#### The project in a nutshell



Science and demographic data suggest that soon 10% of the population born in Europe will result from assisted reproduction techniques (ART). About half of people that wish to have children will go to specialized centers. Therefore, Assisted Reproduction Technology (ART) plays a significant role in the reproductive health of European society and is a fast-growing part of the health industry.

Surprisingly, nobody has worried about how young people understand, react to, and interact with Reproduction technologies. Human reproduction is presented as a privileged confluence between science, industry, government, and citizens. In this context, "B2-InF - Giving voice to citizens towards improving Assisted Reproduction Technologies for Society" will help understand the evolution of reproductive science and society to promote proactive and anticipatory policymaking, align research developments with the needs, expectations, and values of society.

The B²-InF project is the first project of its kind. There are in Europe many studies on Assisted Reproductive Technologies (ART); however, they mainly focus on the experiences of patients or on medical practices and the issues they raised. Very few studies explore ART knowledge and representations in the general population, i.e., in ART non-users and people who are not, a priori, infertile.

We know even less among young adults. Do they know fertility problems? The existing techniques to overcome these problems? The law and policies that regulate these techniques in their country? What do they think about it? Would they be disposed to use ART? What are their expectations in this respect? These are all questions that the project addresses. The other component of the highly innovative project is the analysis of the offers made by the clinics, primarily through their advertising (Websites, flyers, etc.). Do they generally target a particular audience? What techniques do they offer? How do they explain infertility and represent parenthood?

In other words, B2-InF will seek to answer two questions:

- How do young people perceive and think about ART?
   How can ART clinics better align their research, services, and
- information with the views, concerns and expectations of citizens?

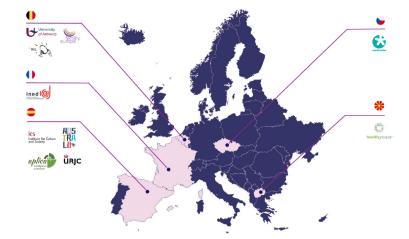
By answering these questions, B2-InF aims to promote public participation in the science and provision of ART so that these become more responsive to the needs and concerns of society.

The Consortium will carry out the project in three stages. In the first stage, we collect data about perceptions and awareness of ART in young populations and the information offered by clinics to their clients through several structured interviews. In the second stage, this data is analyzed from sociocultural, legal, and gender perspectives to detect misalignments and other weak points and determine ways to improve the information offered by clinics. The third stage will focus on the dissemination of the findings.

The main result that the B2-InF consortium would like to achieve is the development of national and international guides with concrete and practical guidelines to significantly improve ART for the European society of tomorrow.



#### Meet the consortium



This project brings together an international team with 10 European partners working in different but complementary fields and sectors, driven by a shared ambition.



Our project coordinator, Prof. **Güell**, joined the consortium as member of the <u>ICS</u>, which is a research center for humanities and social sciences, part of the esteemed Universidad de Navarra. The institution provides the project with cutting-edge research about the challenges faced by today's society.



Aplica Coop is a cooperative devoted to social research in health and welfare, conducting multicenter studies meant to explore social perceptions of different topics. It integrates research with citizens. They offer the project an extensive expertise in research and public engagement.

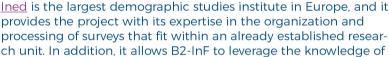


patients' associations from 21 countries. They are dedicated to raising fertility and infertility awareness. It provides the project with a well-established network and expertise in fertility research.



<u>Healthgrouper</u> is an NGO that brings health workers closer to patients and enable doctors to communicate with each other. It

provides B2-InF with high quality data through research and expertise in improving the link between healthcare and patients.



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the Sexual and Reproductive health rights network that Health-grouper is part of.

Universidad Rey Juan Carlos

<u>Universidad Rey Juan Carlos</u>'s mission is to foster innovative research and high-quality education. It provides the project with



The Walking Egg is a unique NGO that brings together science and ART in an effort of strengthening fertility care. It provides

B2-InF with research and innovation advocacy and network



training.

Medistella is a company that aims to making fertility therapy smooth, offering the best pricing, enhance availability and provide a 360-degree service range to patients. It provides the project with



Australo is a marketing agency specialized in European projects

centered on Science & Innovation, helping to thrive in the lab-to-market gap. It provides the project with its skills in marke-ting and community building and innovation management plans.

its priceless network of clinics and patients and vast experience in



University

of Antwerp

The University of Antwerp is characterised by its high standards in education, internationally competitive research and entrepreneurial approach that fuels the project with much knowledge about

the ethical side of the sensitive topic B2-InF works with.



#### Who is Professor Güell?

A short introduction about our Project coordinator and the story behind his vision.



### **Dr. Francisco Güell**Coordinator of the Mind-Brain Group of the Institute for Culture and Society, University of Navarra.

Dr. **Francisco Güell** is a researcher in the Institute of Culture and Society, part of the University of Navarra.

He holds two degrees, both in Biological Sciences and Philosophy, and teaches Bioethics Research at the Rey Juan Carlos University (Madrid). Author of the book "The biological and ontological status of the human embryo: the epigenetic paradigm of the 21st century from the theory of the essence of Xavier Zubiri", specialized in the epistemology of biology and the philosophical approach of Xavier Zubiri.

His research area is framed within the Philosophy of Biology and Neuroscience; he deals with problems related to the genetic and epigenetic dimension of organic development and the characterization of the unity of the living being, with research stays at King's College of London and Georgetown University.

"What inspired B2-InF is a beautiful story of self-reflection" - says Dr. Francisco Güell, Coordinator of the project.

It all began over ten years ago when a family friend asked him for recommendations regarding assisted reproduction technologies, trusting on his vast expertise in the realm of embryo development. But unfortunately, the question took him off-guard.

Dr. Güell realized that he did not know what to tell her, and this quickly became a frustration for him. He could not believe that he could not help a friend out with practical guidelines despite years of a professional career in the field.

It was at this moment that he decided to do anything in his power to change this. He then began his journey of research and analysis, which led him to explore some sides of ART processes from the axis of "responsibility", considering embryo development, patient, clinicians, publicity, and govern perspectives.

During this life journey, Dr. Güell quickly realized that Infertility awareness was lacking among the public. It was absurd that most people did not know that around 10% are now born in Spain thanks to infertility treatments. Things had to change.



## Why does it matter?

#### Hear it from our experts.



Vera Dimitrievska

"Fertility represents a topic that targets biological families, straight couples, and many other categories of people. For example, B2-InF is fundamental for all those women who are very active in their careers and postpone becoming mothers later. I believe that the scientific knowledge generated by B2-InF will fill the gap in the grey literature around this issue."



Virginie Rozée

"The project proposes a legal, gender, and socio-cultural research perspective, which will allow a global and transversal analysis. This perspective is interesting and original as most studies on ART usually mobilize a single discipline. In addition, there is an undeniable pragmatic need for such a project as it aims to enlighten those working in the ART field, including policy makers, so that they can adapt their policies, medical offers, practices, communication and make them better fit with the young generation's expectations.'



**Jaime Onofre** The Walking Egg

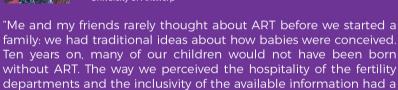
"Over the last years, ART has interceded with much success, but also with many limitations in the current European socio-cultural context. Within this context, the assessment of knowledge, attitudes, and perceptions towards ART is of paramount importance. B2-InF recognizes this gap and is working to engage the public in the conversation. Our goal is to deliver clear and structured guidelines and recommendations to harmonize and direct future developments and provision services within the EU. Only this way ART can be a mainstay technology to support the Health and Wealth of European nations.



lity Europe advocates for fertility treatment accessible to all and

**Anita Fincham** Fertility Europe

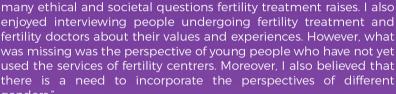
fertility education as an essential life skill! Therefore, we support B2-Infs research on the perception of ART and information provided by the clinics in diverse European countries as we believe it to be a crucial step towards creating guidelines on reaching the young people with the right information at the right time! It can also help remove the stigma still associated with infertility and create friendly dialogue with young people and their educators."



**Joke Struyf** 

major impact on our experiences. It is an honor to contribute to a project which aims to understand more about the expectations of and the way ART information is perceived, to improve the experiences people have with ART ultimately.

"Ten years ago, I started working as a postdoctoral researcher on the ethics of preimplantation genetic screening. I was fascinated by the





**Kristien Hens** University of Antwerp

there is a need to incorporate the perspectives of different genders." Anna Dostalova & Michaela Novotna

"We witnessed an increase in the number of people around the globe who are seeking advanced medical assistance to start their families. We hope that the B2-InF project will allow society to be

better informed to make the best decisions possible in their journey towards building a family. Some countries that lack information on IVF will be able to implement adjustments in favor of their citizens and help spread awareness. The project aims to deliver potential patients the correct information they need saving them time and worry.



**José Miguel Carrasco** Aplica Coop "B2-InF matters to me because I strongly believe in giving voice to citizens and listening to those voices to act to improve societies. Reproduction and everything around it did not capture my attenit, and the scarcity of scientific knowledge. Moreover, B2-inF matters to me because of the scientific and technical challenge that it presents. We have planned to carry out around 100 semi-structured interviews in 8 countries. Anyone who knows what implies the recruitment for and analysis of qualitative research will be aware of what it means!"



# General state of the industry now and next steps



Since Loise Brown was born 43 years ago, more than 10 million have been born around the world today. Assisted reproductive techniques were proposed, from the beginning until now, for couples with fertility problems. The social users of ART -with no medical reasons- are increasing over the years. The mean age of women in the EU giving birth to their first child was gradually growing and stood at 29.4 years in 2019, according to Eurostat (in a range from 26.3 in Bulgaria to 31.3 in Italy in EU member states). Work and lifestyle in Europe can push women to delay their plan to have a child, which may also affect the expectations experienced that lead woman to ART. There is also some new evidence that contamination is affecting fertility. These factors, and others, are behind the high increase in demand for these techniques.

This exponential increase in demand has transformed an eminently clinical sector into a large commercial enterprise. The line between the public and private interest is blurred, and the regulation of practices by the authorities is not an easy task in a sector where scientific evidence does not find a decent home. From an ethical perspective, there is an essential tension between maximizing benefits -commercial mood- and quality of care -biomedical perspective.

Accessibility and affordability are also crucial, principally -but not only- in developing countries. In a nutshell: What is the relationship between the public health system and the private sector? How is the relationship between doctors and patients? What should be the role of authorities in the private sector? What impact does the incursion of clinics into large commercial enterprises have for the practice of reproductive health? What is the relationship between medical and professional ethics and economic policies? All these questions, and many others, must be approached scientifically to get a global idea of the implications of assisted human reproduction in society and its impact on the next generations.

B2-InF begins by exploring how young people understand, react, and interact with reproductive technologies and analyze the information offered by clinics to society. To align the information given by clinics with and for society through practical guidelines will empower citizens in their decisions and illuminate other ongoing research to comprehend better-assisted reproduction. In this field, the individual, technical and social dimensions are indissoluble.

