

The importance of registers for the fair regulations and quality of treatments

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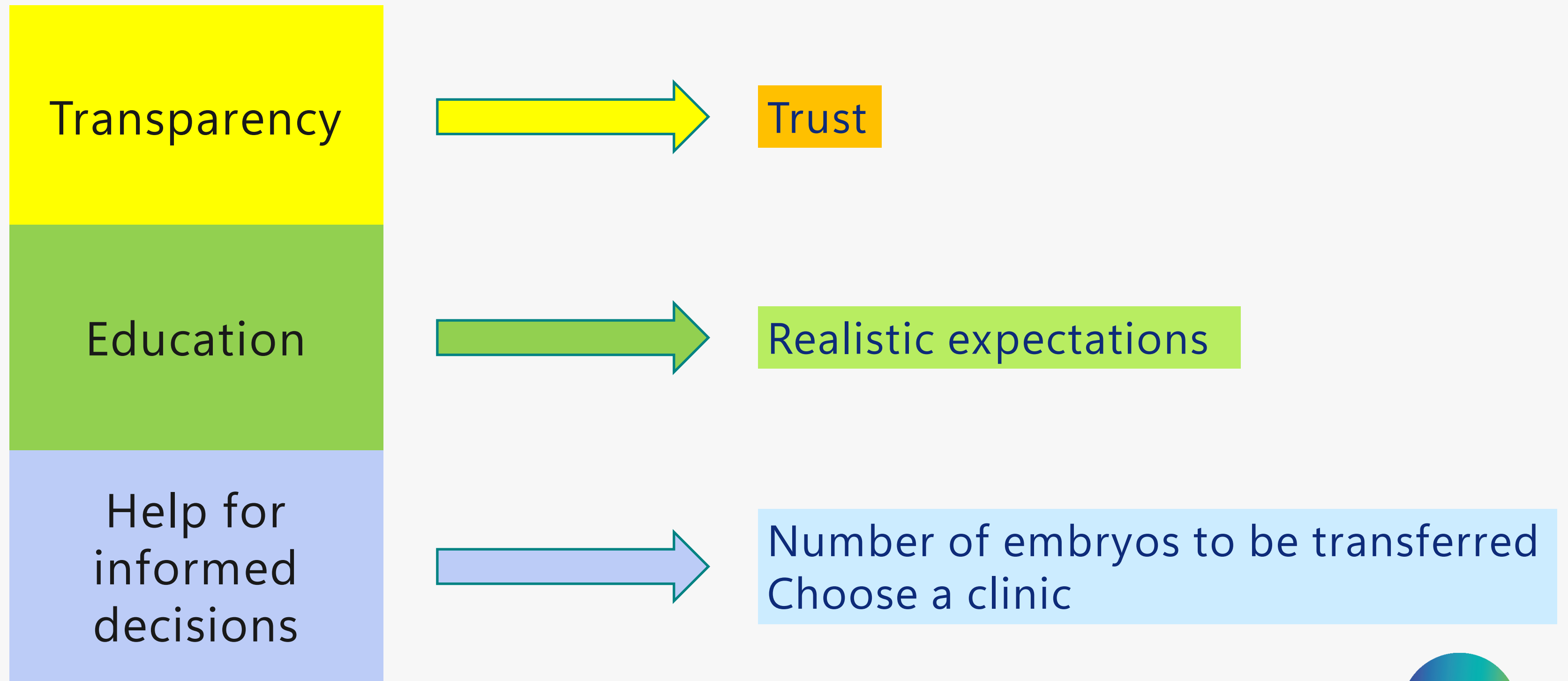
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ART/MAR registers are crucial for



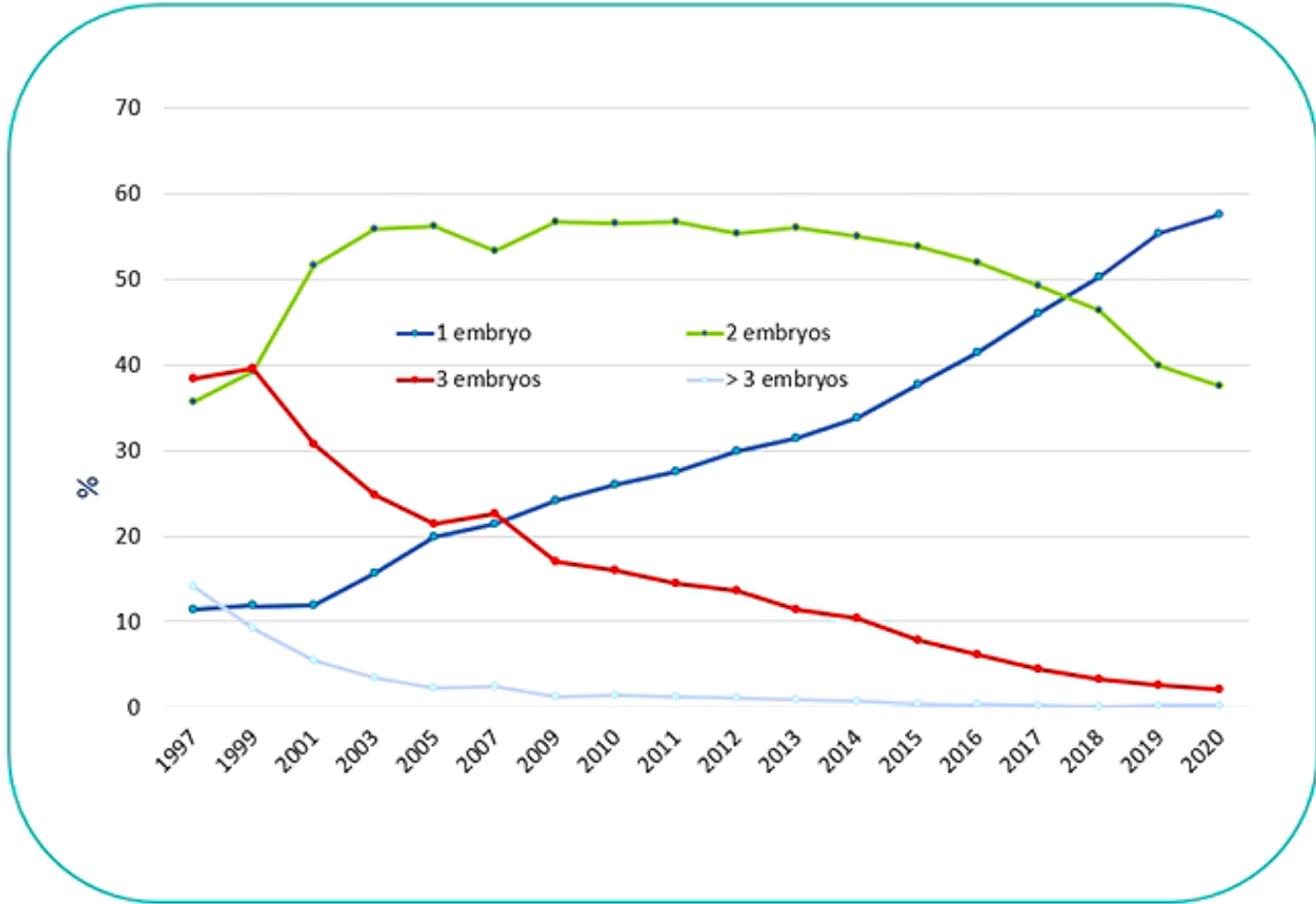
Importance of data registries for **patients**:



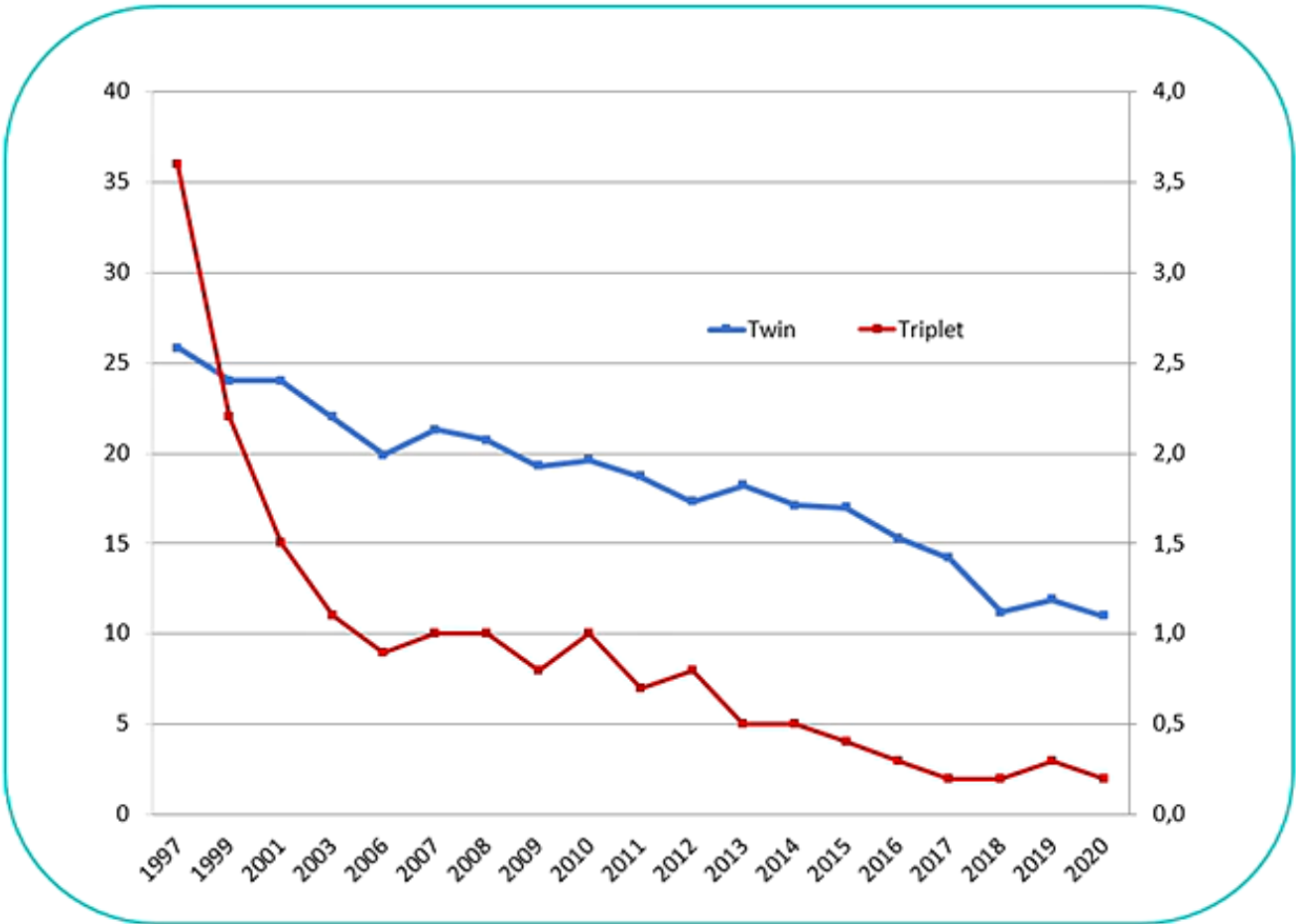


Relation number of embryos transferred and multiples

Number of transferred embryos in IVF/ICSI



Twin and triplet deliveries after IVF and ICSI



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Information obtained from summary (aggregate) data registry – EIM



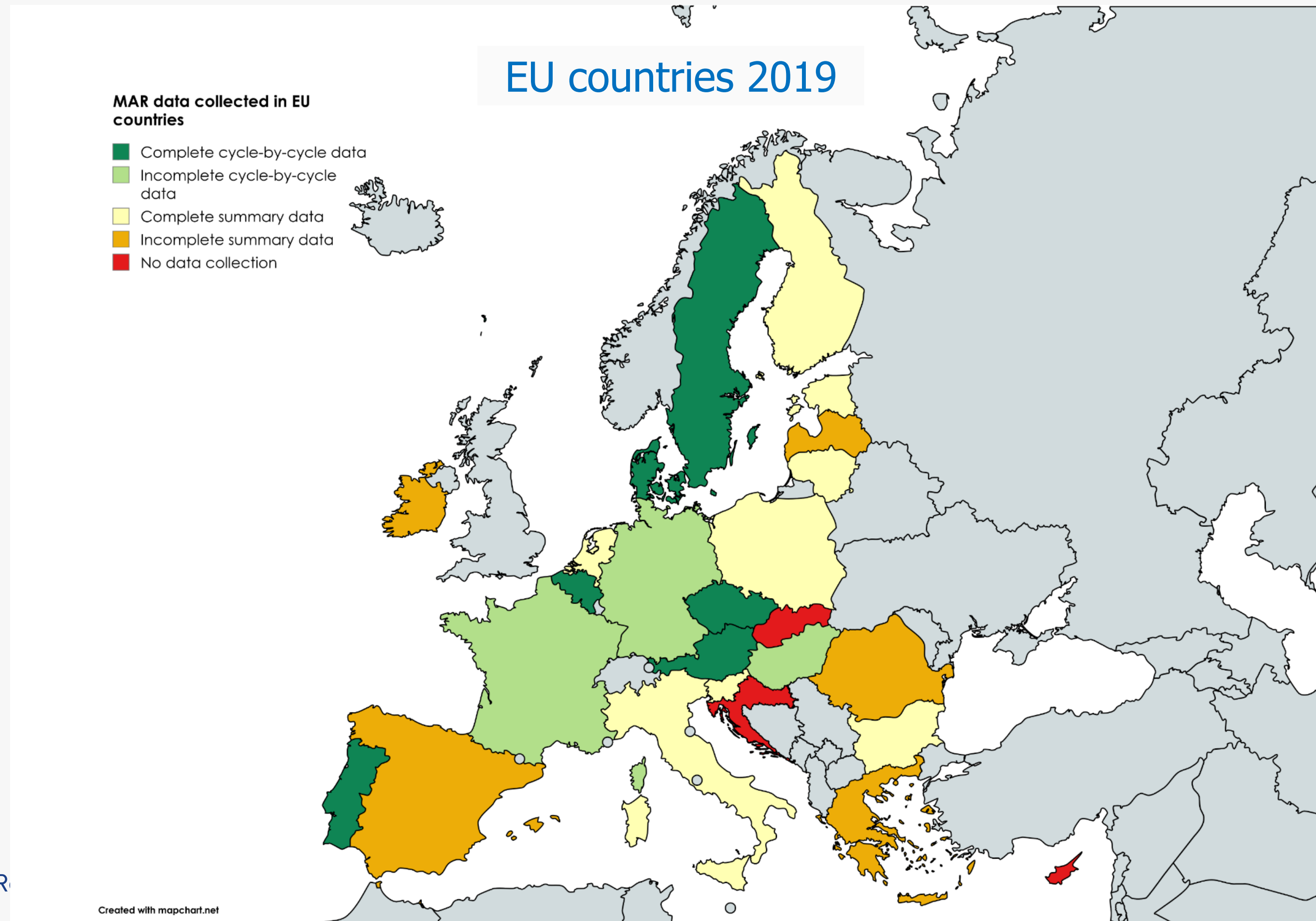
Characteristics of an ideal registry:

- Cycle-by-cycle 
- Harmonisation and (balanced) completeness
- Full coverage
- Data quality (validation)
- Flexibility

- cumulative data
- cross-border treatments



Data collection in Europe: overview on types of data





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EuMAR

European monitoring of Medically Assisted Reproduction

EuMAR is a three-year project aiming to develop a **pan-European registry of prospective cycle-by-cycle data** on the use and outcomes of MAR treatments.



Co-funded by the European Union.

Project: 101079865 — EuMAR — EU4H-2021-PJ2





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Objective 1: Data flow

Develop a **flexible data flow model** adjusted to the local contexts of all Member States

Objective 2: Core parameters

Develop a **list of standardised parameters** with corresponding definitions on which data is to be collected

Objective 3: IT solution

Establish a **web-based data registry**, including a unique **Individual Reproductive Care Code (IRCC)** for MAR patients and donors

EuMAR intends to respond to the need for



Biovigilance
and risk
prevention

**Cross-border
care** and
cumulative
outcomes

Harmonisation
of definitions and
parameters

Accessibility
of data to ensure
transparency

Flexibility to
connect with other
registries

EuMAR update:

- Meetings with all National Competent Authorities

- Pilot study:  Germany

 Portugal

 Slovenia

- Assessment of the collected data

- Proposals for action

- The future?

Development
Expansion
Sustainability

Donor registries ...



In summary, accurate ART/MAR registries are crucial to enable:

- A detailed look at different phases of the technical procedures and a benchmark exercise
- Research initiatives otherwise not feasible
- Full transparency and a more well-based patient counselling
- A global perspective for the public and the policy-makers

A harmonised pan-European registry is a critical tool for giving to all stakeholders (and mainly the patients) complete and honest information about the real MAR world

