



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

**Final report**

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

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# 1. Public dialogue Introduction: Objectives and Methodology

## 1.1 Background

This public dialogue is positioned within the framework of the EU-funded ORION project (**O**pen **R**esponsible research and **I**nnovation to further **O**utstanding **k**nowledge). The Project's long-term vision is to "embed" Open Science, Responsible Research and Innovation principles in Research Funding and Performing Organizations (RFPOs). These principles are ethics, gender, governance, open access, public engagement and science education.

ORION explores ways in which research and funding organizations in life sciences and biomedicine can open up the way they fund, organize and do research.

Since its commitment to the Open Responsible research and Innovation principles, the CRG has been exploring ways to incorporate the views and ideas of civil society and different stakeholders into their 2021-2024 research strategy. With a view to doing this, it has conducted a Public Dialogue (PD hereinafter) with two fundamental goals:

- 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 strategic considerations of this exercise include:

- How can the CRG address the societal and ethical questions related to their research considered most important by the public and stakeholders?
- In what ways can the CRG promote Open Science?
- How can the CRG build a body of knowledge on public attitudes to medical genomics that it can then use to drive discussion in the research and policy sector and beyond?

## 1.2 Objectives

The broad objectives throughout the Dialogue 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 for designing a **fundraising strategy**.
- **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.

### 1.3 Methodology: Public Dialogue in Covid-19 times

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.** With the advisory group involvement, 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 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.

The cases chosen were:

- The super synthetic vaccine, by Serrano lab.
- Mucin and cystic fibrosis, by Malhotra lab.
- Can any cell type be generated in the laboratory? by Payer lab
- The what and the how matter in the genome, by Di Croce lab.
- The discovery of something unexpected, by Guigó Lab
- The CRG and the coronavirus pandemic: on the CRG's contribution to the mass detection of coronavirus thanks to the PCR test.

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

2. **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 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 at the end of phase 2 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 PD were replaced with a three-phase design, combining the following methodologies.

**Stage 1: 11-day online community with the general public** running from September 28<sup>th</sup> to October 13<sup>th</sup>, 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 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 (stage 1), 9 participants from the stakeholders workshop (stage 2) and 5 CRG researchers.**

This workshop took place on November 4<sup>th</sup>, 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.

The design of the general public sample was as follows:

**Table 1. Sample profiles**

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

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

- 4 journalists and science communication experts
- 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. The Context of Science in Spain

### 2.1 Investment in Science

Current **R+D investment in Spain constitutes 1.24% of the GDP while the European average is around 2%**. Spain occupies sixteenth place among the countries of our continent (Eurostat, 2019).

**Table 2: GDP dedicated to science by country**

<b>EUROPEAN RANKING: % OF THE GDP DEDICATED TO SCIENCE</b>			
1. Sweden	3.31%	15. Portugal	1.35%
2. Austria	3.17%	<b>16. Spain</b>	<b>1.24%</b>
3. Germany	3.13%	17. Luxembourg	1.21%
4. Denmark	3.03%	18. Poland	1.21%
5. Belgium	2.76%	19. Greece	1.18%
6. Finland	2.75%	20. Ireland	1.15%
7. France	2.2%	21. Croatia	0.97%
8. Netherlands	2.16%	22. Lithuania	0.88%
9. Slovenia	1.95%	23. Slovakia	0.84%

10. Czechia	1.93%	24. Bulgaria	0.75%
11. United Kingdom	1.71%	25. Latvia	0.64%
12. Hungary	1.53%	26. Cyprus	0.55%
13. Estonia	1.4%	27. Malta	0.55%
14. Italy	1.39%	28. Romania	0.51%

In addition, **the amount budgeted is not always fully executed**. For example, in 2018, the Government had allocated 7 billion euros but in the end 3,288 million were actually spent.

The recent economic crisis has also impacted investment in science with accumulated cuts from the start of the recession of 30%, translating into 20 billion euros less invested in science in Spain (Hora 25, Cadena Ser, 26/04/2020)<sup>1</sup>.

## 2.2 Relevance 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.

*“The thing is, there’s no scientific culture in this country, we lack it! People aren’t interested in science”. Stakeholder*

*“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.*

The data supports this perception shared by the general public, the stakeholders and the researchers consulted. Hence, according to the survey on the social perception of science and technology conducted by the Spanish Foundation for Science and Technology (FECYT) in November 2018, **only 16% of Spaniards mention science and technology as subjects they feel an interest in when they receive information** (from any source). **This contrasts with the subjects of medicine and health or work and employment, that occupy first and second place in the ranking** (mentioned by 37.9% and 31.9% of Spanish people respectively).

This data, along with public and stakeholder perceptions of interest in science, suggest that the field of science could benefit and arouse greater interest if it were associated with medicine or health rather than technology. **The association between science and technology appears to exert a negative impact on public interest**. Linking science to healthcare rather than technology, could be a way of increasing the people’s interest and eventually impact funding.

*“There’s always a lack of funding and, for instance, people need to be made interested in what’s being done. We’ve associated R+D+I with technology rather than other areas such as health. The strategy is to make society understand how necessary basic research is.” Man, 51, Bilbao*

<sup>1</sup> Article from the Hora 25 programme on Cadena Ser: “El agujero de la ciencia en España: un nivel de inversión de precrisis y recorte acumulado del 30%”: [https://cadenaser.com/programa/2020/04/26/hora\\_25\\_fin\\_de\\_semana/1587917114\\_612515.html](https://cadenaser.com/programa/2020/04/26/hora_25_fin_de_semana/1587917114_612515.html)

Moreover, according to the European Values Study (From BBVA Foundation, conducted by Ipsos) this association is perfectly compatible with the Spanish people's perception when they give a score of 8 (on a 0-10 point scale) to the statement "Thanks to science, peoples' health is constantly improving" (BBVA Foundation, 2019).

*"The need to reach people interested in science is clear, but so is the need to interest people who could be interested but don't know that because of a lack of contact with these matters and news." Stakeholder.*

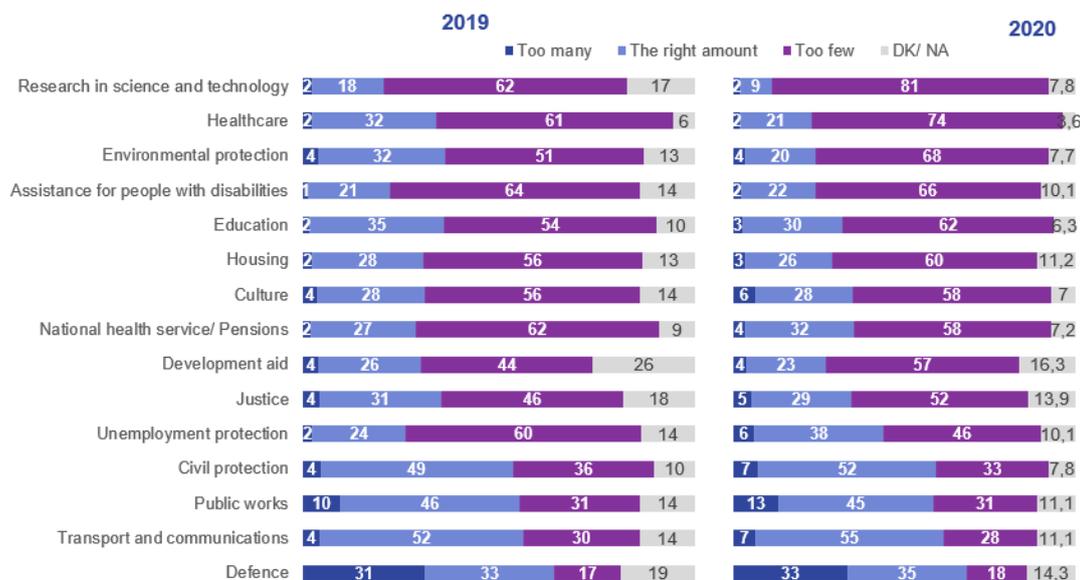
## 2.3 A reality that is changing.

### The Covid-19 health crisis has turned the spotlight on both science and investment in science.

One example is the corporate responsibility campaign, Campaña de Responsabilidad Corporativa Constantes y Vitales, promoted by the television channel La Sexta TV together with Fundación AXA. This campaign is collecting signatures to increase the investment in science to 2% of the GDP<sup>2</sup>.

Data from the study conducted by the national statistics institute, CIS, on public opinion and tax policy in July 2020 confirms this. According to this study, 81.2% of **Spaniards consider the investment of resources in scientific and technology research to be very low**. This figure has increased by 19.1 points compared to the previous year (when 62.1% considered it low). A similar phenomenon has occurred in healthcare investment, which has gone from 60.5% of Spaniards considering the investment low in 2019, to 73.8% in 2020 (CIS, 2019)<sup>3</sup>.

**Figure 1: evaluation of the amount of economic resources assigned to each service, 2019 vs 2020**



<sup>2</sup> <https://www.lasexta.com/constantes-vitales/>

<sup>3</sup> Question asked: As you know, the different public administrations spend the money we in Spain pay as taxes to fund the public services we have been talking about. Please tell me if you think too many, the right amount or too few resources are dedicated to each of the services I call out to you.

The whole world is following the research into the development of treatments and vaccines for Covid-19 in real time. They are aware of the different phases of the process, the timings and the results being obtained by the different work groups.

Thus, we observe that the population is now more sensitive to these areas and increasingly aware of the importance of science and public health investment in Spain.

*“Maybe the current situation (Covid 19) has shown us how vulnerable we are, the need for an urgent vaccine and the “slowness” of obtaining it.” Woman, 45, Bilbao.*

*“I believe far more should be invested (in basic science) to understand where things come from and be able to stay a few steps ahead. I think it’s really important and that has been made patent by the whole Covid-19 issue.” Man, 33, Madrid.*

This situation represents **an opportunity for the communication of science, particularly health-related research**, such as the projects being undertaken at the CRG.

*“During the COVID crisis science has had an excellent platform, but that’s not normally the case. People show off their ignorance, for instance, by expecting a magic solution that a scientist knows won’t arrive.” Stakeholder.*

*“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.*

## 2.4 Starting point for this public dialogue: how researchers and the general public perceive each other

*“I’m in favour of letting the researchers put the limits on their research, I trust them.” Woman, 56, 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.

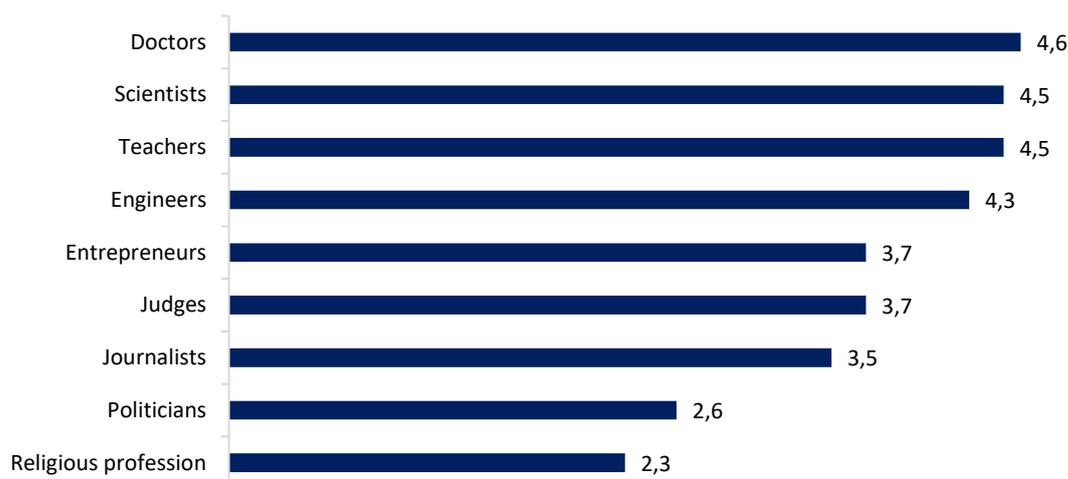
*“I think we have a lot of young people studying in our country with money we all pay and then they need to go abroad to find work and feel useful because they’re not given any opportunity here in spite of being very valuable educated people.” Woman, 50, Seville.*

With a score of 4.53 (scale of 1-5) it is the second most valued profession by Spaniards after medicine, positioning it ahead of other professions such as teachers, engineers and judges (FECYT, 2018).<sup>4</sup>

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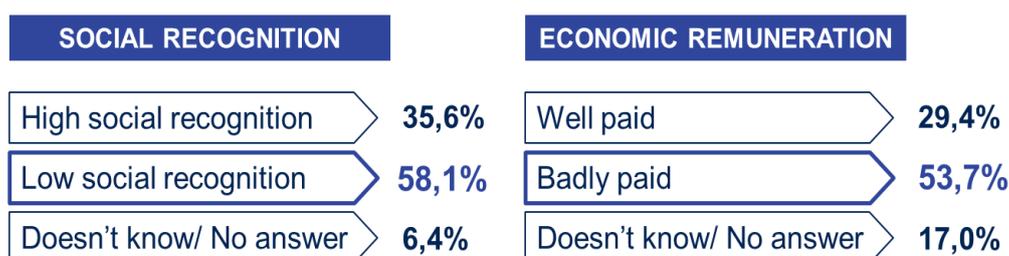
<sup>4</sup> Question asked: “We would like you to tell us to what extent you value each of the professions or activities that I am going to read out to you. To do this, we will use a scale from 1 to 5, where 1 means that you value it very little and 5 that you value it very much.”

**Figure 2: rating of professions on a scale of 1 to 5**



Moreover, 53.7% of those interviewed consider it a poorly remunerated profession and 58.1% believe it gets very little social recognition (FECYT, 2018).<sup>5</sup>

**Figure 3: opinion on social recognition and remuneration of the research profession**



In Spain in particular, the general public believes there is a loss of scientific talent to other countries due to lack of funding and remuneration:

*“The proof that there is little or no investment in research is that we can see many scientists demanding more investment in research and many are forced to go to other countries in order to grow and develop their talent” Man, 43, Barcelona.*

In terms of trustworthiness, the scientists are positioned closely behind the medical profession with a score of 7.3 out of 10 and they are considered people who act ethically in their profession (score of 7.1 out of 10).<sup>6</sup> (BBVA Foundation, 2019)

**Figure 4: trust level according to profession**

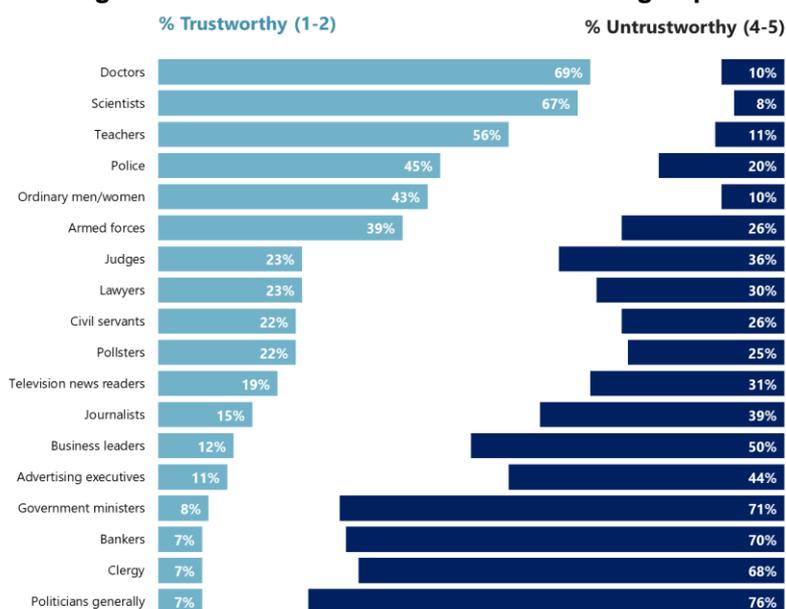
<sup>5</sup> Question asked: What is your image of the research profession? I would say that it is a profession...

<sup>6</sup> Question asked: “How much do you trust the following groups and persons? Average on a scale from 0 to 10 where 0 means “you do not trust them at all”, and 10 means “you trust them completely”.



A different research study shows that **67% of Spaniards consider scientists the most trustworthy profession**. Again, positioning them in second place after doctors (69%) and ahead of professions such as teachers, police, judges, etc. (Skinner and Clemence, 2019)<sup>7</sup>

**Figure 5: level of trust and mistrust according to profession**



*“I trust the professionalism of the vast majority of scientists.” Man, 61, Barcelona*

In general, scientists are seen as the most trustworthy in 12 of the 23 countries included in the survey. **They are seen as the most trustworthy profession globally, followed by doctors and teachers.** (Global trust in professions, August 2019, Ipsos)

<sup>7</sup> Question asked: Please look at this list of different types of people. In general, do you think each is trustworthy or untrustworthy in Spain? Please use a scale of 1 to 5, where 1 is very trustworthy and 5 is very untrustworthy.

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 scientists occasionally feel 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.*

*“it is very difficult to sell the usefulness of basic research and for people to understand it” Researcher.*

On the one hand, a need is identified to bring perceptions and discourses that are not *per se* distant from each other closer; on the other, the scientist/ researcher needs to be humanised, transformed into one more member of society. One-to-one dialogues need to be held to make science better known among the public and create an established scientific culture in Spanish society.

## 3. The perception of the CRG

### 3.1 Public awareness and projected image

The general public consulted was not aware of the CRG's existence before the dialogue and first reactions to the presentation video were extremely positive.

For them, **it is 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**. Many believe that the communication of science meets three very relevant objectives: it increases transparency, it reduces endogamy and it satisfies the curiosity of a population increasingly open to learning and knowledge.

*"I had never heard the name of this centre but it sounds useful, curious and innovative as, apart from being dedicated to scientific research, it aims to communicate all this information to the rest of the citizens. That allows us to learn about subjects that we probably didn't know anything about before." Woman, 19, Bilbao*

*"I like the fact that it's an open project, both to the scientists who can and want to contribute new learnings and to the general public interested in it. It's a way of placing everything that's been kept within a very small circle for a long time at the disposal of everyone. It's also a way of contributing new wisdom." Man, 56, Barcelona.*

*"I also quite liked the point about communicating science, new research to the general citizens, bring it closer to us and making us participants." Man, 23, Madrid.*

*"What grabbed my attention most is the concept of Open Science, as like I said before, society is accustomed to scientific research being only visible to people in its circles. However, with this new mode of communication and visibility of certain studies, there may be improvements." Man, 23, Seville.*

They also value the CRG's holistic and multidisciplinary approach, along with its policy on diversity, animal protection and environmental concern. **The CRG is a centre of excellence with very relevant and contemporary ethical and social values**.

*"What I liked best is the holistic vision, from the genome to the universe. It all forms part of everything... and the interest in equality, energy expenditure and sharing knowledge." Woman, 63, Bilbao*

*"I like that they focus on an integrated vision of diseases. Normally, medicine fights disease symptoms. If it can be treated from the origin, then a lot of collateral damage that worsens diseases can be prevented." Woman, 58, Madrid*

*"It's important that they're trying to approach the interdisciplinary nature of things and basing it on ethics." Woman, 45, Bilbao*

*"I really like the part that talks about us being a whole, united and interacting from the genome, to the cell, the organ and the complete organism, which in turn interacts with the environment." Woman, 56, Bilbao.*

*“The ethical points of equal opportunities and gender equality are the most important aspects to me and what I liked best to hear mentioned. The point about protecting the animals they use in the tests too.” Man, 23, Madrid.*

**The CRG’s 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 by the CRG.

*“One aspect that I wondered about as well is whether the CRG is under pressure to research those objectives that are most profitable for some profit-making company.” Man, 61, Barcelona.*

*“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.*

*“Who’s really behind it? Foundation? Government? Private or public companies? How do they get money or funds?” Man, 43, Barcelona.*

*“I’m concerned that the most important priority for many of these companies is money, and ethics and values are relegated to secondary or tertiary importance.” Man, 23, Madrid.*

## 3.2 Overall assessment of the areas of research and the projects presented

The evaluation of the CRG’s research projects is very positive. The general public believe these cover different, complementary areas, all of which are highly 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*

*“Really interesting, especially when it refers to words we’ve all heard or experienced close up (cancer, rare diseases, genetic malformation...) and you know that society in general is familiar with them.” Woman, 45, Bilbao.*

*“I wouldn’t opt for any one of the areas as I think they all deserve the same level of interest without neglecting any of them. I have kids and I’m really worried about diseases and whenever I think that a member of my close family could get one of those “unmentionable” diseases, I just hope that the researchers work as fast as possible to cure or minimise the damage and that said cures should be within everyone’s reach and not just for a small few (rich, private insurance, etc....). Man, 43, Barcelona.*

*“I found all four topics interesting, among which I’d highlight organ regeneration and the development of tissues because to give a solution and a response to so many problems that exist in the human body that cause you to deteriorate so rapidly would really be almost miraculous.” Woman, 63, Seville*

In relation to the projects analysed, all held enormous interest for the public because of their link to health and the treatment of diseases. The researchers’ straightforward explanations also contributed to this positive assessment; explanations that, furthermore, made the public feel close to and excited about science.

*“This dialogue increased my curiosity (...). This change was wrought by the researchers’ explanations and the effort they put into them, as they endeavoured to explain things in an easy way that we could understand no problem.” Woman, 19, Bilbao*

*“I’d like to thank all the researchers for giving such excellent explanations in a language that you appreciate when you’re not specialised in the subject. I’d also like to wish them every good fortune and inspiration in their studies.” Man, 43, Barcelona.*

Of all the projects, **the 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.**

PCR testing represents a rapid response to a pressing global problem and reflects the solidarity of those working in the centre.

*“I think that all the research is of great importance to humanity, but today I’d choose the coronavirus detection in first place. The way I see it is that it’s a problem that we are going through and that affects the majority of the human beings in the world and it is causing a huge number of deaths.” Woman, 66, Barcelona.*

For its part, the super synthetic vaccine is an excellent example of synthetic biology put to good use. It’s a clear case of basic research with an important future benefit in curing a large number of diseases.

*“The “Super Vaccine” project is what I’d choose in first place. I think the creation of a “multi-purpose chassis” is really interesting to gradually include all those complements and to fight different bacteria or viruses.” Man, 61, Barcelona.*

*“The synthetic super vaccine sounds to me like the future of preventive medicine.” Woman, 58, Madrid*

*“I think the super vaccine is a fascinating project, and the search for it to cover the maximum number of pathogens would have an incredible effect on the health of humanity which is becoming increasingly compromised by the climate change that disrupts the balances in nature and benefits the development of new diseases, which can lead to pandemics.” Man, 56, Barcelona.*

The project *Can any cell type be generated in the laboratory?* is also considered highly relevant by the majority owing to the possibility of creating cells and tissues.

*“It’s a fundamental piece of research, particularly to obtain stem cells capable of generating any tissue from the human body, application in the possible creation of*

*organs to save millions of people would be an enormous advance for humanity.” Man, 56, Barcelona.*

*“What I find most interesting about this project is the study of pluripotent cells and the possibility of generating any new cell or tissue type.” Man, 62, Madrid.*

*“I think the possibility of creating pluripotent cells is truly “powerful”. (I’m not talking about being God). I think that behind this, a vast world opens up from which to extract a whole load of life-improving projects and understand the process of life.” Woman, 58, Madrid*

The application for the creation of oocytes relates to a very contemporary, close and familiar subject for the public yet, at the same time, triggers a certain amount of controversy from the ethical and social point of view.

*“In this case, perhaps the bias is more moral, particularly when it comes to the creation of oocytes and the dilemma of who sets the age cut-off point for the possibility of procreation. If application focuses on the production of stem cells for treatments and if they are even capable of creating organs, I understand that it could be used to improve the lives of certain people with high purchasing power, and it could end up promoting trafficking of organs.” Man, 56, Barcelona.*

*“I’ve always thought that human reproduction is important and fertility issues affect a lot of women and men, preventing them from having children or meaning they may suffer risks if they have them at an older age. So, really interesting! Woman, 20, Madrid*

*“I find the whole question of assisted reproduction very interesting, but I wouldn’t want it to be a sort of artificial selection, of á la carte babies. When applied to health matters, of course it’s reasonable, but if it’s for beauty treatments or very frivolous choices, it would be very, very worrying.” Woman, 56, Bilbao.*

*“I don’t agree much with this ethical project. I mainly think that it’s aimed at satisfying a whim rather than fighting a disease.” Woman, 54, Barcelona*

Interest in the *Mucin and cystic fibrosis* project is fundamentally triggered by its link to the mechanisms of action involved in certain types of cancer, particularly colon cancer, one of the most prevalent. It’s also a good example of how basic research (the study of a mechanism inside a cell) can help prevent diseases.

*“I also think that regulation of the mucosa is a very interesting project as cystic fibrosis and colon cancer are very frequent diseases among the population.” Man, 62, Madrid.*

For its part, participants find the project called *The what and the how matter in the genome* attractive because, apart from mentioning rare and children’s diseases, it makes the influence of lifestyle on genetics clear. It is a fascinating topic for everyone and they very quickly see applications for healthcare and disease prevention in it.

*“It’s always interesting to know the reason for things. Whether the genetic change is caused by environmental triggers or the individual’s history, it will be possible to avoid these alterations in other people.” Man, 62, Madrid.*

*“I find it fascinating to know that our genetics are less rigid than was previously thought, that they have a certain plasticity. It’s an optimistic view given that, if the environmental and historic conditions influence us, we can intervene to foster changes that help improve the human being.” Woman, 43, Seville*

*“I find epigenetics fascinating, particularly in order to control all sorts of cancers that also affect millions of people. I find it really important to try and counter the damage before it appears and pass it on to our descendants as little as possible.” Man, 56, Barcelona.*

Lastly, *The discovery of something unexpected* project awakens huge curiosity and a certain amount of worry among participants. It also reflects the fruits of combining research and technology, resulting in Artificial Intelligence. Nonetheless, this is the research they find it hardest to see a benefit in as they believe its use is more limited.

*“Very interesting. The application of knowledge found in samples and the time the same are alive for together with the application of artificial intelligence may represent a significant advance in forensic matters and in organ transplants.” Man, 61, Seville.*

*“Really interesting but quite hard. The question of death affects me, but it is spectacular. I think it could be very helpful in a criminological setting, in crimes, the extra support it could contribute to the investigation is great. On a personal level, it perturbs me to think that genes keep on expressing even after death!!!” Woman, 56, Bilbao*

*“This project in particular transports me to films and series about forensic medicine to solve murders 😊. But I think the most interesting part is its application in the preservation of organs for donation.” Man, 62, Madrid.*

*“This discovery is magnificent, demonstrating that cells continue to express after death. Very interesting but perhaps less relevant in terms of benefits”. Woman, 56, Bilbao.*

### 3.3 A good relationship between the CRG and its stakeholders

*“We have a great relationship with the CRG, that I’m very happy with. We share ideas, we share resources, machines and we share hopes.” Stakeholder.*

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.

**Professionals with very different profiles were included: journalists, scientists, researchers from public and private centres, directors of different public and private institutions.** Thus, we obtained a complete, though quite homogeneous, vision in terms of opinions.

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, as we will see further on.

*“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*

*“They are always an excellent source of information, not only to cover all the science they do, but also to understand science.” Stakeholder.*

To sum up the findings related to the perception of the CRG, the public consider all the projects shown interesting and attractive, particularly those with a direct link to disease treatment and prevention. It is again clear that an association with health increases the relevance of the science.

With regards to the concerns, the most significant are those relating to applications of the results that could unbalance the natural way of things or trigger social inequality.

*“I find it fascinating. (...) This is what I expect of science. Studies about what we are made of and how to use the knowledge obtained to improve both health and the treatments of diseases.” Man, 27, Barcelona.*

*“In this case, the criteria I followed was to think about which of these applications I believe could have undesirable effects or could escape the intended application and its controls, I’m worried about altering the natural balance and the consequences doing this might lead to, in spite of the fact that we have the means to predict the results.” Woman, 43, Seville*

*“Anything involving the creation of new cells, interpreting the genome or the appearance of something unexpected has certain risks causing the situation to get out of control, or it may result in other inappropriate purposes or interests focused on certain sectors of the population.” Woman, 54, Barcelona.*

## 4. Basic research

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

### 4.1 A priori, basic research seems difficult to justify

The general feeling is that if research does not deliver immediate and easily applicable results (defining characteristics of basic research) it will encounter difficulties awakening interest and securing support, both from society and investors.

Hence, 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 presenting the basic research concept, **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 suppose that to be able to reach major discoveries, years of work, people, studies, research, tests, trials, errors, investments, etc., are all necessary... and the expected results will not always be obtained. I suppose that they must depart from basic foundations and concepts that need to be mastered to move forward, even if they are small steps.” Woman, 45, Bilbao.*

*“From the basic research we go on to understand and delve deeper into the more complex concepts, to gradually build more important structures. Nothing should be neglected if it has a potential future application.” Man, 65, Bilbao.*

*“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.** Without the knowledge base we have, we couldn’t have monitored infections or developed vaccines in such a short time. The long-term impact of research into basic science done in the past makes the short-term of the applied research possible in the present.

*“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.*

*“There’s a clear need to invest all the resources necessary to generate vaccines and therapies as fast as possible when the disease is causing harm, but I’m sure that if there’s previous investment in studying pathogens that can trigger a pandemic, it will be easier and faster to generate solutions. All of which will result in future savings on resources, minimisation of damages and the suffering of people.” Man, 56, Barcelona.*

*“I think that after what’s happening to us now with the Coronavirus pandemic, investment in research should be priority, it’s a pity that in this country the priority is tourism. Pandemics are going to continue to come into our lives to a greater or lesser degree. We had better be prepared.” Woman, 63, Seville.*

*“The obligation now is to find a cure, a vaccine and/ or therapies because we already have the disease, we’re suffering from it and the hospitals are saturated. But ideally it should not be an “action-reaction” situation. Ideally, there should be investment in basic research to prevent these disasters on a global level.” Woman, 65, Madrid*

## 4.2 Basic research vs. translational research

“From outside” the scientific framework, **the differentiation between basic and applied research is blurred and counter-intuitive**. The term “basic” emerges as a label that, while making sense in the scientific community, loses significance when its definition reaches the general public. Some researchers confess that they also find it increasingly difficult to distinguish between the two types of research; which 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.*

The public sees **basic research as a 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.

*“I think it might all be very interesting, in the short or long term any research or discovery, however insignificant it might appear, could provide the key to a major discovery in the future. And if it is publicised then any scientist in the world can benefit from the experience and talent from the other side of the world.” Man, 61, Barcelona.*

*“Of course, as its name implies, it is basic. Maybe it doesn’t offer impactful and immediate results but that doesn’t mean it’s not necessary.” Woman, 63, Bilbao*

*“When we see machinery, however complex it is, for it to function all the pieces are necessary, and they all need to be fitted together... The most important thing is the fact that it functions, and the fruits harvested. Basic research is the beginning, but it’s essential.” Woman, 50, Seville.*

*“I think that a basic research or study may not be profitable in the here and now, but in the short term it could become profitable because it could save other researchers time and resources, given that they could take advantage of these preliminary research projects for a more complex research or it could open the window to some factor that they hadn’t taken into account but that could affect their research.” Man, 61, Barcelona.*

*“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.*

**What matters to the general public**, rather than the distinction between basic and applied research, **is the obtainment of valuable knowledge for humanity**, whether used today or tomorrow. Thus, why distinguish between the two research types?

*“I find basic research really interesting; I don’t think the fact that it has no immediate practical purpose is relevant, I think of the journey, the development, they’re very important to ramify knowledge and come up with solutions to problems in the long term. I think it’s really positive to support these projects because, in the long term, more open rather than linear research is fundamental, as you can gain far broader knowledge and develop new fields of research.” Man, 33, Madrid.*

*“Knowledge is the basis for any other research type. And that’s why research is a value in itself.” Man, 61, Seville.*

This is why it will be important to communicate the possibilities implicit in acquiring certain specific knowledge when addressing the public in the communication; **to build a story around 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, this is not that easy. What the future application of the knowledge acquired in the framework of basic research will be is not always easy to predict. 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. Nor should they be.

*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.*

### 4.3 The creativity and freedom of the researcher

**The public largely empathises with the basic science researcher.** It trusts the scientists, their criteria and also their decisions when choosing an area of study. It also knows that research requires a great deal of work and dedication and is highly respectful of the effort and timings necessary to undertake it.

*“Science is not a short-term world. Everything requires its due time.” Man, 27, Bilbao.*

*“I am worried about the scientific mind feeling the pressure to achieve rapid results, breaking the concentration on the work being done, which is what really matters.” Man, 65, Bilbao.*

In general, both the public and the stakeholders agree that **researchers must have the freedom to decide what to research.** The scientist’s curiosity and motivation are fundamental for “quality” research.

*“I think freedom to decide is really important, as perhaps their experience or what they’re most interested in is what will most motivate them to keep going and that’s vital, especially in the long term.” Stakeholder.*

Nonetheless, due to the possible social impact of their scientific discoveries and the fact that they are funded by public and private entities, a debate does arise: Should the scientist study whatever they want, even if it is not going to have any social/ economic impact?

*“I think scientists have to have the freedom to choose what to research but, at the same time, they themselves should have clear goals and priorities in their research. It’s not the same thing to research the life of a cactus as it is the life of a disease.” Man, 23, Seville*

The public and stakeholders agree that **the key lies in finding a balance of interests between the 4 main players involved in any scientific research.**

- **The researcher:** must be able to study what motivates them, but must also consider the possible benefit of said knowledge.
- **The centre (the CRG):** must promote research that delivers social and economic benefits, addressing and agreeing on topics with the researchers, for instance: by promoting work groups.
- **The entity that finances the study:** must finance causes that are beneficial for society or social groups in both the short and the long term, respecting science’s timings.
- **Society:** the receptor of the benefits of the research without differentiating between classes or socio-economic status.

In the following diagram we see these 4 players involved in any scientific research and their motivations. It also includes possible actions that could be taken by the Research Centre to find the balance between the different interests.

**Figure 6: representation of the 4 main players and their role in scientific research**



The majority of the proposals include **freedom and creativity as an important source of motivation, but with a certain amount of direction by the centre.**

*“It’s always more creative when you work on something that motivates you. Although I do also understand that multiple lines of research can’t be opened either. Projects are presented and then teams are created to develop them.” Woman, 58, Madrid*

*“In my opinion, the researchers should be given a certain margin for decision-making to choose which types of project they want to carry out, but always prioritising those research initiatives with the biggest contemporary impact. One example of this idea would be the search for a cure for Covid-19, as I think that right now it’s the research that should take precedence.” Woman, 19, Bilbao*

*“It is certainly important for there to be freedom of choice, as long as it is justified within the centre’s guidelines and the research is geared towards the expected results, I imagine that sticking to these guidelines is what balances both needs.” Woman, 43, Seville.*

*“There’s a need to work with scientists who, apart from being scientists, are also aware of the subjects that may have the biggest impact on society, that have a certain sense of social responsibility” Stakeholder.*

*“I think that it’s easy to balance by creating work groups by preferences or interests. This would be possible by mentioning in the beginning what the research topics are, so that the scientists can choose the one they like best or they are most interested in researching to obtain results, and subsequently they should be given freedom to research, as long as they share their results with the group, which at the end of the day is a tribe.” Woman, 22, Barcelona.*

In any case, balance is not only about researching topics of significant social impact. **The public also considers it important to research minority diseases**, even if the benefit is not clear or it’s only going to affect a small sector of the population.

*“The big multinationals already concentrate their efforts on researching fields in which the benefit is bigger (lots of people affected + sales + higher turnover). I think it’s good that the public entities invest in research into minority diseases.” Man, 61, Barcelona.*

*“Minority diseases also need research and government financing as entire families suffer just as much as the families with other more frequent diseases and it’s harder to cope with them.” Woman, 32, Barcelona.*

*“I think that all the diseases should be studied, regardless of the number of people affected, as both studies could be conducted simultaneously, in coordination with other centres. The pharmaceutical companies’ interests are another matter, as they prioritise the most common diseases because they’re more profitable for them. I’d insist on coordinating with more centres, even ones in other countries, to encompass the maximum.” Woman, 54, Barcelona.*

The CRG must also deal with the “fashions” in science. At certain times, there are “hot topics” that are more likely to be funded.

*“I have a doctor who has switched to pancreas because they’re going to give him more financing”. Stakeholder*

*“Right now, anything related to coronavirus is going to get more funding and have more repercussions”. Stakeholder*

*“Coronavirus has to be studied, what I’m afraid of is that they’ll stop researching other things that affect us just as much and are equally important” Woman, 43, Seville.*

In this respect, the public believes that, **as a centre of excellence in basic research, the CRG should choose a multidisciplinary approach in its lines of research rather than being guided by fashions and trends**. It should raise the profile of the types of research it is conducting; particularly in the face of the public administration because this research will form the foundations for any future research:

*“In the field of basic research, the CRG should play an essential role as, since it is almost entirely funded with public money, it should undertake lines of basic research*

*that are not typical, but which could have very relevant applications in the long term”.*  
*Woman, 19, Bilbao*

In times of emergencies and crises such as Covid-19, it's vitally important to re-arrange timings to ensure no efforts are wasted and the rest of the research is not neglected:

*“I think that balance can be achieved through rotating work teams. Each scientist can have their own research interests, as long as they donate part of their time to a research that requires urgent results and practical applications. For example, the COVID vaccine that is so contemporary.”* Man, 27, Barcelona.

Hence, the CRG must focus on those research projects put forward by its scientists within certain “margins of action”, considering the common good and the social benefit as the ultimate goals. It must also continue to promote excellence in the research the centre conducts, organising its scientists into teams to be able to cover as many subjects of interest as possible.

*“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

### 5.1 The funding of basic science is everybody's biggest concern

As mentioned above, funding is the primary concern of the public consulted when it comes to science. And the same occurs among the stakeholders and researchers who experience this problem first-hand. This concern becomes even more pronounced in the case of basic science, as its health applications are not always clear.

In a context of very limited investment in science (as we've seen, below the European average), **the general perception is that we got to a point in which science is commercialised; a short-term conception based on profitability.**

*"This is the big problem with financing. We want investments that are rapidly fruitful, but not all the studies and research encounter the same difficulties. There are studies that can take years of research and major investments." Man, 65, Bilbao.*

*"There's a clear imbalance between the timings of science, those of the investors and those of society. One example is the coronavirus vaccine. Science takes time." Stakeholder.*

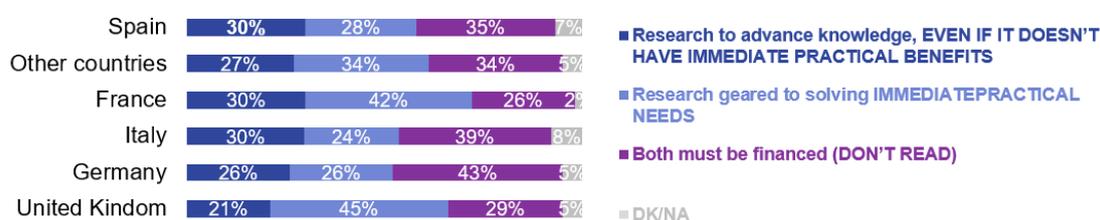
*"I'm scared when I see that while the communication director's profile has traditionally been journalism, it's now closer to marketing director." Stakeholder.*

The public is surprised by the need of the CRG researchers 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 competitiveness." Researcher.*

But the concern and support for basic research funding is not just in relation to 2020 and the post Covid-19 era, or unique among the participants in this public dialogue. According to BBVA's Report on European Values completed in 2019, the data shows that the **Spanish people were already willing to support basic science even before the pandemic.**

**Figure 7: Opinion on types of research to be publicly funded by country**



30% of the Spaniards considered that basic research should receive public funding and 35% believed that both research types (basic and applied) should receive it (BBVA Study, 2019).<sup>8</sup>

<sup>8</sup> Question asked: "Which of the following types of scientific research do you think should receive public funding?"

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.** And, of course, they should not be mutually exclusive.

*“The CRG must open up and be proactive in the private world.” Stakeholder.*

*“In general, there’s no objection to private funding in a public institution, as long as the essence of the research or the organisation’s objective is not perverted.” Stakeholder.*

*“Public funding should be ironclad, and private should be added on, not rendered equals” Stakeholder.*

## 5.2 Public vs. private funding

The public establishes significant differences between public and private funding right from the beginning:

- The overall perception is that **public funding tends to be less demanding in terms of timings and is not so clearly pursuing profitability.** It is associated with more freedom and less pressure. This leads the majority to conclude that **it’s the right type of funding for basic research.**

*“Basic research, as it’s primordial, is not at all attractive in profitability terms. That’s why I think it should be supported and funded by state/ official research bodies.” Man, 62, Madrid.*

- In the private setting, however, the view shared by public and stakeholders is that rapid results and profitable research projects are expected, meaning it is associated more with translational research.

*“It seems obvious that to deal with complex problems, it’s necessary to know all the basic concepts, but I also understand that if the investments are private, they have to try and reach profitable results in a reasonable period of time.” Man, 62, Madrid*

However, according to the stakeholders, private companies also demand basic research, and collaboration between these companies and the research centres is a reality in other countries.

**Breaking this public funding-basic research and private funding-translational research association could help the CRG to find new funding options.** The objective needs to be to forget these associations and dichotomies and, as we mentioned above, to find a balance of interests between the 4 main players involved in a research project (researcher, centre, funding entity and society).

## 5.3 Funding options for the CRG apart from public funding

Both the public and the stakeholders approve the following funding options for the CRG: collaboration with private companies, creation of start-ups under the CRG umbrella, sponsorship and philanthropy.

- **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.

Some stakeholders indicate that if the alliance with the company proves fruitful, the continuity of the projects and researchers will be guaranteed and, at the

same time, more talent will be attracted. One formula for this collaboration could work along the same lines as company-university chairs agreements.

In short, **collaboration with private companies could help bring their projects down to earth**, taking the CRG (and its basic research initiatives) closer to the people and their real needs.

*“Of course I think that the CRG should also collaborate with private companies to create opportunities, as otherwise the application of these clinical results would be more difficult.” Man, 27, Barcelona.*

*“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 only limit to this type of collaboration has to be the centre’s ethical code.**

*“The CRG must be open to any type of collaboration that a study or scientific advance can lead to, whether with public or private companies, but it does need to have a very clear idea of where to draw the line in the research (let’s call it code of ethics, or whatever you prefer). Woman, 45, Bilbao*

- **The creation of start-ups under the CRG umbrella is applauded by everyone** as they consider the foundation of new private companies very positive. 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 fact that these companies are created using public money is not a problem** for the majority, 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.

*“When it comes to the public investment in funding research, this should be done, as we live in a country that invests very little in research and development. I think it’s a fundamental driver for the motivation and creation of private companies which, at the end of the day, would improve the country’s economy and depend less on other economies. Many researchers educated here are forced to go abroad to keep working.” Man, 65, Bilbao.*

*“In principle, I’m against using public resources for the creation of private companies but there are always exceptions. And this could be one. As long as there is maximum control over the use and purpose of these public resources.” Man, 27, Bilbao.*

*“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*

To avoid any grey areas, **it is essential to be absolutely transparent.**

*“I agree with it being financed with public money, as we, the general public, will be the beneficiaries. What I would like to know is if these private companies discover the SUPER VACCINE, will we have to pay for it as occurs with so many of the children’*

*vaccines or has the state already made sure that whatever is discovered will be in benefit of everyone, without additional costs?" Man, 43, Barcelona.*

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**. Thus, the centre will have to control what's done with this public investment and supervise the advances and results that will also be at their (and everyone's) disposal. The stakeholders also add the 'ethical supervisor of the research' role to these functions.

*"I understand that the role is, on the one hand, to provide technical support and control of the research and, on the other, participation in the achievements and benefits obtained." Woman, 43, Seville.*

*"When funds are put into a start-up, the first thing done is to verify its viability plan and the level of interest of the project. Once it has passed this filter, invest the funds and supervise the advances. And, of course, control that the funds are being invested in accordance with the project plan." Woman, 58, Madrid*

*"It could be that of ethical supervision of the project and, should the project be successful, also be a beneficiary of this success. It would be the same as with elite athletes, that the club that trained them receives a part in exchange for the training." Man, 61, Barcelona.*

*"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.

*"The achievements of the companies that grow under the umbrella of the CRG must revert to strengthen the institution. On the one hand, to support the research and on the other to create new companies as new projects arise. I suppose that one of the CRG's fundamental tasks is to achieve balanced, though not equal, distribution of the profits between both options in order to keep the whole structure stable." Man, 56, Barcelona.*

- Finally, the participants in this public dialogue approve the idea of the **CRG turning to patronage and philanthropy to fund its research**. They are all thinking of the major American fortunes that donate a considerable part of their returns to research or campaigns aimed at fund-raising or crowdfunding as a formula to achieve financing.

In their opinion, the CRG together with the scientific community, should fight to incentivise these donations to science by making them tax-deductible or including them as a deductible option in tax returns.

*"I consider the possibility of carrying out this research essential and if all the entities can contribute, then all the better. It's so important, that a part should be donated in your tax returns." Woman, 63, Seville.*

*"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.*

## 5.4 Aspects to take into consideration in relation to funding

Although they all consider a big variety of channels valid to obtain funding for the CRG's research, this does not mean that anything goes to get a project financed.

Thus, it's important to **define a series of evaluation criteria for a project to receive funding**. For this purpose, some stakeholders propose a review and update of the current measures.

Along the same lines, the participants in this dialogue speak of **supervision or control mechanisms and success indicators** that would provide a valid and objective evaluation of whether a project is reaching its goals and should continue to receive funding, or on the contrary, is a project that has dried up. This aspect gains particular relevance for the basic research projects which tend to be long-term.

*“Both the CRG and the government or the companies that offer finance have to have staff that, apart from giving the money, ensures that it is really used for what it was given and supervise whether the established criteria, timings, extensions, etc., are complied with.” Man, 43, Barcelona.*

*“The time used is not an indicator that the project is not going to achieve its main goal, and therefore, other types of mechanisms that could reliably indicate whether the project really has any future or not needs to be found.” Woman, 19, Bilbao.*

Lastly, and given that funding and ethics are closely connected, the stakeholders demand **maximum transparency and faithful reporting throughout the whole process**. This will eliminate any shadow of doubt about potential conflicts of interest.

*“Given that financing and ethics go hand in hand, who is funding, what they're funding and how they're funding always needs to be communicated transparently.” Stakeholder.*

## 5.5 Should the CRG invest resources in getting private funding?

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.

*“It's part of the CRG's unfinished business” Researcher.*

*“Yes, resources need to be invested, yes with people who know science and who know how to sell, “we don't know how to negotiate in Spain”. Stakeholder*

They all envisage **commercial profiles with a science background and objectivity acting as a “bridge”** between scientists and the entities or people funding them.

*“This is the cornerstone of any company (...) Personnel that navigates constantly through all the possible networks (governments, Europe, private companies...) is necessary to secure the money they really have and don't want to spend. That's why it's necessary to be a veritable Wolf in this field.” Man, 43, Barcelona.*

*“They need a panel of experts, not scientists, who spend their time searching for possible companies that might be interested in the research projects. A control group that maintains its objectivity and not the bias of the research, even if funded privately.” Stakeholder.*

In short, all those consulted believe it is essential to obtain funding for science, that resources need to be allocated to it and all possible channels explored. In this

respect, they mention recommendations that range from lobbying to have science introduced into parliamentary life to diverse marketing and communication actions aimed at the general public. These ideas will be covered in the last chapter of this report.

*“I’d try to secure more government funding either directly or indirectly (apart from the grants, with tax deductions for investment or a donations box to tick on the tax returns form) and I’d involve society in general more by making the benefits of the research known. I’d continue with the collaboration with other entities and of course with the creation of start-ups that could be converted into companies with profits that return to be invested in research.” Woman, 58, Madrid.*

## 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.*

### 6.1 To begin with, genetic engineering is a “delicate” area

To present the CRG to the general public means, among other things, to speak of genetic engineering and synthetic biology. This is an attractive field that awakens expectation and opens up a world of opportunities, making the apparently impossible possible; **it sounds almost like science fiction.**

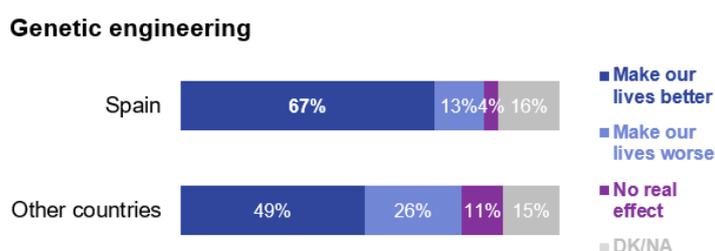
Apart from being attractive, **genetic engineering is a very relevant and highly valued field of study because it may serve to cure and prevent diseases or even create synthetic vaccines.**

*“Regarding synthetic biology, I see that it’s trying to create other different alternatives to those that exist in nature, making it possible to programme these cells or micro-organisms to cure diseases. But I also see another really essential line of research. I think that currently diabetes is treated with synthetic insulin, that was a very important invention in its day, as the body didn’t create enough on its own.” Man, 65, Bilbao.*

*“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.*

What’s more, according to 2019 data, **67% of Spaniards believe genetic engineering will improve their lives**, reflecting a positive opinion of this research type (BBVA Foundation, 2019)<sup>9</sup>

**Figure 8: Opinion on the effect of genetic engineering on our lives**



Nonetheless, it is important to remember that 13% state it will worsen their lives. This data confirms what we found in this dialogue: **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?**

In this sense, **transparency and correct communication when spreading awareness of the scientific results and future findings is fundamental.**

<sup>9</sup> Question asked: “I am going to read out a list of technologies and scientific applications. I would like you to tell me if you think this technology or scientific application will make our lives better, worse or have no real effect on our lives.”

*“I don’t believe there can be limits in the research, but there can be in the application of the research.” Woman, 63, Bilbao.*

*“It’s quite a pioneering technique, but I think the key in this field will be where to place the limit, who or which body determines whether it is ethical or not. What will be permitted and what won’t, will we be playing “God”? Man, 61, Barcelona.*

*“I believe all the research on DNA, the genome has a huge responsibility. We’re talking about leaving the most valuable information about the human being in the hands of the human being. We are the most generous and perverse beings on the face of the earth.” Woman, 58, Madrid.*

*“I think that any genomic discovery would give us privileged information that could have a direct impact on people and could be used to harm the individual if not really well regulated.” Woman, 54, Barcelona.*

*“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.*

## 6.2 The limitations of ethics in scientific research

Everyone agrees that **limits governed by more or less “objective” ethical principles must be imposed**. A task perceived to be particularly difficult.

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**. Nonetheless, dialogue is considered essential and the main tool.

*“I suppose that there’ll be a whole ethical battle behind this engineering on what can and cannot be done, where the limits lie... but I also understand that without research no results will be obtained. This “code of ethics” would have to be well regulated on a global level, without leaving any cracks especially for profiteers.” Woman, 45, Bilbao.*

*“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.*

In any case, the “limits” of what can and can’t be done and who should be responsible for setting them are subjects of heated debate.

*“I totally agree. It’s something that is not limited by either science or by Law. And in the long term that could lead to a lot of conflicts. Nobody knows what line should not be crossed in the area of genomic engineering, but, like another one of our colleagues rightly said, there’s no opportunity to be lost in research. So, this gap should be used to do some good for humanity” Woman, 19, Bilbao.*

*“The limits in gene edition are set by the researcher. If it’s done to help cure diseases and improve human or animal quality of life, I don’t think there should be limits. Another question would be research with war-like intentions (bacteriologic warfare)”. Woman, 28, Seville*

So where do the limits lie? Although there is no clear and objective response and it depends on each case or research project, it would appear that **the limits revolve**

around two variables: the purpose of the results (or their motivation) and use (or implications).

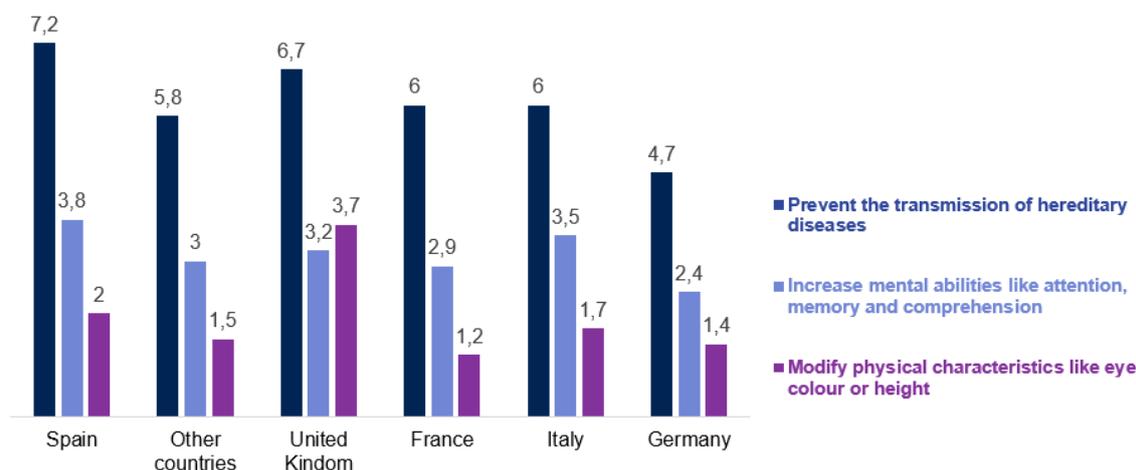
Not all purposes are ethical or morally acceptable, and there may be “collateral” results that are not positive for society, so... when do the ends justify the means?

For example, according to the Values Study by BBVA in 2019, **58% of Spaniards accept in vitro fertilisation as morally acceptable**, giving a score of between 8 and 10 (on a 10-point scale where 10 means completely acceptable). Nonetheless, this acceptance could change if the context were to evolve, if the fundamental rights of others were put at risk, or directly harmed; for instance, in the case of surrogacy motherhood.

*“I think that what is wrong is to apply advances in any matter that are harmful for the planet... example: in vitro fertilisation is really good and even when I heard for the first time that a woman was going to carry the embryo of other people thanks to love and generosity, I was deeply moved, but when this situation became the use of women as surrogate mothers with all of the implications of this, pure business, mafioso practises..., it’s at that point that it becomes negative. And I understand the frustration these people feel about not being able to have a biological child of their own..., but maybe the gestation of a dehumanised human being should not be purchased from the woman gestating it. (...) Every fibre of my being rejects that practise.” Woman, 63, Bilbao.*

In addition, **the limits also become apparent when the motivations behind scientific advances are not considered important or relevant enough**. According to the data, genetic editing is accepted if conducted with a view to preventing hereditary disease transmission (obtained a score of 7.2 out of 10). Nonetheless, this is not acceptable if the point is to alter physical characteristics such as eye colour or height (rated with a 2 out of 10) (BBVA values study, 2019).<sup>10</sup>

**Figure 9: Opinion on under which circumstances the genetic alteration is acceptable or not**



Thus, **not just any purpose is valid for the public, and those that improve the life and health of human beings will be accepted more**. Any purpose that could be considered “capricious” or not perceived to be a real need, will be subject to criticism and debate.

*“It should be done, but only to improve diseases, not for frivolous or aesthetic improvement, or personal wishes, these would be very inappropriate implications,*

<sup>10</sup> Question asked: “To what extent do you think the genetic alteration or editing of embryos is or is not acceptable in order to...” Average on a scale of 0 to 10, where 0 means “completely unacceptable” and 10 means “completely acceptable”.

*associated with money and the possibilities of obtaining genetic improvements. It doesn't worry me much, I trust the professionals working in this, and in their good management." Woman, 56, Bilbao*

### 6.3 Researchers, centre and society: roles and positionings to take into consideration when it comes to scientific ethics

#### **The public trusts the scientists and believes the majority would act ethically.**

Which is why some say these matters need to be left in the hands of the professionals in question.

*"I believe this is unavoidably the future. I trust the people doing the research, I have no ethical qualms with the subject, because ethics are needed in every field in society. I'm not going to get all het up about genetic engineering. Of course, there are things that are valid and things that aren't, but that could be said of all the sectors. Why would I distrust the people doing research so much and not my primary care physician, for example? (...) The limits are set by the professional person, that's what they're trained for, them and internal and external control groups. I'm not in favour of such an inquisitive examination of research." Woman, 56, Bilbao.*

*"I can't answer these questions (on ethics) because of a lack of knowledge about them, but I trust in the professionalism of the vast majority of scientists." Man, 61, Barcelona.*

*The scientific community will always be a step ahead of general society's mentality. Keeping distances, the same mindset or ethics do not exist in all countries everywhere. I think that the scientific community must know how far it can go and what's good or bad for humanity. The scientific community needs to decide. A Multidisciplinary Board could exist (made up of different scientific professionals, psychologists, sociologists, etc.)." Man, 61, Barcelona.*

Likewise, **dialogue and the obtainment of different opinions of the ethical issues are considered fundamental.** The public, researchers and stakeholders all consider it important to gather society's point of view so that these limits are adapted 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.**

*"I don't know who should decide, but the research put forward to the organism that approves and finances it is decided by a committee of experts that is advising the government in power at the time... Experts with different opinions would need to be consulted first and a social debate opened." Woman, 63, Bilbao.*

*"For research with a social impact, social players that study society's behaviour should intervene. They know better than anyone if society is ready for this type of research." Man, 27, Barcelona.*

*"Maybe they could create a consensus, do surveys among society, but the experts and the Government that would give the financial support, the grants, should have the last word." Woman, 65, Madrid*

*"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.*

The existence of trust in the scientific community and in researchers does not mean that the public is not demanding. They sustain that **since researchers are equipped with knowledge and the advances are in their hands, they must play a more active role and actively partake in any ethical issues that might arise from their research**. It is important to the stakeholders and the public 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*

**The researchers consulted are also in agreement with this demand from the general public and stakeholders. They are willing to take responsibility and play an active role in this matter.**

*“it’s a good reflection (...) in the end, technique and science evolve very fast, and since we are the ones who are there maybe we should get a little more involved (...) I also see it from my point of view of basic science that is perhaps a little different, that in the end the ethical issues you come to touch are not as relevant as working with human embryos or patients”. Researcher.*

*“I agree, I believe that as researchers we are responsible for what we do and we cannot skip the ethical foundations of society simply because our purpose is different (...) I also think that maybe things can change (...) I think over time technology is changing a lot, then we have to do this task of explaining things well so that people understand them, because maybe then the perception of the public will also change, and then the ethical concept on certain topics may change (...) technology can not stop and less in the 21st century, everything will go forward, but we must learn to explain it well, to lead this ethical debate in which we must be responsible, obviously, and we must be responsible for knowing how to explain it, I think that this is part of our responsibility, it is very important, because maybe then the debate will be more open and maybe we will reach different conclusions than we would have reached”. Researcher.*

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**, involving different profiles (including the public) to obtain a diversity of opinions.

## 6.4 Values and ethics within the CRG

Researchers cannot have a proactive attitude to ethics if the centre they work in doesn't support them. Hence, **the centre must provide scientists with a series of values, “ways of working” and tools to ensure no ethical issues or problems arise when it's too late.**

In this sense, the CRG plays a key role as a centre when it comes to conflict and problem management, not just in relation to its research but also among its researchers. The public and stakeholders consider it important:

- **For the CRG to have ethical and moral values that are met with both on the inside and the outside**, for example, an internal code of ethics, like the one that it already has.

- For there to be **internal discussions about the research projects**; debates involving different profiles.
- **Creation of a multidisciplinary committee** that serves as a consultant or adviser in certain moments.
- **Attention to diversity**: there should be representation of different cultures, ethnic groups and genders in the CRG to enrich debates and respond to the need for a more “universal” ethic.

In addition to these demands, **they take for granted that codes of ethics with technical requirements are already in place and applied to ensure that no morally or ethically questionable actions are carried out.** They assume, for instance, that there are regulations and laws to guarantee the confidentiality of the data given.

*“All that data given to the research companies is in danger, as any hacker could steal it and spread it. Logically, there are specific confidentiality laws.” Woman, 19, Bilbao.*

*“In this case, the criteria responds to the massive amount of information we can cede to research, and to the use made of it if it reaches third parties who do not comply with a code of ethics that should exist. I believe that the creation of a very solid and broadly agreed legal framework is essential, with severe consequences for the organisms or companies who fail to comply with it.” Man, 56, Barcelona.*

In fact, **the public trusts in it and would be willing to share their genetic data and information.** All they ask in exchange is to be informed of how the information would be used.

*“Categorically yes, I would cede my data. In the end, I trust that the researchers are not going to spread any confidential data around and everything will be used solely for the purposes of science, and in the end it’s important for all of us to be aware that data is needed to advance and study. So, I would definitely share everything.” Woman, 20, Madrid*

*“I would be willing to share my health data and information to advance in research, as long as I am informed about how this data is going to be used, for what, how they’re going to use this personal information, what their objective is and how advanced the research is.” Woman, 22, Barcelona.*

In any case, **when data is “donated” to science for a good cause, they don’t tend to ask questions or question the use of this information by third parties.**

*“What if your data ended up in an insurance company and they could use it to charge your children more for their insurance policy?” Researcher*

*“The truth is that I hadn’t thought of it, I understand that I donate my genetic information precisely for this and that there are laws to protect it.” Participant from the general public (mentioned live in an online session).*

Again, the general public’s trust in the scientist does not mean they don’t demand an internal debate to ensure action guidelines are put in place that go beyond the current regulations.

In addition to data management, another issue that arose during this public dialogue is the use of animals within the framework of scientific research. It is a controversial topic and, while accepted as inevitable, it is increasingly “regulated”

*“They are putting more and more restrictions on us for testing with animals”. Researcher.*

The issue of animals is interesting as an example of how society’s values have changed over time and how stricter regulations and requirements have been

implemented for the “use of these animals”. When values change, pressure is applied, debates take place and regulations are amended.

In short, ethics in science constitute a tricky issue to cover and to do so from a totally objective perspective is impossible. Every ethical or moral issue that arises is unique and different to the one that came before it. Plus, it is volatile and changes as society’s values advance. This is precisely why it’s important to uphold an ongoing dialogue in time without deadlines. The dialogues, advice and committees proposed here must all have representatives from different backgrounds, including society in general.

But in this context, it’s important to remember that the most knowledgeable players and those most interested in advancing research are the scientists themselves. Which is why informed researchers with an awareness of the different implications of their research are demanded. They should have considered and formed opinions and be capable of communicating these in a one-to-one dialogue with society.

## 7. Communication

*“I am honestly grateful for them making us participants of these studies as none of us participants had a clue about them and I’d just like to say it would be great if they’d continue with this campaign to spread their work. I’d also like to thank everyone for giving us such an excellent explanation in a language comprehensible to non-specialists like us. I wish them every good luck and inspiration in their studies.” Man, 43, Barcelona.*

### 7.1 Taking advantage of the moment

Over the course of this public dialogue, it’s been made very clear that **the public is open to science**. We are at a point in time in which people are eager to know more about what’s being done and what the consequences for the health and wellbeing of everyone might be. To communicate these aspects is, moreover, essential to obtain funding from sources other than public entities.

As a result, the key need to bring the two worlds close to each other and break prejudices from both sides is clear. **It’s time to be transparent and communicate on a “one to one” basis with an increasingly empowered public**. Some stakeholders go even further, stating that it is an ethical obligation to spread science.

And this is precisely the goal of Open Science, the new paradigm that promotes the idea that science needs to be open, transparent, collaborative, accessible and made with and for society.

On this point, some stakeholders are critical and mention a certain “lack of interest” among the CRG and the scientists in spreading their research beyond the scientific community. The researchers, for their part, explain that their work structure and professional success assessments are not designed to include time dedicated to spreading and communicating their work. The priority is to produce and for the results to reach the scientific community:

*“Of course, the problem is that we are assessed by the number of publications. Our obtainment of funding for a project is precisely dependent on the number of publications, quotations and the scientific journal they are published in.” Researcher*

Within this context, a series of questions need to be asked with a view to designing the CRG’s communication strategy. That may serve as a guideline and should be answered according to the results of this public dialogue:

- **To WHOM do we need to communicate?**
- **WHY communicate? WHAT do we want to achieve?**
- **WHAT do we need to communicate?**
- **HOW will we communicate?**

## 7.2 To WHOM? Science needs to belong to everyone.

The commitment to Open Science implies communication to all the targets of interest to the CRG: direct collaborators, scientific community, governments and institutions, investors and society.

According to the participants, with regards to the public, **the efforts have to be aimed at everyone**; both people who are interested in and closer to science, and those who are more removed from it; the children and younger target but also the older.

*“The need to reach people interested in science is clear, but so too is it important to reach those who might be interested but don’t know it because of a lack of contact with these subjects and news.” Stakeholder.*

*“It’s obvious that we need to start at a school age: give young people the opportunity to think. On the other hand, more emphasis should be placed on the media too.” Stakeholder.*

They are very different audiences, so it’s necessary to segment them and design the best strategy for each one of the resulting segments.

## 7.3 WHY? Awareness as the first goal.

The goal of this project is to explore the channels used to incorporate the ideas and perspectives of the public and stakeholders into their research strategy for 2022-2026, in which public engagement is an important communication goal.

But before achieving this goal, **it’s essential for the centre to become better known to the general public**; it’s necessary to reach as many people as possible and to use different channels to do so. The participants in this dialogue fundamentally speak of:

- **Education centres:** schools, secondary schools and universities. It’s vital to reach the youngest targets and awaken curiosity about science and the CRG research projects among them. The school and university contexts could be one channel.
- **Traditional mass channels like television and press.** Nobody questions the importance of these channels to create an impact on a lot of people at the same time and become a phenomenon of the masses.
- **Digital channel:** websites and, fundamentally social media (“upload” the advances online). It’s a global and universal channel that offers a great many possibilities, not just for communication, but also to listen and to dialogue.

*“The centres such as the CRG must create training programmes for education in science, small things like webinars for primary school teachers to show them how to communicate the scientific method, a science and ethics programme for secondary school students.” Stakeholder.*

*“In my opinion, this type of information should be spread through basic education, both in the primary and secondary schools, and should be renewed each year as science is constantly changing. For more adult people, who don’t go to a school, it would need to be communicated via social media and newspapers, as these are the most frequent channels in their everyday lives. Put them on the front pages of the media in large print so that they’re perfectly visible and draw the eye of the readers. The advantages of this mass media is that it’s within everyone’s reach, regardless of age, countries, and sex,*

*meaning it will definitely extend knowledge about these subject types far more.”  
Woman, 19, Bilbao*

*“Since TV and the Internet are the most active means of communication nowadays, it should find an attractive and effective way of presenting these studies, something that appeals to people and at the same time serves as funding. Like... Documentaries, programmes/interviews, etc. Man, 32, Seville.*

*“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*

## 7.4 WHAT? Message to be transmitted

The stakeholders believe that no efforts are made to ensure basic research reaches society in general. They are convinced that it’s necessary to be educational in the communication of science in general and basic science in particular, and to raise its profile by highlighting its benefits.

*“It’s essential to design programmes to educate the part of society not close to science in the beauty it holds.” Stakeholders*

The researchers consulted agree with this and mention that communicating is their duty.

*This year, with all this of the coronavirus, there is so many people communicating scientific concepts without any rigor at all that I am a little bit annoyed... also I feel like starting to explain things well, so that people can understand (...) also it is a duty we have at the end, we are paid also, not only for doing, but also for communicating why we do and which impact it can have in society...” Researcher.*

Moreover, they believe **it’s essential to break away from certain prejudices and associations to give the public a more “realistic” view of science:**

- **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 in this case.
- **Science is not “exact”** and does not always lead to positive outcomes. Science is curiosity and questions; learning from errors and it takes time. It is essential for the public to know how science works and to be familiar with the scientific method, which also means communicating the negative outcomes. There’s a need to be transparent and honest.  
*“The truth needs to be communicated; not made-up applications.” Stakeholders*  
*“There is no teaching, it’s all about us funding applied research but not basic research” Stakeholder.*

- 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.** It’s necessary to put faces to names here, to tell stories and show that they are human beings just like everyone else.  
*“They should find the “heroes of science” and use them to spread science and make it natural.” Stakeholder.*

*“The scientists themselves should be like the Messi of basic research” Stakeholder.*

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. Of all the diseases, cancer is the one that attracts most people due to its high prevalence.

*“Specifically, they should highlight the research into diseases that we can observe in our everyday lives among family and friends, as it’s something that affects us personally and that we’d like to know more about.” Woman, 19, Bilbao*

*“I think this research is very easy to understand and very interesting for the general public, meaning it could be communicated through public television. The most important advantage is that it’s about cancer, which is an issue we’re all interested in and worried about. It is important to highlight that such basic research about colon cancer could help a lot of people suffering from this disease.” Man, 48, Madrid.*

*“The fact is that our society is capable of building an incredible skyscraper but we still don’t know a lot of the most essential information about ourselves (genes, cells, context...). We need to know our essence in order to be better.” Man, 61, Barcelona.*

Making these research studies known and highlighting their benefits and applications will also help the centre obtain more funding.

*“The main message to be communicated would be the need to always keep supporting science in general, showing that it’s the only way to guarantee social progress, and engage the maximum number of people in every possible way to make it a reality. Always communicate truthful, optimistic and positive messages, on the course of past and present scientific studies and the specific applications some have resulted in or others expect to reach.” Man, 56, Barcelona.*

**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.**

*“In order to be able to explain everything much better, not only the science which is very important but also how all the system works both in terms of funding and of publications, which maybe was more difficult for them to understand how it worked, how we prioritize one research above another one (...) all this is very cool and it would be great to be able to explain it much more (...) the CRG is doing it great, but it would be good to implement it in all the other institutes.” Researcher.*

*“Totally agree, in the end it is important to put faces and that people see who is behind (...) often the only one who has more visibility is the Group Leader but not all the people behind who have been working for months, who have their own motivations”.*  
Researcher.

*“It is important, because in the end this profession is very vocational, and showing what moves people to come to work every day and try to know more is important... yes, I think it’s a good idea, actually (...) and also for the new generations to come, role models can be completely different from those projected”. Researcher.*

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

*“I think the human part is really important. Reading about a research study is not the same as listening to the person who conducted it.” Woman, 63, Bilbao*

Additionally, **a gender equality policy needs to be communicated** as it is very highly valued by the participants in this dialogue.

*“It’s important to promote equality in scientific leadership positions and to communicate the figure of the scientist both inside and outside the scientific community.” Stakeholder*

This leads us to conclude that apart from the research being conducted, **it is essential to communicate initiatives in relation to social responsibility to project a friendlier more diverse and ethical workspace.**

## 7.5 HOW? Using simple “one-to-one” language that goes beyond the context of science

**Humanising and “democratising” science gives rise to a need to be proactive and move closer to the public by speaking their language**, avoiding technical terms and simplifying, but without going so far as to be banal or **losing sight of the real complexity.**

*“The simplicity with which the researchers explained their projects on the videos. They explained it in such a way that it was really easy to understand. The advantage is that it could reach ordinary people and they could understand it. I’d highlight how easy it is, for the moment, to understand the projects.” Woman, 56, Bilbao.*

*“The language used needs to be simple and educational, but without oversimplifying.” Stakeholder*

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 is necessary for the communication of science to be realistic and transparent.

*“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.*

*“It’s really important to avoid making overpromises to prevent false expectations.” Stakeholder.*

Moreover, to foster public engagement a story should be built; **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.*

The stakeholders believe it’s necessary, therefore, **to emphasise the creation and diffusion of educational contents**, while also going beyond the boundaries of science itself:

- **Through collaborations**, for instance, with similar brands, artists, videogames on TV, etc.
- **Participating in series, documentaries or films**; make the leap to contents for the masses in which scientists play a starring role.
- **Generating easily transmittable and viral contents**; that spread science not fake news.

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.

*“It would need to be communicated via the online media, communication channels, press and radio. On the other hand, each research team could use certain social media such as Instagram to upload the new results explained by the researchers themselves, as they would receive extra support and would feel more energy to keep researching the project they had on the table.” Man, 27, Barcelona.*

## 7.6 Open Science and Open Access

Open Science has also been put to debate in this open dialogue. This is promoted at the CRG with a view to making its research more collaborative, reproducible, and accessible, and to engage all levels of an inquiring society. Their main activities focus on Open Access to Publications and the CRG Open Science Projects.

Open Science aims to open up the research process by fostering open access to publications, open and fair data, open tools, open peer review, research integrity, stakeholder engagement and citizen science.

The CRG is committed to providing Open Access to all its published research believing that fast, free and unrestricted access to scientific information is a key driver of progress, which ensures that research benefits the widest possible audience and contributes to accelerated discovery, public enrichment and multi-disciplinary innovation.

When the public was asked about this new way of doing and communicating science, the answers reflect their complete agreement. **They all concur 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 contributes to being more transparent and **increases the public’s trust** by telling them 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. The collection of data and research studies is also another way of **validating and checking** techniques, methodologies and analyses.

*“I believe it’s really important for the project to be published and available, as this will really help future research projects. Additionally, every time it is used, they will quote this project, giving it even more reliability and validity. Obviously, there may be risks of plagiarism or copies of this project, but the pros outweigh the cons, as in the future it could save time and work. You don’t start from scratch, but rather there would be a starting point, which would be this project, to improve on it or create another project.”  
Woman, 22, Barcelona.*

4. It fosters **cooperation** between scientific teams rather than competition. This would also result in more rapid advances.

*“In the face of matters of general interest, and when the research is done in official entities, they should be published. I’ve always thought, and even more so in the current times, that when faced with challenges as serious as the current Covid 19, that it would make a lot of sense for all the researchers all over the world to work together rather*

*than a lot of laboratories working individually to find a solution, patent it and sell it before its competitors do.” Man, 62, Madrid.*

*“One of the cornerstones of the CRG is scientific dissemination to inform the biggest segment of the public possible and foster citizen participation. There could be risks, for instance, of the results being used by private companies to continue the developments, but in the end the benefits will continue to go to society in general. There may be brilliant scientists inside and outside of the CRG, and they should all give their best. Maybe a Project could become stagnant in the CRG but get developed outside of it, which would also ultimately be a benefit.” Man, 56, Barcelona.*

*“I think it’s important for every field of science to work on an open basis, we think better together than in isolation. The risks are the harmful applications that could result from dissemination (bioterrorism) but even so, I think it’s more beneficial to share results with the scientific community.” Woman, 43, Seville*

**These benefits of Open Access make up for possible risks**, which include: plagiarism, manipulation and the use of the results in an unethical way by third parties.

The participants of the dialogue call for the national or international entities responsible for safeguarding the security and ethics of the scientific community to control these types of activities. **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 this regulation is complied with.**

*“Obviously, in these circles the ethical use made of the knowledge shared is always going to be a controversial topic. The role of the CRG and the researcher has to be to safeguard, in as far as possible, the compliance of a code of ethics previously drawn up with the biggest possible consensus of the parties involved. That’s where the quid of the question lies, who will draw it up and how, and who will watch the watcher...” Man, 56, Barcelona.*

*“In the last session I learned that the results of a research can be patented before making them public with a view to preventing misuse by third parties.” Man, 62, Madrid.*

*“In the event of patent theft and moreover for unethical use, it would have to be considered a company and a humanity crime”. Woman, 63, Seville.*

*“With regards to the unethical uses, the governments should be the ones to regulate the circumstances in which the results of these research projects can be handled in order to prevent potentially harmful uses for life.” Woman, 43, Seville.*

In short, the CRG’s commitment to Open Science obliges it to also be proactive in science communication. The centre and its researchers must dedicate time and resources to generating educational contents and participate in actions that favour a “one-to-one” dialogue with the general public and their stakeholders.

## 8. Conclusions and recommendations

*“Fellow adventurers, it’s been an enormous pleasure to share these sessions and questions, the opinions and information we share help us grow. We’d like to extend our thanks to the CRG too for this opportunity, and to the scientists that have impassioned us with their projects and explanations. Thanks so much!!!” Man, 56, Barcelona*

### 8.1 Why a public dialogue?

The majority of the public found the public dialogue experience highly satisfactory. It not only awakened an interest in science, but also succeeded in overcoming obstacles and prejudices.

*“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*

*I’m really impressed and my interest has increased considerably. After getting to know the CRG I’m going to take a bigger interest in research and projects being undertaken in our country that we often have no idea about.” Woman, 33, Madrid*

*“Thanks to our talks with the scientists, I’ve glimpsed the very essential role they play to help us advance as a society”. Woman, 43, Seville*

*“The journey to the CRG has served to raise awareness of the work done by the scientific community, work that has not been explained enough to date to the vast majority of people, and the need to support the search for resources to allow this work to continue for many years to come. It has also served to show the importance of studying the smallest part of us all to achieve large-scale balance. And all of this thanks to the information they’ve provided us with, that is so important for making worthwhile decisions.” Man, 56, Barcelona*

The researchers consulted were also satisfied with the experience, claiming they found it very enriching and helpful in changing their perception of how the public sees them.

*“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.*

*“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.*

*“What I gained is asking me questions that in my day to day I would never ask myself, and having the opportunity to see a problem from different perspective (...) a little bit of reflection from a social point of view of the scientific community...” Researcher.*

*“that I was telling you about the final discussion, when we talked all of us, all these possibilities to do outreach (...) the brainstorming was awesome” Researcher.*

## 8.2 Conclusions

The aim of this public dialogue was to explore ways to incorporate the views and ideas held by civil society and different stakeholders into the 2022-2026 research strategy. To cover specific objectives, in the course of this document, we have analysed: the different perceptions of the public and stakeholders about the CRG's research areas, the ethical issues that may arise in research, basic research, the funding of scientific research and basic research, and science communication.

Findings of this Public Dialogue reveal strong support among both the public 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.

In fact, 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 has allowed us to conclude that when science is related to health, it is of far greater interest to citizens than when related to technology.

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, we can conclude that the public not only perfectly understood the 6 research projects shared with them, but also considers it necessary and is in favour of funding it. Suffice to communicate examples of potential future applications or even successful past examples of other research projects in the communications. We also observed internal obstacles and fears among scientists themselves about communicating their basic research projects to the public. 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 public's perception of the figure of the scientist. The public considers scientists to be trustworthy professionals who enjoy a certain social status. 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 public made one thing very clear: their trust in scientists. The public takes it 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 general public's 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). We also found that scientists need to move beyond their professional persona and become more humanised. They 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.

All those consulted 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, everybody considers 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, we can conclude that the time for science is now. The public is more interested in science than ever, it is open to supporting basic research and is capable of understanding science when explained by a scientist in a one-to-one conversation. All the scientific research shown to the public 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 public and stakeholders and to be present in their channels. Society must become our main ally.

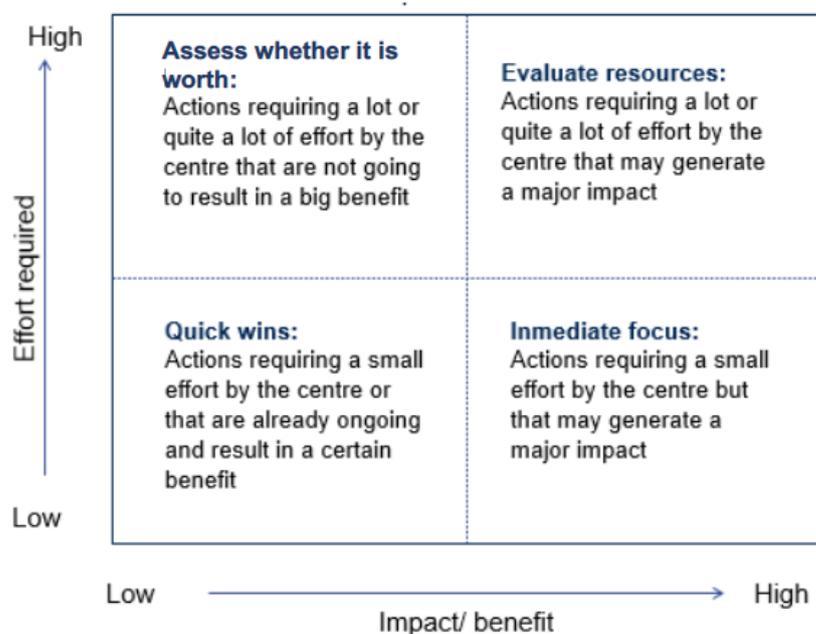
### 8.3 Next steps: prioritizing actions

As proof of their support to the CRG, public and stakeholders alike worked alongside the researchers in this PD to come up with specific actions. These touch on the four areas of this dialogue: basic science, communication, funding and ethics.

The ideas/ actions to be undertaken were listed and ordered with a view to being operative:

- According to their potential impact/benefit: whether on a communication, social or financial level.
- According to the effort required by the centre: time, and above all, financial resources to be invested.

Figure 10: prioritization of actions matrix



### Quick wins

Are actions that require little effort and have a low-moderate benefit/impact

### **Internal actions**

- Create some sort of trainer figure for supervision and follow-up, responsible for:
  - Setting limits of the projects while also motivating the researcher
  - Establishing strategic times and lines
  - Carrying out follow-up of the project's progress
  - Measuring the elasticity of each project according to the progress and results it is obtaining
- Detect and manage internal conflicts of interest

### **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).

### Immediate focus

Actions requiring little/ moderate effort from the centre that could yield considerable benefit. Many are conceived for mass communication channels such as the Social Media and TV.

### **Ethics-related actions**

- Committee of advisers who 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.
- Carry out 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 dialogue.

### **Actions on communication and funding**

- A professional (not a scientist) whose function is to verify who might be interested in funding the research projects conducted (public and private).
- Organisation of fund-raising events that simultaneously increase the centre’s fame: macro-concerts, sports events, special lottery, galas, ceremonies, etc.
- Collaborate with events such as the TV3 Maratón 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.
- Social media presence considering science as a digital product:
  - Social Media profiles of specific projects so that the public can follow the novelties
  - Sponsorship through the Social Media: adopt an apprentice student
- Recurrent public dialogues

### **Evaluate resources**

This section includes actions that could result in a considerable benefit/impact but would require a major effort from the centre. Those actions aimed at promoting major structural or social changes in science in Spain have also been included.

### **Actions to promote “major changes” / collaborations**

- Conquer politics and introduce science into parliamentary life (a science commission in the parliament). This could go hand in hand with the industry, associations and centres
- Create a consortium for direct communication with the government. Monthly meetings with directors or a committee
- 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 objective is to reach the same level as other countries.

### **Communication actions**

- Create an internal marketing department:

- Collaborate with brands that share values. E.g. Ecoalf (technical and sustainable clothing); Doctors without Borders, NGOs...
- Campaigns with like-minded brands. Benetton could be one example
- Alliances with foundations. E.g. Rafael Nadal
- Organisation of inter-university competitions
- Engage IBEX companies in campaigns with science
- Scientific debates programme
- Sponsorship/ creation/ collaboration with televised science competitions
- Netflix documentary or a series about 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

Beyond these actions, it should be noted that **the CRG is already working on and implementing some of the initiatives suggested by the public and stakeholders.** These are listed below:

### **Internal actions**

- Development of an Internal code of ethics
- Minimisation of the use of animals in research
- Attention to diversity. It’s important for the minorities to be represented to convert the CRG into a safe and open space.

### **Actions on communication and funding**

- Employment of a public relations officer/spokesperson for the CRG
- Talks to young people and children (the scientists of the future). Explain what a scientist’s job consists of, not just the results.
- Physical and online open days. Advertise them in leisure guides and newspapers.
- TED talks
- Transference office: hire professionals who do not spend 100% of their time on research, capable of identifying possible applications and opportunities for the application/transferability of the results obtained in the basic science research.
- Linking up to the idea of having a professional whose job is to verify who might be interested in funding the research projects conducted, the CRG has a Grants office which actively looks for grants.
- Related with the idea of having journalists or reporters in the Centre to “translate” the science, the CRG has a press officer.
- Alliance with universities for the most high-profile topics, e.g. in areas of design.
- Use of multiple communication channels segmented by targets.
- Open communication channels: debates, talks with the public
- Social media presence
- Presence in the mass media: the goal is to normalise science and make it a phenomenon of the masses.
- Work side by side with specific science reporters
- Reports on the centre and how it works: who works there, where it is, its history
- ....

### **Actions to promote “major changes” / collaborations**

- Partnership with hospitals; focus on curing and preventing diseases

- Related with the idea of conquering politics, the CRG is part of Somma, an organization that aims to promote excellent Spanish science, also among politicians. Also, through Somma, meetings with politicians have been arranged.

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## Appendix 1: stakeholders and researchers who have participated in the PD

### Stakeholders

In alphabetical order

**Alberto Duque**, MD, Country Patient Safety Head at Novartis Spain

**Carla Conejo González**, Head of Science Programs at Catalunya La Pedrera Foundation

**Carmen Ayuso**, Head of the Genetics Department at the Fundació Jiméneez Díaz University Hospital. Scientific Director at the Fundació Jiméneez Díaz Health Research Institute (IIS-FJD, UAM)

**Cristina Sáez Torres**, Journalist specialised in science and health

**Daniel Arbós**, Head of Communications at IDIBAPS (Institut d'Investigacions Biomèdiques August Pi i Sunyer)

**Elena Gayán**, Teaching technician at Cesire. *Departament d'Educació. Generalitat de Catalunya*

**Fèlix Campelo**, Ramón y Cajal research fellow at ICFO-Institut de Ciències Fotòniques

**Isabel Orbe**, General Director of the AECC Scientific Foundation

Dr. **Jaume Mora**, Scientific Director at the Pediatric Cancer Center Barcelona

**Joan Comella**, Director at Vall d'Hebron Research Campus - VHIR

**Jordi Camí**, Professor of Pharmacology at Pompeu Fabra University, General Director of the Barcelona Biomedical Research Park (PRBB) and Vice-President of the Pasqual Maragall Foundation for Alzheimer's research

**Juan Manuel Báez**, Biotechnological Projects Coordination Department at PharmaMar

**Laura Clèries**, PhD, Director of Elisava Research. Project Lead @materialdesigners.org. Director of Master in Design through New Materials. Co-editor @visions-by.com. ELISAVA Barcelona School of Design & Engineering

**Lluís Armengol**, Co-funder, CEO and CSO of qGenomics

**Lluís Rovira**, Director at CERCA Institute

**Marcel Cano**, Dr. in philosophy, professor of ethics at the UB, of bioethics at the UVic and of intercultural competencies at Pere Terres Foundation – URL

**Mateo Valero**, Director at Barcelona Supercomputing Center (BSC)

**Núria Jar Benabarre**, Freelance journalist specialised in science and health

**Pere Puigdomènech**, Research Professor at CSIC Ad Honorem. Centre for Research in agricultural Genomics. CSIC-IRTA-UAB-UB

**Raquel Álvarez**, Insights and Strategy Dept., Head of Intelligence and Statistics, Asebio

And all the other stakeholders that are not mentioned in this list.

## CRG scientists

In alphabetical order

**Ariadna Montero**, PhD Student at the CRG

**Bernhard Payer**, Group Leader at the CRG

**Gerard Cantero**, Principal Investigator at Vall d'Hebron Research Institute, former postdoc at the CRG (during the public dialogue)

**Isabel Espejo**, PhD Student at the CRG

**Luciano Di Croce**, Co-coordinator of the CRG Gene Regulation, Stem Cells and Cancer Programme

**Luis Serrano**, Director of the CRG

**Manuel Muñoz**, PhD Student at the CRG

**Maria Lluch**, Scientific chief officer at *Pulmobiotics*, former staff scientist at the CRG

**Michela Bertero**, Head of the International and Scientific Affairs at the CRG

**Mònica Morales**, Head of Core Facilities at the CRG

**Roderic Guigó**, Coordinator of the CRG Bioinformatics and Genomics Programme

**Sergi Aranda**, Staff scientist at the CRG

**Sílvia Llonch**, Postdoc at the CRG

**Sílvia Pérez**, Staff scientist at the CRG

**Vivek Malhotra**, Coordinator of the CRG Cell and Developmental Biology

## Appendix 2: materials for the PD

### Discussion Guide: online community with the public

11 effective days of online community in the period from September 28th to October 13<sup>th</sup>, 2020

#### DAY 1- INTRODUCTION

Hi everyone, welcome to our, and now your, community!  
First and foremost, thanks so much for participating!

Over the coming 12 days, we're going to go on a journey through the world of science. We'll show you videos and scientific research that is currently being carried out, we'll ask you questions and we'll have a debate between all of us.

These activities form part of a Public Dialogue being conducted by the CRG and Orion. The public dialogue is a technique used to share concepts with citizens and experts/scientists for them to debate and reflect on subjects of scientific research. Before we do anything else, let's introduce ourselves: we are Olga and Maria, the community managers and we'll be the one asking you questions. We'll leave you with a couple of video-selfies for you to get to know us a bit better. And now it's your turn! Set aside any shyness you might feel!

To move on to the next questions, please upload your introduction video telling us:

- Name (first name is sufficient)
- Age
- Occupation
- Interests

And to start talking about the subject at hand, please answer the question, What does science mean to me?

*(alternatively, if you can't upload a video, you can introduce yourselves via text and photos).*

As we've already mentioned in the blog's welcome post, we're going to be talking about and specifically debating the research being conducted by the Centro de Regulación Genómica (CRG). But... what is the CRG? What do they do?

#### LET'S LET THEM EXPLAIN IT TO US! VIDEO!

After watching the video, please answer the following questions.

1. Had you ever heard of the CRG before?
2. What did you think of it?
3. What did you like best about it?
4. Do you have any questions?
5. Is there anything that worries you?
6. Would you like to know more?

#### BASIC RESEARCH

1. What do you think of the basic research\*?

2. Do you think this sort of project that has no apparent application needs to be supported? Why?

*\*The main focus of the CRG is basic research, which is the science that aims to improve knowledge, theories or the prediction of natural phenomena. In other words, it's the science or research conducted without any immediate practical purpose, but rather with the goal of increasing knowledge about the fundamental principles of nature or reality itself.*

3. Everything goes, ok? Last question for today:
  - a. What do you think of genomic engineering\*? Are there things that can and can't be done? Where is the limit?

*\*it's the direct manipulation of the genes in an organism using biotechnology to modify, eliminate or duplicate the genes.*

## DAY 2 -QUESTIONS ABOUT THE CRG AND INTERACTION

Regarding the CRG:

1. Is there anything else you'd like to know before we tell you about the research projects they have underway and that we'll be looking at over the coming days?

We have Marta with us in the community, she works at the CRG and can answer any questions you may have! Don't hold back 😊

It's really important for you to answer all the questions we ask you in as much detail as possible, please!

THANK YOU! More tomorrow!

## DAY 3 SCIENTIFIC PROJECTS

After showing the scientific project of the super synthetic vaccine:

Let's begin with the questions!

1. What do you think of synthetic biology? (remember you can consult this term in the glossary).
2. And what about in this specific case in which the genes of a bacteria are modified to create a vaccine?
3. Are there limits in gene editing? Where do the limits lie in genome editing?
4. A private company, a start-up, has been created from this research project on the super vaccine.
  - a. What do you think of that?
5. Do you consider it appropriate to invest public money in financing research that ultimately improves/makes the creation of private companies possible?
6. What needs to be the role of the financing institution (the CRG, for example) when a company is created under its umbrella?
7. Should the profits from patents\* be invested in research, or should the foundation of more companies in the institution be promoted?

*\* A patent is a series of exclusive rights granted by a State to the inventor/ discoverer of a new product or technology. Holding the patent for something means that whoever owns it is the exclusive holder of the rights to commercially exploit their discovery or product during a limited period of time in exchange for the spread of this invention/ discovery.*

8. Do you think it's important for the results of this project to be published and for them to be available in an open forum for future research?
9. Might there be risks? What do you think the risks might be? And the benefits?

#### After showing the scientific project: mucin and cystic fibrosis

Basic research takes time and may take years to yield results with an actual application.

1. Do you think these sorts of very long-term projects need to be financed? Why?
2. Do mechanisms need to be found that determine whether a project has already been exhausted on a research level?
3. Is it important to give scientists the freedom to decide which type of research they wish to carry out?
4. How can the need for "results" and practical applications be balanced with the need to give scientists the freedom to choose?
5. How do you think this research that is so basic needs to be communicated? What are its most important advantages? What should be highlighted?
6. How should it be communicated? Through which channels? To whom?

### **DAY 4- LIVE ONLINE SESSIONS**

Today we have the live online sessions!

Which is why there are no questions to be answered today! We're only going to ask you to read the answers of other community members on the scientific projects shown yesterday and think about whether anything surprises you, grabs your attention and whether you have any questions.

The only other thing we ask of you is to be punctual for our appointment! And to connect at least 5 minutes before the meeting begins.

See you at whatever time has been communicated to you 😊

THANKS!

### **DAY 5- SCIENTIFIC PROJECTS**

#### After showing the scientific project: can any cell type be generated in the laboratory?

1. Thinking about the study of reproductive cells (eggs and spermatozoon), what do you find most interesting?
2. Do you think it's acceptable to use eggs generated in vitro for human reproduction?
3. Do you think it's ethical? Why?
4. Should the CRG collaborate with private companies to find and create application opportunities in clinics?
5. In the event of unethical use by third parties of results published in an open forum by the CRG researchers, what role and position should the researcher and the centre adopt in the face of this situation?

*A very well-known example is that of Einstein and the atomic bomb: the results of his research contributed to the manufacture of the atomic bomb.*

6. The use of the patient's own stem cells to generate oocytes could allow for women's fertility to be prolonged, leading to a possible ethical dilemma.
  - a. What do you think of that?
7. Do you think the CRG should conduct research into areas like this that could have a social impact?
8. Who should make the decisions on this type of research with this type of impact?
9. Should the experts or society be consulted about it first?

After showing the scientific project: the what and the how matter in the genome

1. Which aspects of epigenetics that is, how an individual's context and history affect the expression of genes, do you find it most interesting to study?
2. What benefits do you see to this? And drawbacks?

This project is studying a rare tumour type ...

3. Should the CRG focus on the study of diseases that affect just a smaller number of people but have not been studied much, or should it focus on the diseases that affect most people in the western world?

Epigenetic treatments can change the patient's epigenome and epigenetic studies can reveal their habits or living conditions:

4. Should the patient be informed of this to obtain their consent before starting a treatment or study of this type? So, why yes? Or, why not?
5. When it comes to funding a scientific project, should this always have an impact on health and/ or economy?
6. What do you think of the scientific projects that only offer knowledge but do not in principle seek an impact on health and/or economy? Is the obtainment of knowledge "per se" a value in itself?
7. Perhaps in the future we will be able to modulate the epigenomes to make them better:
  - a. Do you think this should be done? What might the implications be? Anything that worries you? What worries you?

## DAY 6- LIVE ONLINE SESSIONS

Today we have live online sessions!

There are no questions to answer for these. You already know how it works! All we're going to ask you to do is to read the answers of other colleagues on the scientific projects shown on Friday and think about anything that surprises you, grabs your attention and whether you have any questions.

The only other thing we'd ask of you is to be punctual for the appointment. And to connect at least 5 minutes before the meeting begins!

We'll see you at whatever time has been communicated to you 😊

THANKS SO MUCH!

## DAY 7- SCIENTIFIC PROJECTS

### After showing the scientific project: The discovery of something unexpected

1. What did you think of it? What sprang to mind on reading this? Do you find it interesting?
2. As we've seen in this example, basic research can give rise to unexpected results. What do you think?
3. Do you think that whenever a research project is set in motion it's necessary for its results to have an application? Why?

Here the issue of using personal details and (health) information in research also arises.

4. Would you be willing to share your health details and information for the advancement of research? Would you share the details and information of a deceased or sick family member? And your own details? Genomic data?

### After showing the scientific project: the CRG and the detection of coronavirus

1. What do you think of this? What benefits do you see to investing in basic science? Any disadvantage?
2. Should more be invested in basic science to understand the mechanisms of certain pathogens and thus avoid or minimise the risk of suffering a pandemic?
3. Is it preferable to invest resources in the generation of vaccines and/ or therapies and the hospitals once the diseases have appeared?

## **DAY 8- LIVE ONLINE SESSIONS**

Today we have live online sessions! You already know how it all works.

As usual, there are no questions to answer! All we're going to ask you to do again is to read the answers of other colleagues on the scientific projects shown yesterday and think about anything that surprises you, grabs your attention and whether you have any questions.

The only other thing we'd ask of you is to be punctual for the appointment. And to connect at least 5 minutes before the meeting begins!

Remember that tomorrow the new questions will be published on the community! Today is the last live online session but the community will continue for a few more days!

We'll see you at whatever time has been communicated to you 😊  
THANKS SO MUCH!

## **DAY 9- RANKINGS OF THE CASES**

Hi again everybody!  
Today we have a slightly different exercise for you ...

After seeing all the cases over the last few days and even speaking to the scientists responsible for these research projects, we'd like to suggest two new tasks that will consist of ranking these cases.

Ranking according to relevance or benefit from your point of view.  
Ranking according to the risk it might pose from an ethical point of view.

By ethical risk, we are referring to the fact that the results of this research could be used for purposes we don't entirely agree with.

Allow us to remind you of the cases:

- The super synthetic vaccine
- Mucin and cystic fibrosis
- Can any cell type be generated in the laboratory?
- The what and the how matter in the genome
- The discovery of something unexpected
- The CRG and the detection of coronavirus

Before answering, remember that the cases available to you in the community in case you'd like to review or re-read them.

We have to rank the cases from most (which would be number 1) to least (which would be number 6) according to the benefit or relevance of the same and explain why we position each one of them in the place you chose to put them:

We're going to do the same thing again but this time using the criteria of the ethical risk we believe conducting this research implies: from most (number 1) to least (number 6). It's important that you explain why you believe each case implies or does not imply a risk:

#### **Questions from researchers:**

Maria Lluch, Gerard, Sergi, Silvia, Mónica and Manuel would like to know if you have any outstanding questions about the scientific projects before we close the community: Would you like to ask them anything? Do you have any doubts? Is there anything that concerns you that has not been mentioned in the meetings?  
Now is the time! We will pass on your comments to them and get their answers back to you.

## **DAY 10- Ranking Results**

Hi again everyone! Here are the results of yesterday's rankings!

### **RANKING BY BENEFIT**

1. The CRG and the detection of coronavirus
2. The super synthetic vaccine
3. The what and the how matter in the genome
4. Mucin and cystic fibrosis
5. Can any cell type be generated in the laboratory?
6. The discovery of something unexpected

### **RANKING BY RISK**

1. Can any cell type be generated in the laboratory?
2. The what and the how matter in the genome
3. The discovery of something unexpected
4. The super synthetic vaccine
5. The CRG and the detection of coronavirus
6. Mucin and cystic fibrosis

Let's move on to the questions!

1. What do you think of these results?
2. Do you agree? What do you agree with? What do you disagree with?
3. Would you like to add anything?

*Please comment on the results of the two rankings.*

Now we're going to put a somewhat difficult question to you but we hope you'll be able to answer it...

4. If you had to choose just three lines of research, which would you choose? Why? *Please explain clearly what your choice of these research projects rather than others is based on.*

Line 1 \_\_\_\_\_

Line 2 \_\_\_\_\_

Line 3 \_\_\_\_\_

## **DAY 11- LAST DAY OF THE COMMUNITY**

We've come to the end of our scientific adventure together. Now that we've got to this point, imagine you want to tell a friend about your experience and that they in turn ask you questions about what we've seen.

What would you tell them about:

1. Basic research: what is it, what's it for, what are its pros and cons?
2. The CRG: what is it, what are its lines of research, who are its partners or its financing?
3. Some of the ethical debates we've dealt with, such as where the limit of genome editing lies.

### **The CRG is listening to you!**

4. What would you say to them about what their role/ positioning should be in relation to:
5. Basic research?
6. The ethical debates its research projects could trigger?
7. Financing and collaboration with other entities?
8. The strategy they should follow and the priorities?
9. Has your opinion of these subjects changed after our trip to the CRG? What has the change consisted of? Why do think the change has occurred?

### **Regarding their communication...**

10. Who would you address? Why?
11. Through which channels?
12. What would be the main message to communicate? What do you think has to be told?

### **That's everything! The community has come to its end...**

Regarding the questions you put to the researchers, we will answer them over the next few days and we'll make the answers available so that you can have a look and comment on them this week if you like, but there won't be any more questions!

Thanks so much for your collaboration in both the online sessions and the community! You've been great and you've helped us loads!  
THANKS!

OLGA AND MARIA

## Case studies

Each one of the case studies were presented on the platform through a short text and video lasting approximately 3.5 minutes with the explanation of each of the researchers involved.

The texts are presented below:

### **THE SUPER SYNTHETIC VACCINE**

Vaccines are tools designed to control infectious diseases caused by virus or bacteria. Many respiratory diseases are caused by mycoplasmas, a series of bacteria that can infect both humans and animals. To fight the respiratory diseases caused by these bacteria, the CRG is working on a two-pronged research project.

In one of these lines of research, work is being done to develop synthetic vaccines to decrease the rate of diseases associated with the different mycoplasma species in farm animals. To this end, the objective is to design an inactivated mycoplasma that generates immunity against different species and thus serves to protect against numerous diseases simultaneously. Mycoplasma infections in livestock lead to the loss of millions of euros in Europe and around the world. Which is why the project has a strong impact on both the economic and the healthcare systems. The development of vaccines against the mycoplasma infection in farm animals will significantly reduce the production time and expenditure associated with treating the disease. This is of particular interest to developing countries, where investment and resources are both limited.

The other line of research is based on the development of an attenuated mycoplasma to offer specific treatments for diseases. The ultimate goal of the project is the production of therapeutic molecules that will be released by the attenuated bacteria to treat the causes of pneumonia. The vaccines and the development of attenuated bacteria are also expected to reduce the impact of excessive antibiotic use, in addition to the resistance and allergies to these. Furthermore, they will make effective treatment of viral infections that cannot be treated with antibiotics possible. Hence, the development of a treatment for ventilator-associated infections will largely decrease the importance of respiratory infections in humans, improving patient wellbeing and decreasing the costs of healthcare.

A private company (a start-up) has been created with all these results to continue researching and developing new treatments to treat wide-reaching respiratory diseases.

## **MUCIN AND CYSTIC FIBROSIS**

Since 2009, the CRG has been conducting a research project to study how the body's largest proteins are transported and secreted in the cell.

An interesting example of this research are the findings relating to mucins, the proteins which, in normal conditions, form the mucosa that covers the respiratory and gastrointestinal tract. This is how they protect us from external aggressions such as pathogens, allergens or chemical products, but they also prevent, for instance, the acid from our stomach digesting our own tissue.

The findings in relation to the mechanisms that regulate mucin secretion could be relevant for the treatment of important diseases such as cystic fibrosis or some colon cancers, characterised by the dysregulation of mucin levels.

Cystic fibrosis is a potentially fatal disease that mainly affects children and young adults, causing an accumulation of thick and sticky mucosa in the lungs, digestive tract and other areas.

On the other hand, in 10% of the cases of colon cancer, the cancerous cells start to create a mucosa barrier that protects them from the immune system and from chemotherapy, rendering them highly resistant and decreasing patient survival.

Therefore, the discovery of ways to control mucin levels in patients could lead to new treatments for these diseases.

## **IS IT POSSIBLE TO CREATE ANY CELL TYPE IN THE LABORATORY?**

At present, Spain and Italy are the EU countries in which maternity is delayed most. On average, Spanish women have their first child at the age of 31. Nonetheless, it is well-known that women's fertility decreases with age. Moreover, the rate of miscarriages increases as the woman ages.

This is due to the fact that with age there is a decrease in the quality of the oocytes, the female germinal cells stored in the ovaries which, with each menstrual cycle, complete their maturation to become eggs.

To get around the problems associated with reproductive cells ageing, a growing number of women turn to fertility clinics and undergo an egg donation programme.

The CRG has joined forces with Clínica Eugén with a view to reproducing the first phases of the egg maturation phases in the laboratory. The generation of eggs is a quite difficult process to study as in humans it occurs in the early stages of development and sample collection is both ethically and legally controversial. This is why this study uses pluripotent cells (cells that can be converted into different types of body cells or tissues) as its point of departure.

In the coming years, the availability of such systems will be relevant to understand the cornerstones of human reproduction and uncover the possible causes of infertility. These systems will allow us to understand and develop models to test new drugs for the treatment of infertility. In the very long term, these systems could be used to generate eggs with the same DNA as the patients in the laboratory, using cells from the patients themselves. This way, the likelihood of 35-year-old women having babies

without having to go through an egg donation protocol would increase. To get to this point, it will be necessary (apart from the numerous scientific discoveries yet to be made) to demonstrate the safety of this procedure for both the mother and for the possible future baby, to have a profound ethical debate with society and draw up regulations for these processes.

## **THE WHAT AND THE HOW MATTER IN THE GENOMA**

Brain tumours are the most common cause of death by cancer among children under the age of 15, with a survival rate of just 20%. In particular, the diffuse intrinsic pontine glioma (DIPG) is very aggressive. Half of the children diagnosed with DIPG die within a year and only 2% survive beyond five years.

Unfortunately, despite recent efforts to identify new therapies for DIPG, all have proven to be ineffective to date. Around 80% of patients with DIPG present the same mutation in their tumour cells. The presence of this mutation and the pre-clinical studies have identified the chromatin nucleus of the tumour cells as the driving force behind the development of DIPGs. Chromatin is the complex made up of DNA and its associated proteins.

Through its research, the CRG aims to identify the epigenetic changes characteristic of the DIPGs with a view to selectively eliminating the tumour cells. Epigenetics study the changes in the structure and expression of the genome caused by environment (lifestyle habits, exposure to contamination, the legacy of previous generations...), or genetic alterations.

With a view to obtaining patient samples for the study and also to transfer outcomes directly to clinics, the CRG has joined forces with expert oncologists from the children's hospital, Hospital Infantil de Barcelona de Sant Joan de Déu.

For a medium-term impact, the findings of the study to identify epigenetic changes in the DIPG will be shared with a view to advancing the development of drugs to attack the tumour cell weaknesses.

## **THE DISCOVERY OF SOMETHING UNEXPECTED**

The genetic content of all our body's cells is identical; however, the cells that form the different tissues of the individual's organs are very different and perform very different functions. This is because each cell expresses different genes to the rest. Genetic expression is the process by which all organisms transform the information coded by the DNA into the proteins necessary for them to function and develop. Hence, each cell can specifically synthesise the proteins it needs to carry out its function.

In this context, the CRG researchers are collaborating on an international project called GTEx, that aims to study the relationship between the genes expressed in the cells of different tissues and in different individuals and the functions these cells have in the organism. To this end, the researchers analysed over 7000 samples from the post-mortem tissues of 540 healthy donors.

To verify the health condition, age, lifestyle, etc., of the donors during the project, the consortium worked hand in hand with their families, who shared details and information about them, and remained in contact afterwards to inform them of the state of the research.

The research conducted in the CRG with this data revealed an unexpected fact: the expression of some genes undergoes controlled changes in different tissues following

the death of the individual, that is, the cells remain active over a short period of time after death.

Thanks to this finding, outside the initial endpoint of the study, scientists from the CRG have developed a protocol to predict the time from the individual's death to the obtainment of the sample that could be applied in forensic pathology.

Other applications of this discovery could be related to better tissue preservation and, above all, for the preservation of organs prior to transplants.

## **THE CRG AND CORONAVIRUS DETECTION**

The CRG has contributed to the massive detection of coronavirus through the PCR test, a technique that has been used for years in biomedical research. On the other hand, basic research that aims to gain in-depth knowledge of how viruses such as the SARS-CoV-2 behave may lead to the development of a quick, effective and safe vaccine against viruses of this type thanks to the fact that the knowledge necessary for them has been studied before the appearance and spread of a possible disease.

## Discussion Guide: online groups with the public

October 1st, 5th and 7th 2020

### **WELCOME THE PARTICIPANTS (2 MIN)**

*Brief introduction and explanation of the rules of play*

- Thank them for their participation
- Moderator and researcher introductions
- Explain there are no right or wrong answers, but what is important is for everyone to talk and to share their points of view;
- Mention that there are other people listening to our session, and that it will be recorded;
- Explain the dynamic

### **IN-DEPTH EXPLORATION OF THE CASE: (28 MIN)**

Yesterday in the community you read about the scientific project (x)

Let's briefly review it

- What was the first thing you thought when you read it? What came to mind?
- What do you think? What grabbed your attention most? Did you think it was possible for something like this to happen/ be studied?
- Do you have any questions? Now's the time to get answers to them! *Allow space for them to ask the researcher questions.*

*Moderator: keep questions and comments expressed by the participants the previous day to hand at all times to stimulate the conversation if necessary*

- One of you said that... what do you think? What do the rest of you think? Do you agree? Why? Why not?

THANKS

## Discussion Guide: workshop with stakeholders

October 20<sup>th</sup>, 2020 from 4pm to 7pm

### **WELCOME THE PARTICIPANTS AND PLENARY SESSION (60 MINUTES)**

*(Record the session)*

- Thank them for their participation.
- The CRG welcome and public dialogue context (very short). Luis Serrano
- Very brief introduction of moderators: From Ipsos, Jaime will be with the Darwin group, María with Rosalind Franklin, Huini with Einstein, Marina with Ramón y Cajal and I'll be with Marie Curie.
- Introduction of the researchers conducting the research projects you have read about and seen on the platform. If you'd like to introduce yourselves ...
- Mention that there are other people listening to our session, and that it will be recorded;
- Explain that there are no right or wrong answers, but that it's important for everyone to speak and share their points of view;
- Explanation of the session dynamic and presentation of the agenda
  - Plenary session 4pm to 5 pm
    - Brief introduction of the participants: name, where they work and relationship with the CRG
    - Questions and comments on the 5 research studies we've shared with them (ask them to click the raised hand icon)
  - Smaller breakout groups in which (from 5 to 6pm)
    - We will choose a spokesperson
    - Debate matters such as basic research, the ethical and social implications, financing or communication.
    - There are no right or wrong answers. Share your points of view ...
    - Conclusions and recommendations for the CRG.
  - Plenary session (from 6:30 to 7 pm).
    - Share the conclusions of the debate and the CRG recommendations with the rest of the groups

*Each of you has been assigned to a group: the Darwin group will have moderator X from Ipsos and researcher X from the CRG. When we split up you'll have to click on the link we sent you and you'll meet them and your other 5 group members.*

*We'll all be back here in an hour and a half to share our conclusions.  
See you at 6:30!*

### **DEBATE PER GROUPS (1.5 HOURS)**

*(Record the session)*

- Choose a chairperson:

*We're going to talk about different topics in blocks: basic research, ethical and social debates that may arise from the research projects or aspects related with financing.*

*We have xxxx from the CRG with us to take part in our debate.*

*We will write down the conclusions as we go along*

## **1. BASIC RESEARCH**

- What do you think of basic research? Has your perception changed after reading the cases we sent you?
- Is it always necessary for the results of research to have an application *a priori*?
- What do you think the balance should be between the need for results in research and the need to allow researchers to be guided by their curiosity?
- What do you think of the fact that the CRG needs to collaborate with different players in order for their discoveries to reach society? (hospitals, clinics, companies...)

## **2. ETHICAL DEBATES**

We've seen in some of the cases, like in the oocytes for example, how research of this type can have important social and ethical implications.

- The CRG's research may have a long-term social impact. Should the potential findings/ products be discussed with experts or society during various phases of the research process (before, during and after)? How could this be done?
- What is the role of the researcher and the institution in the ethical debate on the research results that could be used in unethical ways by third parties? Is it enough to comply with the requirements of the different ethical committees (that normally deal with technical matters)?
- Linking up to the subject of ethics, do you think it's important for the project results to be published and made available in an open forum for future research? What might the risks be? And the benefits?

## **3. FINANCING**

- Should the CRG collaborate with private companies to find and create application opportunities, for example, in clinics?
- What role does the financing institution (the CRG, for instance) need to play when a company is created under its umbrella? Should the profits received from patents be invested in research, or to foster the foundation of more companies in the institution? (This refers to the example of María Lluçh, the first of all).
- Should the CRG invest resources in searching for and obtaining private funding, from both big and small donors? How could it do so?

## **4. COMMUNICATION**

- How should the basic research be communicated?
- What do you think needs to be the main message?
- Through which channels? To whom?

## 5. CONCLUSIONS AND RECOMMENDATIONS

To conclude this group, we'd like to summarise and ask you to share the conclusions you've reached with us and, above all, tell us what recommendations you would make to the CRG.

Here the chairperson takes notes to subsequently present in the plenary session (we can lend them our notes).

If the CRG were listening to you ;), what would you conclude from today's sessions about:

- Basic research
- Ethical-social debates
- Funding
- Communication

And **what recommendations** would you make in relation to the research that needs to be prioritised, the financing policy, its role in the social and ethical debates and the communication and engagement strategy?

Thanks everyone. We'll leave this meeting and return to the link we used in the beginning to meet up with the rest of the groups again and share the conclusions.

### SHARING (30 MINUTES)

*(Record the session)*

In the next 30 minutes, we're going to share the conclusions and recommendations of each one of the groups. Afterwards, we'll open up a final space for comments and questions.

Let's begin with the first group. What were the conclusions of the Darwin group?...

Would you like to add anything else?

THANK AND CLOSE

## Discussion Guide: final workshop

November 4th, 2020 from 4 to 6:30 pm

### WELCOME PARTICIPANTS AND PLENARY SESSION (30 MINUTES)

#### *(Record the Session)*

- Thank them for their participation and welcome them
- Very brief introduction of moderators and researchers by us.
- Mention there are other people listening to our session and that it may be recorded.
- Explanation of the dynamic (agenda):
  - Plenary session 4 to 4:30pm:  
We'll present the main conclusions of the community, the groups and the session of October 20th with collaborators and researchers as a whole.
  - Smaller groups (from 4.30 to 5.55 pm)
    - Brief introduction of the participants.
    - Choose a spokesperson
    - Brainstorming/ recommendations for the CRG.
  - Plenary session (from 6 to 6.30pm).
    - Share with the rest of the groups

Before we move on to our brainstorming session we need to talk about the rules:

- Active listening: no criticising or questioning.
- Everything is possible: open your mind.
- All ideas are good: even if they're not yours.
- Be positive: don't say no.
- Don't be afraid to get it wrong: today there are no bosses or experts, we're all part of a team.
- Quantity for quality.

And while we're waiting to connect to the link you have on the table, we're going to ask you a question via Mentimeter. We'd ask you to enter menti.com using your mobile phone and introduce the code xxxx to answer the following question: If you were on the managing committee of the CRG, what's the first thing you'd do?

*Each one of you has been assigned to a group. The Margarita Salas group will be with Marina from Ipsos... When we split up you'll have to go to the link we sent you and there we'll meet up with your group and colleagues.*

*After one and a half hours we'll all come back here and share our conclusions. See you at 6pm!*

### DEBATE PER GROUPS (1.5 HOURS)

#### *(Record the session)*

- Brief introduction of the participants.
- We'll name a chairperson.
- We'll go over the Mentimeter results together (they'll serve to choose a point of departure).

*We're going to talk about actions or recommendations in different blocks:*

### **BASIC RESEARCH**

What can the CRG do to find a balance between the scientist's curiosity (and freedom) and social interests (or the interest of whoever is funding)?

### **FINANCING**

What can the CRG do to obtain funding?

### **ETHICAL-SOCIAL DEBATES**

What can the CRG do in terms of ethics?

- Towards society?
- Internally?

What could the CRG do to reduce the risks of opening up science to everyone?

### **COMMUNICATION**

How can we help the CRG become known to more people?

What's the best way of communicating basic science? How should it be done?

How can we take advantage of the current "science" moment?

*Let's write the conclusions as we go along in a Word document*

## **SHARING (30 MINUTES) AT 6pm**

*(Record the session)*

In these 30 minutes, we're going to share the recommendations of each one of the groups.

Let's begin with the first group. What were the conclusions of the Margarita Salas group?...

Would you like to add anything else?

**THANK AND CLOSE**

## Appendix 3: list of ideas in the brainstorming sessions

Final workshop, November 4th, 2020.

### **Role of the CRG in relation to basic research**

#### Culture

- Basic science is born of human curiosity. We should not become obsessed with its usefulness.
- Failure is the lever to continue growing. If we end our system of educating in fear of failure, then basic research will become easier in Spain.
- In relation to the previous point, it would be a good idea to publish negative results to help the community avoid making the same mistakes. But first and foremost, we must put an end to the fear of failure and ensure these publications are not penalised with a lack of funding.

#### Education

- Hire good scientists who are decent people/ citizens with a social conscience. This would be a factor to take into consideration when looking for scientific talent.
- Universities and schools as a launch pad to awaken researcher curiosity.
- Allocate more resources/ financing to Spanish universities to prevent the good scientists from going abroad. Work to make the universities cutting-edge institutions.
- Well-trained professors.
- Foster creativity among children: understand the importance of basic science from childhood.

#### Scientific Community

- The science evaluation systems (Open science) need to be changed. They are evaluated using archaic systems that seek only scientific, but not social, impact.

#### The CRG

- To avoid smothering the researcher's creativity and enthusiasm, they advocate for giving them the freedom to propose a subject. The CRG filter would come later.
- Research grants for those researchers who present the most creative/craziest projects.
- A person to coordinate and approve projects one wishes to start; like, for instance, hospital managers.
- Find a balance between more basic and more applied research:
  - o Combine basic and applied research: transfer office (trained in both science and business) capable of identifying applications and opportunities.
  - o Impact evaluation, that is, knowing the impact of what has been researched in order to encourage researchers to research more.

- Design a figure responsible for establishing limits while also motivating, for setting times (whether long or short), the strategic lines and for carrying out follow-up and measuring the elasticity of each project according to its progress.
- The CRG must see itself like a football trainer that encourages the most interesting projects. It must also promote collaboration and the spread of its successes and failures so that each one makes a contribution and goes so far as to benefit society in some way.

#### Regarding the **ethical and social debates**:

##### Internally

- Companies have to have established ethical principles: an internal code of ethics.
- Minimise the use of animals.
- Committee of advisers that decides the “limits” of the projects. A multi-disciplinary committee with scientific and social players (scientists, academics, philosophers...).
- Attention to diversity. A multidimensional vision contributes to improvement. It's important for there to be a representation of the minorities to transform the CRG into a secure and open space.

##### The Scientific Community:

- The researchers need to have global limits because the legislation is not the same in all countries. If science is global, then the controls must be global.
- Review the researcher protocols, promote reflection in the research groups.
- The scientist must “expose themselves” to society. At present they find it hard to emerge from their circle.

##### Consultations

- Consult the small groups and ask them to see what they can contribute (e.g. Vegans).
- Conduct consultations or surveys (for instance, in the newspapers).
- Researchers need to be aware of the possible ethical conflicts of their research. Which is why they need ask those potentially affected by their results for their opinion.

##### Information and social debate:

- Public talks on social debates (on television). The scientists should speak in an “educational” way to generate social conversation.
- Inform about Open Science: its benefits and its risks
- The ethical committees also need to expand their communications.

#### **To obtain funding:**

##### The CRG

- Commitment from the centre, stability, support, centre with a strategy and support (E.g.: IRG).

- Let no child be born in Spain with a rare disease and go untreated if this disease is treatable (creating alliances with different players).
- The centre must support the researcher. We give money to whoever is going to do things well, provides support and has a strategy.
- Creation of companies/ cures/ therapies under the CRG umbrella dedicated to applied research to attract public funding.

#### On a political-social level:

- Conquer politics: Lobby for science funding/ talk to the politicians (get industry, associations and centres to work hand in hand). Introduce science into parliamentary life (science commission in the parliament).
- Create a consortium to communicate directly with the government. Monthly meeting with directors or a committee.
- Fight for the investment that already exists in science.
- A box to tick in tax returns forms to choose to make a donation to science.
- Patronage/ Large fortunes: tax reductions, advertise this/ communicate it.
- Tax reductions for personal donations.
- Promote society involvement in ways other than donating money. Blood, oocyte donation ...
- Philanthropy. In Spain this is more closely linked to the arts.

#### Marketing and Communication Actions:

- Marketing department: initiative of hiring some companies.
- Collaborate with brands that share values. E.g. Ecoalf (technical and sustainable clothing); doctors without borders, NGOs ...
- Speak to the IBEX companies for them to engage in a science campaign
- Organisation of events to raise money while at the same time communicating: macro-concerts, sports events, special lottery, galas, ceremonies, etc.
- Collaborate on events, e.g. TV3 marathon, don't just focus it on specific diseases but on the funding of the CRG jointly with other research centres.
- Marquees at sports events to communicate and raise funds. E.g. tennis or golf tournaments, football game, etc.
- Participation in music festivals. E.g. Primavera Sound, Sonar..., that combine technology + design.
- Create a website with the projects and seek public and charity funding. Example: IRB (platform for donations to cancer research)
- Crowdfunding
- Campaigns for contributions/ donations similar to those received in the food bank campaign (e.g. round off shopping receipts in hypermarkets, food stores...)
- Tourist kiosk: we read information about the genome.
- Promote science, make society aware that the CRG exists and what it does and that it's seeking private donations. Science propaganda for increased funding.

#### **In the area of communication:**

##### Message:

- Make society understand how necessary basic research is. We've associated R+D+i with technology rather than other areas such as health.
- Highlight the importance of science, the research being conducted and its benefits.

- Communicate the scientific method rather than the results to make society fall in love with the science.
- Humanise research and use visible faces.
- Find the “heroes of science” and use them to educate and naturalise science.
- Simple and educational language, but without oversimplifying.
- Avoid *overpromises*.
- Build a story. “Tell stories that the people can identify with”.
- Values to transmit: excellence, reliability, future, advances, life, knowledge, information, progress, closeness, enrichment, social cohesion, diversity, bravery (aiming for the impossible), creativity (improvisation), enthusiasm.
- Promote equality in positions of scientific leadership. Communicate the female scientist figure inside and outside the scientific community.

### Communication Actions:

- Public relations/ spokesperson for the CRG.
- Journalists or reporters in the research centres to “translate” science for the public
- Use multiple channels segmented by targets.
- Open communication channels: debates, talks...
- Presence in **mass media**: the goal is to normalise science and make it a phenomenon of the masses.
  - o A good interview with a passionate researcher and Good Communicator in a “prime time” forum, like for instance the TV programme El Hormiguero.
  - o A science section, like the sports section.
  - o Specific science reporters.
  - o Science competition on TV.
  - o Reports: who works in it, where they are, visit.... Netflix Documentary or scientist series.
  - o Ambassador or “media sponsor” that people listen to (e.g. Neil Harbisson (the first cyborg) or Stay Homas.
  - o Scientific debate programmes.
  - o Campaigns with like-minded brands. Benetton could be an example.
  - o Alliance with foundations. E.g. Rafael Nadal
- Digital Context
  - o Presence on social media. Science as a digital product.
  - o Collaboration with influencers and platforms
  - o Online platform where you can choose which research to follow, that sends out notifications, that’s interactive. Where you can ask the scientists directly.
  - o For specific projects to have their profile on Social Media so that followers can track the news about them.
  - o Applications, games, gaming.
  - o Sponsorship via Social Media: adopt a student.
  - o TED talks.
- Talks in universities and companies.
- Talks to young people and children (the scientists of tomorrow). Explain what a scientist’s work consists of.
- Open doors and online open doors sessions. Advertise these in leisure guides and newspapers.
- Periodic public dialogues.

- In the theatre, performance programme. We would link it to culture to reach a profile engaged with culture.
- Design + science: experimental exhibitions (e.g. La Casa Encendida)
- Alliance with universities in relation to more high-profile issues, e.g. In areas of design. Organisation of competitions.