the CRG community.

The following specific aspects have been covered:

- Observation of the public and stakeholders' reactions to the CRG research.
- Understanding how public and stakeholders rate basic research and pinpoint reasons for increasing investment in it: basic vs translational research.
- Identifying their interests in the CRG's research and concerns about its ethical and social implications.
- Exploration of insights for communication and activity design, while also finding an optimal CRG positioning.

With a view to achieving the aforementioned goals, a public dialogue (PD) was conducted. As defined in the Sciencewise Guiding Principles, a **public dialogue is a process during which members of the public interact with scientists, stakeholders and policy makers** to deliberate on issues relevant to future policy decisions. It enables constructive conversations amongst diverse groups of citizens on topics which are often complex or controversial.

The initial approach used in this PD was:

- 1. **Stimulus development, scoping and framing**. 6 research projects were selected to present to the public and stakeholders. These also served as the basis for debate around the aspects at the heart of this PD.
- The Dialogue. The initial plan was to conduct two substantive full-day workshops, one with stakeholders and one with the public (30 participants at each), followed by a half-day reconvened workshop involving 30 representatives, 15 from each of the previous workshops. All three workshops were to take place in Barcelona, Spain.

**However**, the eruption of the coronavirus pandemic at the end of phase 2 made it necessary to modify the Dialogue methodology. Thus, the 3 face-to-face workshops of the PD were substituted by a design in three stages, combining the following methodologies.

**Stage 1**: **11-day online community with the general public** that took place from September 28<sup>th</sup> to October 13<sup>th</sup>, with 30 participants. Using the Ipsosowned platform Ipsos Live, participants were able to analyse the materials designed and answer the questions put to them.

Additionally, **three online sessions** were held on October 1st, 5th and 7th in which the public, divided into groups of 5-6 people, interacted with the 6 researchers responsible for the case studies shown.



**Stage 2**: **1 online workshop lasting 3h with stakeholders** selected by the CRG held on October 20<sup>th</sup>, 2020. With 21 stakeholders and 10 CRG researchers, debate groups on 4 main topics were established: basic research, funding, ethical and moral debates, and science communication.

# Stage 3: 1 online workshop lasting 2.5h with 13 participants from the general public (stage1), 9 participants from the stakeholders' workshop (stage 2) and 5 CRG researchers.

This workshop took place on November 4<sup>th</sup>, 2020 and its goals were to obtain feedback from the analysis of the information collected in the two previous stages and gather all ideas to incorporate into the CRG's strategy.

3. Analysis and final summary report.

# 2. The context of Science in Spain

There is a general perception among the participants in this PD that **Spain lacks any** "scientific culture". Science is of no interest to society and therefore is a topic that is not spoken about in either the public arena or the media.

"Research does not appear to be one of the priorities, plus it's a subject that doesn't appear in the media much and doesn't seem to awaken much interest." Man, 48, Madrid.

In this context, the Covid-19 health crisis has turned the spotlight on science and investment in it. The whole world is following the research into the development of treatments and vaccines for Covid-19 in real time. This situation represents an opportunity to communicate science, particularly health-related research, such as the projects being undertaken at the CRG.

"Funding is always an issue for research. Funds are always limited and that's why it's necessary to make people interested in what's being done. COVID has offered a leap that has to be taken advantage of." Man, 51, Bilbao.

It is interesting to see how in a context in which science is of little relevance, the scientist/ researcher is a respected figure in society. They are considered highly intelligent, hard-working and committed people who do a complex job, of social interest that is not very well-paid.

"I think we have a lot of young people studying in our country with money we all pay and then they need to go abroad to find work and feel useful because they're not given any opportunity here in spite of being very valuable educated people." Woman, 50, Seville.

Nonetheless, delving deeper into the perceptions, **the public finds it difficult to see beyond the scientist and their "professional persona":** they are considered distant people who live lives removed from reality in their "laboratory", who speak a different and difficult language.

"What grabbed my attention was how simply the researchers explained things in the videos. Their explanations were really easy to follow. The advantage is that they can reach ordinary people and these can understand. I'd highlight how easy it is to understand the projects for the moment." Woman, 56, Bilbao

For their part, the scientist occasionally feels misunderstood or even judged by the public that may question the "usefulness" of their scientific research.



"I bet people wonder, should this person be paid to spend years and years researching something when we don't even know what it's for?" Researcher.

# 3. The perception of the CRG

The general public consulted was not aware of the CRG's existence before the dialogue and their first reaction on seeing the presentation video was extremely positive. For them, it was a pleasant surprise to discover that Spain has a centre of international excellence such as the CRG. In a way, it puts Spain on the science map.

Regarding its activity, **genomic research is particularly appealing to the public because of its association with multiple advances in the healthcare area**.

"The work done in the CRG came as a surprise to me and I think it's really interesting and hopeful for many diseases." Woman, 33, Madrid

They rate the CRG's interest in communicating its activity to the general public and its investment in Open Science highly. They also value the CRG's holistic and multidisciplinary approach, along with its policy on diversity, animal protection and environmental concern. Its talent-attracting objectives surprise them positively. This contrasts with the general idea that there's a major problem in Spain with promising talents in health and science going abroad.

"I had never heard of the CRG and the idea of crossing frontiers on an everyday level so that science reaches everyone unfamiliar with its work as information. On the contrary, I thought that science had always been obliged to beg for aid to be able to keep researching, many researchers have even had to leave the country to continue their projects due to insufficient resources..." Man, 65, Bilbao.

Lastly, they highlight the simplicity of the language used and its educational/ didactic character, considered essential if they wish to reach everyone.

*"I found the presentation really interesting. It's a very straightforward and understandable way of presenting a very complex scientific work." Man, 51, Bilbao.* 

From the outset, **the concerns that emerge spontaneously are linked to the sources of funding, the possible conflicts of interest and the ethical limits** of the research conducted in the CRG.

*"I'm fundamentally concerned about the sources of funding to develop this project. Unfortunately, these are uncertain times that have brought numerous crises, both of a financial and a social and public health nature." Man, 56, Barcelona.* 

The CRG's research projects are very positively rated. The general public believe they cover different, complementary areas, all of which are very relevant for health. Among these, they highlight *Gene Regulation, Stem Cells and Cancer* because of the high prevalence of this latter disease and the importance of regenerating organs from cells.

"Though I found all of them really interesting, the ones that grabbed my attention most are the areas of genetic regulation, stem cells and cancer as it's a very well-known issue, but one that a lot remains to be learned and researched about. Cancer is a disease that kills a huge number of people and there's no cure for it yet, in spite of the amount of research that's been done over the years." Woman, 19, Bilbao

The stakeholders who participated in the public dialogue are professionals who either have or have had some type of relationship with the CRG since its foundation. The



relationship between these professionals and the CRG is close and cordial. However, this does not mean they are not demanding and critical of some of the subjects discussed during the dialogue, such as the scientists' position on basic research and its funding.

"I've had the privilege of getting to know, assisting and accompanying the CRG since it was first conceived, its gestation, pregnancy, childhood, adolescence and adult life, which is what we're going to discuss today". Stakeholder

"I think that those of us involved in spreading science have an enviable relationship with the CRG because we believe they do a really good job and they do a lot of very powerful things and they're an example for those of us involved in dissemination." Stakeholder

### 4. Basic research

*"Basic science is like wardrobe basics. Always available for any situation." Woman, 58, Madrid* 

Any discourse on "basic research" goes hand in hand with a search for the general interest of the research projects, their usefulness and their application in time. Nonetheless, after the basic research concept has been presented, **the general public understands and considers knowledge for knowledge's sake extremely relevant; meaning any future finding will be more robust and solid**. They are all in favour of funding basic research projects.

*"I still think that without basic science, profound and complex research cannot be sustained. It's like the pillars that hold a building up to grow. And often there must be a lot of unexpected doors. Nothing that can lead to something positive in science should be discarded. The disadvantage is that it's not economically profitable in the short term." Man, 65, Bilbao.* 

In addition, the Covid-19 crisis has driven up the importance of both basic research and a good knowledge base to build on with medium and long-term discoveries.

"According to the video, thanks to previous research in basic science, it was possible to purify the Covid-19 proteins to create serological tests in a very short period of time. Here the benefits are clearly visible." Man, 62, Madrid.

"From the outside" the scientific framework, the differentiation between basic and applied research is blurred and counter-intuitive. The term "basic" emerges as a label that may make sense in the scientific community, but loses significance when its definition reaches the general public. Some researchers confess they also find it increasingly difficult to make the distinction between the two research types; that end up forming part of a continuum.

"The more I penetrate the world of basic research the more difficult it is for me to find the difference versus applied research." Researcher.

"When there's no pressure, the translational research happens naturally" Researcher.

Thus, the public sees **basic research as previous research; the condition necessary for major discoveries to be made later on and to obtain outcomes that are more immediately applicable in the framework of other research studies** (applied research). It is, therefore, equally valuable research that may lay the foundations of the knowledge needed for future research and discoveries.



*"It's necessary to support basic projects because I think they represent what most people demand and worry about, and in the end they become the master lines of the subsequent research that is materialised in specific actions." Man, 56, Barcelona.* 

Bearing this in mind, when communicating to the public it will be important to convey the possibilities implicit in acquiring certain specific knowledge; to build a story about why a theme is chosen and what its possible future applications might be.

# *"It's necessary to work on the narrative and the story behind the basic science for it to reach the public." Stakeholder*

However, according to the researchers and stakeholders, it is not that easy. There aren't always clear future applications and it is not easy to identify how valuable said knowledge might go on to become. Furthermore, they believe the researchers immersed in the projects are not always capable of pinpointing the possible application of their findings.

# "The scientist doesn't necessarily know when their finding is going to be applicable, it would be ideal to have people who did, who had that double vision" Researcher.

**Transference offices emerge as an opportunity for the CRG to contribute to "oriented" basic research.** This would consist of using professionals who understand the research but are also capable of seeing the transferability and application of the results. A "bridge" between the research and the opportunities of its results. Partnerships with institutions not specialised in basic research and hospital centres are also good options to foster future translation.

# *"If Martínez Mojica had had a good transference office, what happened to him with the CRISPR technique and the Nobel Prize wouldn't have happened" Researcher.*

In general, both the citizens and the stakeholders agree that **researchers must have the freedom to decide what to research.** They believe the CRG must focus on those research projects that its scientists suggest within certain "margins of action", considering the common good and the social benefit as the ultimate goals. In addition, it must continue to promote excellence in the research the centre conducts, organising its scientists into teams to as many subjects of interest as possible are covered.

"The CRG has to be omnipresent, whether it is more or less attractive, with more or less acceptance, with more or less studies... It has to be present in everything possible, you never know when a glimmer of light is going to appear, an idea, a concept..." Woman, 45, Bilbao.

In short, this public dialogue has made it clear that the general public appreciates and values basic science and knowledge for knowledge's sake and trusts the researchers completely.

# 5. The funding of basic research

The citizens are surprised that the CRG researchers need to find their own funding from different sources. They are surprised that they have to dedicate time and effort to "selling" their projects instead of just focusing on research.

"On the one hand, we have the baseline funding and, on the other we have to fund ourselves by "fishing" here and there. This really side-tracks us and detracts from our competitivity." Researcher.

In this situation, when the project viability depends on finding methods of funding, everyone agrees that both the public and the private initiative are valid options.



Regarding other funding options explored in this PD, both the public and the stakeholders approve the following options for the CRG:

• Collaboration with private companies is an option with an important advantage as it favours the application of the results and leads to society benefitting sooner. This type of funding help bring their projects down to earth, taking the CRG (and its basic research initiatives) closer to the people and their real needs. The only limit has to be the centre's ethical code.

# "Of course it should collaborate with these centres as they are the ones with the opportunities closest to the people and with experience in practise." Man, 32, Seville.

• The creation of start-ups under the CRG umbrella is applauded by everyone as the creation of new private companies is considered very positive by everyone. These are synonymous with entrepreneurship, modernity, advancement and progress, while, at the same time, generating jobs for young researchers who, otherwise, would have to continue their career abroad.

"It sounds really positive, as in this century it's important to have initiative and move away from the traditional work structures. It offers employment to young people with ambitions who are willing to give their all, and that's what's needed right now, people who give their full dedication to the project and whose goal is to improve everybody's standards of living." Woman, 19, Bilbao

The majority do not consider the **fact that these companies are created with public money a problem**, as long as they share their results and all of society can benefit from them. It's one way of compensating for the serious lack of public funding. To avoid any grey areas, **it is essential to be absolutely transparent**.

"I feel that anything that is done to improve, whether public or private, is perfect. I do agree with public money being used to invest in private companies, as long as these private enterprises don't speculate with the achievements obtained, but rather they should be re-invested in the common good." Woman, 63, Seville

Once these companies have been created, the **CRG's work will have to be linked to them at all times, supervising and supporting but also controlling**. The stakeholders also add the 'ethical supervisor of the research' role to these functions.

"Regarding the role played by the CRG in the companies formed under its auspices, it should act as an ethical guide and ensure that the CRG's values and objectives are abided by." Stakeholder.

Similarly, they all believe the profits from patents should be invested in research and continued advancement. This implies investment of these profits in both other the CRG research and in the creation of new companies under its umbrella.

• Finally, the participants in this public dialogue approve the idea of the CRG turning to patronage and philanthropy to fund its research. In their opinion, the CRG and the scientific community, should fight to incentivise these donations to science by making them tax-deductible or including them as a deductible option in the taxpayers' returns.

"There should be a box that you could tick in your tax returns to donate money, in the same way that there is one for the NGOs and the church." Stakeholder.



Hence, the answer to the question "Should the CRG invest resources in getting private funding?" is a rotund yes for all participants in the dialogue. Though the general belief is that "selling" science projects or going out to "fish" for funding is not ideal, the current conditions make it obligatory to do so. They all envisage commercial profiles with a science background and objectivity acting as a "bridge" between scientists and the entities or people funding them.

# 6. Ethical and social debates

*"I think research and scientific projects have enabled us and continue to allow us to have better quality of life. Who could be against the evolution of humanity?" Woman, 50, Seville.* 

In principle, genetic engineering and synthetic biology are attractive fields that awaken expectation and open up a world of opportunities, making the apparently impossible possible; **they sound almost like science fiction.** Apart from being attractive, **genetic engineering is a very relevant and highly valued field of study because it may serve to cure and prevent diseases or even create synthetic vaccines.** 

"The modification of a bacteria's genes sounds like science fiction to me. I'd love to know more, how they do it, how they act against these changes, and what causes one micro gene or another to be changed." Man, 27, Barcelona.

Despite its appeal, it is a controversial topic that causes reticence and may trigger discomfort and fears. The use made, or potentially made, of the results is of particular concern. A debate on different ethical issues inevitably arises: Are humans breaching the natural balance of things? Who are we to go against nature? Are we ready, as a society, to manage these findings? Is the scientist playing god?

This is why transparency and correct communication in the spread of the scientific results and its future findings is fundamental.

*"I don't believe there can be limits in the research, but there can be in the application of the research." woman, 63, Bilbao.* 

"I'd like to imagine a future in which human knowledge meets the standards of that balance, but the interventions in the ecosystem to date prove to me that we are far from achieving it. I'm afraid that by trying to improve something, we'll end up ruining a lot". Woman, 43, Seville.

Everyone agrees that **limits governed by more or less "objective" ethical principles must be imposed**. A task perceived to be particularly complicated. They propose different "control" methods to ensure good practise, like for instance: **the establishment of a national and supranational regulation or the creation of a code of ethics within the framework of the research.** 

"The limits are those that ethically they want to impose. The problem is that the idea of ethics differs greatly from one culture to another. Imagine the contrast between the North American, the Muslim and the orthodox Jewish cultures. The limits are the ones that ethically they wish to impose. We will have to reach an agreement, bearing in mind that these limits are alive and will change with our own evolution." Man, 51, Bilbao.

Similarly, **dialogue and the obtainment of different points of view on the ethical issues are considered fundamental**. It is important to understand society's perspective to adapt these limits to the ethical values of each given moment. What is considered ethical today, will not necessarily be considered ethical tomorrow. **Ethics** 



# are like a living organism that changes, advances, and evolves in time together with the human being and society.

"We are living in a time in which human life has been prolonged a lot. We all have close acquaintances who are nearly a hundred or more. We are moving towards a very different life to that of our grandparents. Nowadays, the lifestyles of the past are of no use to us. The future is both uncertain and surprising. Ethics evolve with the human being." Man, 65, Bilbao.

Just because the public trusts the scientific community and researchers does not mean it is not demanding. They sustain that **since researchers are equipped with knowledge and the advances are in their hands, they must play a more operative role and actively partake in any ethical issues that might arise from their research**. Both the stakeholders and the public consider it important for them to engage and take a side, not just as scientists meeting the ethical requirements of the project they're conducting, but as human beings who form part of society willing to engage and go beyond mere technical matters.

"Scientists have very little humanist culture." Stakeholder.

"Scientists need to take a Hippocratic oath like doctors do, promising to be ethical and responsible in their work". Stakeholder

In this context, the **CRG should be able to offer the researchers guidance on the one hand, and foster spaces for debate and dialogue on the other**, engaging different profiles (including the public) to obtain a diversity of opinions.

# 7. Communication

Over the course of this PD, it's been made abundantly clear that **the public is open to science**. There is a key need to bring the two worlds closer to each other and overcome prejudices on both sides. **It's time to be transparent and communicate on a "one to one" basis with an increasingly empowered public**. Some stakeholders go even further and claim it is an ethical duty to spread science.

In this context, a series of questions need to be asked with a view to designing the CRG's communication strategy:

• To WHOM do we need to communicate? Science needs to belong to everyone

**Efforts need to address everyone;** both those interested in and closer to science, and those who are more removed from it; children and the younger target but also the older. They are very different audiences that need to be segmented to design the best strategy for each one.

• WHY communicate? WHAT do we want to achieve? Awareness as the first goal.

It's essential for the centre to become better known among the general public; as many people as possible need to be reached, using different channels to do so. The participants in this dialogue fundamentally speak of: education centres, traditional mass channels like television and press, digital channel

"The communication of basic research to the scientific community is usually through conferences, publications or in universities, I don't know whether in its entirety or whether there are subjects that never leave the laboratories. Society should be



communicated the advances in research to raise awareness of its importance and obtain the necessary support, recognition and funding." Woman, 33, Madrid

• WHAT do we need to communicate? It's key to show faces.

The stakeholders believe it's essential to break away from certain prejudices and associations and present a more "real" view of science to the public. Three examples are:

- Science and research do not always go hand in hand with technology or R+D. There are also scientific research projects in other areas, such as health.
- Science is not "exact" and does not always lead to positive outcomes. It's essential for the public to know how science and the scientific method work, and that negative outcomes must also be communicated. There's a need for honesty and transparency.
- Similarly, scientists are not strange and superior beings who hide away in their laboratories without any contact with society, removed from what's happening outside. Faces must be put to names here, to tell stories and convey that these are people just like everyone else.

With regards to the CRG, the general public is most interested in finding out the type of research conducted and the health-related outcomes and disease cures obtained. But **it's also relevant to communicate the CRG's values**, introduce the people who work there, how they work and what the centre is like inside, what are the motivations and concerns of those who form part of it; **it's key to show faces and humanise the centre.** 

Among the values to be communicated, the public and stakeholders highlight some of those projected by the CRG, such as excellence, reliability, talent, progress, advance, youth, diversity, creativity, daring and enthusiasm.

HOW will we communicate?

Humanising and "democratising" science gives rise to the need to be proactive and approach the public by speaking their language, avoiding technical terms and simplifying, but without becoming banal or losing sight of the real complexity.

In this sense, it's also important **not to "overpromise"**; don't make the public think the results and implications of the research studies are always positive. It's necessary for the communication of science to be realistic.

# *"It cannot be possible that every certain amount of time the TV news reports that a cure for cancer or for Alzheimer's has been found." Stakeholders and researchers.*

Additionally, a story should be built to foster public engagement; **tell stories that citizens can identify with**. These stories must have characters and "heroes" that resonate with the public and its emotions. Some suggest how the scientist could communicate their passion for science through these stories.

"With a view to broad diffusion of science, trained professionals are necessary, but they also need to be capable of communicating their passion for knowledge. Authentic storytellers." Stakeholder.

For one-to-one communication in which the opinion, support and concerns of the public are collected, the most "interactive" means of communication are necessary. **Social media is, undoubtedly, the best channel** for this type of communication.



Finally, Open Science has also been put to debate in this open dialogue. **Everyone** agrees that opening science up to the world, as a broad concept, is an opportunity because:

- 1. It serves to **highlight the importance** of science, the scientific community and the scientific culture in society.
- 2. It **increases** transparency and **the** public's **trust** as they know what their taxes are being invested in.

"It's important for us citizens to gain a certain knowledge of the research happening in our country, our money is being useful, and also because knowledge is a human right. The risk implies speculating with the publications and how publication would be implemented. The benefits would be important for both those researching because of the prestige it would gain them and the public because of their right to knowledge." Woman, 63, Seville

- 3. Data collection and research studies constitute another way of **validating and checking** techniques, methodologies and analyses.
- 4. It fosters **cooperation** between scientific teams rather than competition. This would also result in more rapid advances.

These benefits of Open Access make up for any possible risks, which include: plagiarism, manipulation and the unethical use of results by third parties. Participants of the dialogue call for control of these types of actions by the national or international entities responsible for safeguarding the security and ethics of the scientific community. The role of the CRG and its researchers is to protect their research and, as mentioned above, play a more active role in ethics and ensuring compliance of this regulation.

# 8. Conclusions and next steps

The citizens and researchers found the public dialogue experience highly satisfactory. It not only awakened their interest in science, but also overcame any obstacles or prejudices they had.

"I feel far closer to the research, I've even read articles on the subjects dealt with. This change is thanks to getting to know you, to hearing the researchers live, understanding their work, seeing real people in important subjects achieving small advances that make life better". Woman, 56, Bilbao

"As a personal experience, I think it is an opportunity to contact with people (...) and specially at the end, when we had the general discussion (...) it is kind of very enriching, they have very different ideas than we think, or they think of super different things, I mean as a scientist I wouldn't have thought of (...) I think it is very enriching, and it has changed my perception of how others see us and how I feel about others". Researcher.

The analysis of these PD findings reveals strong support among both the public and the stakeholders for the CRG, its values, its research projects, its way of working and its commitment to Open Science.

Now that they have discovered the centre, they value the work and efforts of Spanish scientists, particularly given their limited funding conditions. Admiration for the figure of the scientist has increased even further.



Thus, we see how a centre like the CRG must actively approach society, speak in simple and transparent terms and reveal its more human side. The only way to do this is to go to where the public is: use the information and communication channels it uses; use its language to explain findings, but also elicit its opinion and, why not go even further and ask for its support with funding.

All PD participants are aware of the effort required for this *rapprochement*, but they consider it necessary to seize on the interest the COVID crisis has triggered in science. The time is ripe to raise awareness of science and attain the acknowledgment it deserves.

As proof of their support of the CRG, public and stakeholders alike worked alongside the researchers in this PD to come up with specific actions. Some of them are:

#### Actions to promote "major changes" / collaborations

- Lobby to have a box to tick in the tax returns form allocating part of the taxpayers' returns to science.
- Patronage/ philanthropy/ major fortunes: work to raise awareness and achieve tax deductions to foster personal donations. The goal is to reach the same level as other countries.

#### **Ethics-related actions**

- Committee of advisers to set the projects' "ethical limits". A multidisciplinary committee with scientific and social players (scientists, academics, philosophers...). The scientist must "open up" to society. Right now, scientists find it hard to leave their circle.
- Conduct surveys or consultations (for instance, in the newspapers)
- Public talks on social debates (on television). Scientists need to speak in an "educational" way to generate social conversation.

#### Actions on communication and funding

- Talks in universities and companies.
- Conduct genetic tests among the public (or at a tourist stand)
- Consult certain groups and ask them what they can contribute to the functioning of the centre (e.g. Vegans and research using animals).
- Organisation of fund-raising events that, at the same time, increase the centre's fame: macro-concerts, sports events, special lottery, galas, ceremonies, etc.
- Collaborate with events such as the Marató de TV3 and focus it on funding for science (not on specific diseases).
- Participation in music festivals. E.g. Primavera Sound, Sonar..., that have the added advantage of combining technology + design.
- Marquees at sports events to communicate and raise funds. E.g. Tennis or golf tournaments, football matches, etc. (depending on the competition, this could be an action of more or less effort and impact)
- Crowdfunding: through platforms established for this purpose, with advertising on the website and Social Media. (Depending on the donations and investment in communication, it could be a big impact action)
- Campaigns for contributions/donations similar to the food bank campaign (e.g. round off shopping receipts in supermarkets, shopping centres...)
- A good interview of a passionate researcher and good communicator in a "prime time" TV format, like for instance the programme, El Hormiguero.



- Recurrent public dialogues
- Create an internal marketing department:
  - Collaborate with brands that share values. E.g. Ecoalf (technical and sustainable clothing); Doctors without Borders, NGOs...
  - o Campaigns with like-minded brands. Benetton could be one example
  - o Alliance with foundations. E.g. Rafael Nadal
  - Engage IBEX companies in campaigns with science
  - Scientific debates programme
  - Sponsorship/ creation/ collaboration with TV televised science competitions
  - o Netflix documentary or a series on scientists
  - "Media sponsor" or ambassador. Someone who shares values and who is listened to for what they have to say. E.g. Neil Harbisson (the first cyborg) or Stay Homas

# Guidelines for organising a publi dialogue on the strategy of a biomedical research centre

# Methodology and learnings from a public dialogue on the CRG´s strategy

January 2021



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# About this guide

This document is based on a public dialogue conducted for the Centre for Genomic Regulation (CRG). The objective of this document is to use this experience to create a simple guide on how to carry out a public dialogue for a scientific research centre.

## What is a public dialogue?

There are a number of definitions available. According to Sciencewise<sup>1</sup>, a public dialogue is:

"An approach to involving citizens in decision making. Dialogues bring together a diverse mix of citizens with a range of views and values, and relevant policy makers and experts, to discuss, reflect and come to conclusions on complex and/or controversial issues."

Research Councils UK (RCUK), on the other hand, gives a broader definition:

"Dialogue is generating debate and interaction between individuals and groups and creating a climate where people discuss scientific issues in the way in which they discuss other issues of public and social policy. This dialogue may not lead anywhere in terms of decision-making, but it is stimulating interest in, and awareness of, issues. Scientists may be talking to the public, the public may be talking to each other, there may be television and radio programmes, web chat sites, etc. with no end in sight other than that science becomes just another facet of life, rather than something different and difficult."

In other words, a public dialogue is a way to create democracy, connect as a society, break down prejudices and stereotypes. A way to ensure that we make informed decisions in the near future.

## What should a public dialogue be like?

Public dialogue provides in-depth insight into citizens' views, concerns and aspirations on issues relating to science and technology. These issues are often complex and unfamiliar to citizens and therefore their exploration is better suited to a qualitative approach.

In addition, according to Sciencewise, a public dialogue is:

- Informed participants are provided with information and access to experts;
- **Two-way** participants, policy makers/ decision makers and experts all give something to and take something away from the process; dialogue is neither solely about informing the public nor extracting information from them;
- Facilitated the process is carefully structured to ensure that participants receive the right amount and detail of information, a diverse range of views are heard and taken into account and the discussion is not dominated by particular individuals or issues;
- **Deliberative** participants develop their views on an issue through conversation with other participants, policy/decision makers and experts;
- **Diverse** participants tend to be recruited to ensure they represent a diverse range of backgrounds and views (participants are not self-selecting)
- **Purposeful** dialogue engages the public at a stage in a decision-making process where decisions are not yet made

<sup>&</sup>lt;sup>1</sup> https://sciencewise.org.uk/about-dialogue/what-is-public-dialogue/

- **Impartial** public dialogues are often convened, designed, delivered and facilitated by independent individuals or organizations to help ensure the process is not biased in favour of a particular outcome; and
- **Expansive** public dialogue opens up conversations rather than closing them down

Following the Ipsos experience with the CRG, we would add another item to the list:

• Flexible- a public dialogue should be flexible in the design and methodology applied. Capable of adapting to the social circumstances of the moment and to the capacities of the specific organization commissioning the study. The important thing is to reach different representatives from society and create a one-to-one dialogue on the topics that are relevant to the specific objective. The public dialogue mindset and methodology should help us, never encapsulate us!

# The CRG's public dialogue case study

### Objectives

The primary objective and starting point for the public dialogue commissioned by the CRG was to explore how to incorporate the views and ideas of civil society and different stakeholders into the research strategy for 2021-2024.

With this main objective in mind, other more specific objectives were also set:

- Explore the different areas of research conducted, the strategic decisionmaking processes involved in prioritising this research, and open up a dialogue on ethical and societal considerations around the CRG's research.
- **Identify priorities, concerns, hopes and fears** relating to fundamental research in general and the CRG's work in particular.
- Explore funding options and opportunities.
- Identify the content and messages for communications and outreach that will enable the public to engage further with all issues.

Additionally, the following specific aspects were covered:

- Observe the reactions of the public and stakeholders to the CRG research.
- Understand how the public and stakeholders rate basic research and pinpoint reasons for investing more in it: basic vs translational research.
- Identify their interests and concerns about the CRG's research and the ethical and social implications of the same.
- Explore insights for communication and activity design, while also finding an optimal positioning for the CRG.

### Methodology and approach applied

The initial approach used in this Public Dialogue was:

1. **Stimulus development, scoping and framing**. With the CRG's advisory group involvement, 6 research projects were selected to present to the public and stakeholders and, at the same time, used as the starting point for the discussion of aspects that constitute the objective of the public dialogue.

The material designed for the presentation of these projects consisted of a brief descriptive text along with an explanatory video presented by one of the researchers involved in the project.

A short introductory video about the CRG was also made as an introduction to the dialogue.

- The Dialogue. The initial plan was to conduct two substantive full-day workshops, one with stakeholders and one with the public (30 participants at each), followed by a half-day reconvened workshop involving 30 representatives, 15 from each of the previous workshops. All three workshops were to take place in Barcelona, Spain.
- 3. Analysis and final summary report. A report was to be prepared incorporating all elements of the project that the CRG could use to convene and prompt wider discussion on how basic science and genomics can be open to public debate.

The eruption of the coronavirus pandemic at the end of phase 2 made it necessary to modify the Dialogue methodology. The health and safety measures did not allow groups of 30 people, meaning the objectives had to be adapted to an online format.

Thus, the 3 face-to-face workshops of the PD were replaced with a three-phase design, combining the following methodologies.

**Stage 1**: **11-day online community with the general public** that took place from September 28<sup>th</sup> to October 13<sup>th,</sup> 2020, with 30 participants. Using the Ipsos-owned platform Ipsos Live, participants were able to analyse the materials designed and answer the questions put to them.

Additionally, **three online sessions** were held on October 1st, 5th and 7th in which the public, divided into groups of 5-6 people, interacted with the 6 researchers responsible for the case studies shown.

Stage 2: 1 online workshop lasting 3h with stakeholders selected by the CRG held on October 20<sup>th</sup>, 2020.

With 23 stakeholders and 10 CRG researchers, debate groups on 4 main topics were established: basic research, funding, ethical and moral debates, and science communication.

Stage 3: 1 online workshop lasting 2.5h with 13 participants from the general public (stage1), 11 participants from the stakeholders' workshop (stage 2) and 5 CRG researchers.

This workshop took place on November 4<sup>th</sup>, 2020 and its goals were to obtain feedback from the analysis of the information collected in the two previous stages and gather all ideas to incorporate into the CRG's strategy.

The design of the general public sample was as follows.

Variables	32 people were recruited and a total of 31 took part		
Location	Barcelona Madrid Seville Bilbao	8 8 8 8	
Sex	Men Women	16 16	
Age Groups	18 to 30 31 to 45 46 to 60 61 to 75	8 8 8 8	
Work Situation	Working Not working	20 12 (students, unemployed people, housewives and pensioners)	
Activity	Services Industry Agriculture and livestock Public administration	12 5 2 1	
Social Class (education level, occupation and income)	Upper class Middle class Upper middle class	8 16 8	
Nationality	Spanish Other	29 3	

#### Table 1. Sample profiles

In relation to this sample, it is important to observe that:

- It reflects the Spanish population but is not a statistically representative sample as occurs with the quantitative studies samples.
- The switch to an online format allowed for the geographic scope of the sample to be broader than initially planned, which had only included people residing in Barcelona.

The guest stakeholders invited to the PD process were people with a professional relationship with the centre. Ultimately, a total of 23 took part with very diverse profiles: journalists, researchers from public and private centres, research centre directors, members of a Bioindustry Association and members of the education community.

A total of 15 CRG researchers also took part in the online dynamics of the 3 stages.

### Results and outputs

The culmination of this public dialogue was a report that gathered information regarding citizen, stakeholder and researcher perceptions. The information was accompanied by a series of recommendations aimed at taking the findings to a more operational level to enable the CRG to implement them in its strategy.

The main chapters of the report are:

- 1. Context and views on science and scientists in Spain
- 2. Perceptions of the CRG and the CRG's projects
- 3. Perceptions of Basic research (vs applied research)
- 4. Funding of science and basic research
- 5. Ethical and social debates around scientific research
- 6. Communication of science by the CRG
- 7. Conclusions and next steps

### Possible questions and issues to consider

### How is this public dialogue useful to decision-making?

A dialogue is a valid and robust way to inform a strategy or even to change a work culture, break stereotypes and find different ways of doing things that lead to success. It is also a particularly valid tool to understand the range of options open to decisionmakers that reflect public feeling; and why the public think the way they do. The public dialogue ends with a report that provides detailed and nuanced evidence on how citizens' views, concerns and aspirations can be operationalized.

### Other considerations

#### A public dialogue needs a team of professionals to be successful.

The team must be composed of:

- **Experts to run the public dialogue:** to design the research, recruit participants from civil society, moderate the sessions, analyse and report results. An independent organization (to avoid bias) with experts in qualitative research.
- **Representative of the research Centre**: a person(s) who oversees the dialogue from the inside of the organization, to communicate the objectives to the team of experts, to ask for the participation of the different players from their organization when necessary and, in short, to provide the information necessary to carry out the dialogue.

### A public dialogue means involving people

It is important to note that a public dialogue requires the participation not only of the public or external stakeholders, but also professionals from the Centre running the dialogue. Above all, the idea is to involve those with a certain decision-making power to enable informed decisions.

In the case of the CRG, in addition to the internal people in charge of the project, the participation of the general director, members of the advisory group and researchers from different areas was key.