

B<sup>2</sup>-InF



**INFERTILITY AND MEDICALLY ASSISTED REPRODUCTION. CLOSING THE GAP BETWEEN CITIZENS' CONCERNS AND THE INFORMATION PROVIDED BY CLINICS.**



Funded by  
the European Union

# ABSTRACT

Infertility is a critical public health issue that affects millions of individuals and couples worldwide and can seriously impact their quality of life. However, general knowledge about infertility and its treatments is scarce, and the information provided is not always properly communicated. Technical language and misleading data (e.g. success rates) often hinder the general public in making well-informed choices. B2-InF project has explored European young people's

perceptions and experiences with infertility and its treatments through close to 100 interviews, analysing information provided by approximately 40 clinics and exploring legal regulations in 8 European countries. As a result of all the analyses conducted, B2-InF provides recommendations and guidelines to bridge the gap between the public's concerns and expectations about Medically Assisted Reproduction and fertility care and the information and services offered by clinics.

## INFERTILITY. A CRITICAL PUBLIC HEALTH ISSUE

The World Health Organization states that infertility is a global health issue affecting around 48 million couples and 186 million individuals worldwide<sup>1</sup>. The difficulty in having children can have important social, economic, psychological and physical effects that seriously impact the quality of life of people concerned. Furthermore, there are significant social inequalities in the prevalence, diagnosis and treatment of infertility, as well as health risks for women, men and their offspring associated with these treatments<sup>2</sup>. In addition, socio-cultural and environmental factors

such as the increasing average age of pregnancy in the general population will likely amplify the social significance of this already important issue. For all these reasons, and because reproductive care is key to the promotion of sexual and reproductive health and rights, infertility and its outcomes have become a critical public health issue.

Unfortunately, the general knowledge about infertility and Medically Assisted Reproduction (MAR) treatments is scarce, and the related information is not always properly communicated.

<sup>1</sup> World Health Organization. Infertility [Internet]. World Health Organization [accessed 16 December 2022]. Available from: <https://www.who.int/health-topics/infertility>

<sup>2</sup> Centers for Disease Control and Prevention. National Public Health Action Plan for the Detection, Prevention, and Management of Infertility. Atlanta, Georgia: Centers for Disease Control and Prevention; June 2014. Available from: [https://www.cdc.gov/reproductivehealth/infertility/pdf/drh\\_nap\\_final\\_508.pdf](https://www.cdc.gov/reproductivehealth/infertility/pdf/drh_nap_final_508.pdf)

# BE BETTER INFORMED ABOUT FERTILITY. B2-INF RESEARCH PROJECT

The research project “Be better informed about infertility -B2-InF-”, funded by the European Union, was created to explore the knowledge, expectations and concerns of young people aged 18 to 30 and the information provided by Medically Assisted Reproduction (MAR) clinics from 8 European countries (Albania, Belgium, Italy, Kosovo, Macedonia, Slovenia, Spain, Switzerland) with the final objective of providing recommendations to align the services, research and information of MAR clinics with the views, concerns and expectations of young citizens.

To reach this objective, 98 interviews were conducted with young people (10-

15 interviews per country) and 38 clinics’ websites were examined (3-5 clinics’ website per country). The transcripts of the interviews and the clinics’ information collected were analysed following qualitative approaches from a socio-cultural and gender perspective. Additionally, a documentary analysis was conducted to ascertain the legal regulation of MAR in each country. Based on the knowledge generated, the B2-InF research team has elaborated the global recommendation summarized in this document, as well as specific guidelines for each country available in the B2-InF project website.

## B2-INF RESULTS. CONCERNS AND INFORMATION NOT PROPERLY ALIGNED.

In general, young Europeans view MAR treatments favourably, as a good option for dealing with infertility, expressing positive perceptions about them despite a recognized lack of knowledge, and supporting equality of access for all. However, young Europeans also express concerns about critical issues related to MAR. Primarily, concerns were raised about the close relation between infertility and social pressure in terms of gender roles. While infertility and especially male infertility remain taboo, partially due to a lack of knowledge about their prevalence and causes in society, an unfair blame, burden and responsibility for infertility are socially attributed to women. Furthermore, inequalities of access to MAR treatments for some population groups due to costs and restrictions are described as barriers to be addressed. Finally, young people express concern for the reliability of the information provided by private clinics due to perceived commercial interests that could affect the quality of this data. In particular, young Europeans express a clear desire to increase the availability of accessible, clear and trustworthy information about MAR success rates, risks and psychological care support.

Regarding the information provided by clinics, the explored websites present a large amount of information with an excess of technical and scientific terms without plain language interpretations, thus hindering its understanding by the general population. In addition, information about success rates and risks is not always available or it is presented in an unspecific or unclear way. Furthermore, information about infertility treatment services, and the marketing resources used to present this information, are primarily directed towards white and heterosexual couples and skewed towards women, which may contribute to the unequal social burden of female infertility.

Finally, although the information provided by MAR clinics is regulated by legal standards for truthful advertising, clinics do not always meet these standards. In particular, clinics’ websites often lack transparency about MAR costs, and do not always provide information about success rates, add-ons (supplementary procedures offered by clinics for the purpose of improving fertility treatment outcomes) and possible risks, or do so in ways that are misleading or difficult to understand.

# RECOMMENDATIONS FOR A BETTER-INFORMED CITIZENSHIP

# GENERAL RECOMMENDATIONS FOR CLINICS AND GOVERNMENTS

To better inform European citizens about infertility and MAR, clinics must align the information they provide with the concerns and expectations of the public, by all means meeting the legal standards for truthful advertising. Aiming to destigmatize infertility and to promote quality MAR treatments, governments should make efforts to develop and

implement public campaigns to raise awareness and to better educate the general population about infertility, its causes and treatment, with a focus on gender biases and misconceptions, and to check for the fulfilment of relevant legal regulations for health services and advertising.

## SPECIFIC RECOMMENDATIONS:

### 001

The information provided should contribute to reduce social taboos, de-stigmatize infertility and avoid presenting it as a women's issue. Information should be gender-balanced and should use gender-neutral colours, language and logos.

### 004

Legal restrictions on access and procedures (e.g. single mothers, LGTB+ couples, nullity of surrogacy contracts) should be clearly stated by the clinics in a way that is consistent with national regulations.

### 007

Health authorities should promote accessibility to "information sheets" and "informed consent forms". It is suggested to create a catalogue of these documents that comply with current regulations.

### 002

Motherhood and parenthood should not be represented as a condition for happiness in life, and clinics should avoid presenting themselves as "dream facilitators". It is strongly recommended to avoid superlatives when describing MAR clinics' services to reduce false hopes and deflate social pressure.

### 005

The information provided by clinics should be more objective, reliable, intelligible, clear, and accessible to the general public and patients, in support of adequate understanding and well-informed choices. It should be based on best available scientific evidence, providing evidence-based data sources, and should provide explanations in nontechnical terms, using the most commonly spoken languages of local populations.

### 003

The information (content and visuals) provided should be gender-inclusive, less heterocentric and aimed at a more ethnically diverse population. The advertising strategies and information provided by clinics and health authorities should be addressed to all prospective parents and those contributing to reproduction (e.g. donors), regardless of gender, sexual orientation, or disability and reflecting the ethnic, cultural and racial diversity of their context.

### 006

To reduce misunderstandings and false hopes and promote informed choices, clinics should use an intelligible, clear, homogeneous and common language when providing information about cost, length, success rates (it is recommended to disclose live-birth rates, not only pregnancy rates), possible health risks for each MAR technique (taking the sex and age of users into consideration), and psychological challenges.

# CONCLUSIONS

There is room for improving information provided by MAR clinics and also by the health authorities so as to address the general public's concerns and expectations about fertility care, Medically Assisted Reproduction and other services offered by clinics. It is strongly recommended to implement the guidelines produced by B2-InF to promote better knowledge of infertility and its treatments, with the purpose of raising awareness, reducing stigmatization and providing reliable, intelligible and clear information for the general public and patients that will contribute to well-informed choices. The extended guidelines are available on the B2-InF project website.

## DISCLAIMER

The information, documentation and figures available in this deliverable are written by the B2-Inf project consortium under EC grant agreement 872706 and do not necessarily reflect the views of the European Commission. The European Commission is not liable for any use that may be made of the information contained herein.

## COPYRIGHT NOTICE

© 2020 - 2023  
B2-Inf Consortium Reproduction is authorised  
provided the source  
Contact information: Francisco Güell.  
Email: b2-inf@unav.es

## B2-INF CONSORTIUM

Universiteit Antwerpen, APLICA. Investigación y traslación, Australo, Fertility Europe, Health Grouper, Institut national d'Études démographiques, Medistella, The Walking Egg, Universidad Rey Juan Carlos, Universidad de Navarra.

### HOW TO CITE THIS DOCUMENT

Carrasco, J.M., López-Toribio, M., Ramón, J.A., March, S., Dimitrievska, V. Meloska, J., Fuller, M., De Bayas Sánchez, A., Rozée, V. Vialle, M., Ombellet, W., Hens, K., Struyf, J., Albert, M., Tapia, M.R., Farfán, J., Muñoz, S., Vicente, A., Fincham, A., Pastor, G., Abu, S., Perez, B., Barrett, N., Güell, F. B2-Inf Be better informed about fertility. Global policy brief [Internet]. Pamplona: UNAV, 2023.

Available from: [https://zenodo.org/communities/b2inf\\_h2020/](https://zenodo.org/communities/b2inf_h2020/)



Funded by  
the European Union