European monitoring of Medically Assisted Reproduction (EuMAR)

D3.1 Policy recommendations

Infertility treatment data in the EU: policy recommendations

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Introduction

Registries of medically assisted reproduction (MAR) have existed for many years, both at national level and international levels, and they have proven essential to promote trust, inform policies and support the effectiveness and safety of infertility treatments. It has been established that prospective, cycle-by-cycle data registries of MAR are key to monitor patients' and couples' paths through different treatments, which happen sometimes across different MAR centres and even countries (De Geyter et al. 2020). Collecting MAR data per cycle offers the possibility of calculating improved estimates of time to live birth, rather than the rough estimates that can be performed with aggregated datasets. The outcome calculations that are possible with cycle-by-cycle registries have the potential to help patients make informed decisions, provide evidence for public policies on infertility treatment and support fertility clinics' in monitoring their quality of care.

Cycle-by-cycle MAR registries have already been established in many parts of the world, including 13 EU Member States (Achótegui Sebastián et al. 2024), but a centralised European cycle-by-cycle MAR registry is not yet in place. The European Society of Human Reproduction and Embryology (ESHRE), with co-funding from the European Commission, launched the EuMAR project in 2023 to build and test the first European registry of cycle-by-cycle MAR data, with a model to collect cumulative including the cross-border data on infertility treatments in EU countries. During the EuMAR project, stakeholders from the scientific community, as well as patient representatives and national health authorities were involved and consulted to evaluate the feasibility and the challenges of establishing such a registry.

This document highlights some of the findings of the EuMAR project with the aim to inform policymakers in the European Union and its Member States on the urgent need and recommended policies to maintain the EuMAR cycle-by-cycle registry in Europe.

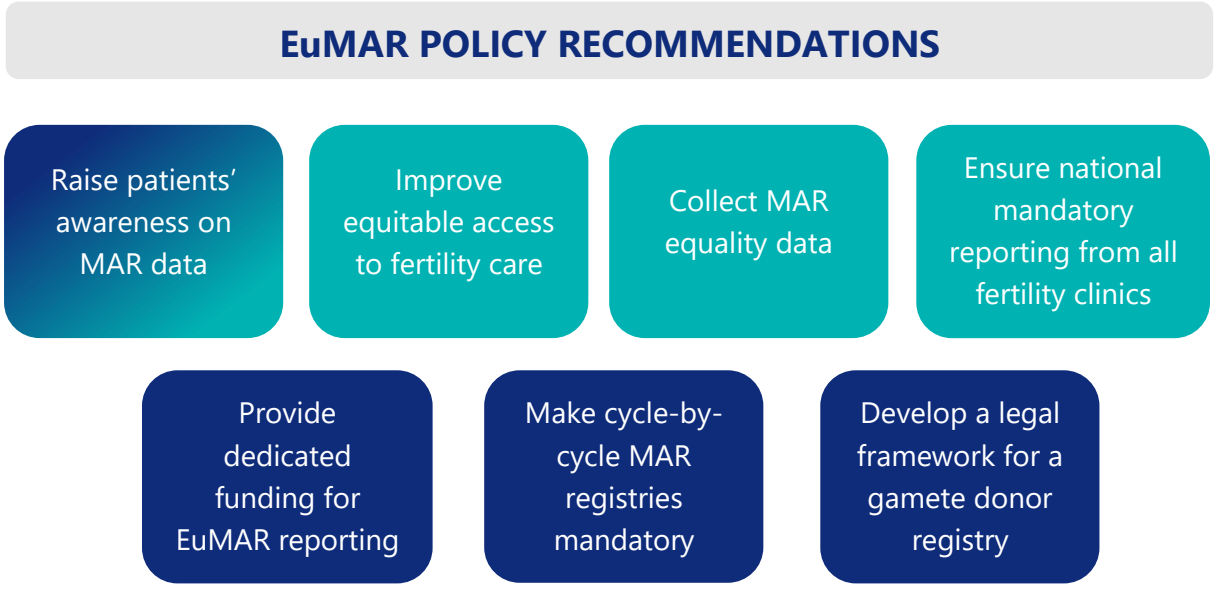

Figure 1: EuMAR Policy Recommendations. Light blue represents recommendations for member states, dark blue represents recommendations for the European Union (EU), and the two-toned box indicates recommendations applicable to both Member States and the EU.

Research overview

The policy recommendations presented in this document are based on the findings of the research conducted during the development and test phase of the EuMAR registry. Between January 2023 and December 2025, the EuMAR project mapped national competent authorities of EU Member States and shaped different data flow models to adapt the centralised collection of data to the national contexts of EU countries. It also defined a list of parameters and their definitions to standardise MAR data collection and built an online registry with two different patient codes to allow the collection of cumulative including national interinstitutional as well as cross-border data: the Individual Reproductive Care Code (IRCC) and the ClinicSwitch Code (CSC). A test of the registry was carried out between July 2024 and September 2025 in four pilot countries – Estonia, Germany, Slovenia and Portugal –, submitting infertility treatment data of ca. 30,000 patients to EuMAR. Additionally, evaluations with pilot study participants were conducted, a survey and focus group sessions with patients were carried out to include patients' perspectives in the registry development process and data assessment.

Results and policy recommendations

Building and testing the EuMAR registry – which included consultations with EU national health authorities, MAR professionals in the four pilot countries and infertility patients –, supports the growing literature suggesting that cycle-by-cycle registries in MAR are the most accurate way to collect MAR data. In addition, it provides an overview on some of the challenges and best practices to achieve a comprehensive European cycle-by-cycle MAR registry for real-world evidence to advance treatment efficacy and safety in the field of MAR.

Patients' awareness on MAR data

Finding

The majority of patients are not sufficiently aware of health and MAR data registries. In the survey organised by EuMAR, when asked about knowledge of data registries, 60% of infertility patients indicated that they did not know about health data registries in general, and only 25% of respondents indicated knowing that their infertility treatment data was collected in a national MAR registry. As one of the factors contributing to this, patients reported that when starting infertility treatment, the high levels of new information to absorb often make it difficult to give relevance to the questions about data.

Policy Recommendation for the EU and Member States:

1. Raise patients' awareness on MAR data

ESHRE recommends that efforts are strengthened to **raise patients' awareness about the role of data in improving care and advancing research**. Enhancing general public understanding of how health and MAR data contribute to scientific progress is a critical step toward increasing patients' trust and willingness to share their information. This is essential for the collection of appropriate, more comprehensive, and representative data registries across Europe.

Universal access to fertility treatment

Finding

Cross-border reproductive care often results from limited access to fertility treatment in patients' countries of residence. Both professionals and patients reported experiences with cross-border care due to restrictions, such as countries not allowing a particular type of treatment; or treatment being denied based on relationship status or sexual orientation; or long waiting lists for specific treatments. These waiting lists also reflect issues of sufficiency and supply within national health systems and data collected on the topic could be valuable.

Policy Recommendation for Member States:

2. Improve equitable access to fertility care

In line with the Coalition for Fertility (2025), ESHRE recommends that Member States improve equitable access to fertility care by addressing systemic barriers that compel patients to seek treatment abroad. Ensuring that individuals can access appropriate, timely, and affordable fertility services in their home countries is key to reduce the need for cross-border care and promote fairer access to reproductive healthcare across Europe.

Equality data for informed policy choices

Finding

Current data on MAR treatments does not allow for adequate analysis of disparities in access, use, and outcomes across different identity groups. While sex-disaggregated data is inherent to the collection of MAR data, gender-disaggregated, ethnicity and other equality data are not systematically collected in national MAR registries.

Policy Recommendation for Member States:

3. Collect MAR Equality data

Adhering to the European Commission's definition of Equality data as 'any piece of information that is useful for the purposes of describing and analysing the state of equality', ESHRE recommends advancing toward the collection of clinical and non-clinical **indicators that help identify and address inequalities in access, experience, and outcomes across different social groups.** This includes data on age distribution, partnership status; racial or ethnic origin (in line with the European Commission guidance, 2020); data disaggregated by sex assigned at birth and gender identity; use of donor gametes; presence of disability or more specific clinical conditions; socioeconomic factors, such as education level; or geographic elements, such as whether treatment involves cross-border care. Collecting more inclusive and detailed demographic data will enable researchers to identify disparities, and support policymakers in designing and evaluating targeted, equitable interventions in reproductive healthcare.

Complete data from all fertility clinics

Finding

Accurate data reporting and transparency from fertility clinics cannot always be guaranteed. MAR centres and national authorities described certain difficulties in ensuring complete and prospective reporting from MAR centres. According to the EuMAR survey, the causes for incomplete data reporting vary and can include a lack of resources in centres for data registration or in authorities for audits. It can also happen that reporting requirements do not cover all cycles/centres, for instance if data reporting is linked to only public funding for treatments. It is also possible that centres intentionally hide certain data that could lower statistics of their success rates.

Policy Recommendation for Member States:

4. Ensure national mandatory reporting from all fertility clinics

ESHRE recommends that Member States **ensure mandatory data reporting from all fertility clinics – public and private – towards national health authorities.** Standardised and comprehensive reporting is necessary to ensure treatment safety and to improve transparency for patients and ensure the collection of high-quality, complete data across all types of service providers, without distinction between public and private centres, and regardless of whether the treatment is reimbursed or not.

Facilitating the right context

Findings

There is very limited data available on cross-border reproductive care, despite large volumes of activity across Member States. The patients' consultation provided insights into the cross-border reproductive care activity within the EU. For instance, 4% of patients identified Spain as their country of treatment although coming from another country. This suggests that Spain serves as a major destination for patients seeking treatment abroad. The opposite was true for Germany, where there were more respondents identified as German nationals than those that received treatment in the country, suggesting that a significant number of German patients seek reproductive care abroad. A review of the existing literature revealed a clear lack of data and research on cross-border reproductive care in Europe, highlighting the need for more systematic studies and data collection in this area, a gap that EuMAR aims to address.

High quality data collection systems require specific human resources and financial investments. Limited means of national authorities and MAR centres could constrain data quality in the EuMAR registry and may limit participation from some countries. The stakeholder mapping exercise showed that authorities and clinics are reluctant to introduce novelties when significant financial and human resources are required for the change to materialise. This raises emerging uncertainties of the institutions' capacity to participate in a new European data collection.

Policy Recommendation for the EU:

5. Provide dedicated funding for EuMAR reporting

ESHRE calls on the **European Union to provide dedicated funding to support Member States' participation in the EuMAR registry**. This support should include resources for improving interoperability, ensuring data quality control, and strengthening national capacity. Targeted EU investment can enable broader participation and maintain high standards of fertility data collection, - including that of cross-border treatments – across Europe.

Finding

Despite existing incentives, achieving comprehensive participation in a voluntary European MAR registry remains challenging, with inconsistent data submission from fertility clinics and national registries across Europe.

Policy Recommendation for the EU:

6. Make cycle-by-cycle MAR registries mandatory

ESHRE recommends that the European Union makes it **mandatory for all MAR centres in EU Member States to report to a single, harmonised MAR registry at the European level**. This should include the adoption of a common minimum dataset and the implementation of cycle-by-cycle data collection standards. A unified and mandatory approach will ensure complete, comparable, and high-quality fertility data across Europe, enabling better transparency, traceability, research, surveillance, and policy development.

Gamete donors

Finding

There is strong stakeholder interest in establishing a European donor registry, but its implementation remains limited in the absence of specific EU-level legislation. As a professionals' organisation, ESHRE does not have the legal basis to collect identifiable data nor to apply enforcement mechanisms for vigilance alerts. EuMAR data remain non-identifiable, making it impossible to link specific treatments to specific donors that would, for example, allow informing about serious genetic conditions related to a donor, and monitoring that the maximum number of children born from the same donor is not exceeded.

Policy Recommendation for the EU:

7. Develop a legal framework for gamete donor registry

ESHRE recommends that the European Union explores the **development of a legal framework to support the creation of a European donor registry**. Such a registry would promote traceability, transparency, and safety in gamete donor treatments across borders, while respecting ethical and legal standards. Establishing a clear legislative basis is a necessary first step toward making a cross-border donor registry feasible and effective.

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