EuMAR by ESHRE

European monitoring of Medically Assisted Reproduction (EuMAR)

D2.2 Project Leaflet

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Acronyms and abbreviations

D	Deliverable
ESHRE	European Society of Human Reproduction and Embryology
EU	European Union
HaDEA	European Health and Digital Executive Agency
IRCC	Individual Reproductive Care Code
MAR	Medically Assisted Reproduction
PST	Project Support Team
WP/s	Work Package/s

Executive Summary

This deliverable report provides an overview of the EuMAR project leaflet, which has been designed and developed in collaboration with external designers, based on the content prepared by the Project Support Team (PST). The EuMAR project leaflet (Annex 1) provides a valuable overview on the project background, aim, objectives, work packages, expected impact and the Individual Reproductive Care Code (IRCC). This leaflet is the first of several foreseen throughout the project, to print and distribute at different meetings and activities. The impact of the project leaflet will be monitored by tracking the number of copies printed and distributed to different target audiences. Additionally, this report also provides insights into the different sections of the leaflet and potential future brochures to be developed.

Introduction

The creation of leaflets for the EuMAR project is an important step in disseminating information about our work to a wider audience, i.e., medical professionals, patients and patient organizations, policymakers and authorities, researchers and the general public. The objective of the project leaflet (Annex 1) is to have something tangible, to take and display or hand out at different activities and events, allowing participants to get a better understanding of the project, its aims and what is to come.

The EuMAR project aims to develop a pan-European registry of prospective, cycle-by-cycle data on the use and outcomes of medically assisted reproduction (MAR). The project addresses the need for more transparency, surveillance and biovigilance of MAR across national borders, including better data on the safety of MAR for offspring, donors and recipients, in line with the revision of the EU Directives on blood, tissues and cells.

The first EuMAR project leaflet was distributed at the Kick-off Meeting on 10 March 2023 as the first in a series that will be produced throughout the three-year timeline, recognising key updates along the way. The purpose of this report is to outline the process of creating the leaflet, its content and future developments.

Project Leaflet

This chapter describes in detail the EuMAR project specific leaflet and its sections that have been included to serve as an introduction to the project and its aims.

The EuMAR project leaflet (Annex 1) will be printed and handed out at various events and activities, including but not limited to ESHRE's Annual Meeting, meetings and congresses at which the project is being presented, internal and stakeholder meetings. This provides an additional level of visibility to the ESHRE community and external interested parties.

The project leaflet was designed and printed by the ESHRE communications team along with external designers, printers and in collaboration with the Project Support Team. The leaflet was designed to be visually appealing and in line with ESHRE's branding colours, easy to read and to give a nice clear introduction to the project (Figure 1). The creation of the leaflet involved several steps, including the size and type of a leaflet, the selection of appropriate content and the design implementation.

Figure 1: Final version of the first EuMAR project leaflet

Current leaflet section structure

The EuMAR project leaflet (Annex 1) has the following sections; Background and Aims, Work packages, Expected impact, Individual Reproductive Care Code (IRCC), Key steps and Contact. It also hosts the European flag along with the funding statement and disclaimer, in accordance with article 17 of the Grant Agreement [1].

Background and Aims

The Background and Aims page briefly describes ESHRE's current data collection in the European IVF Monitoring (EIM) consortium as the background of the project and highlights the improvements that are aimed to be achieved through more detailed data collection in the EuMAR registry (Figure 2).

Figure 2: Background and Aims page

Key Steps and Contact pages

The Key Steps of EuMAR page identifies the three main steps that will be undertaken to successfully complete the three-year project. The Contact page includes the disclaimer and the project specific contact details including an email and website URL (Figure 3).

Figure 3: Key steps of EuMAR and Contact pages

Work packages

The Work packages (WP) section gives a concise description of the five core work packages, WP3 to WP7, and outlines their respective focuses (Figure 4). Additionally, at the bottom of the leaflet page, the section highlights the presence of three horizontal work packages: WP1, WP2, and WP8.

Figure 4: The EuMAR Work packages page

Expected Impact & Individual Reproductive Care Code page.

The following one page (Figure 5) is split into two parts, with the top half giving a short statement of the anticipated impact of the EuMAR project and the insights that will be of benefit to patients seeking care, professionals pursuing medical excellence and health authorities. The lower part of the page gives an introduction, including a graphical overview, to the Individual Reproductive Care Code (IRCC), which is one of the key elements of EuMAR, (Figure 5).

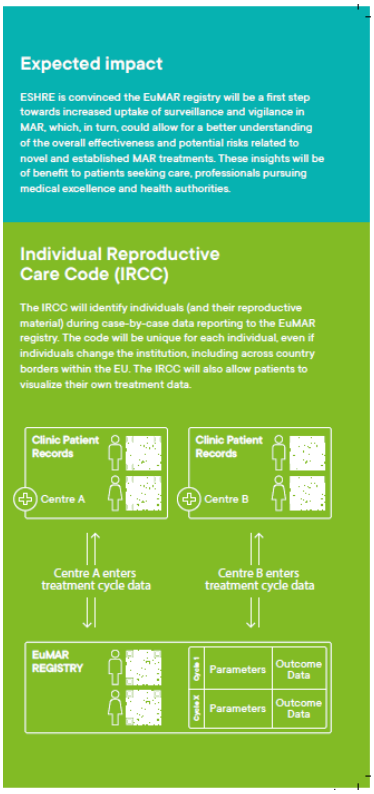

Figure 5: Expected Impact and IRCC page

Further Development

The EuMAR project leaflet (Annex 1) is the first in a series of leaflets that will be created throughout the three-year project and in line with the dissemination strategy of WP2. It is not yet confirmed how many leaflets will be produced, however, it is aimed to publish minimum two, this one to start the project and a final leaflet to end the project. These will be part of a series that includes infographics as well. For example, target group specific leaflets and/or infographics will be developed to further promote the project, its results and to provide targeted information on its added value to different audiences.

It is planned to add the digital copy of the leaflet to the project specific website (EuMAR (eshre.eu)), under Resources, as part of the toolkit for wider dissemination and easy access.

Impact Monitoring

The impact of the EuMAR project leaflet (Annex 1) and any future handouts will be monitored by tracking the number of copies printed and distributed. We will report on it as a dissemination impact indicator in the dissemination reports. It will also be counted the number of downloads/clicks of visits on the website.

Conclusion

The creation of the EuMAR project leaflet has been an important step in promoting the project and raising awareness on how the project will be structured through its work packages, its aims and the key steps being taken. The leaflet provides important information about the project and its work packages and will be part of a series of leaflets created to show the progress of the project at different stages over the three years. It will also be part of a larger toolkit being developed for the project support team and key stakeholders to have access to, to help with the promotion and awareness of the project.

References

[1] Grant Agreement Number 101079865— EU4H-2021-PJ2

Annex 1: Project Leaflet

See next page

Key steps of EuMAR

1. Develop a tailored data flow model that meets the national requirements of all EU Member States and avoids duplication of efforts;
2. Prepare a glossary of standardised parameters on which data is to be collected with corresponding definitions;
3. Develop an IT solution for data collection, including an “Individual Reproductive Care Code” (IRCC) that allows prospective data collection and cumulative follow-up across different centres/countries.

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EuMAR

EuMAR by ESHRE

Background and Aims

The European IVF-monitoring (EIM) consortium of the European Society of Human Reproduction and Embryology (ESHRE) has been collecting MAR data since 1997 with annual reports summarizing efficacy of fertility treatments and trends. While valuable, the current EIM data collection is limited in terms of the parameters that can be calculated from the collected summary data (such as cumulative pregnancy rates) and in terms of collecting data on cross border activity.

European monitoring of Medically Assisted Reproduction (EuMAR) aims to develop a pan-European registry of prospective cycle-by-cycle data on the use and outcomes of Medically Assisted Reproduction (MAR) treatments.

EuMAR addresses the need for more transparency, surveillance and biovigilance in MAR across country borders, including better data on the safety of MAR for offspring, donors and recipients.

Work packages

The work for the EuMAR project is divided into 8 Work Packages (WP), including 5 core WPs and 3 horizontal WPs, each executed by a dedicated working group.

→ WP3 Integration in national policies and sustainability
The project specifically aims to prepare the implementation of the central EuMAR data registry through developing connections with the national competent authorities and policymakers and gathering their feedback. To achieve this goal, ESHRE will map the different stakeholders across the EU member states, distribute information on the project and gather feedback on barriers to implementation and examine with Competent Authorities on what data they and the centres in their countries need/would like to receive.

→ WP4: Selection and definition of parameters
To prepare the data registry, this WP aims to identify relevant items to be registered and create a glossary of standardised definitions in order to ensure proper data harmonisation.

→ WP5: IT solution for the registry including the IRCC
This WP entails the development of the IRCC and a web-based transnational IT solution able to ensure the prospective collection of cycle-by-cycle and case-based harmonised data sets. This WP brings together the stakeholder input, GDPR analysis, the parameters to be included, as well as the technical possibilities and limitations.

→ WP6: Pilot study
A pilot registration of data by selected participants will be organised to assess and validate the system and adapt it prior to wider implementation.

→ WP7: Plan for incorporation of innovation
To ensure the EuMAR data registry is future proof, WP7 aims to facilitate the flexibility of the data registry with regards to the inclusion of additional parameters, amendments towards innovations and possible future connections to other data registries.

Horizontal work packages:
→ WP1: Project management and coordination
→ WP2: Dissemination & Communication
→ WP8: Evaluation

Expected impact

ESHRE is convinced the EuMAR registry will be a first step towards increased uptake of surveillance and vigilance in MAR, which, in turn, could allow for a better understanding of the overall effectiveness and potential risks related to novel and established MAR treatments. These insights will be of benefit to patients seeking care, professionals pursuing medical excellence and health authorities.

Individual Reproductive Care Code (IRCC)

The IRCC will identify individuals (and their reproductive material) during case-by-case data reporting to the EuMAR registry. The code will be unique for each individual, even if individuals change the institution, including across country borders within the EU. The IRCC will also allow patients to visualize their own treatment data.