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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EU Funding

The EuMAR project is co-funded by the European Union, Project: 101079865 — EuMAR — EU4H-2021-PJ2°

*Co-funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or European Health and Digital Executive Agency (HADEA). Neither the European Union nor the granting authority can be held responsible for them.

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.