EuMAR Final Dissemination Conference

Brussels, Friday 12 December 2025

EuMAR by ESHRE

Co-funded by the European Union.
Project: 101079865 — EuMAR — EU4H-2021-PJ2

European Medically Assisted Reproduction registry Final Dissemination Conference

Welcome and opening remarks

Carlos Calhaz-Jorge

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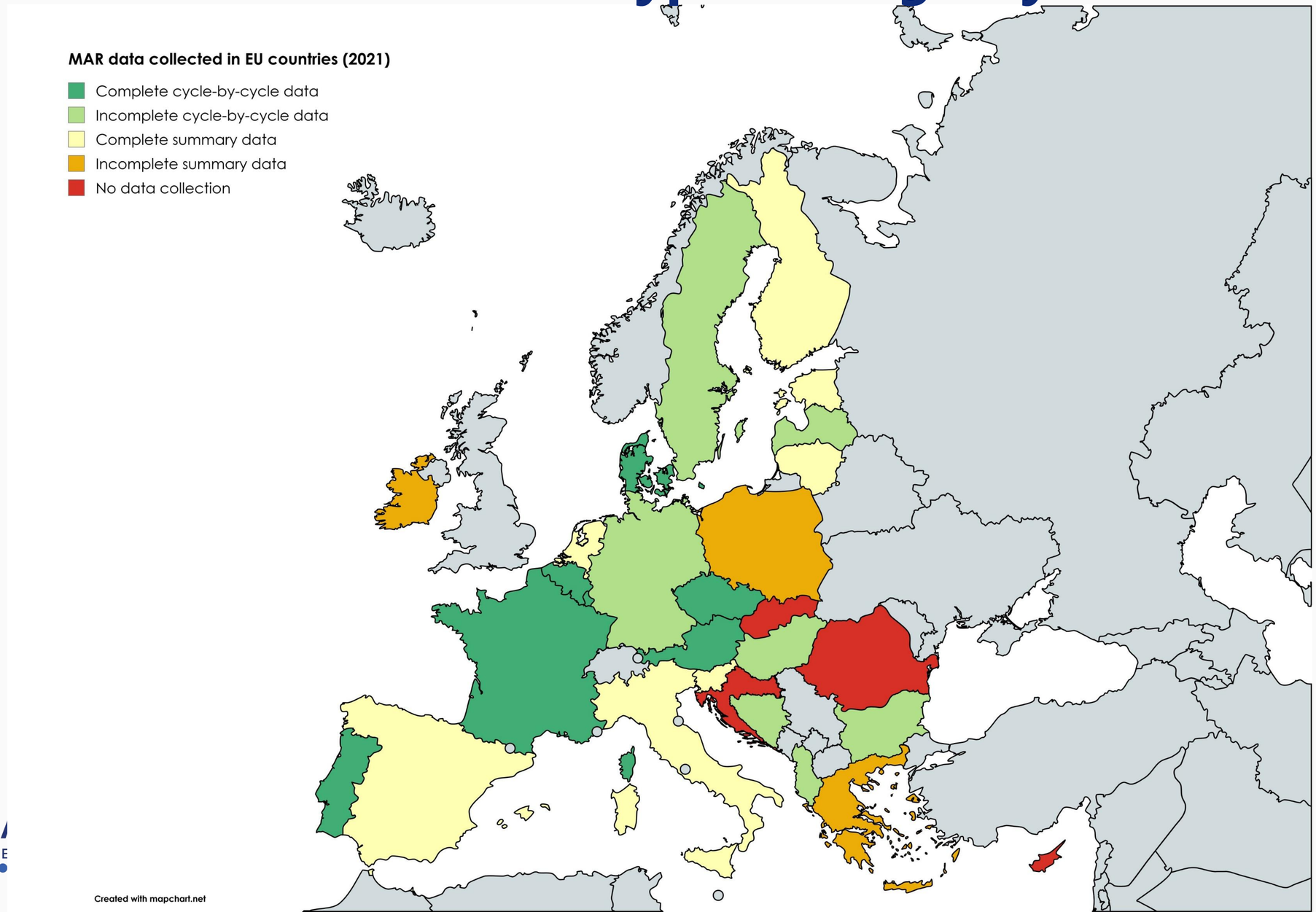
Data collection in EU member states: overview on types of registry



Project Steering Committee

Cristina Magli
WP3 Leader

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Ask your questions

Code: #EuMAR25

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Session 1:
The origins of EuMAR

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Original goals, rationale, policy context

Christian De Geyter

Brussels, Friday 12 December 2025

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Registries in infertility treatments

Common goals:

- Routinely **collect data**
- **Inform stakeholders** on:
  - Accessibility
  - Effectiveness
  - Safety

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Value of registries

- as an extension to evidence resulting from randomised clinical trials -

- Real-world **evidence of day-to-day clinical care**
- **Large cohorts** allowing for detection of **rare Adverse Events (AE)** or **Reactions (AR)**
- **Extended period of observation**
- **Tools for surveillance/vigilance:**
  - Benchmark towards **higher performance** and **risk reduction** or **prevention**
  - Analyse trends to assess **impact of changes in treatment, policies and demographics on outcomes**
  - Inform on countries' **self-sufficiency of care**

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International registries: challenges

Different **data collection systems** and **organisations** that manage data	• Unified approach • Unique European platform
Different **measurement properties**	• Harmonised data
Different **regulations** (e.g. mandatory reporting, socio-economical issues)	• Legal basis (SoHO Regulation)
Different **technological evolutions/innovations**	• Timely uptake
Sequential treatment → **cross-border care/exchange** of biological material	• Identification of procedures linked to the same patient/treatment cycle • Individual reproductive care code • Longitudinal follow-up over long periods

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European IVF Monitoring (EIM) Consortium

The EIM Consortium collects ART data (on a **voluntary basis**) on:

Techniques:

- **Assisted Reproductive Technologies** (ART) : In-Vitro Fertilisation – Intracytoplasmic Sperm Injection (IVF – ICSI)
- **Intrauterine Insemination** (IUI)
- **Within couple use** and/or using **third-party donations**
- **Fertility preservation**
- **FET (Frozen Embryo Transfer)** and **FOR (Frozen Oocyte Replacement)**
- **ED (Egg Donation)** and **Embryo donation**
- **PGT (Preimplantation Genetic Testing)**
- **IVM (In Vitro Maturation)**

European IVF Monitoring (EIM) Consortium

The EIM registry is the largest European registry led by experts in the field

Some countries have a *delay* in sending in **(complete) data**

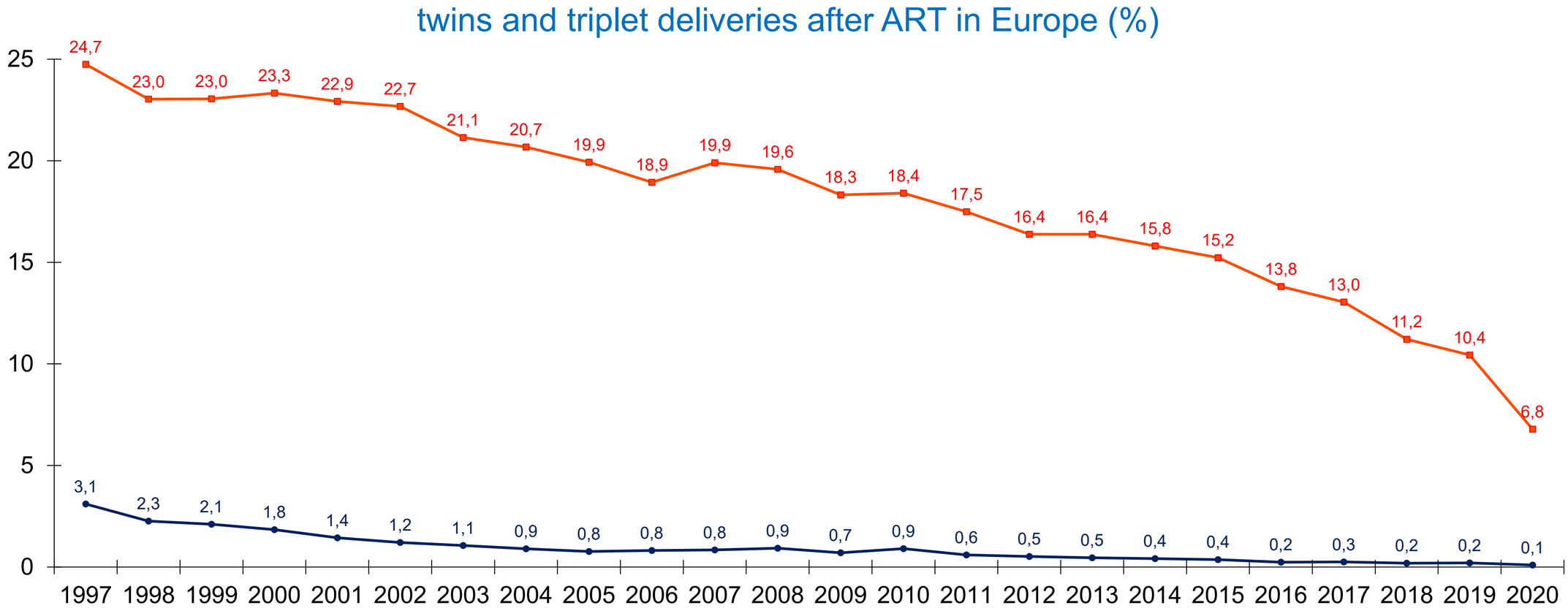
In many countries, reporting is voluntary

23 mandatory /12 voluntary*

*Reference EIM 2018

European IVF Monitoring (EIM)

- cross-sectional data sets, as published annually, have helped to reveal crucial trends in ART -



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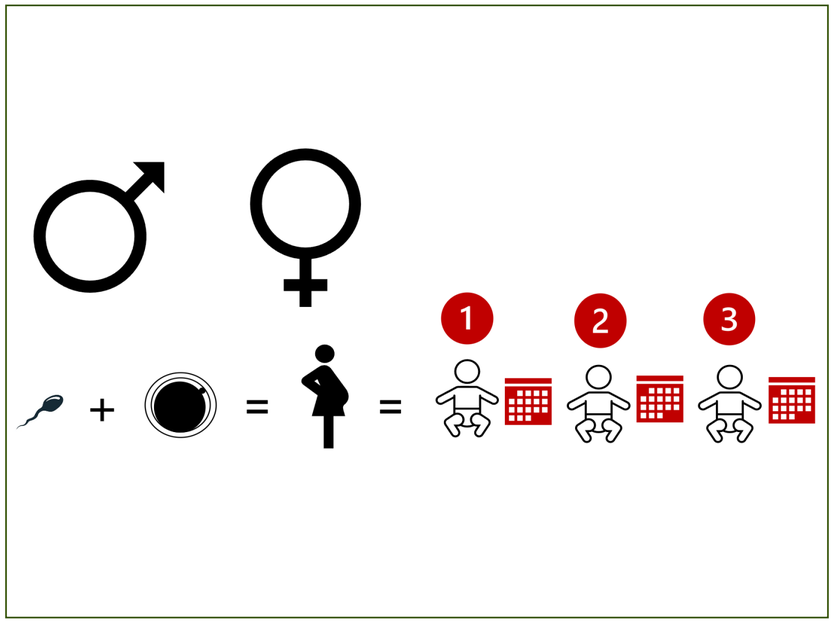
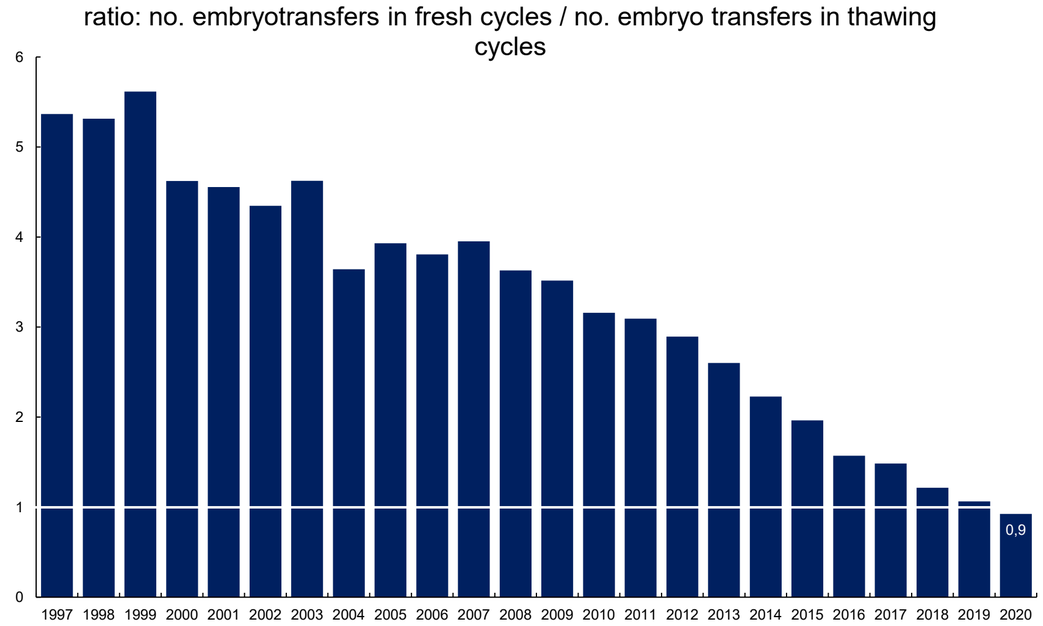
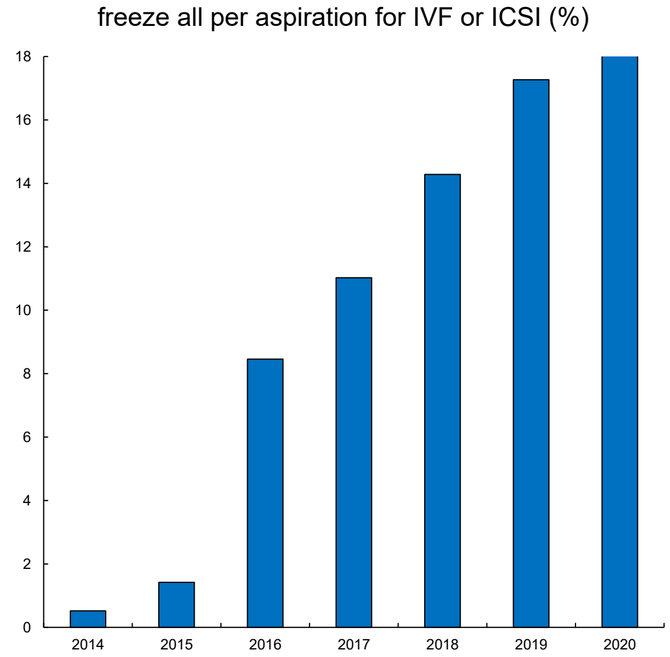
European IVF Monitoring (EIM)







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Data collection in MAR

Highly variable among countries

Summary-level data	Cycle-level data
• **Only aggregate information** is reported.	• **Each cycle** is reported **individually** including **its characteristics** (e.g. number of oocytes, embryos) and **outcome** → **Higher quality data** → Allows **calculation of summary data** → Possibility to **link with other datasets** (e.g. birth registry for monitoring of long-term outcomes of ART)
Retrospective	**Prospective**
	• **Short time frame** for reporting a **limited number of data at cycle initiation**
Voluntary	**Compulsory**
• **Selection bias** and **incompleteness.**	• **Enforced by legislation/certification** for ART practice

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EIM - EuMAR

ESHRE aims at increasing the value of MAR registries by:

- addressing the **lack of standardisation of definitions** and **harmonisation of metrics**
- establishing a **web-based prospective cycle-by-cycle registry** of high-quality data towards:
  - increased surveillance and vigilance
  - interconnection with other registries (**cross-entity registry**)
- achieving **a flexible data flow** that **meets the needs of all stakeholders**

→ **EuMAR project**

Strengthening the legal basis for mandatory data collection in MAR
paves the way to *acquire*, *use* and *share* data with all stakeholders.

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The EuMAR project

Aim of the project

To establish the first 'overarching' European, standardised, web-based data registry, containing high-quality cycle-by-cycle data entries from medical professionals across the EU, facilitating data sharing for open science across institutes and allowing the longitudinal and cross-border follow up of medically-assisted reproduction (MAR) data.

- **Type of action:** EU4H-PJG
- **Project coordinator:** European Society of Human Reproduction and Embryology (ESHRE)
- **Timeframe:** start 01 January 2023, running for 3 years
- **Funding programme:** EU4Health

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The EuMAR project - Objectives

'overarching' European, standardised, web-based data registry, containing high-quality cycle-by-cycle data entries from medical professionals across the EU.

This registry can facilitate data sharing for open science across institutes and allow the longitudinal and cross-border follow up of MAR data.

SO1: Data flow

Develop a **flexible data flow model** that can be implemented in the local contexts of all Member States

SO2: Core parameters

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

SO3: Technical solution

Establish a transnational web-based data registry to collect and store cycle-by-cycle and case-based harmonised MAR data, including a unique **Individual Reproductive Care Code (IRCC)** for MAR patients/donors

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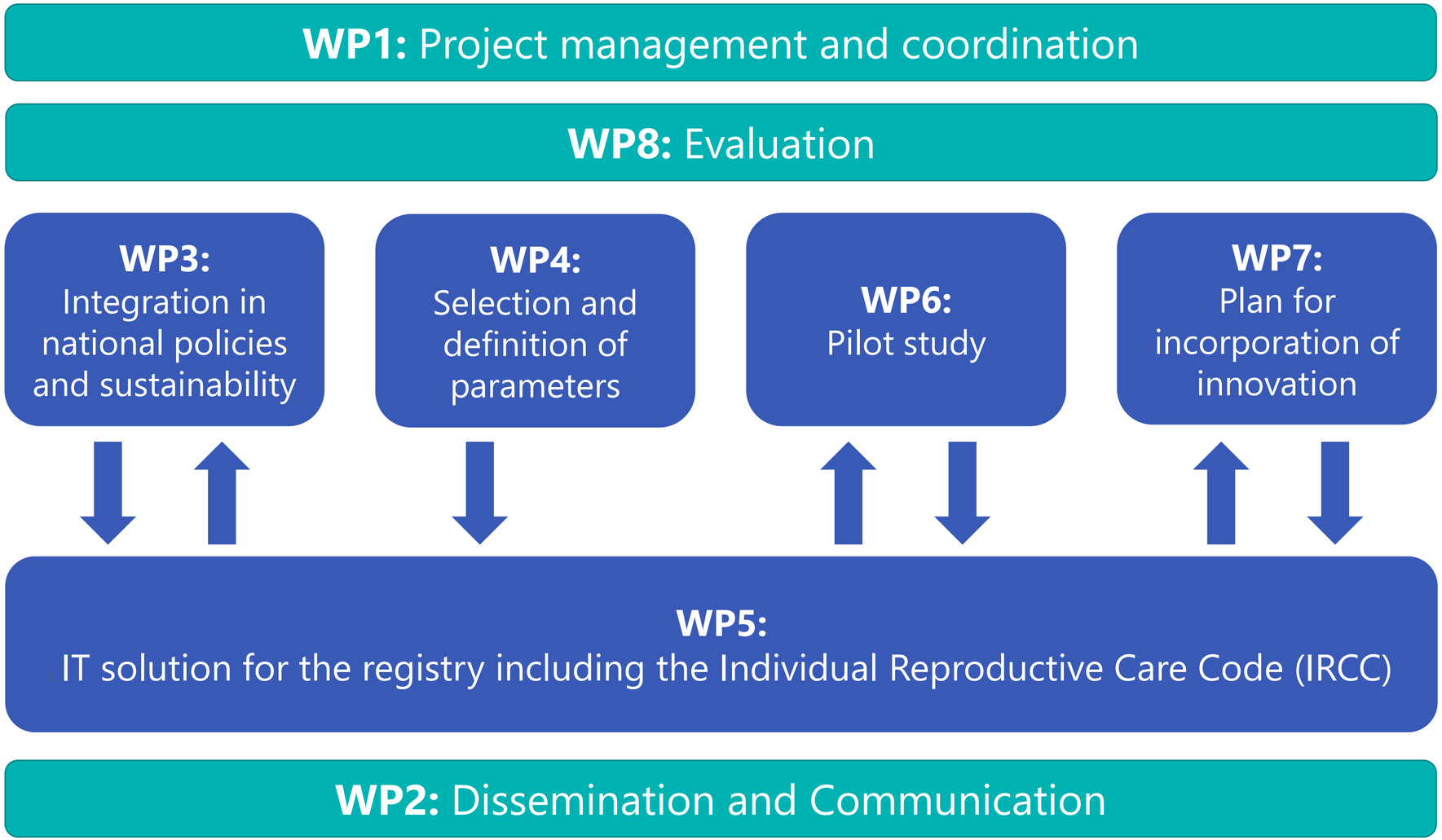
The EuMAR project



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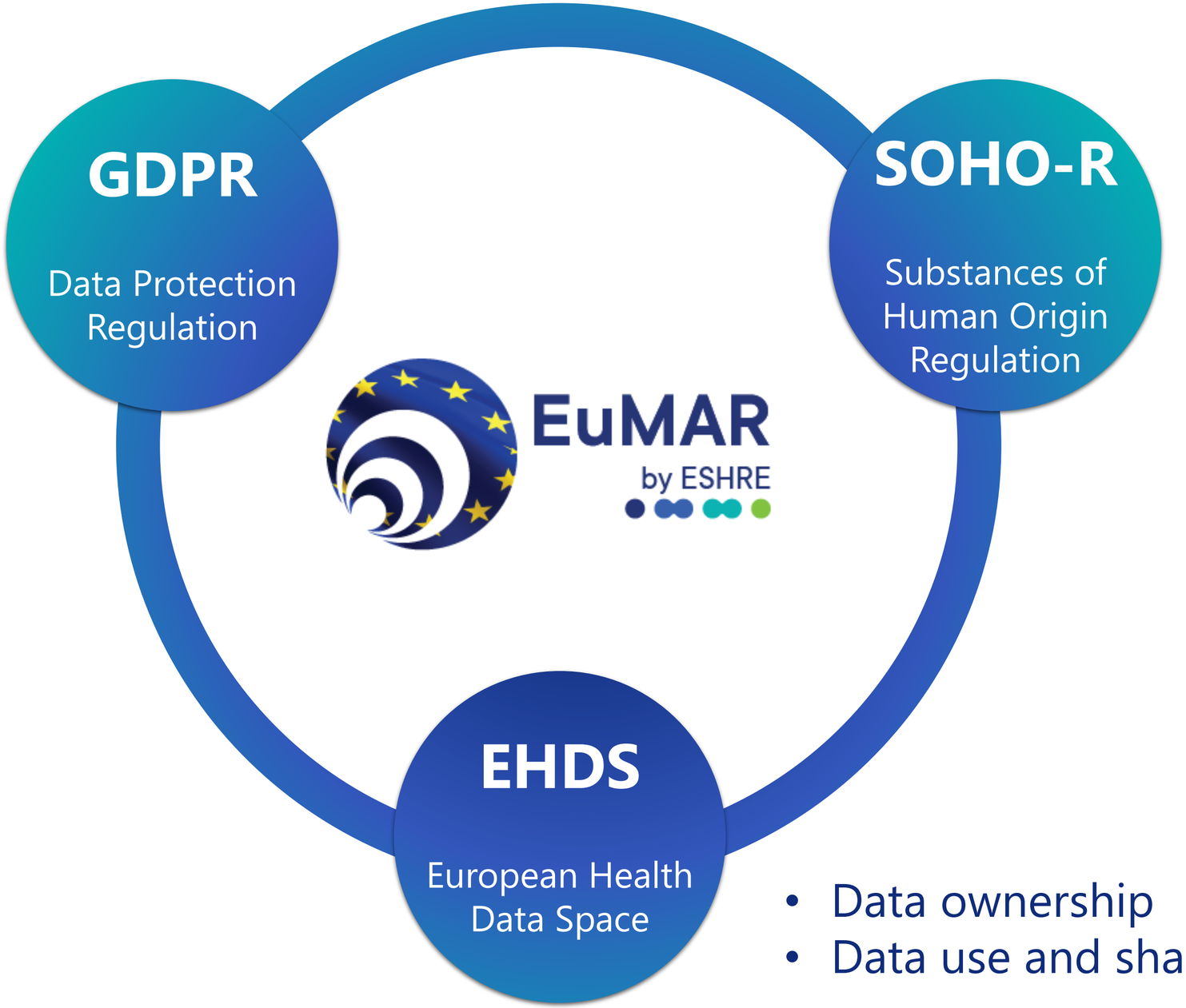
Policy context

- Informed consent
- Anonymity



- Activity reporting
- (Data to be collected is TBD)

- Data ownership
- Data use and sharing

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Thank you!

www.eshre.eu/Data-collection-and-research/EuMAR

European Society of Human Reproduction and Embryology

Stakeholder landscape and engagement

M. Cristina Magli

Brussels, Friday 12 December 2025

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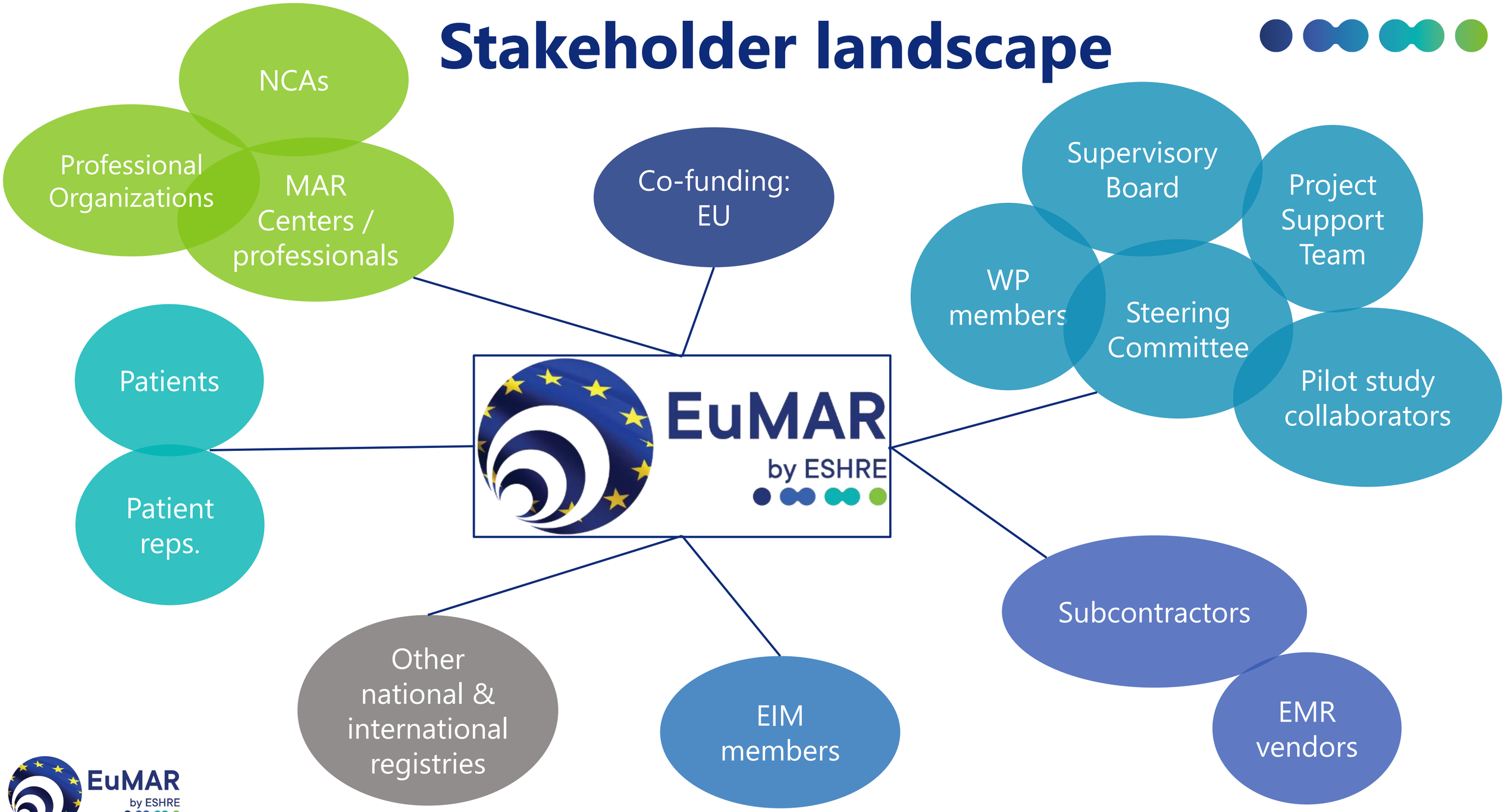
Project: 101079865 — EuMAR — EU4H-2021-PJ2

Stakeholder landscape



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Stakeholder engagement focus

	NCAs	MAR professionals	Patient representatives
Who they are →	Responsible for **authorisations**, surveillance, and compliance	**Clinical teams** and professional organisations	Fertility Europe & national patient associations
What they bring →	**Legal mandate** and regulatory authority	First-hand **clinical knowledge** and operational understanding	Insights into patient priorities and lived experience
What they benefit from →	EuMAR supports their role with harmonised, **high-quality data**	• Cumulative data calculations • Cross-border data collection • EuMAR KPIs • Benchmarking • Data for research harmonisation	EuMAR promotes **transparency** regarding success rates and treatment options

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Stakeholder engagement strategy

2023

EIM members → NCAs → MAR professionals

2024 -2025

Pilot study collaborators → EMR vendors

2024 -2025

Patient representatives → Patients

EMR vendors that are assessed as fit for purpose within EuMAR will receive the necessary technical information to **develop dedicated EuMAR modules** for clinics.

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Stakeholder engagement

EuMAR used a top-down approach, working **first with NCAs** (where applicable) **or with the organisations** responsible for MAR national data collection to…

1

Align with national priorities

2

Support consistent implementation of **data reporting standards**

3

Obtain the necessary **approvals** for data submission

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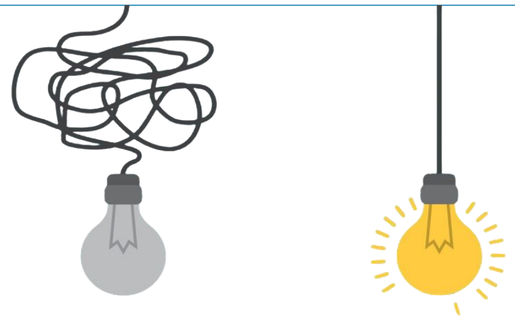
Stakeholder engagement

EuMAR used a top-down approach, working **first with NCAs** (where applicable) **or with the organisations** responsible for MAR national data collection to…

This approach also allows for more **formal and coordinated communication** with clinics, ensuring that information and expectations flow clearly through established national channels



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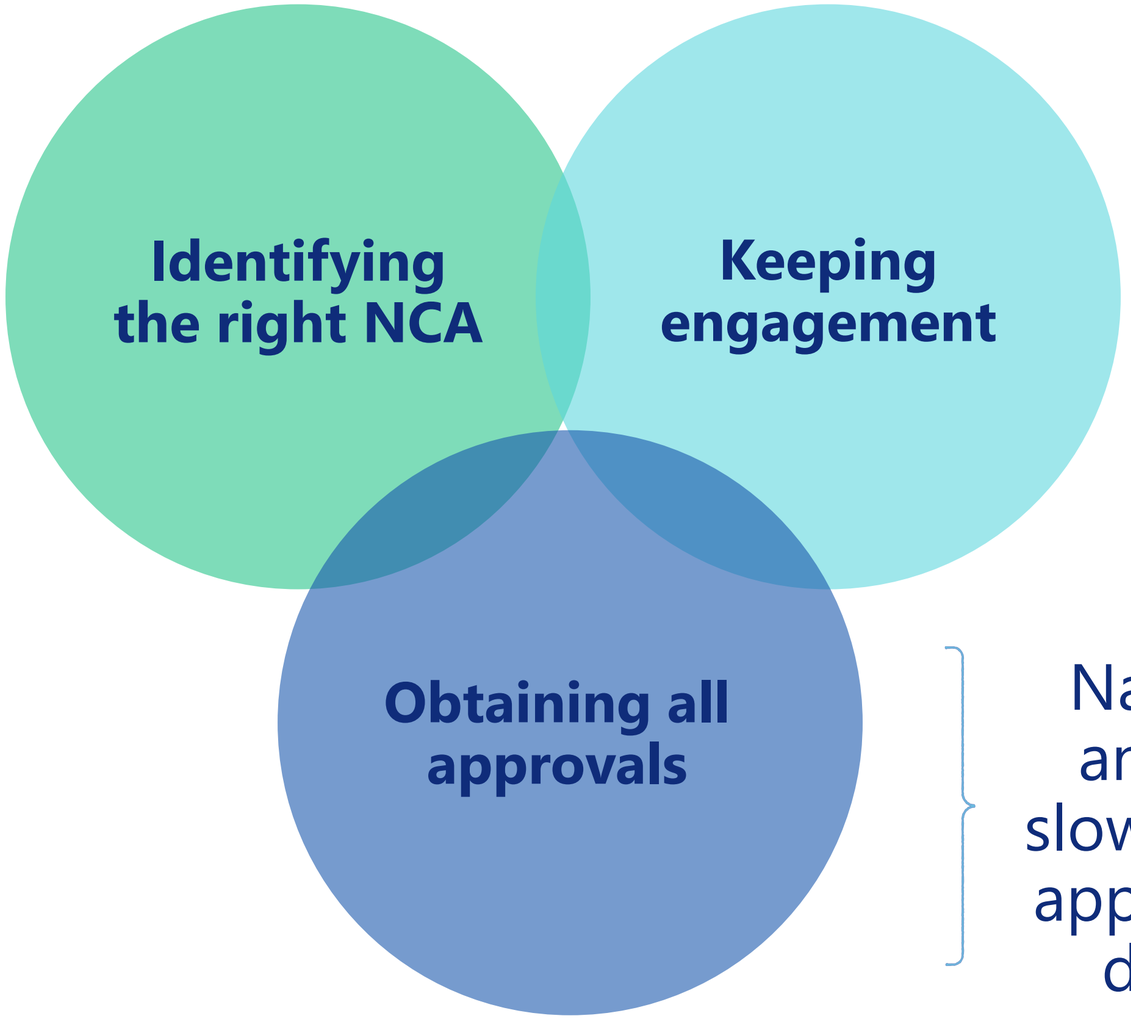
Barriers in stakeholder engagement

Not all countries have a clearly defined MAR NCA



After the first contact, it requires a lot of dedication to keep engagement

National dynamics and activities may slow down or impede approvals for EuMAR data submission

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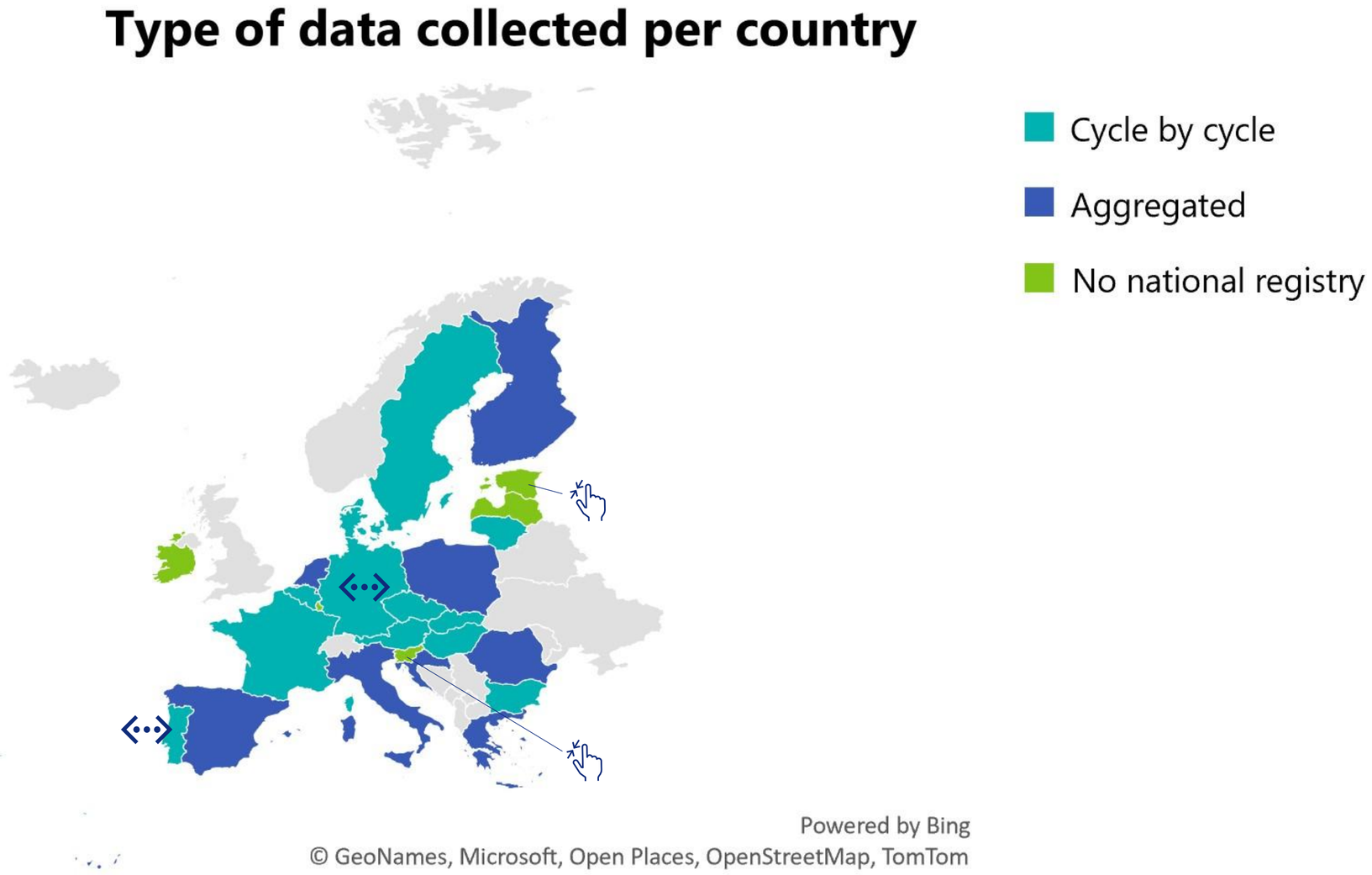
Data Flow Theoretical Model



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Data flows

Two data flows were established within EuMAR:

A) For countries with a cycle-by-cycle national registry

B) For countries without a cycle-by-cycle national registry

In each of these data flows, data could be submitted either **manually** through the EuMAR portal or **automatically** via an API (Application Programming Interphase).

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What did professionals think about EuMAR

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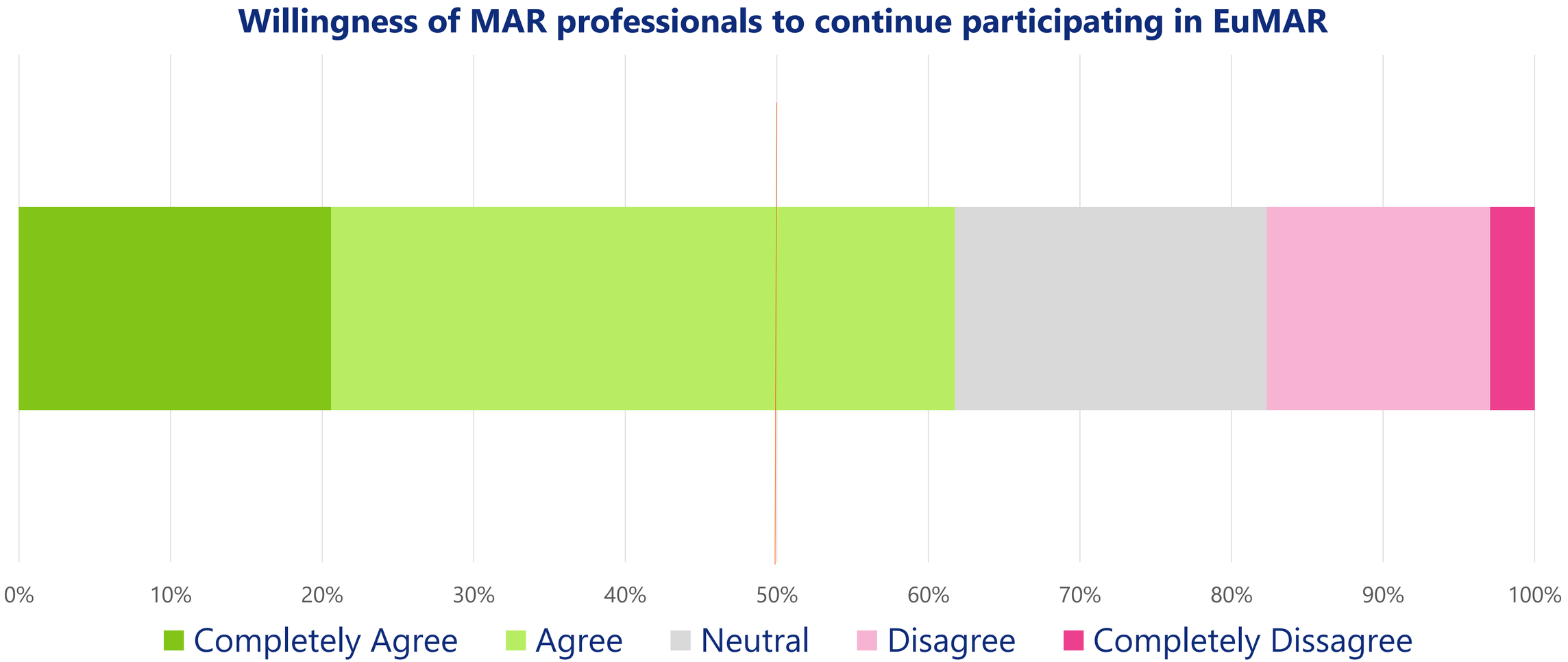
Success in stakeholder engagement



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What did patients think about EuMAR

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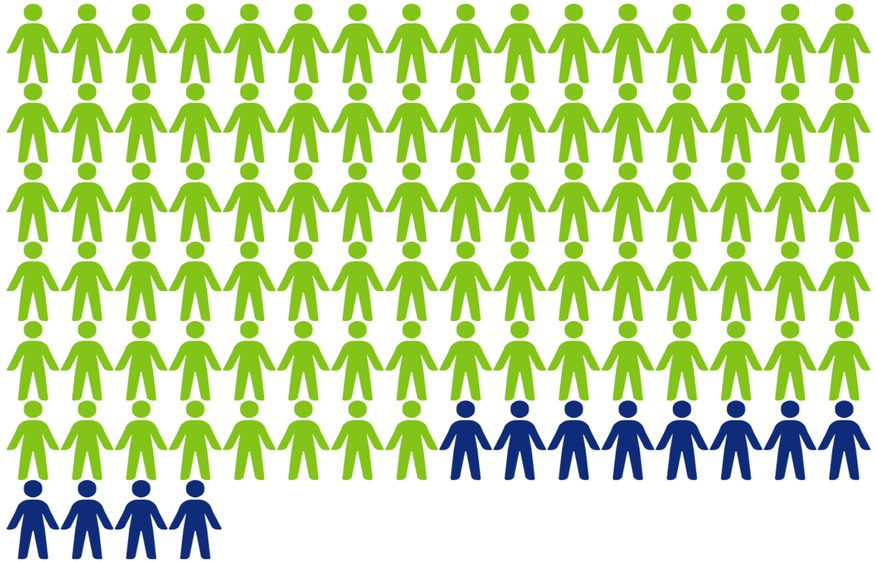
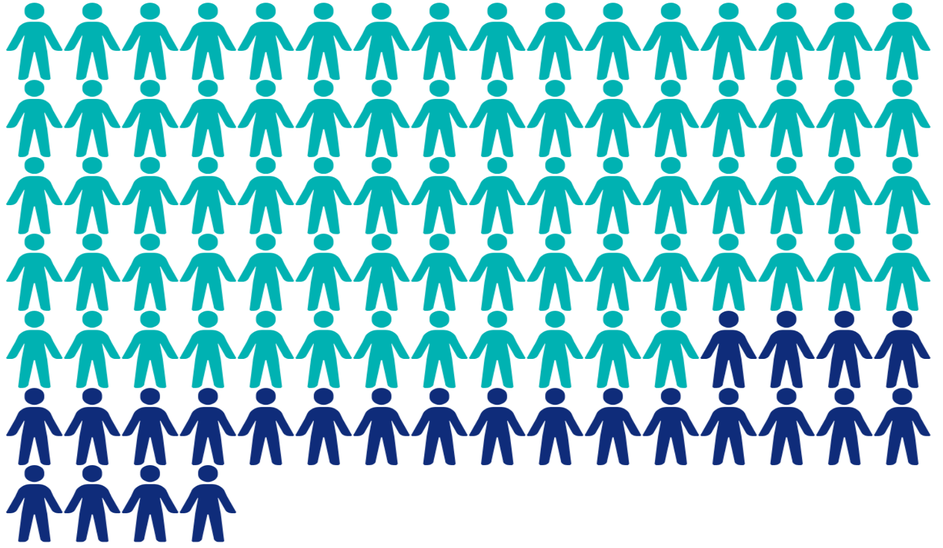
88%

of infertility patients would be **in favour of their data being shared** with a registry like EuMAR



76%

of infertility patients would have **more trust** in a clinic participating in EuMAR.



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Success in stakeholder engagement

Engagement started for next countries to join the phase 2

Greece

Poland

Policy recommendations

EuMAR POLICY RECOMMENDATIONS

1. Raise patients' awareness on MAR data
2. Improve equitable access to fertility care
3. Collect MAR equality data
4. Ensure national mandatory reporting from all fertility clinics
5. Provide dedicated funding for EuMAR reporting
6. Make cycle-by-cycle MAR registries mandatory
7. Develop a legal framework for a gamete donor registry

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WP3 members

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Edgar Mocanu
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Thank you!

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European Society of Human Reproduction and Embryology

Basic concepts of EuMAR

Elena Achótegui Sebastián

Brussels, Friday 12 December 2025

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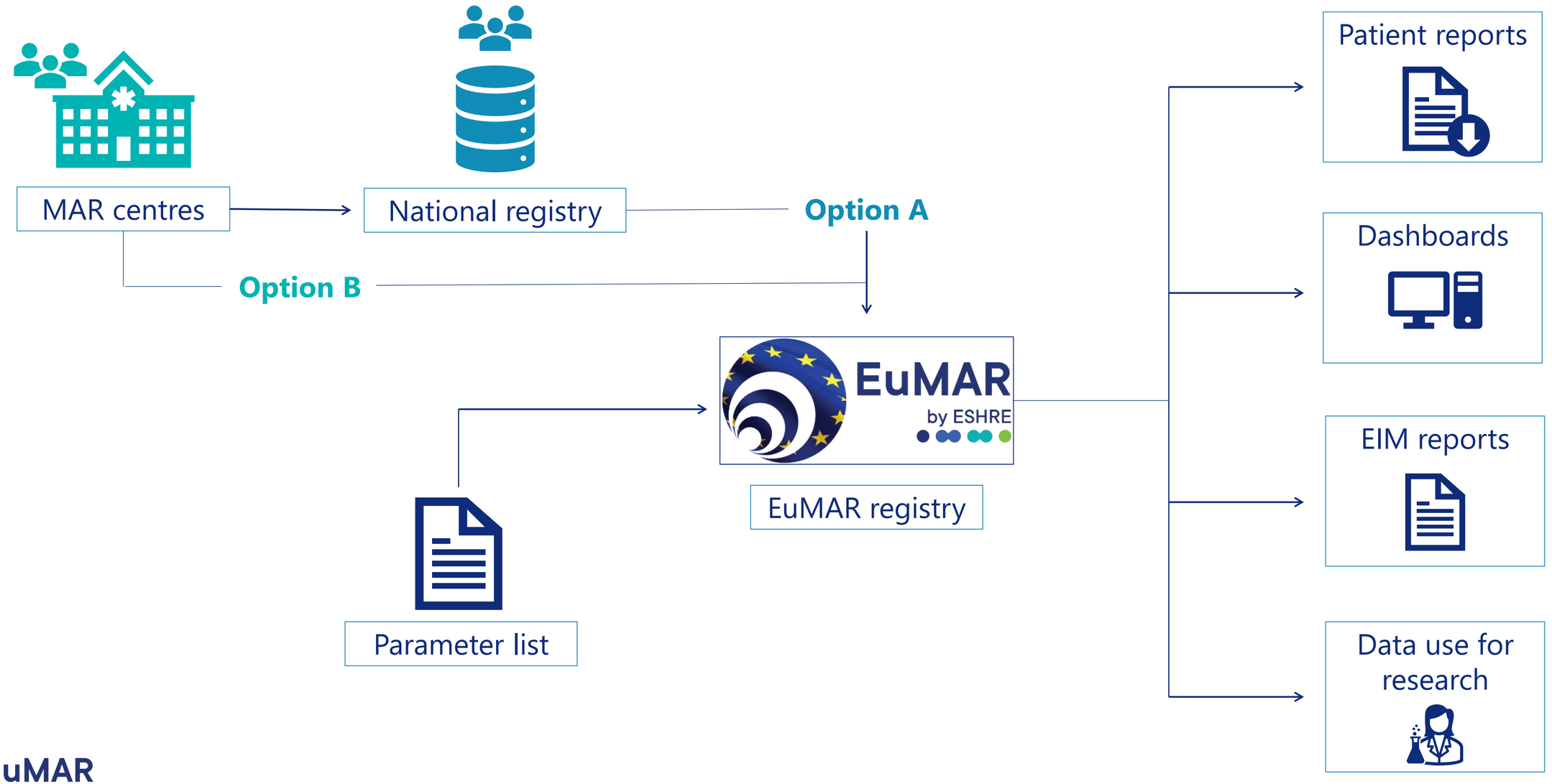
Functioning of the EuMAR registry



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Basic concepts of EuMAR

1. Cycle-by-cycle data
2. Cumulative outcome data
3. Cross-border data
4. IRCC
5. CSC
6. Data privacy

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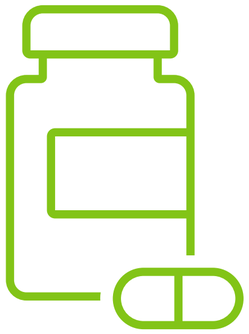
Cycle-by-cycle data

1. Cycle-by-cycle data



- In the EuMAR registry, data are collected for **every individual MAR treatment cycle**, rather than aggregating all cycles together.
- EuMAR is **the first Europe-wide registry** to collect cycle-by-cycle data on MAR treatments.

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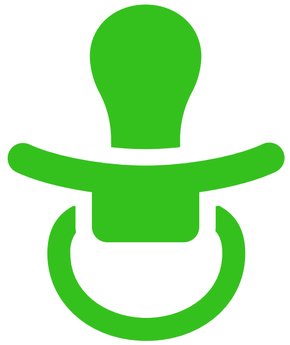
Cumulative outcome data

2. Cumulative outcome data

EuMAR aims to **report cumulative outcomes** by combining results per oocyte pick-up cycle, **rather than per individual transfer,** providing an overall view of the results achieved.



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Cross-border data

3. Cross-border data

One of the aims of the EuMAR registry is to **collect data on cross-border reproductive care** to better understand the extent of this phenomenon and to include cycles performed abroad in the cumulative calculations.

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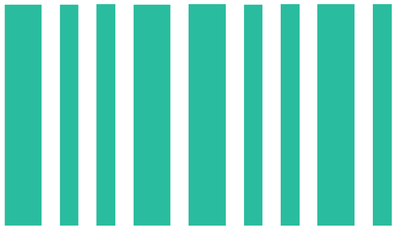
Individual Reproductive Care Code (IRCC)

4. IRCC



- The **Individual Reproductive Care Code (IRCC)** is a code assigned to each member of the couple (when applicable) to link all treatments within a clinic.
- The IRCC is **requested at the clinic level.**
- When sent to EuMAR, it is **encrypted** into the EuMAR code; the IRCC cannot be seen in EuMAR.

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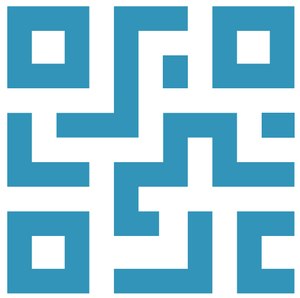
ClinicSwitch Code (CSC)

5. CSC



- The **ClinicSwitch Code (CSC)** is a QR code that a patient receives when following treatment in a different clinic.
- The CSC contains no medical data; it only serves as a **secure bridge** to follow patients that move between clinics.
- It needs to be **scanned** at the new clinic, which generates a new IRCC.

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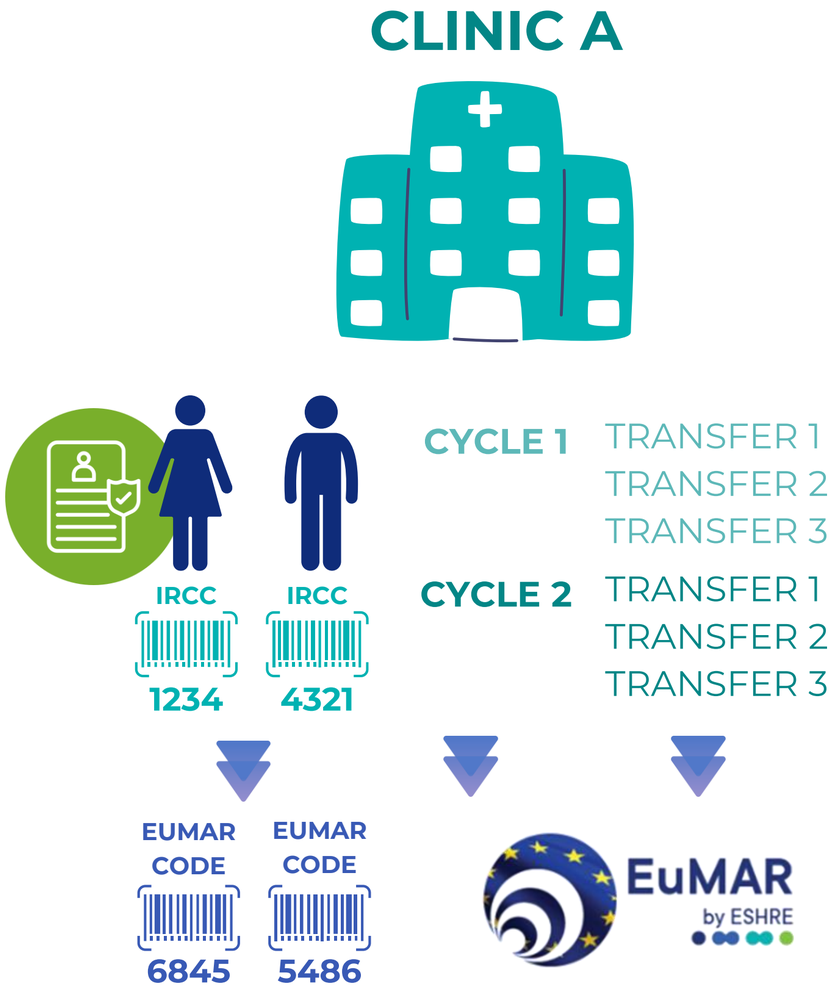
EuMAR structure

IRCC & CSC



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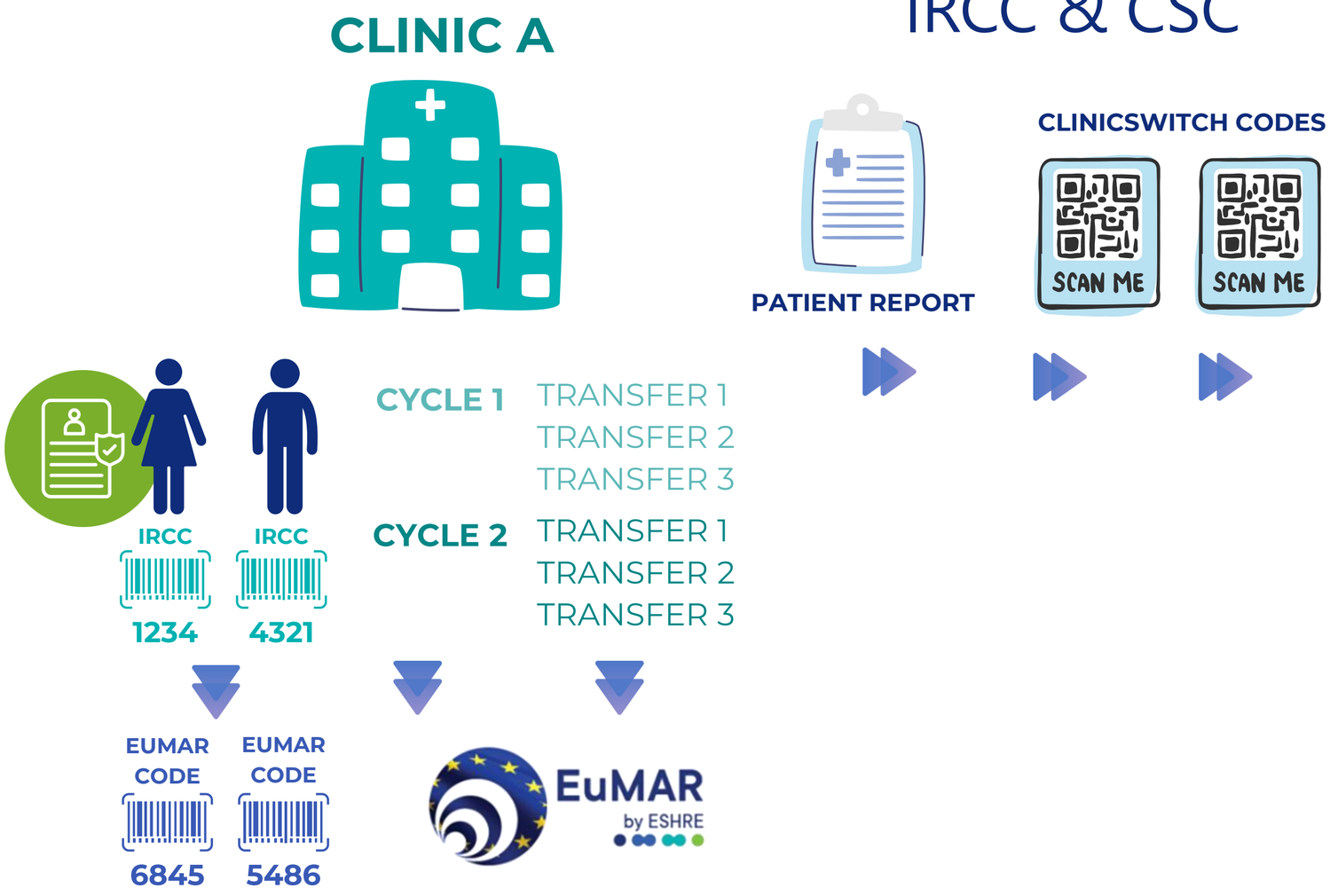
EuMAR structure

IRCC & CSC



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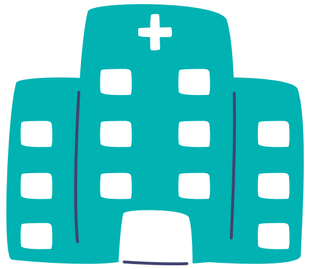
EuMAR structure

IRCC & CSC

CLINIC A



IRCC 1234

IRCC 4321

CYCLE 1
TRANSFER 1
TRANSFER 2
TRANSFER 3

CYCLE 2
TRANSFER 1
TRANSFER 2
TRANSFER 3

EUMAR CODE 6845

EUMAR CODE 5486

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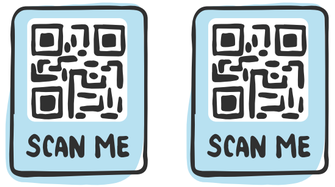
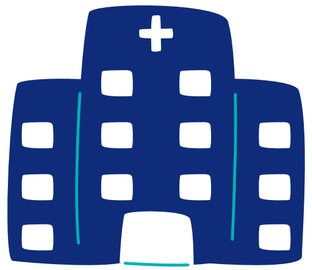
PATIENT REPORT

CLINICSWITCH CODES



CLINIC B



IRCC 2233

IRCC 3232

CYCLE 1
TRANSFER 1
TRANSFER 2
TRANSFER 3

CYCLE 2
TRANSFER 1
TRANSFER 2
TRANSFER 3

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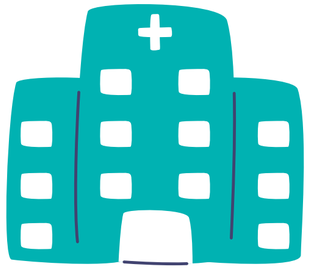
EuMAR structure

IRCC & CSC

CLINIC A



IRCC 1234

IRCC 4321

EUMAR CODE 6845

EUMAR CODE 5486

CYCLE 1
TRANSFER 1
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CYCLE 2
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TRANSFER 3

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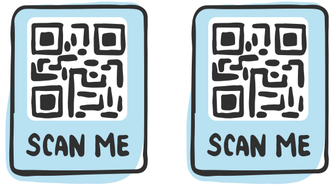
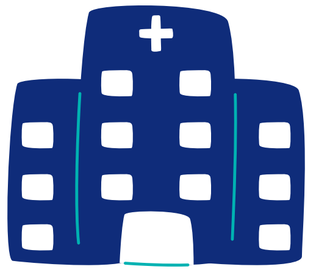
PATIENT REPORT

CLINICSWITCH CODES



CLINIC B



IRCC 2233

IRCC 3232

EUMAR CODE 6845

EUMAR CODE 5486

CYCLE 1
TRANSFER 1
TRANSFER 2
TRANSFER 3

CYCLE 2
TRANSFER 1
TRANSFER 2
TRANSFER 3

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Data privacy

6. Data privacy

- EuMAR operates under the General Data Protection Regulation (**GDPR**).
- Data privacy in the EuMAR registry is based on a **set of features designed to protect data** about patients and clinics.

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Data privacy for patient data

1

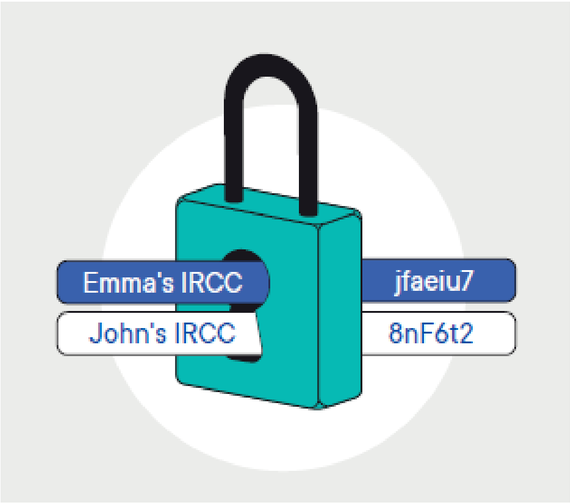
The **different codes and encryptions** ensure that no stakeholder has enough information to identify.

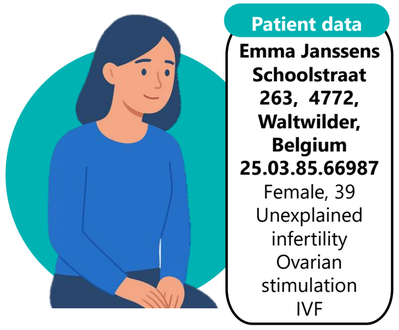
2

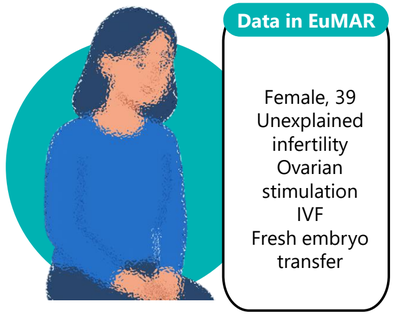
The **EuMAR parameters** collect data from which the patient cannot be identified.

3

Patient **informed consent** will be used as an additional security layer for data privacy.







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Data privacy for clinic data

Clinics' data privacy is also ensured → KPIs from each clinic are only seen by that clinic (and their NCA where applicable).

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Thank you!

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European Society of Human Reproduction and Embryology

Session 2: Implementation, testing and lessons

EuMAR
by ESHRE

Pilot study results: Technical validation and user experience, challenges encountered, and solutions adopted

Christian De Geyter

Brussels, Friday 12 December 2025

EuMAR by ESHRE

Co-funded by the European Union.
Project: 101079865 — EuMAR — EU4H-2021-PJ2

Pilot study design

Pilot study period

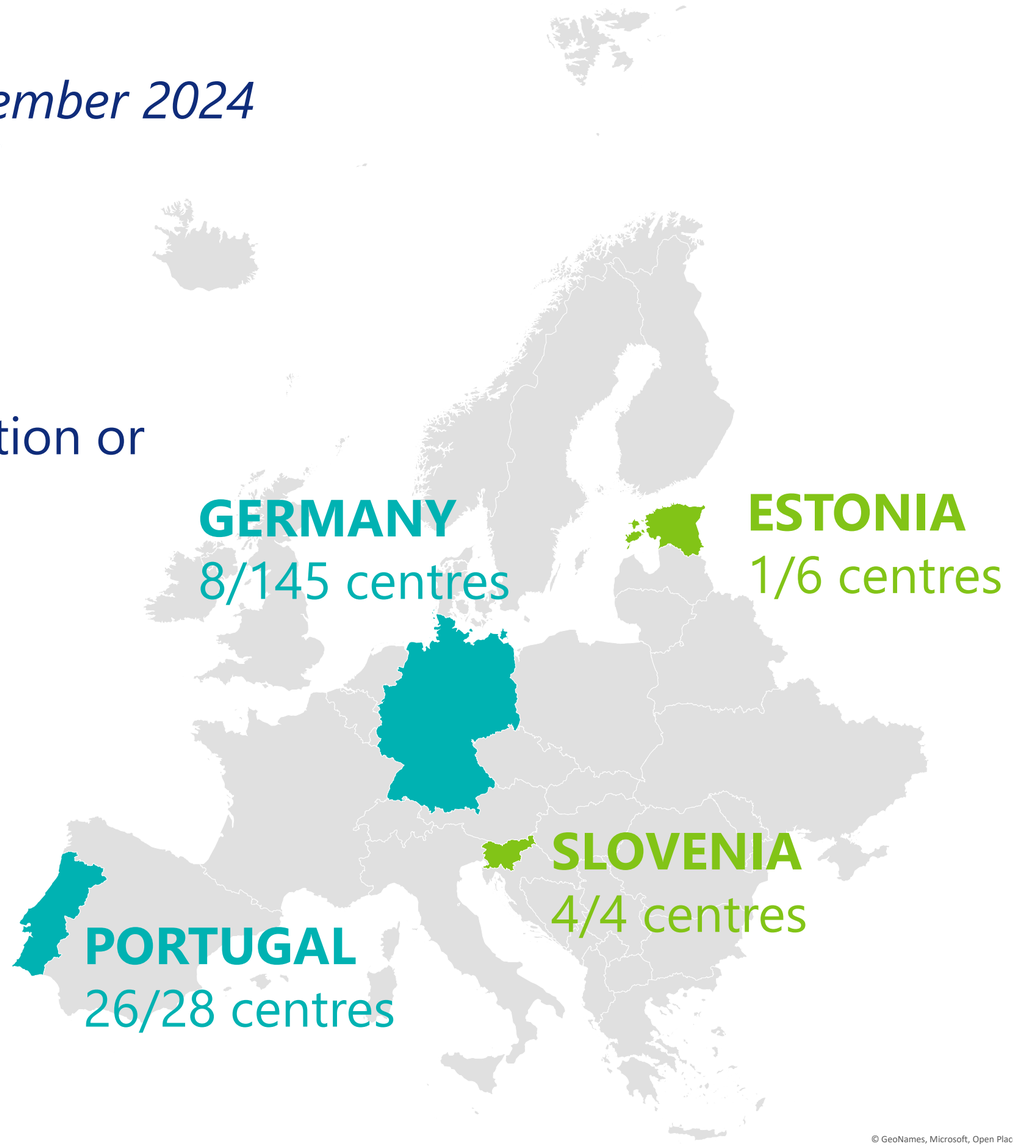
- IRCC requests and cycle data submission *July – December 2024*
- Pregnancy outcome data *January – September 2025*

Study population

- Individuals undergoing medically assisted reproduction or fertility preservation
- Oocyte donors

Prospectivity

IRCCs to be requested up to five days from start of treatment.



EuMAR by ESHRE

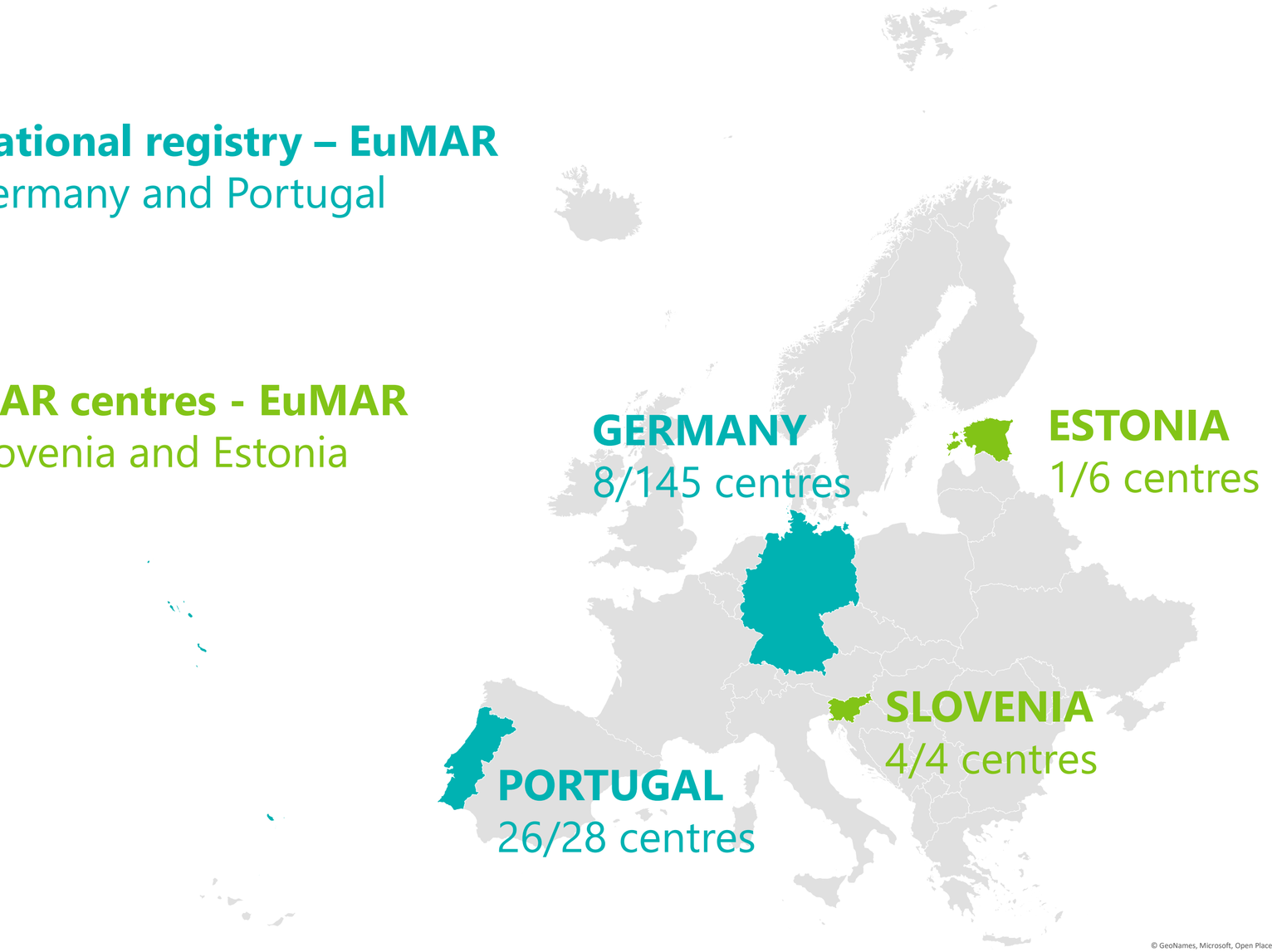
Pilot study design – data flows

National registry

National registry – EuMAR
Germany and Portugal

MAR centres

MAR centres - EuMAR
Slovenia and Estonia



Pilot study design – data flows

National registry

National registry – EuMAR
Germany and Portugal

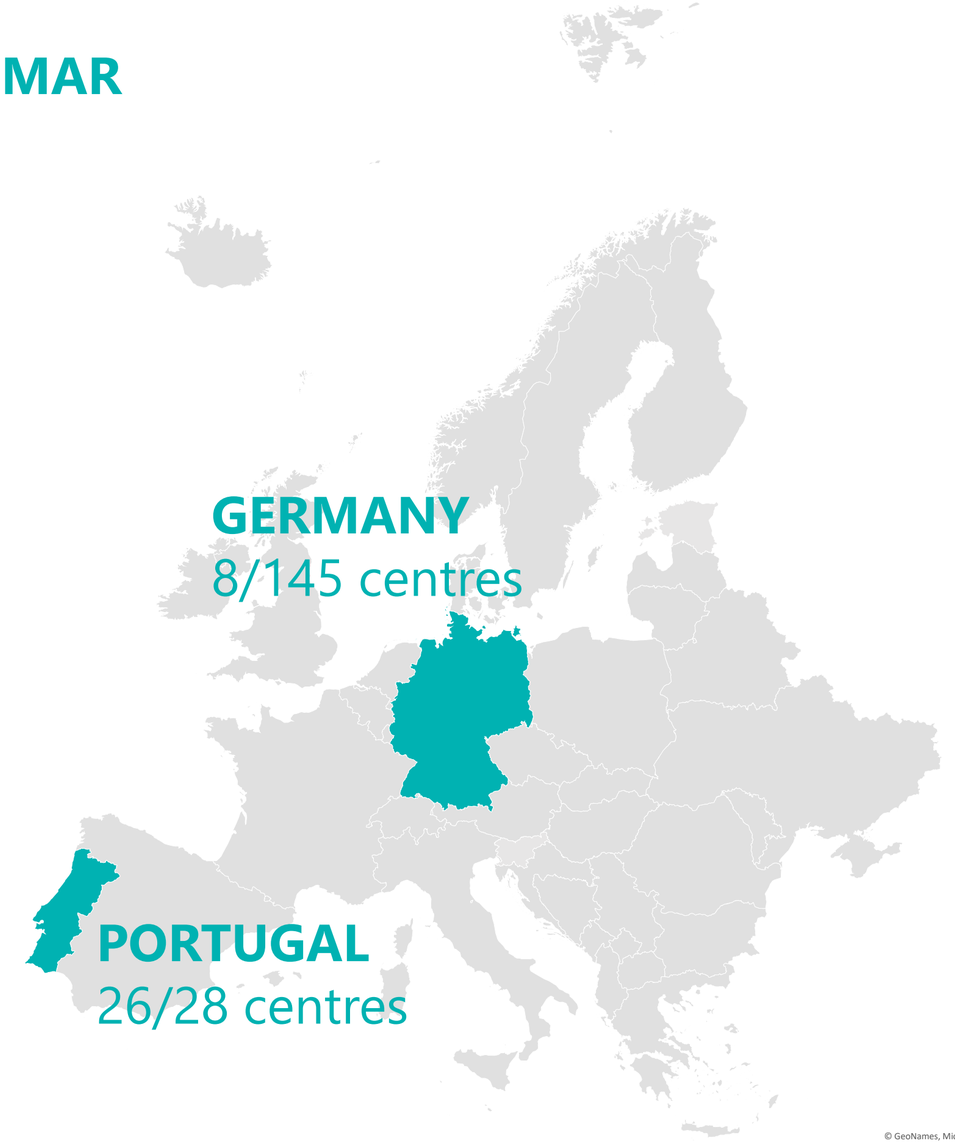
IRCC requests at **MAR centres** either

Manually **API**

Data submission from **national registries**

API

API: Application Programming Interface



Pilot study design – data flows

MAR centres

MAR centres - EuMAR
Slovenia and Estonia

IRCC requests at **MAR centres** either

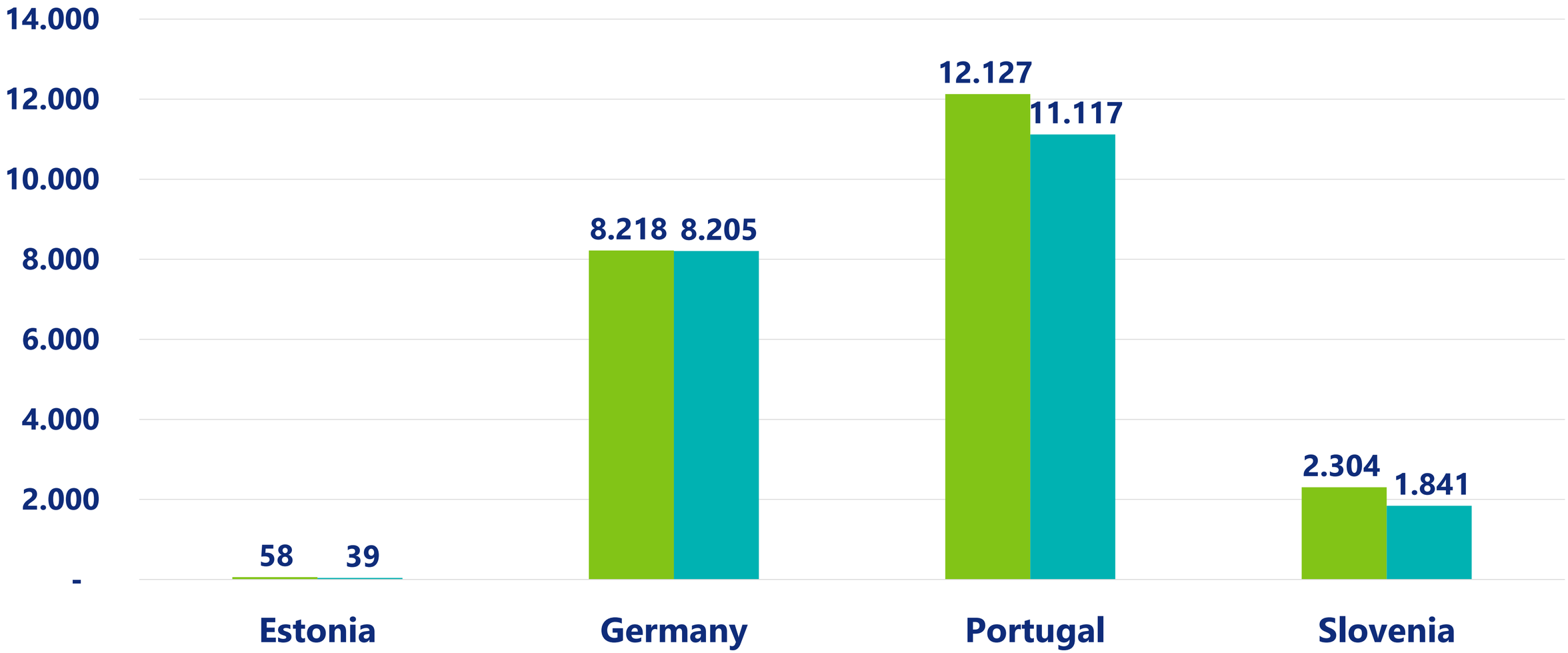
Manually **API**

Data submission from **MAR centres** either

Manually **API**

API: Application Programming Interface

Number of cycles per country



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Number of unique patients/partners

In total, the 21,202 cycles involved:

- 15,477 unique main patients
- 12,691 unique partners

Cumulative data collection within the same institution:

- 4,310 main patients with two or more cycles

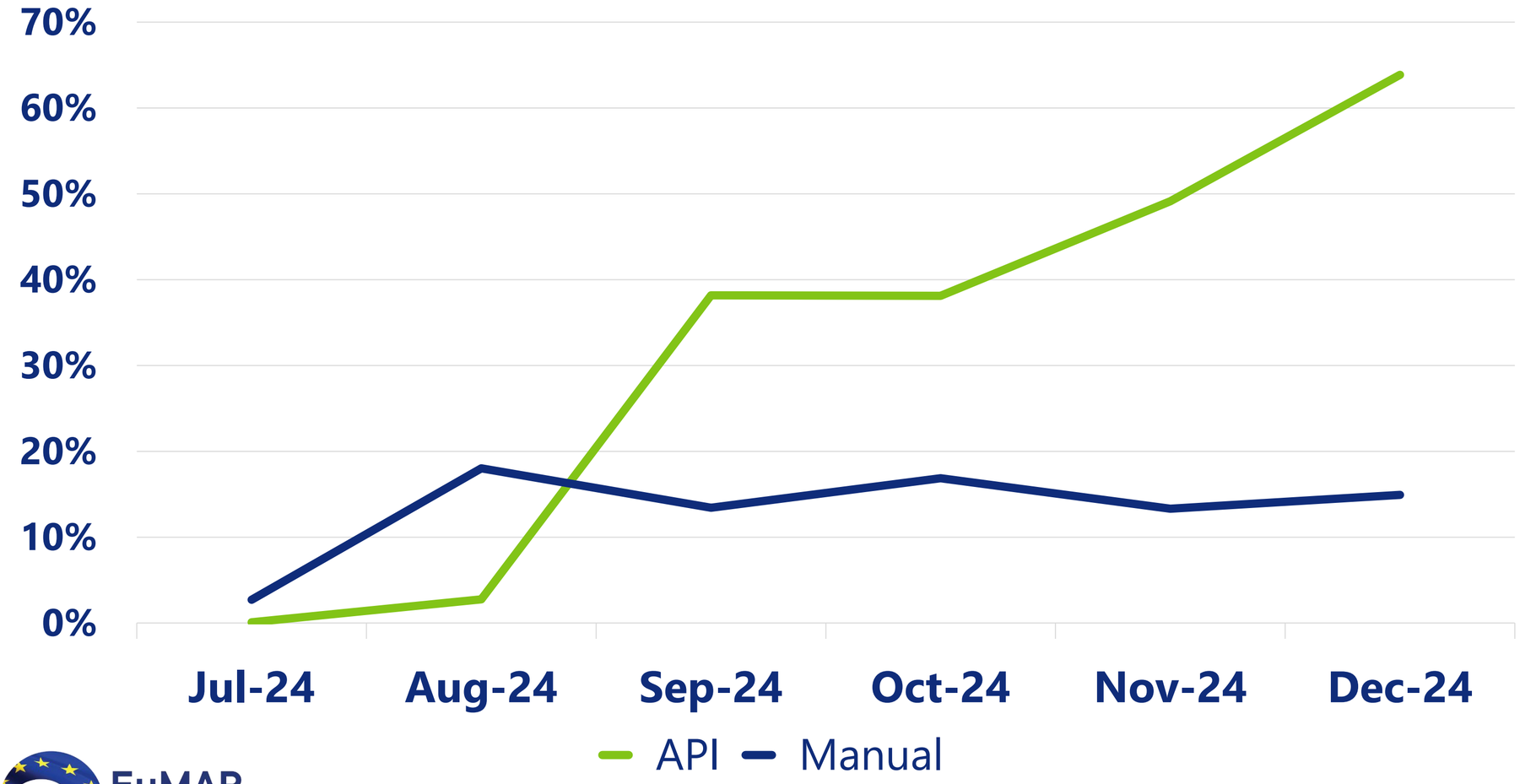
Inter-institutional data collection:

- 16 ClinicSwitch Codes (CSCs) requested within the pilot study period
- Only 4 CSCs (from 2 couples) scanned by another clinic
- Not a single patient with cycle data sent by more than one clinic

EuMAR by ESHRE

Timeliness of IRCC requests

Percentage of IRCC requests on time by cycle start month and IRCC request mode



IRCC request deadlines:

- For cycles with ovarian stimulation: within 5 days of stimulation start
- For cycles without ovarian stimulation: before the day of the procedure (e.g., IUI, FET)

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Empty records (created Jul-Dec 2024)

	Number of IRCCs requested	Number of IRCCs with cycle data	Number of IRCCs without any cycle data	% of IRCCs without any cycle data
Estonia	287	28	259	90%
Germany	11,579	8,241	3,338	29%
Portugal	15,598	14,404	1,194	8%
Slovenia	3,553	3,086	467	13%
Total	**31,017**	**25,759**	**5,258**	**17%**

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Treatment outcomes recorded

	Number of pregnancies	Number of miscarriages	Number of deliveries	Number of live born children
Estonia	10	0	6	8
Germany	1,658	371	896	930
Portugal	2,293	394	1,165	1,207
Slovenia	476	43	222	222
Total	**4,437**	**808**	**2,283**	**2,359**

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Parameters with less than 50% completion

- 13. Treatment protocol
  - Type of gonadotropin (if used)
  - Trigger used for final oocyte maturation
  - Luteal support
  - Luteal support prescribed until
  - Other
- 20. Reason for oocyte cryopreservation
- 23. c. Age of donor at time of oocyte collection (in case donor oocytes were used)
- 24. Date of insemination
- 34. Reason for embryo cryopreservation
- 44. Luteal support in FET
- IUI cancelled
- IUI cancellation causes
- 53. Details of twin pregnancy
- 53. Details of twin pregnancy a. Diamniotic detail
- 54. Fetal reductions
- Child 1 Neonatal outcome (routine care or ICU)
- Child 2 Neonatal outcome (routine care or ICU)

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What professionals thought of EuMAR

From a **survey** with 34 responses sent to participating MAR centres in all pilot countries

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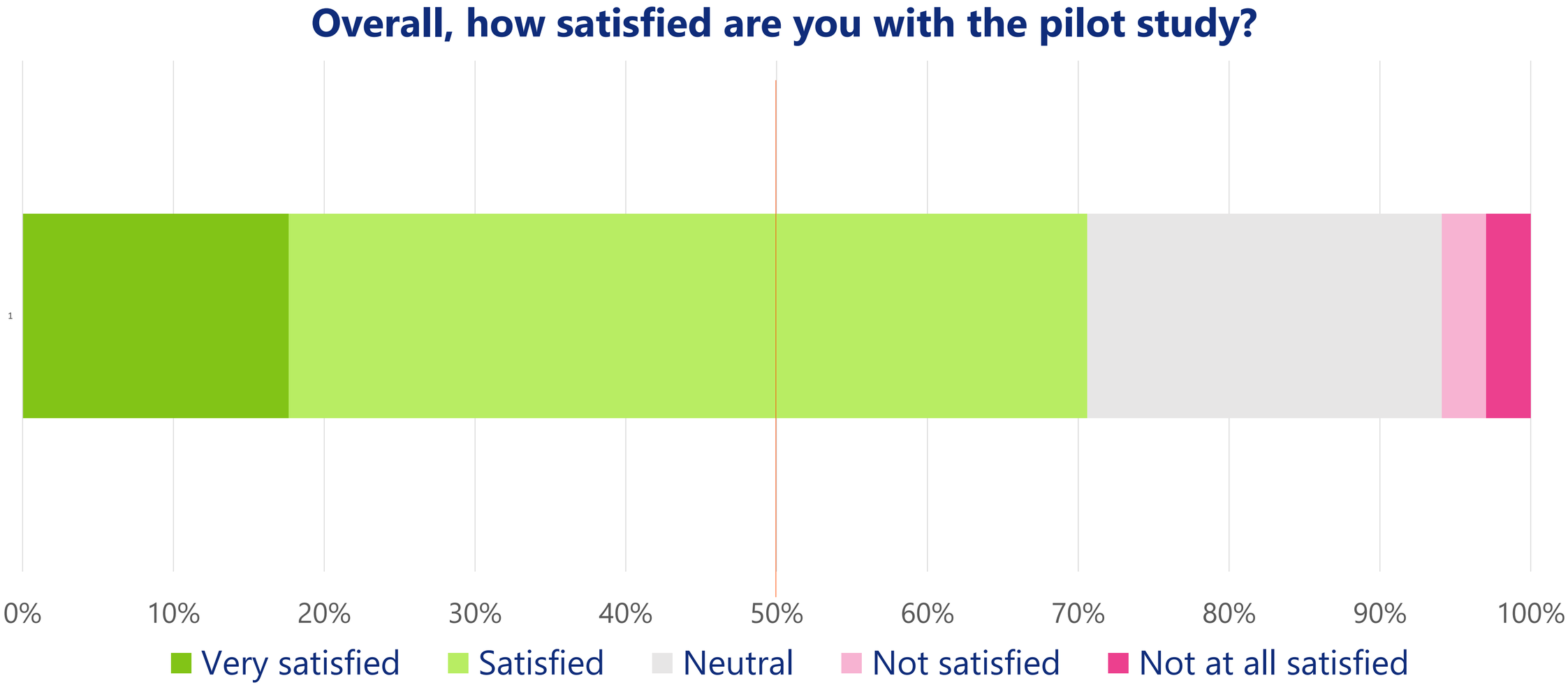
Learnings from all pilot countries



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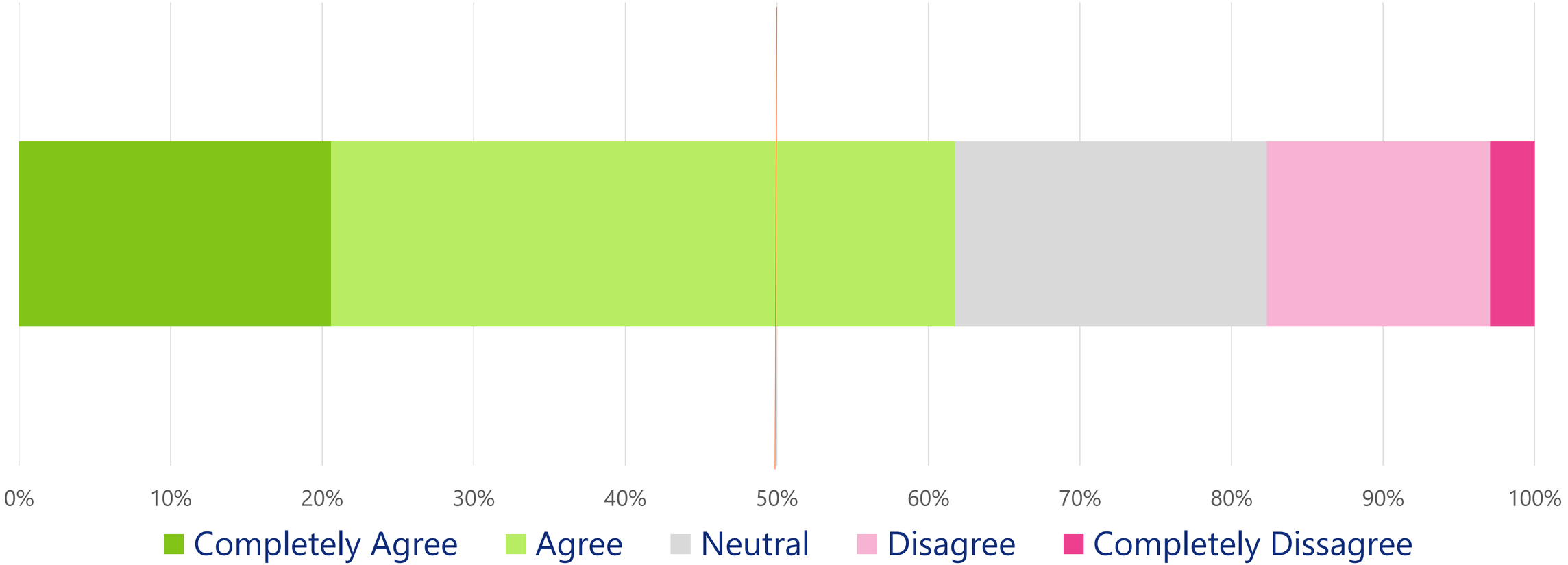
Learnings from all pilot countries

I would be willing to participate in the EuMAR Registry in the long term beyond the pilot study.



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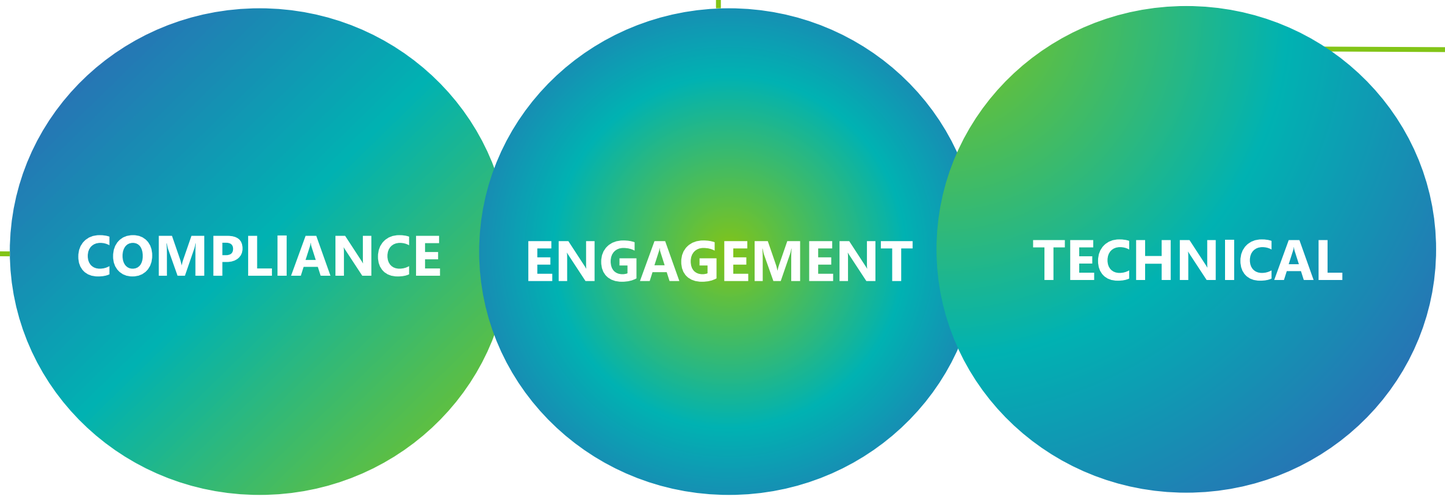
Learnings and challenges

We have **positive** outcomes from the pilot study, but we also encountered some challenges

1. **Approvals** needed at national level cause delays

2. Different **interpretations of legal basis** led to different use of consent forms and changes in internal structure

Involvement of **different stakeholders**, including authorities, clinics and patients is necessary for accurate cumulative and cross-border data



IT connections for automatised data submission are a **long and costly process**

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WP6 members

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WP6 Leader

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WP6 Member

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Thank you!

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#EuMAR25

www.eshre.eu/Data-collection-and-research/EuMAR

European Society of Human Reproduction and Embryology

Session 3: Outcomes

Updated parameters and definitions

Jesper Smeenk

Brussels, Friday 12 December 2025

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Co-funded by the European Union.

Project: 101079865 — EuMAR — EU4H-2021-PJ2

WP4 : Selection and definition of parameters

Aims

- Identify and define relevant MAR parameters, including fertility preservation (Objective 1)

Specific aims

- To identify relevant items to be registered taking into account the different stakeholders (tissue establishments, country, and EU competent authorities ensuring surveillance and biovigilance, patients/donors).
- To create a glossary of standardised definitions in order to ensure proper data harmonisation.

Tasks

T4.1
- **Characteristics and parameters with accepted terminology**
- By 30 September 2023

T4.2
- **Characteristics and parameters: definition of type, format, and validation conditions**
- By 30 September 2023

T4.3
- **Characteristics and parameters: translation to other languages**
- By 30 December 2023

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WP4 : Selection and definition of parameters

D4.1

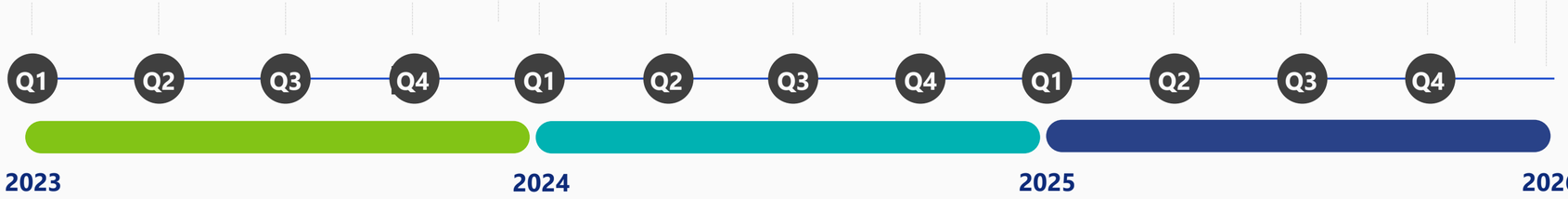
Characteristics and parameters with accepted terminology

Q4 2023

Stakeholder event 05 December 2023

Update Characteristics and parameters with accepted terminology

Stakeholder event 12 December 2025



Deliverables

D4.1 - Characteristics and parameters with accepted terminology

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Parameters – set-up and after revision

Part 1: Parameters to be included in the register

- Module 1 – Identification
- Module 2 – Patient variables
- Module 3 – Cycles with ovarian stimulation
- Module 4 – Laboratory data
- Module 5 – Embryo transfer
- Module 6 – Complications during pregnancy
- Module 7 – Pregnancy and outcome
- Module 8 – IUI
- Module 9 – Fertility preservation

Part 2: Parameters to be derived from the register

9 Modules
64 Parameters

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Usability EuMAR parameters

HARMONISATION is KEY

Developing a parameter list ➡ not reinvent the wheel

EDQM
EuMAR parameters were based on EDQM exercise on harmonising activity data collection in the field of tissues and cells with intention to take up the role of an international registry

ICMART
The glossary was the starting point for the EuMAR definitions

National Registers
Served as a library of parameters already collected in different countries

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What happened after December 2023?

Stakeholder feedback

- 30 stakeholders
  - NCA
  - National registers
  - EIM members
  - ICMART
  - EDQM

Pilot study

- Data submitted in 4 countries (Portugal, Germany, Slovenia and Estonia)
- Feedback on input data

Validation report

- Validation rules need to be clear
- The glossary should be refined
- Parameters poorly answered need to be removed

Revision parameters by WP4 and WP5

- Taking into account:
  - Previous three steps
  - Information from dashboard working group
- Consensus on parameters to be removed, altered and added
- Improved parameter list for further development of the EuMAR register

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Module 1 – Identification

1. EuMAR IRCC
2. Cycle identification Improve list as follows:

a. FRESH cycle with own gametes
b. FRESH cycle with donated gametes
c. Frozen-thawed embryo transfer (FET) cycle with own gametes
d. Frozen-thawed embryo transfer (FET) cycle with gamete/embryo donation
e. Intra-uterine insemination (IUI) with partner gametes
f. Intra-uterine insemination (IUI) with donor gametes
g. Fertility Preservation (FP)

a. IVF, ICSI, IVF+ICSI cycle (aim: fresh cycle)
b. Frozen-thawed embryo transfer (FET) cycle
c. Combination of IVF/ICSI + FET cycle
d. Fertility Preservation (FP)
e. Intra-uterine insemination (IUI)
f. Oocyte donation/ sperm donation
g. In Vitro Maturation (IVM) cycle

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Module 2 – Patient variables

3.	Country of current residence	
4.	Female Date of Birth	
5.	Female Body Mass Index (BMI)	Body Mass Index main patient
6.	Female current smoking status	DELETE
7.	Male Date of Birth	
8.	Male Body Mass Index (BMI)	DELETE
9.	Male current smoking status	DELETE

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Module 2 – Patient variables

10. Indication for treatment — simply list as follows:

a. Unexplained infertility
b. Tubal pathology
c. Ovulatory disorder
d. Endometriosis/adenomyosis
e. Psychosexual (can be an indication for IUI and occasionally IVF)
f. Premature Ovarian Insufficiency (POI)/oocyte issue (women who need donor eggs)
g. Sperm factor
h. No sperm provider (same-sex or singles)
i. No egg provider (same-sex or singles
j. Need for Preimplantation Genetic Testing (PGT)

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Module 3 – Cycles with ovarian stimulation

11. Ovarian Stimulation
12. Date of start cycle
13. Treatment protocol
14. Cancellation prior to Ovum Pick Up (OPU)
15. OPU cancellation cause
16. Date of ovum pick-up
17. Number of cumulus oocyte complexes retrieved
18. In-vitro maturation — DELETE, now part of identification in Module 1
19. Number of oocytes cryopreserved
20. Reasons for oocyte cryopreservation — ADD Duostim
21. Number of oocytes donated

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Module 4 – Laboratory data

22. Source of sperm
23. Source of oocytes
24. Date of insemination
25. Insemination technique
26. N of oocytes inseminated (IVF)
27. N of oocytes injected (ICSI)
28. N of 2 pronuclei (2pn) – IVF
29. N of 2pn – ICSI
30. N of embryos developed (IVF and ICSI)

Parameters remain the same

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Module 4 – Laboratory data

31. Total N of embryos cryopreserved
32. Optional: N of cleavage stage embryos cryopreserved
33. Optional: N of blastocysts cryopreserved
34. Reasons for embryo cryopreservation
35. Pre-implantation Genetic Testing

Improve list to following:

a. Supernumerary embryos
b. PGT
c. Medical reason
    - OHSS risk
    - Infection
    - Intercurrent disease
    - Fertility preservation
    - Uterine or tubal pathology undiagnosed before cycle start
    - other
d. Non-medical reason
    - Religion
    - Legal issues
    - other
e. Planned freeze all (for autologous use /not for fertility preservation)
f. Donation

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Modules 5 – Embryo transfer

36. Embryo transfer
37. Embryo transfer with:
    - a. Fresh embryos
    - b. Frozen **own** embryos
    - c. Frozen **donated** embryos
    - d. Combination of fresh and frozen embryos

<u>Use of fresh embryos</u>

38. Date of embryo transfer
39. Number of cleavage or morula stage embryos transferred
40. Number of blastocysts transferred.
41. Embryo Transfer Outcome

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Modules 5 – Embryo transfer

Use of frozen embryos

42. Date of thawing
43. Frozen embryo transfer protocol (FET)
44. Embryo Transfer
45. Date of embryo transfer (link to OPU if available)

Insert
- Date from cycle from which the embryo originate
- Number of thawed cleavage or morula stage embryos
- Number of thawed blastocysts

46. Number of cleavage or morula stage embryos transferred
47. Number of blastocysts transferred
48. Embryo Transfer Outcome
49. Cause of no embryo transfer

a. No embryos (failed fertilisation/failed cleavage/abnormal embryos)
b. No embryos (failed thawing)
c. Cryopreservation

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Modules 6 - Complications

50. Complications
51. Causes

Improve list as follows, adhering to GDPR:

a. OHSS Severe (Grade III – IV or hospitalization for lesser grades)
b. Infection
c. Bleeding requiring hospitalization, blood transfusion and/or surgery
d. Thrombosis
e. Ovarian or adnexal torsion NEW
f. Other

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Modules 7 – Pregnancy and outcome

52. Highest number of intra-uterine gestational sacs on ultrasound scan
53. Details of twin pregnancy
54. Fetal reductions
55. Pregnancy outcome
56. Date of delivery
57. N of children born — Alive and dead
58. N of stillbirths — DELETE

Liveborn Child 1

59. Sex
60. Birth weight
61. Neonatal outcome
62. Neonatal malformations

Questions for every liveborn child

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Modules 8 & 9 – IUI – Fertility preservation

61. IUI cancelled
62. Outcome

63. Method of fertility preservation
64. Reason for fertility preservation

a. Medical
1. Oncology
2. Benign medical conditions (eg endometriosis, benign haematological disorders in children, Surgical risk for later infertility..)
3. Gender transition
4. Differences in Sex Development (DSD)
b. Non-medical

To be expanded for collection of use of material in the future

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Parameters to be calculated

Part 2: Parameters to be derived from the register

Totals
Timeframes
Rates
Cumulative rates

Part 2: Number of Parameters

25 parameters

# of treated individuals	# of individual persons that had at least one treatment cycle intervention (IUI, IVF/ICSI and/or FET) completed
Age of the individual	Date of start cycle minus date of birth
# of couples that had at least one treatment cycle intervention (IUI, IVF/ICSI and/or FET) completed	# of couples that had at least one treatment cycle intervention (IUI, IVF/ICSI and/or FET) completed
# of treatment cycles without stimulation	# of cycles without ovarian stimulation (includes hormone substituted cycles) that ended up with one of the interventions
Cumulative pregnancy rate	The number of oocyte retrievals resulting in at least 1 clinical pregnancy within 1 year of the oocyte retrieval cycle divided by the total number of oocyte retrieval cycles that had at least 1 fresh or frozen embryo transfer

EuMAR by ESHRE

WP4 members

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EuMAR
by ESHRE

Dashboards: features and KPIs

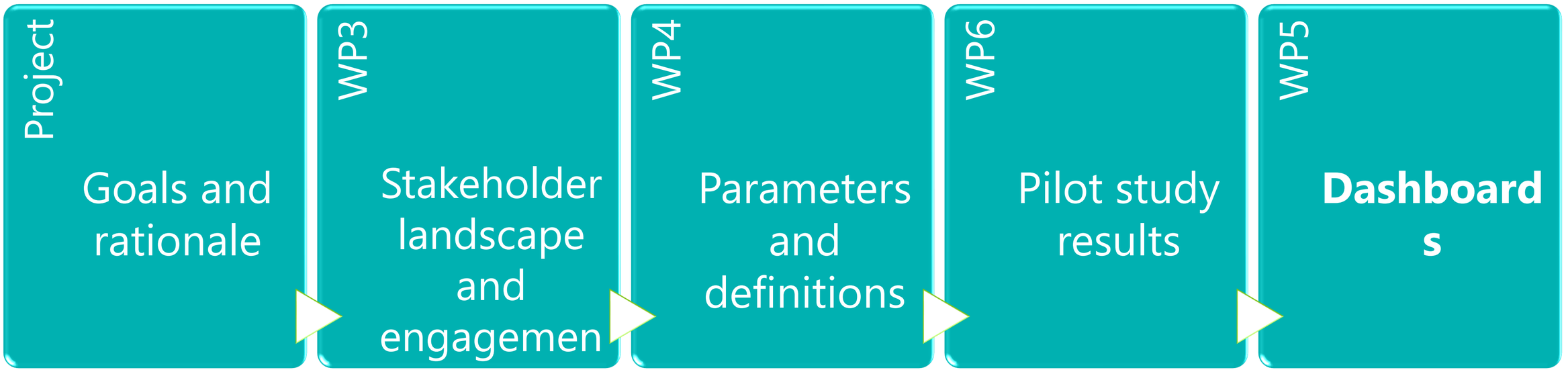
Christine Wyns

Brussels, Friday 12 December 2025

EuMAR by ESHRE

Co-funded by the European Union.
Project: 101079865 — EuMAR — EU4H-2021-PJ2

Introduction



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Benefits of EuMAR

Monitoring of trends and treatment outcomes in MAR

Patient reports

Dashboards

Collection and calculation of cumulative outcome parameters

Harmonised data from EU countries

Inter-institutional and cross-border data collection

Data for Open Science

Quality assurance and benchmarking for clinics

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Benefits of EuMAR: dashboards

Objective:
Transparency for informed decision-making

→ Present QI/KPIs

→ Benchmark against relevant stakeholders

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Quality indicators (QI)- KPIs

QI = tool to **quantify the quality of a selected aspect of care**

= objective measure that evaluates critical healthcare domains (**safety, effectiveness, equity**, patient-centeredness, timeliness, efficiency)

→ **specifications** for the numerator, denominator and data collection requirements

→ **consistent and comparable** across settings and over time

→ **tailored to objectives and stakeholders**

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Designing and tailoring towards objectives

What we want to see presented in the dashboards:

ART in Europe, 2019: results generated from European registries by ESHRE

EIM data

Reproduce at least the data as published in the yearly reports

Cumulative data

Cross Border data

The presented data need to fit the **audience**

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Data visualisation tailored to audience

- Clinicians and MAR centers
- National Registers/Competent Authorities
- Researchers
- Patients/general public
- EU Stakeholders

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Data visualisation: type by stakeholder

Clinicians and MAR centers	• Cycle by cycle data from own centre • Benchmark against national values
National Registers/Competent Authorities	• Aggregated data • Cycle by cycle data for specific country • Benchmark against other Member States
Researchers	• Aggregated data • Specific data upon request
Patients/General Public	• Aggregated data
EU Stakeholders	• Aggregated data

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Development of dashboards content

WP5: Brainstorm on content + IT: transform ideas in output

Dashboards populated with data from the pilot study:
- only limited data/concerns with missing's
- not all features/data can be used

Under development: cumulative data and benchmarking

When dashboard is populated with more data, send to test audience
- feedback on user friendliness and completeness
- suggestions for improvement

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Output

DEMO

Last Data Updates

Click to view the latest data update dates for each center.

Availability if >80% completeness

Benchmarking Page

Click to view the benchmarking report to compare clinics.

Type of benchmarking e.g. based on size of clinics

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Output

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Home > **All Cycles**

DEMO

Hide Values

Clear All

Year of Cycle
Alle

Type of Cycle
Alle

Origin of Sperm
Alle

Freeze All
Alle

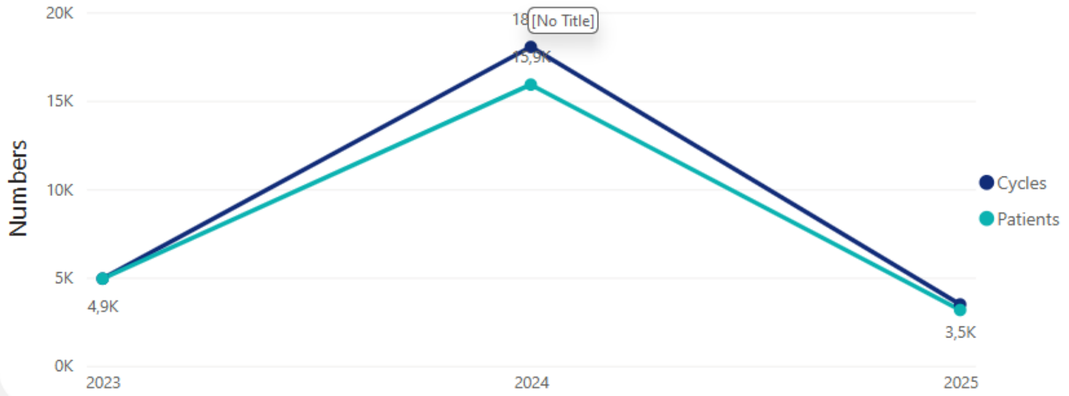
Type of Oocyte
Alle

Origin of Oocyte
Alle

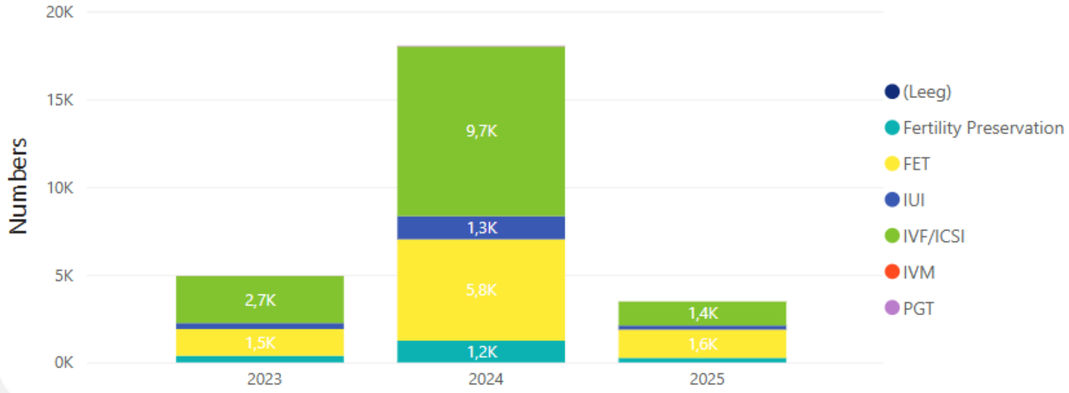
More Filters (2)

Shortcuts
- IVF/ICSI Cycles
- IUI Pregnancies
- Fertility Preservation Cycles
- FET Cycles
- PGT Cycles
- ART Pregnancies

Cycles and Patients



Cycles Per Cycle Type



26.4K

Number of Cycles between 2023 - 2025

23.4K

Number of Patients Treated between 2023 - 2025

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Output

EuMAR by ESHRE

Home > **All Cycles**

DEMO

Hide Values

Clear All

- Alles selecteren
- (Leeg)
- Fertility Preservation
- FET
- IUI
- IVF/ICSI
- IVM
- PGT

Year of Cycle

Alle

Type of Cycle

Alle

Origin of Sperm

Alle

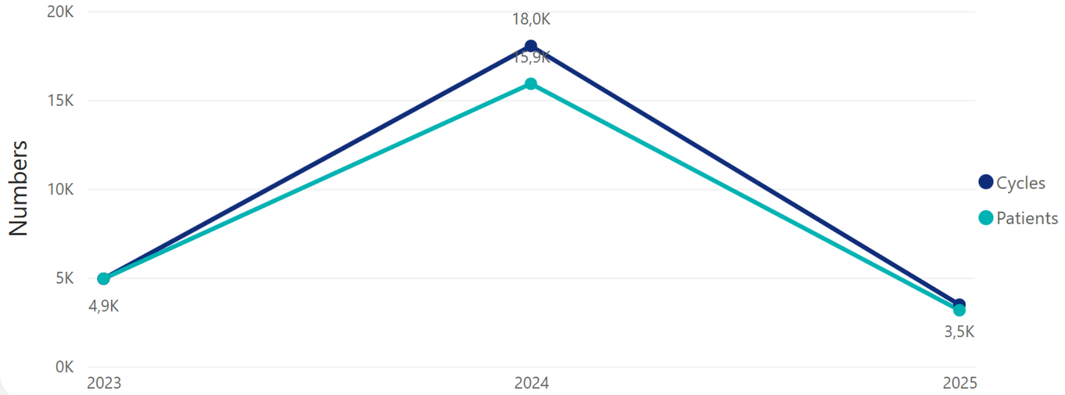
- Alles selecteren
- (Leeg)
- donor sperm
- partner sperm (own sperm)

- Alles selecteren
- (Leeg)
- donor sperm
- partner sperm (own sperm)

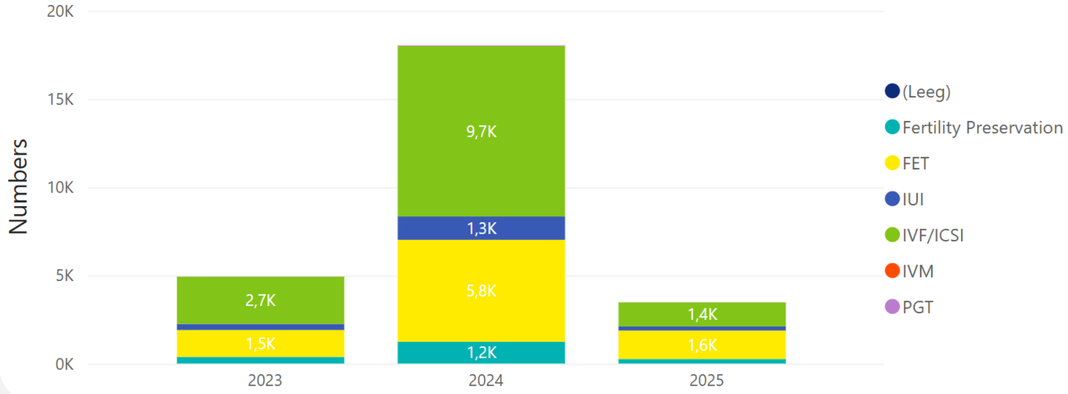
Shortcuts

- IVF/ICSI Cycles
- IUI Pregnancies
- Fertility Preservation Cycles
- FET Cycles
- PGT Cycles
- ART Pregnancies

Cycles and Patients



Cycles Per Cycle Type



26.4K

Number of Cycles between 2023 - 2025

23.4K

Number of Patients Treated between 2023 - 2025

EuMAR by ESHRE

Output

EuMAR by ESHRE

DEMO

Home > **Ovarian Stimulation**

Clear All

Type of Cycle
Alle

Insemination Technique
Alle

Origin of Sperm
Alle

Origin of Oocyte
Alle

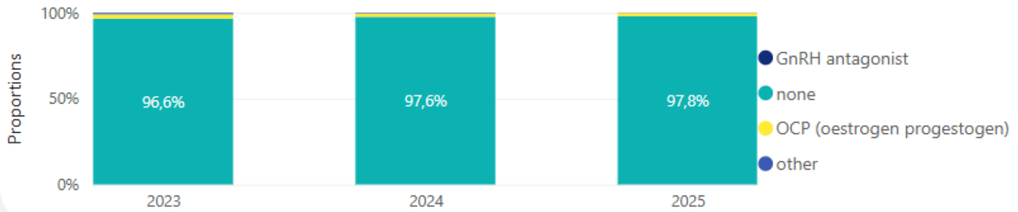
Type of Oocyte
Alle

Patient Age
15 60

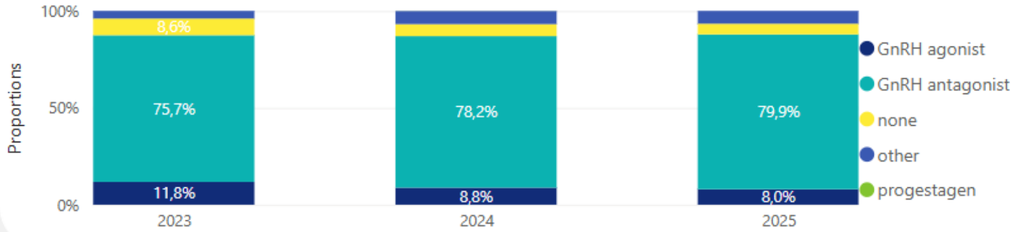
More Filters (2)

Shortcuts
IVF/ICSI - Cycles

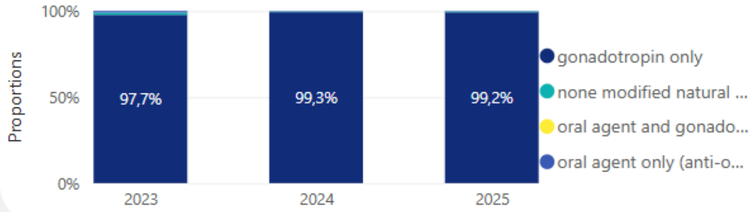
Pre-Treatment Protocol



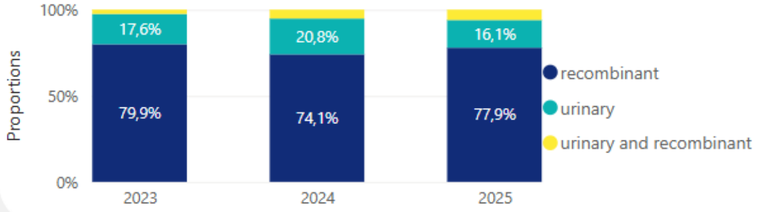
LH Suppression Protocol



Stimulation Drug



Gonadotropin Type



EuMAR by ESHRE

Output

EuMAR by ESHRE

DEMO

Home > **Ovarian Stimulation**

Clear All

Type of Cycle

Alle

- Alles selecteren
- (Leeg)
- ICSI
- IVF
- Mixed IVF and ICSI

Insemination Technique

Alle

- Alles selecteren
- (Leeg)
- donor sperm
- partner sperm (own sperm)

Origin of Sperm

Alle

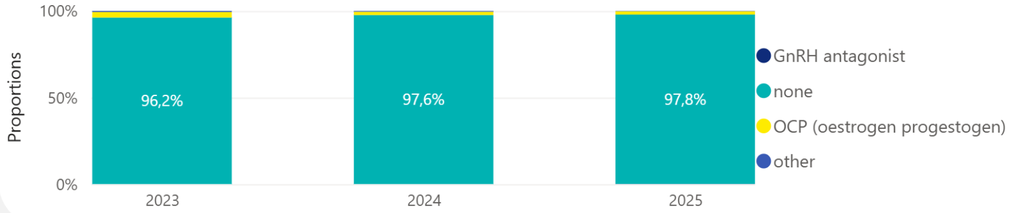
Origin of Oocyte

Alle

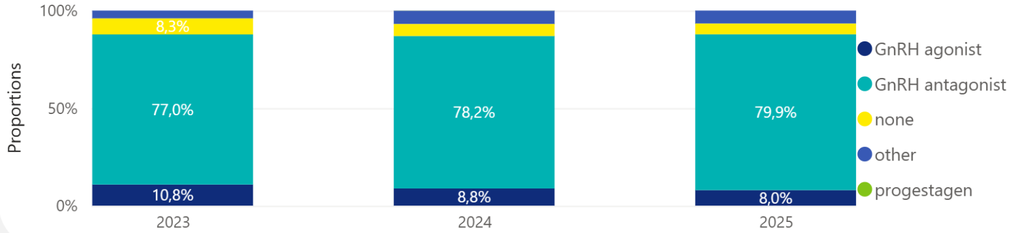
- Alles selecteren
- (Leeg)
- fresh
- frozen

IVF/ICSI - Cycles

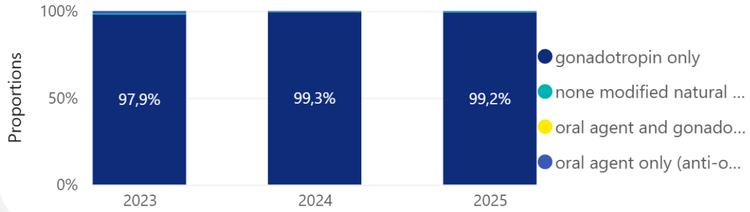
Pre-Treatment Protocol



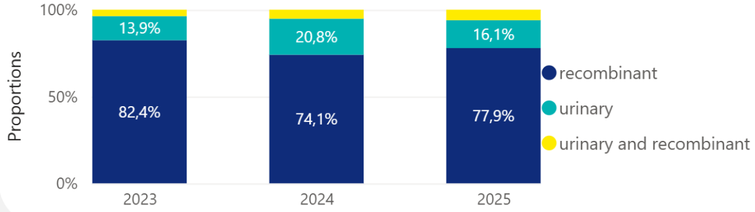
LH Suppression Protocol



Stimulation Drug

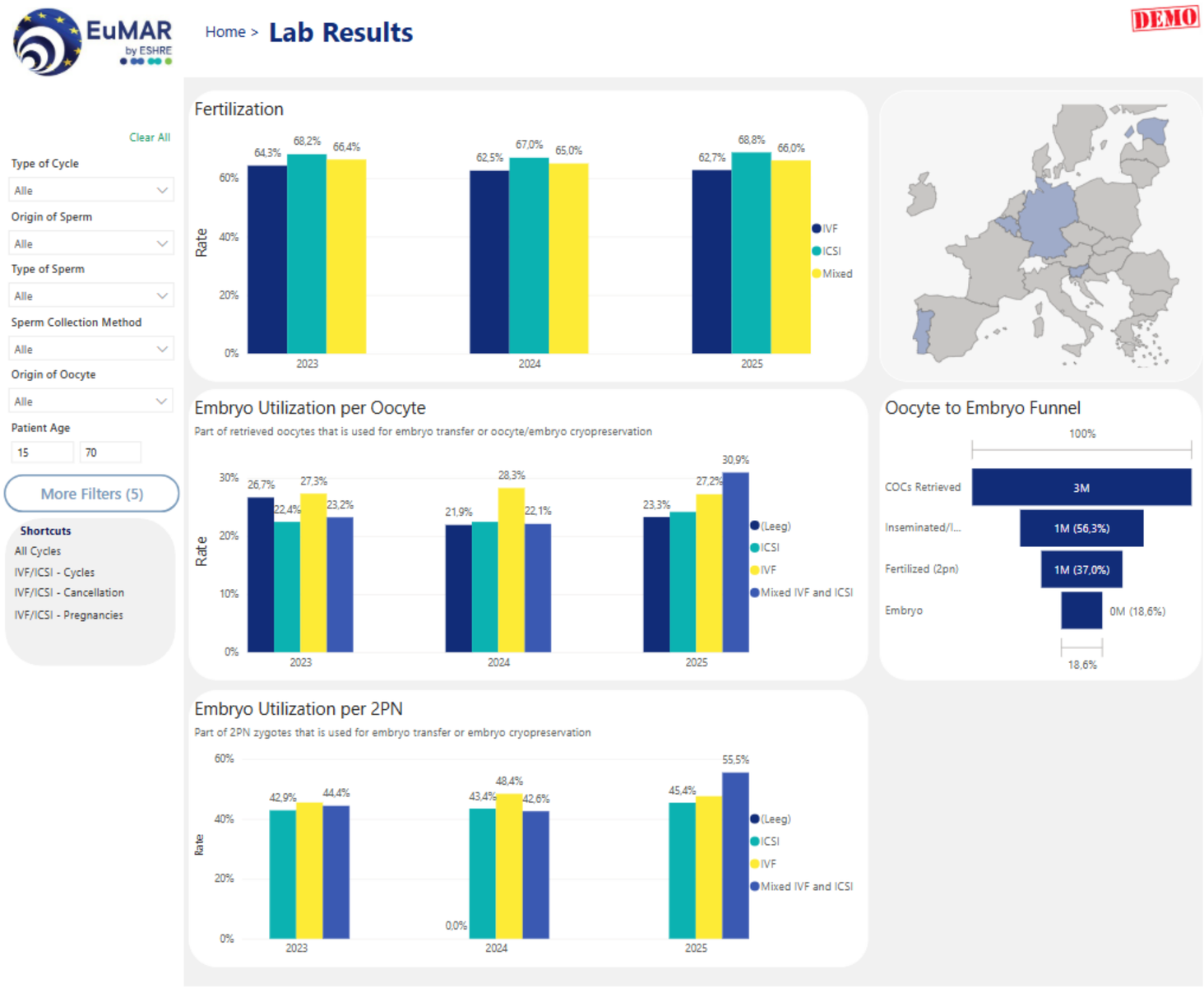


Gonadotropin Type



EuMAR by ESHRE

Output

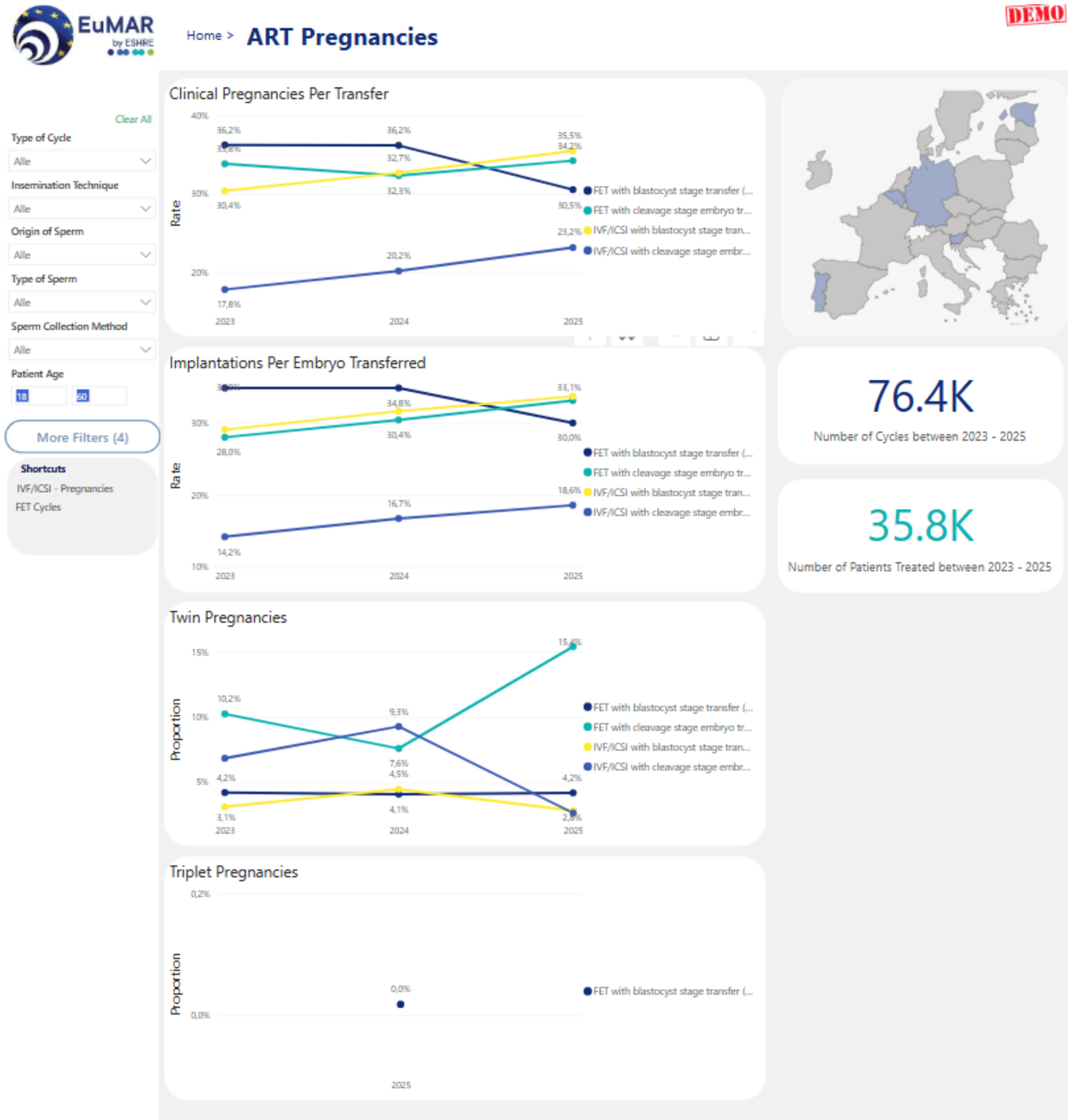


EuMAR by ESHRE

Output

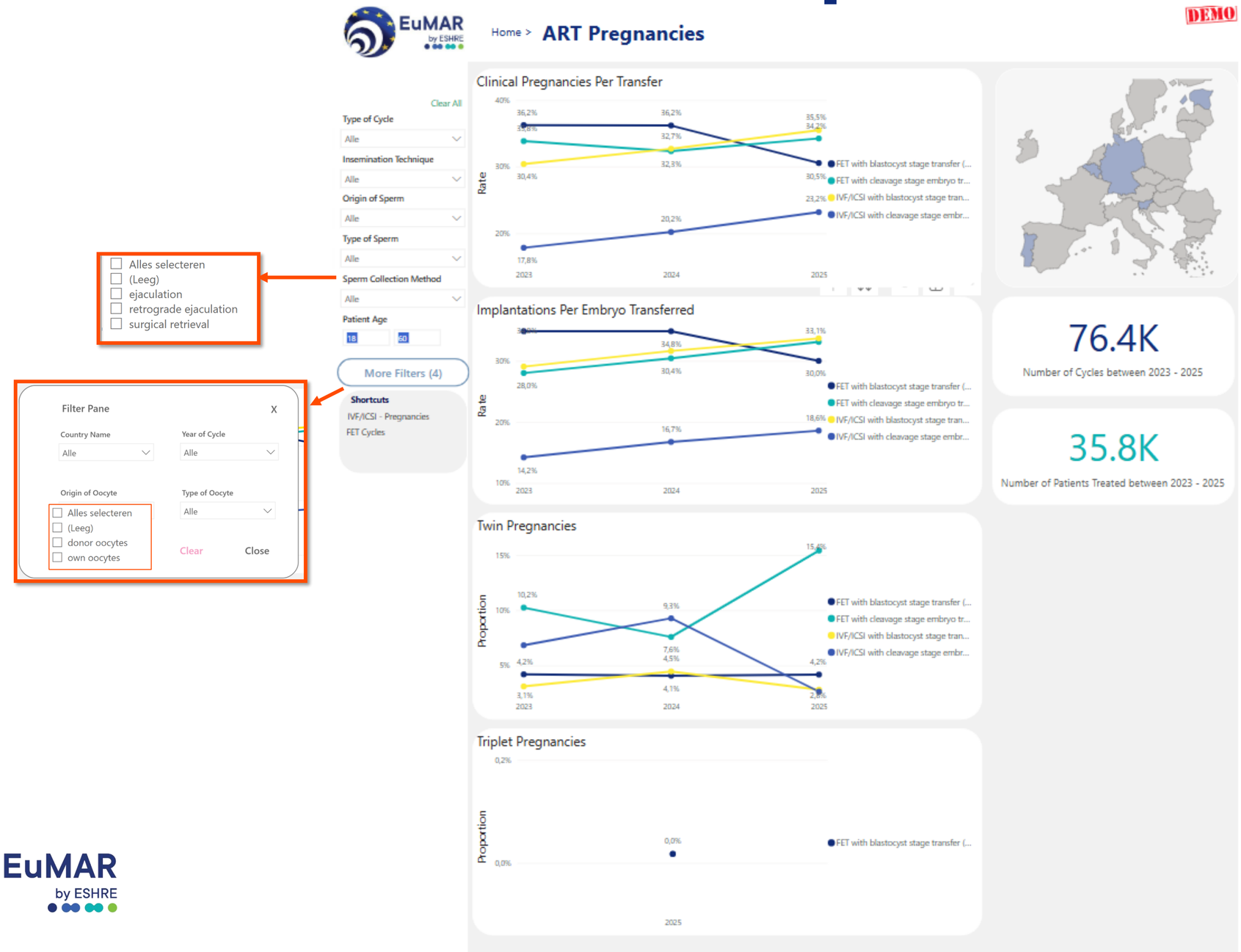
EuMAR by ESHRE

Output



EuMAR by ESHRE

Output



EuMAR by ESHRE

Output

EuMAR by ESHRE

Home > **Benchmarking**

DEMO

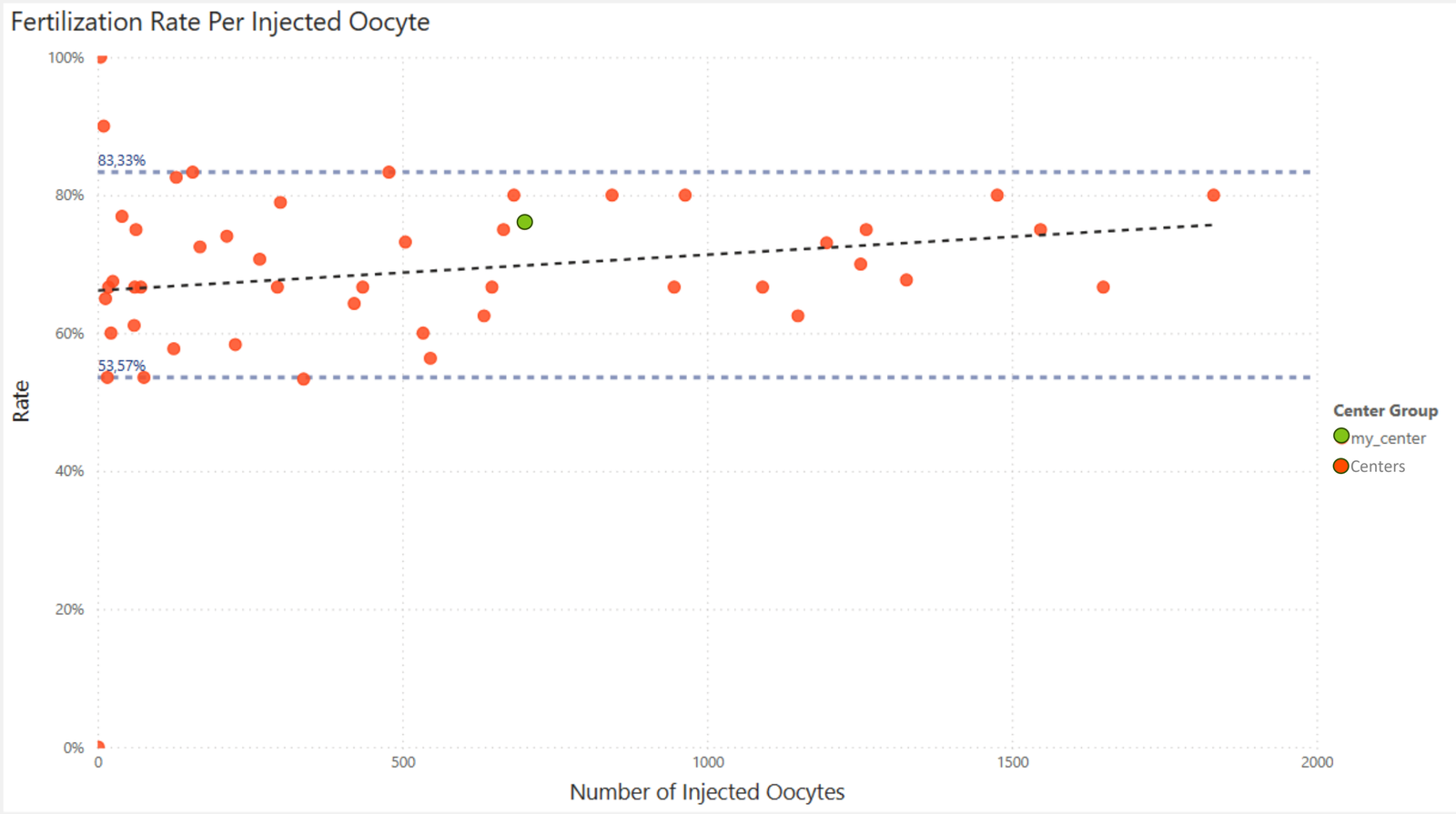
Clear All

Year of Cycle

Alle

Shortcuts

All Cycles



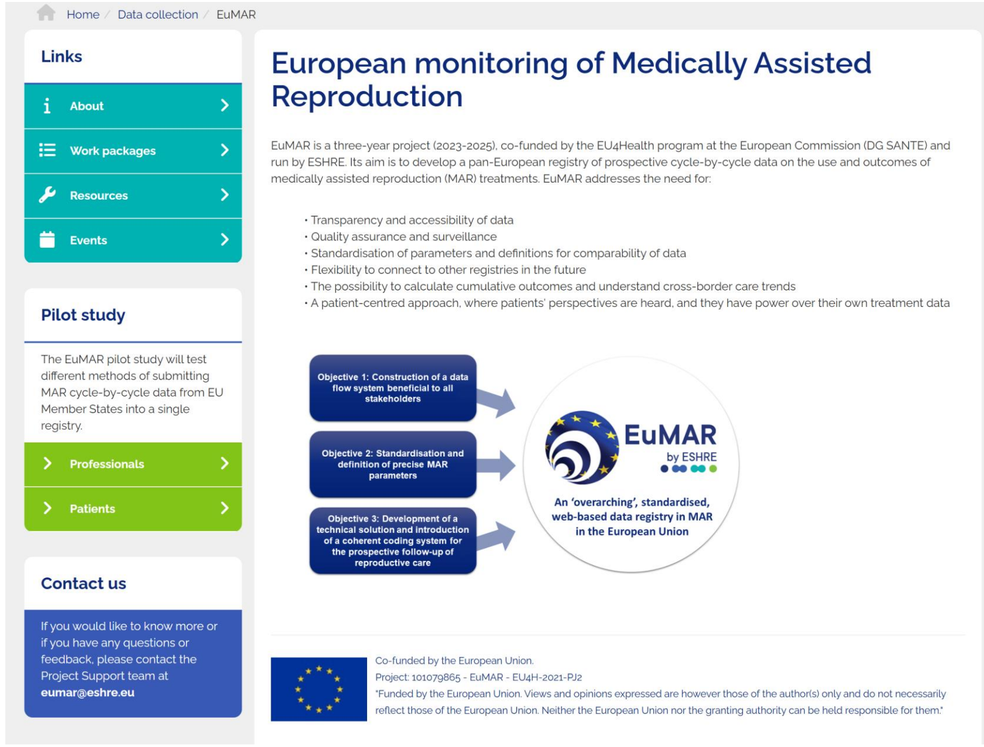
Eul by ESHRE

Where to find the dashboards

Only data from pilot study – no conclusions can be drawn at this time

- Centres/national authority-registers collaborating in the pilot study:
  Log-in to the platform

- General public/patients, once ready:
  ESHRE webpage EuMAR



EuMAR by ESHRE

WP5 members

Veerle Goossens
Project Support
Belgium

Christine Wyns
WP Leader
Belgium

Christian De Geyter
WP5 Member
Switzerland

Irena Antonova
WP5 Member
Bulgaria

Jean Calleja Agius
WP5 Member
Malta

Irene Cuevas
WP5 Member
Spain

Diane De Neubourg
WP5 Member
Belgium

Bogdan Doroftei
WP5 Member
Romania

Karel Rezabek
WP5 Member
Czech Republic

Giulia Scaravelli
WP5 Member
Italy

Rob Goijen (eFertility)
WP5 Member
Netherlands

Rutger Slager (eFertility)
WP5 Member
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Luc Vanoppen
WP5 Member
Belgium

Ruben Roex (Timelex)
WP5 Member
Belgium

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Thank you!

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European Society of Human Reproduction and Embryology

Session 4:
Looking ahead

EuMAR
by ESHRE

Next steps: EuMAR 2

Jesper Smeenk

Brussels, Friday 12 December 2025

EuMAR by ESHRE

Co-funded by the European Union.
Project: 101079865 — EuMAR — EU4H-2021-PJ2

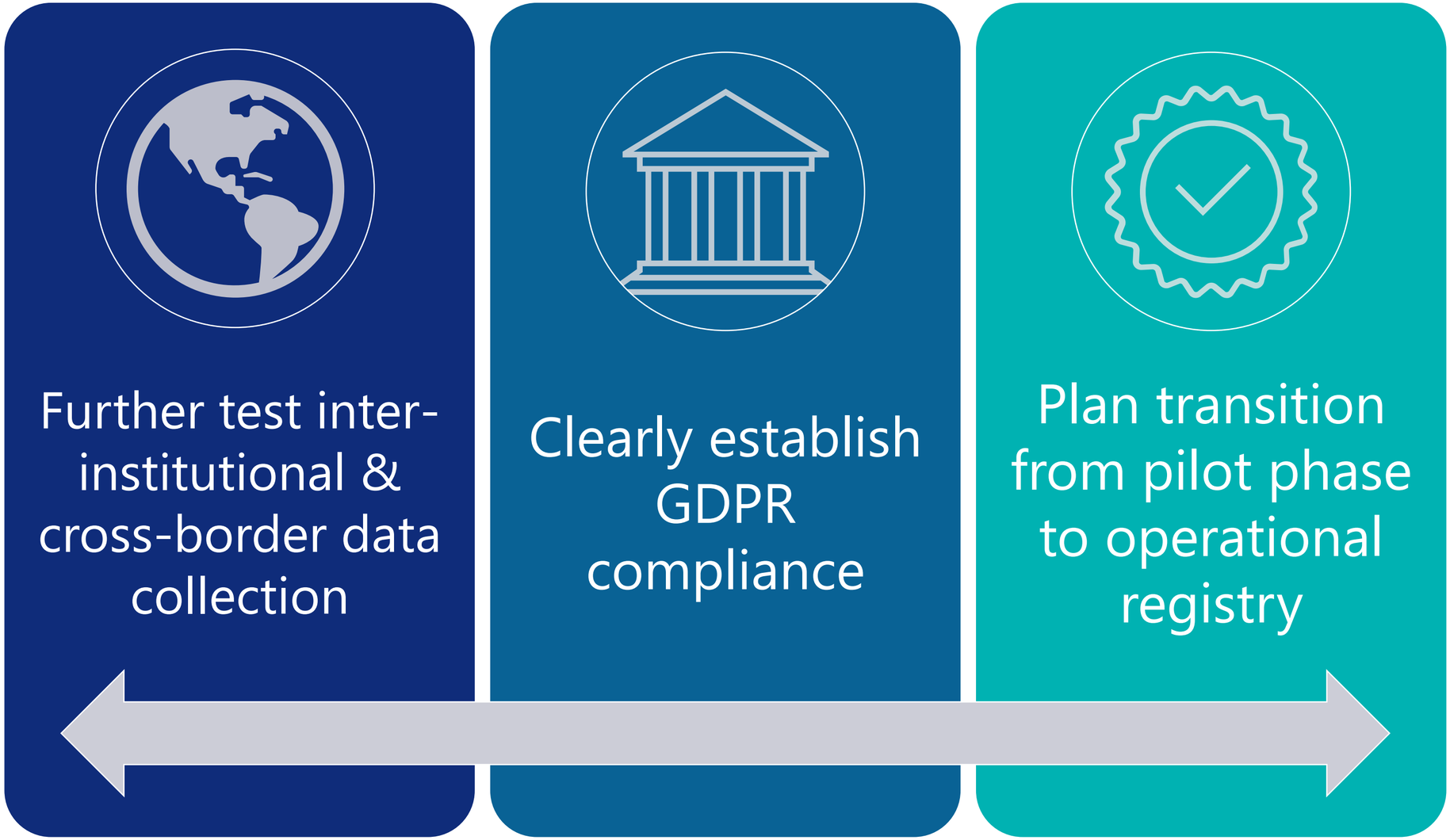
EuMAR 2

- EuMAR 2 is proposed as a **two-year extension** of the project (2026-2028)
- Its **aims** are to bridge the gap between the current pilot project and a fully operational, sustainable European cycle-by-cycle MAR registry
- EuMAR 2 will be entirely **funded by ESHRE**

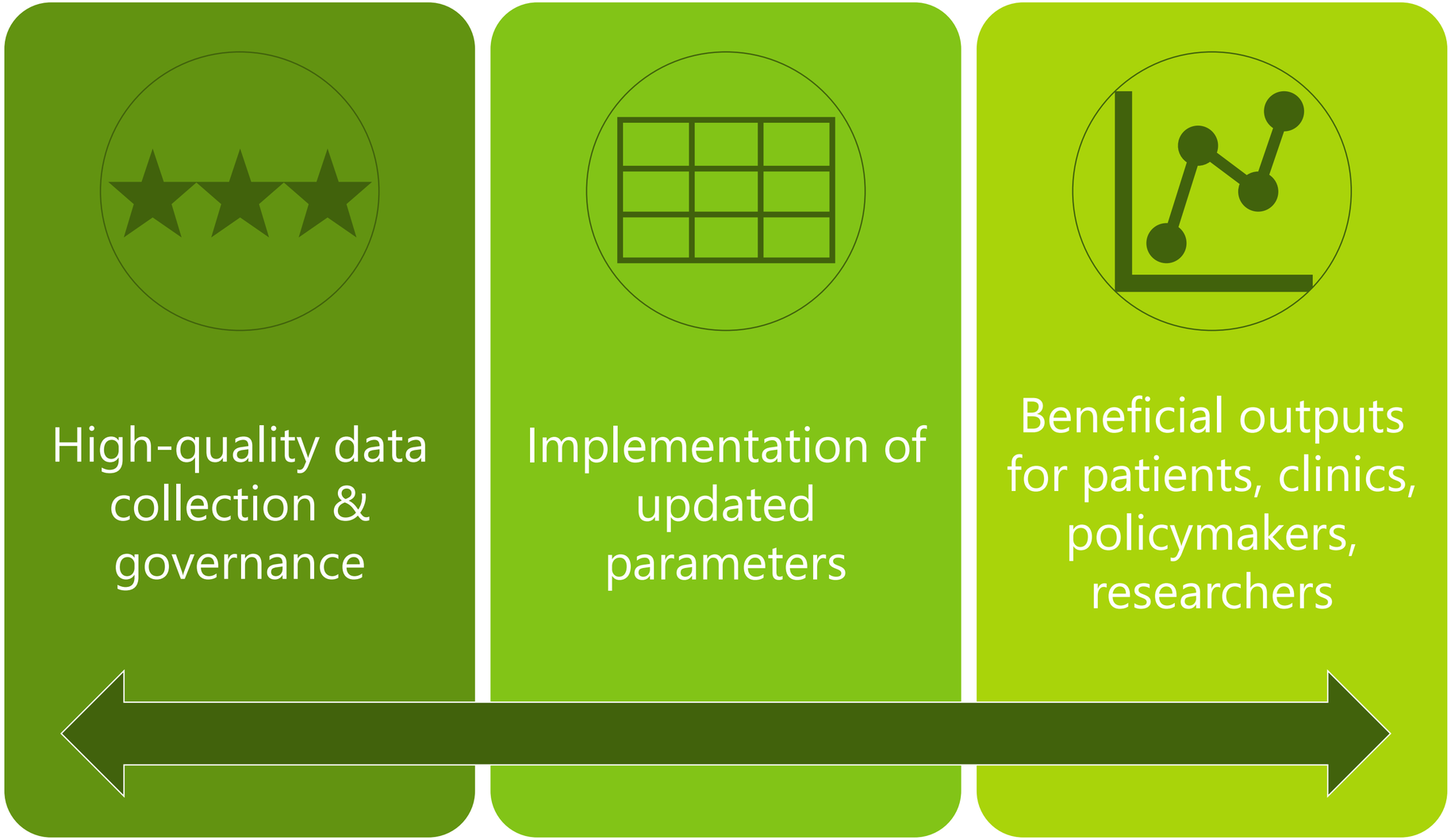
EuMAR 2 aims

1. **Refine** registry **processes** and **features** built in EuMAR 1
2. Ensure **credibility and value** of the data for stakeholders
3. Foster **connectivity** across countries and MAR centres

Aim 1: Refine processes

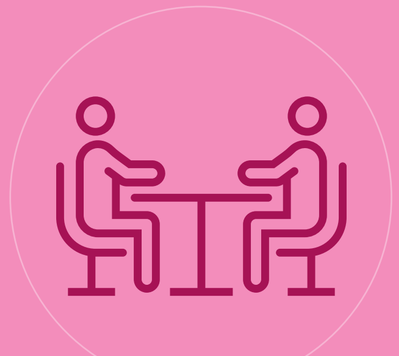


Aim 2: Ensure value



Aim 3: Foster connectivity

Connect up to ten countries by the end of 2027



Promote registry benefits & continue promoting engagement with stakeholders

Develop a sustainability plan that includes integration with EIM & potential external funding opportunities

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Project structure

WP Project Management

The activities related to planning, organising, monitoring and managing the resources and tasks necessary to achieve the project goals in an effective and efficient way.

WP2 Communications

Ensure the correct flows of information to prevent misunderstandings, keep a team cohesion; and reach external stakeholders, to deliver the right message and maximise engagement.

WP3 Data Registry

Logistical and technical aspects of maintaining and expanding the EuMAR registry. It is divided into WP3.1 Data Input and Expansion, WP3.2 Data Processing & Quality Assurance, and WP3.3 Data Output and Utilisation.

WP4 Sustainability

As a bridge between a project activity and an operational activity, EuMAR 2 will define key aspects that will support the future sustainability of the registry.

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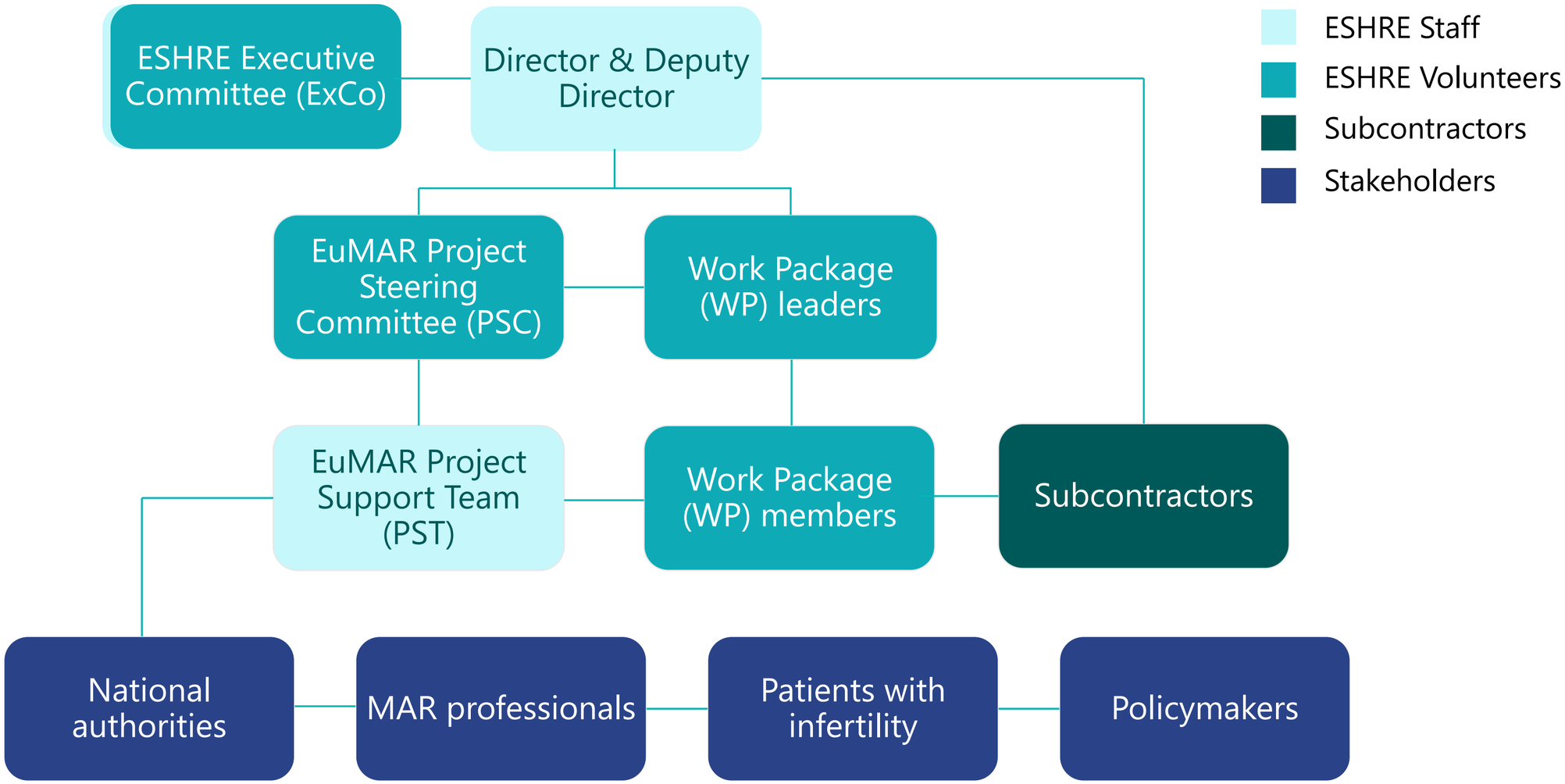
EuMAR 2 governance



EuMAR by ESHRE

Expected outcomes

1. Broad **recognition of the EuMAR registry** and its value across all key stakeholder groups
2. Fully **operational online platform** connected to 10 countries
3. A validated **solution for cumulative and cross-border data collection**
4. **Benchmarking tool** for centres to support high-quality MAR care

EuMAR by ESHRE

Expected outcomes

5. Transparent and **informed decision-making** (from the public dashboards)
6. Greater data literacy and data awareness through standardised **patient reports**
7. Formal **recognition for participating centres** (EuMAR contributor certificates)
8. Solid **sustainability** and operational plans

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Potential of the EuMAR registry

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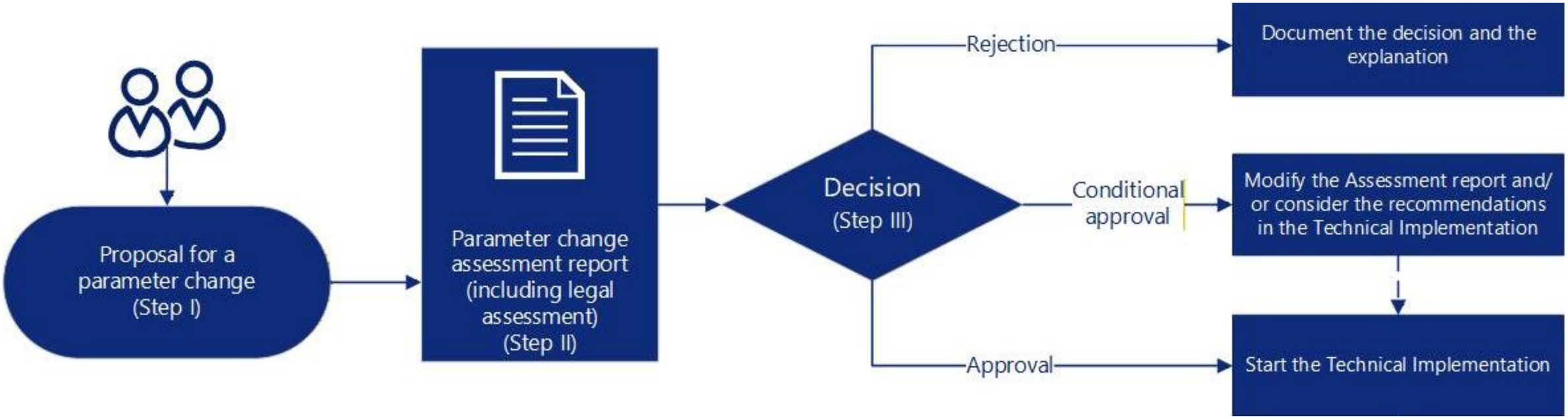
by ESHRE

Incorporation of innovation

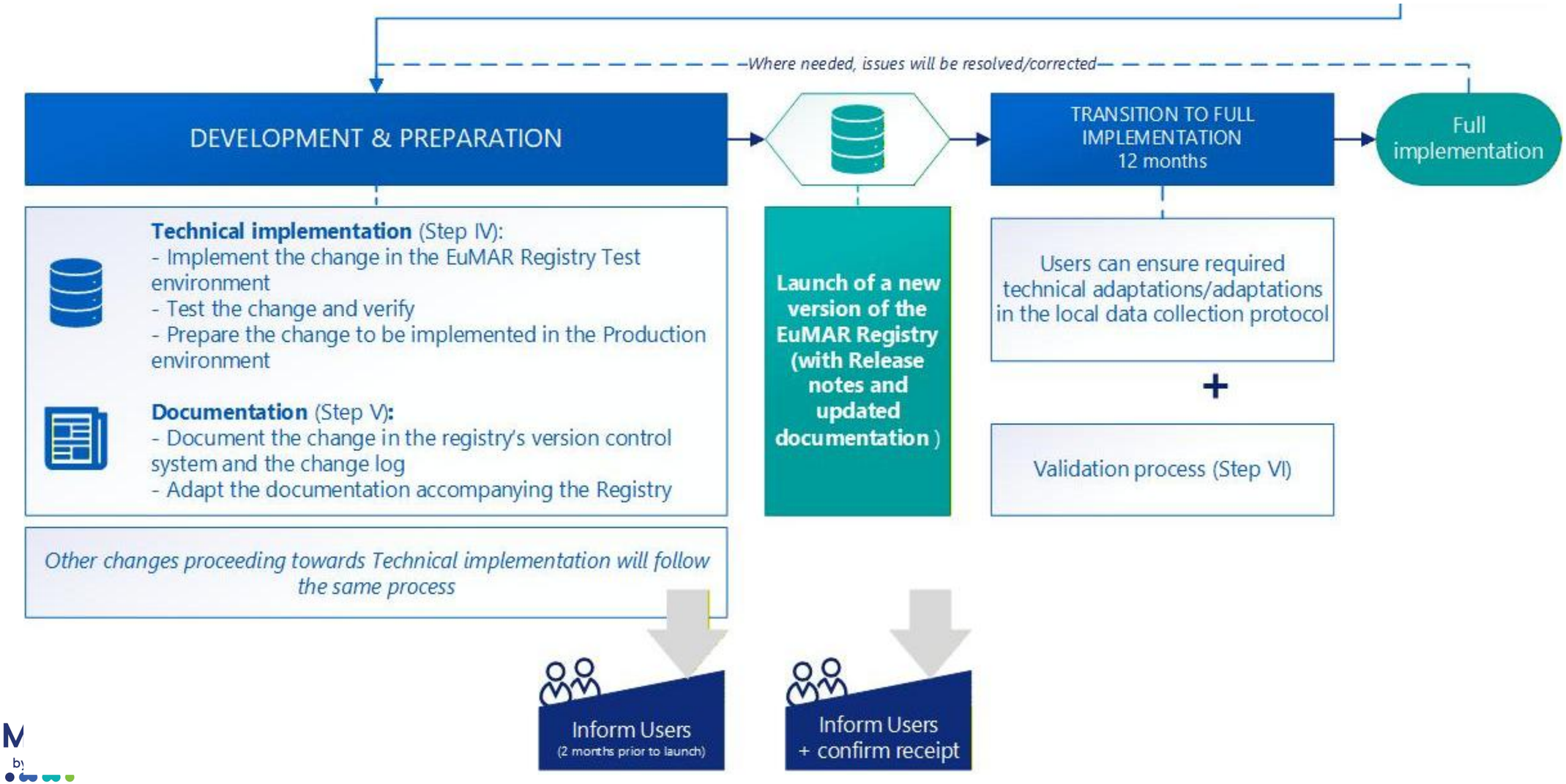
Changing EuMAR parameters



EuMAR by ESHRE

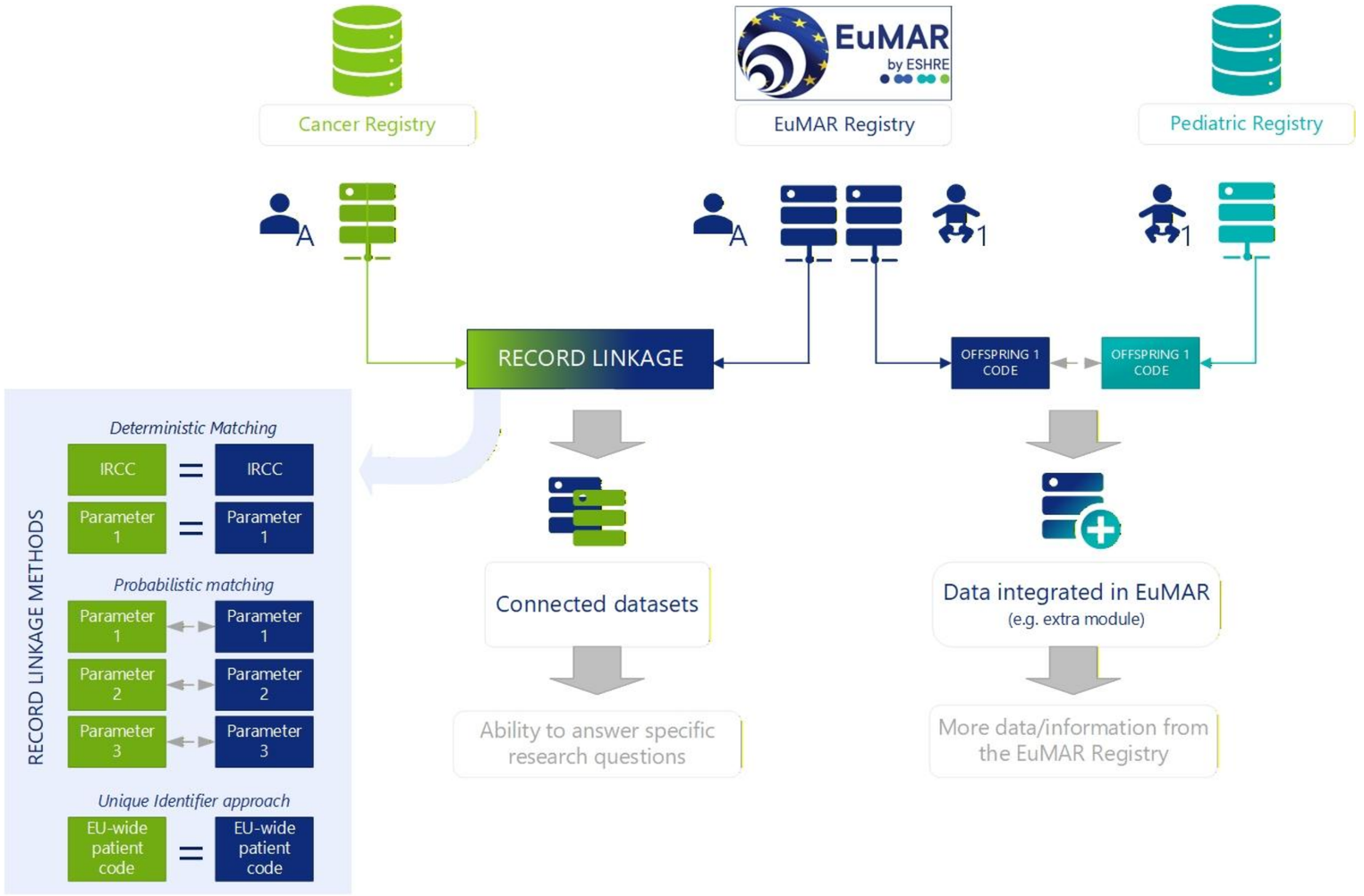
Incorporation of innovation

Changing EuMAR parameters



Incorporation of innovation

Connecting to non-MAR national and international



EuMAR – SoHO connection

EuMAR could provide standardised reports for clinics to facilitate the submission of the annual activity data report that NCAs will need to upload to the SoHO Platform (based on Article 31, SoHO Regulation).

The **exact SoHO parameters are not yet known**, therefore, it is not possible to define exactly how EuMAR can support clinics and NCAs with the mandatory activity data reporting towards the SoHO Platform.

However, the use of EuMAR consent will mean that EuMAR data may not cover 100% of cycles from the reporting country, limiting this option.

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Thank you!

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European Society of Human Reproduction and Embryology

Looking ahead:
The importance of Registries in the SoHO Regulation

Rita Piteira – SoHO Team

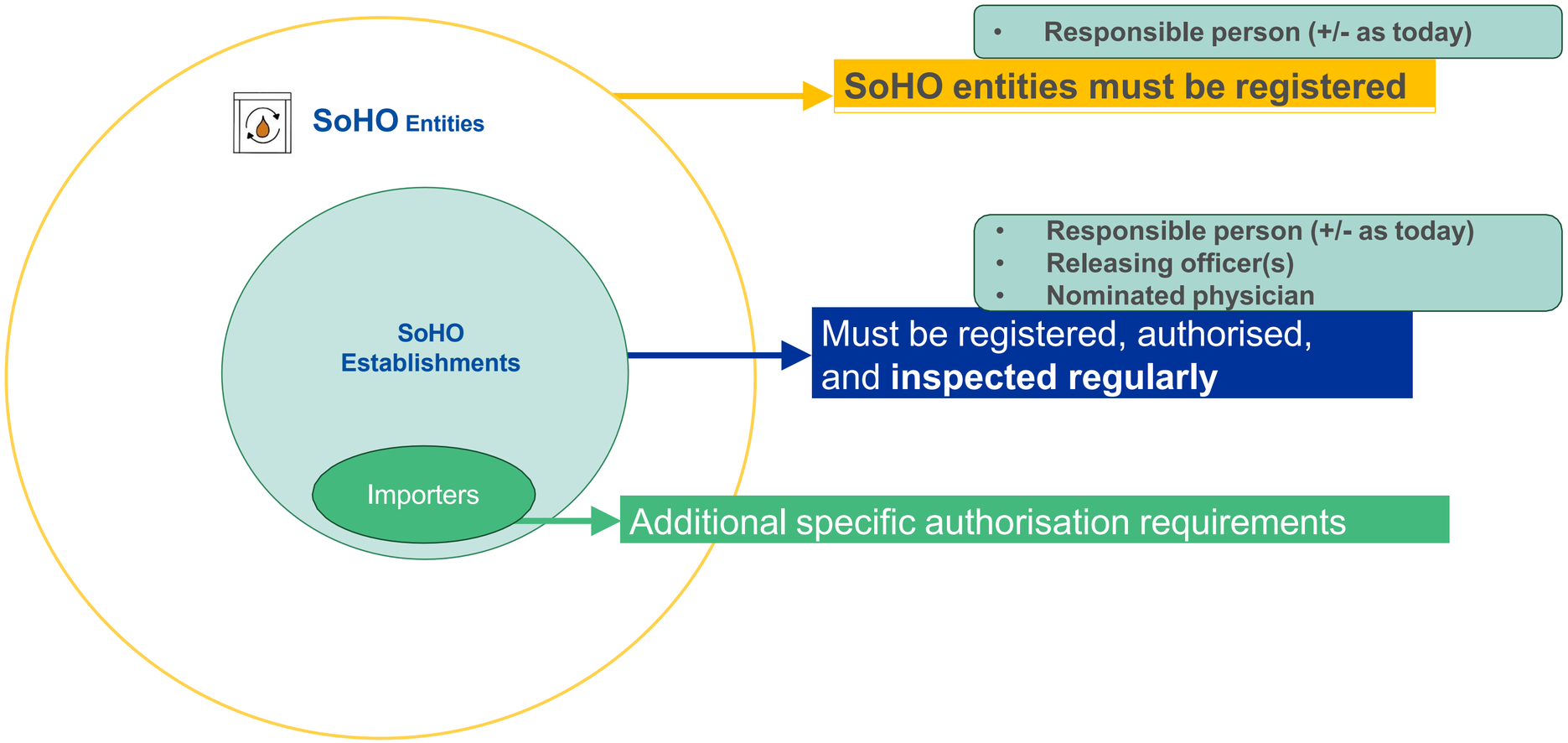
12th December 2025

European Commission

New Concepts 

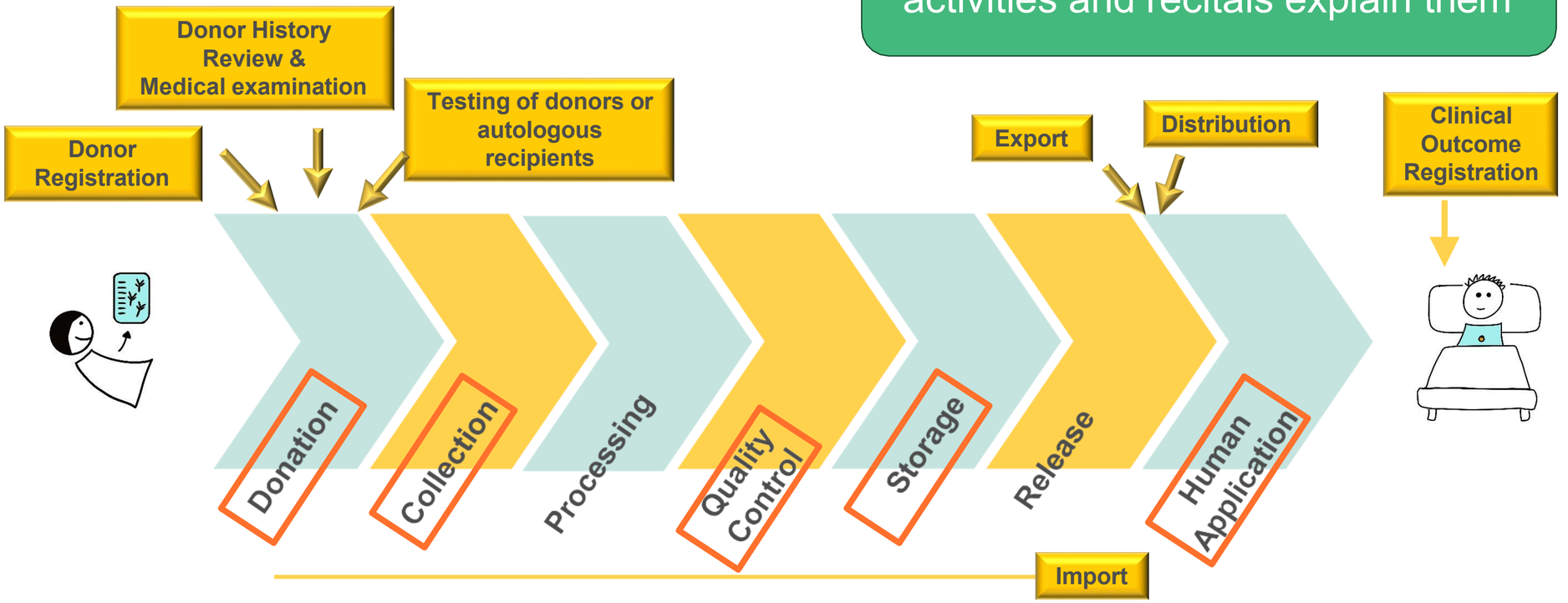
SoHO Entities & SoHO Preparations

SoHO entities Vs. SoHO establishments



Supervision of all SoHO Activities that directly impact safety, quality or effectiveness

Definitions provided for the SoHO activities and recitals explain them



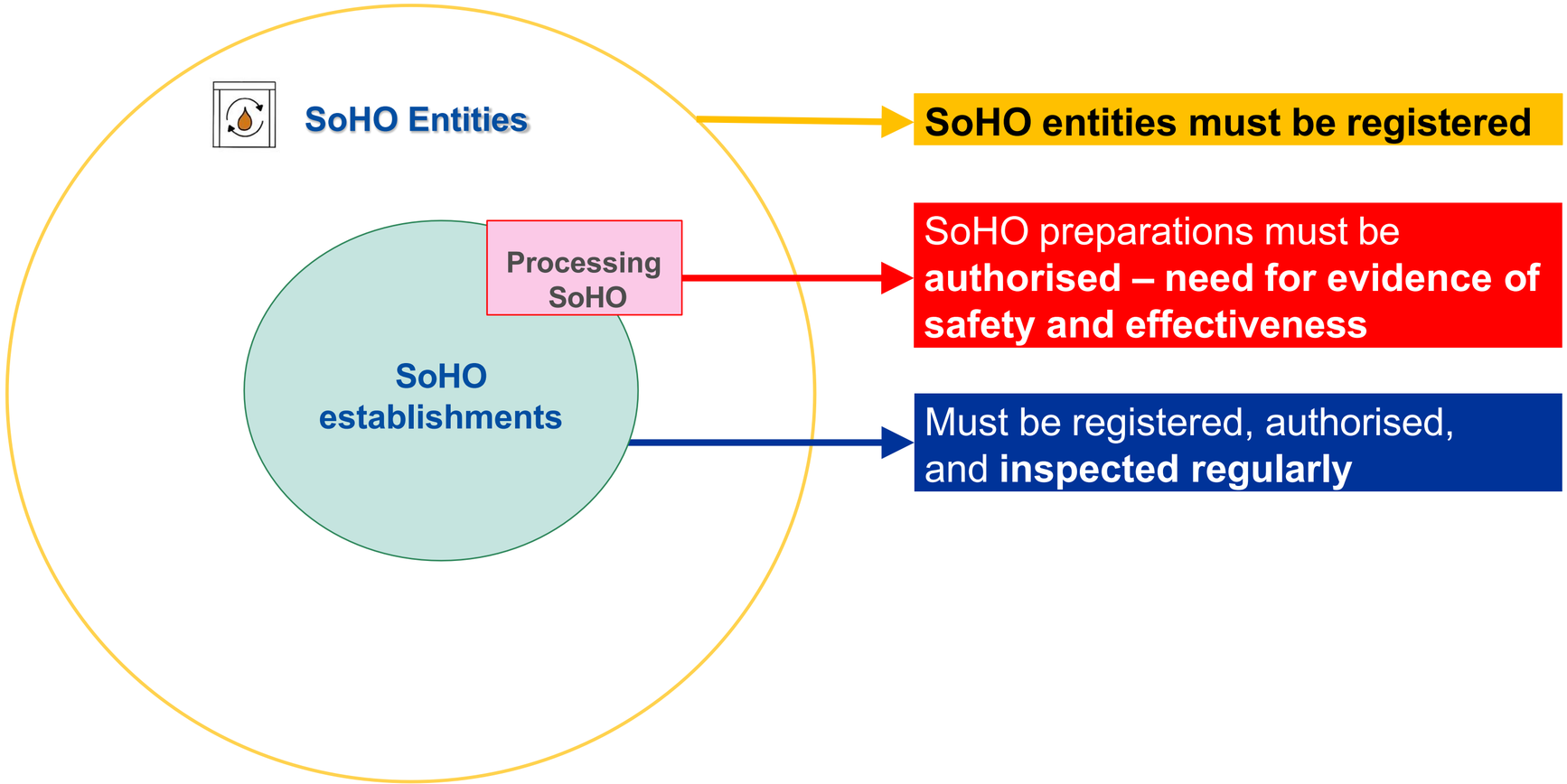
Any actor organising one or more SoHO activity/ies needs to

register as SoHO entity with the Competent Authority

General Obligations of SoHO Entities

- Registration
- Responsible person
- Quality Management System
- Activity data Collection
- SoHO Preparation + Authorisation
- SoHO Clinical Studies
- Traceability and coding
- Vigilance and Reporting

SoHO Preparations NEW



SoHO Preparations

Present

Authorisation of SoHO **Activities**, as part of authorisation of blood/tissue establishments (information on SPs is not (generally) available)

2026

Migration of information related to existing **preparations** (SPs) (SoHO Entities → CAs → Platform) (GAPP Pro Survey?)

Information related to novelty and risk and additional information (when applicable, based on EDQM Monographs and Risk Assessment)

August 2027

Authorisation of SoHO **Activities** and **Preparations**:

- PPD Template and associated procedures (GAPP + GAPP Pro), validated by SCB
- New SoHO Preparations (SP) will require SPA and data registration in the SoHO Platform
- Information to be shared among CAs (when applicable and as appropriate)

- best practices documented and published by the SCB (Art 69(1) and 19(4)

SoHO Preparations Authorisation

NEW

Taking into account any relevant EDQM monograph

1 Systematic Benefit:Risk Assessment to determine the evidence available on safety, quality and effectiveness

2 Submission of an application, including laboratory validation and other safety, quality and effectiveness data and, where relevant, a clinical outcome monitoring plan proportionate to risk

3 Assessment of the application by the competent authority

- Grant authorisation for the SoHO preparation
- **OR**
- Grant an approval of the Clinical Outcome Monitoring plan or request an amended plan
- **OR**
- Refuse authorisation

4 Assessment by the competent authority of evidence of safety, quality and effectiveness data gathered in clinical outcome monitoring

- Grant authorisation
- **OR**
- Refuse authorisation

Based on preparatory work done by GAPP Joint Action
(incl. stakeholders from 17 countries: 15 CAs & professional associations)

SoHO Preparations NEW

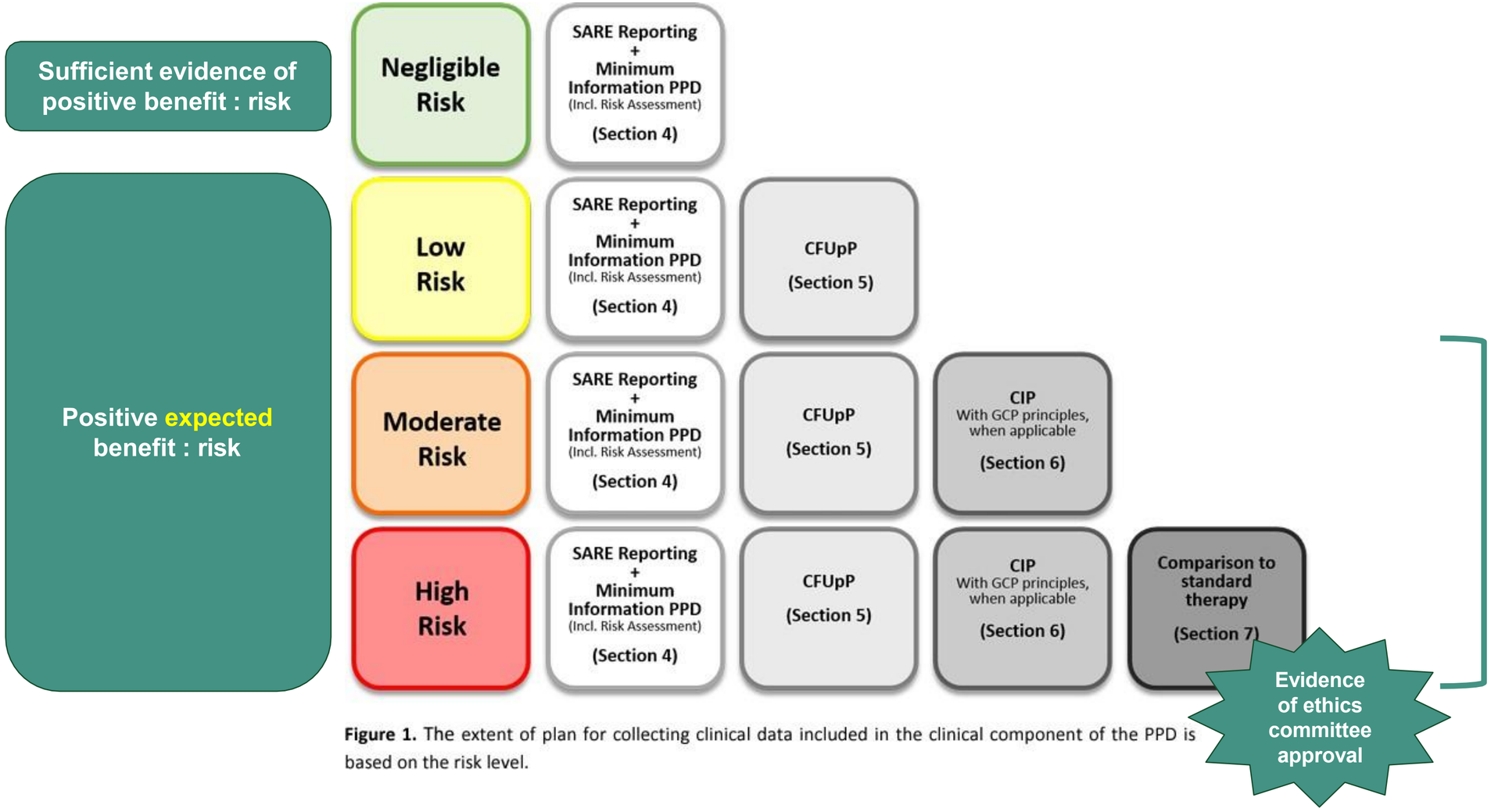


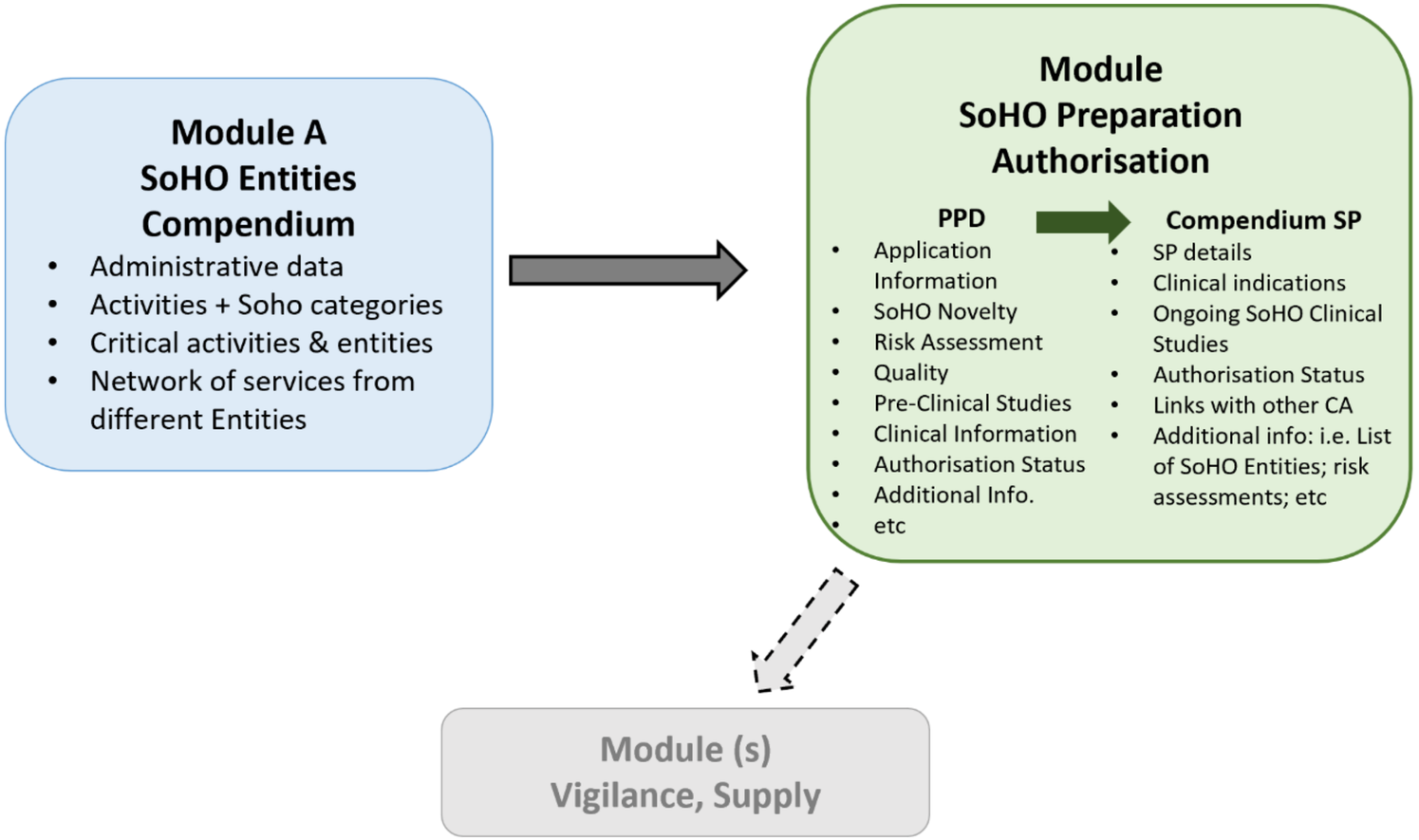
Figure 1. The extent of plan for collecting clinical data included in the clinical component of the PPD is based on the risk level.

Ref: GAPP JA - Technical Annex 3 to overall guidance: assessing clinical data as part of Preparation Process Authorisation (PPA)

SoHO Platform 

SoHO Platform

SoHO Platform

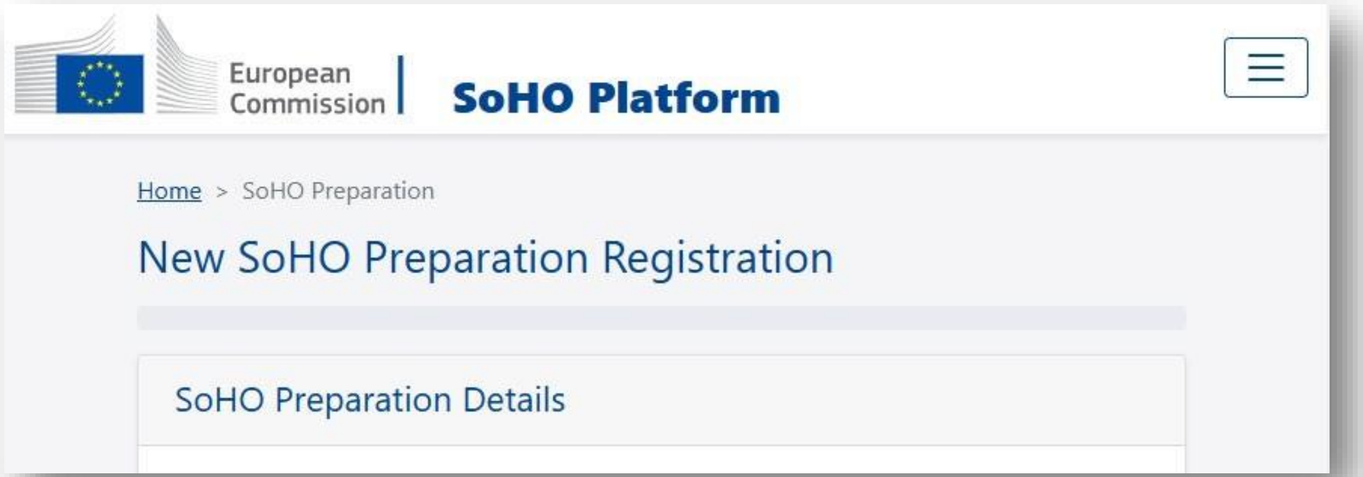


SPA Module – SoHO Platform

Dataset

Monographs

Structure and methodology

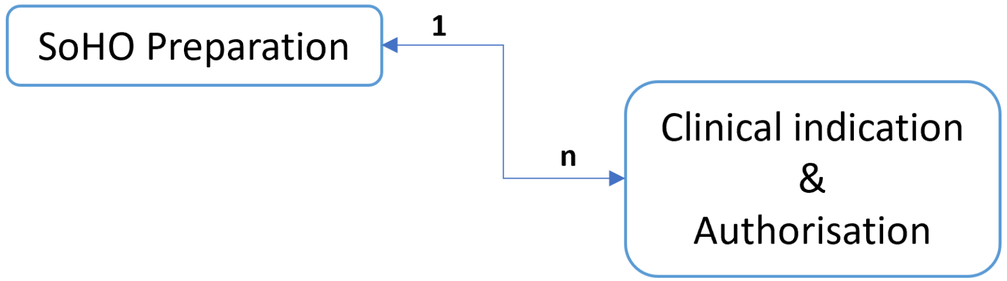


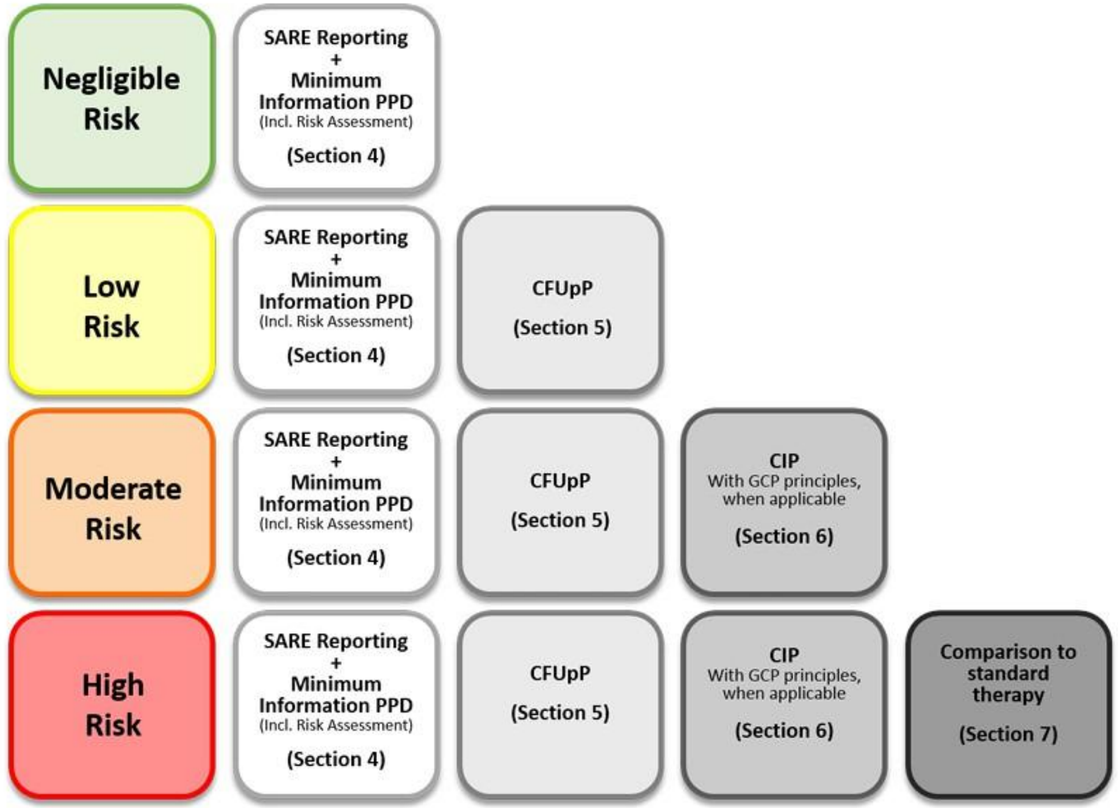
SPA Module – Key considerations

- **Compendium of information:**
  - (with different levels of access: Applicant and CA > Cooperating CA > Public (other entities))
  - (Future) PPD functionalities
  - Information related to the extent of evidence (clinical and non clinical) – Use of Registries!

- Based on data introduced by the applicant (SoHO – E) and validated by the CA

SPA Module – SoHO Platform





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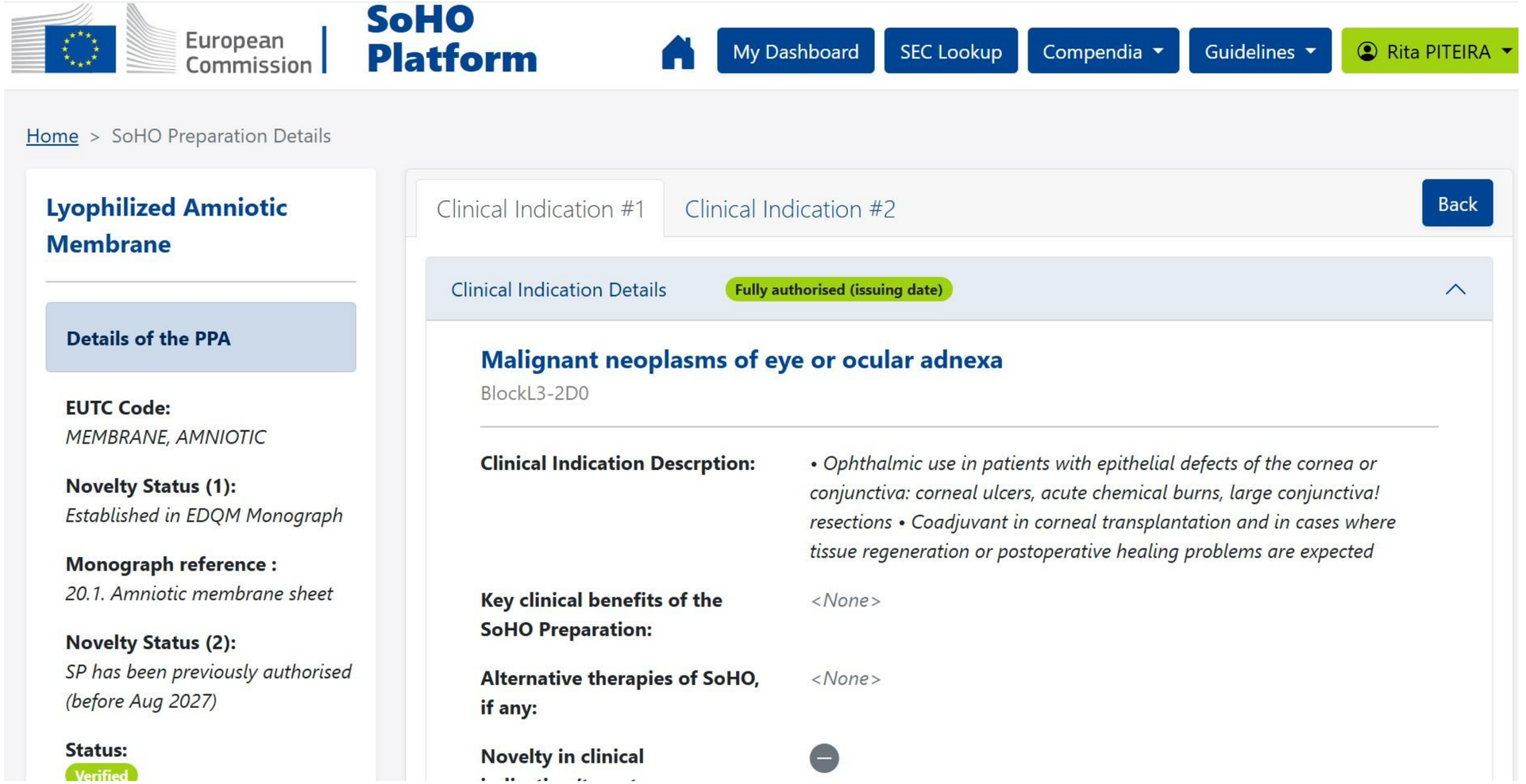
SPA Module – SoHO Platform



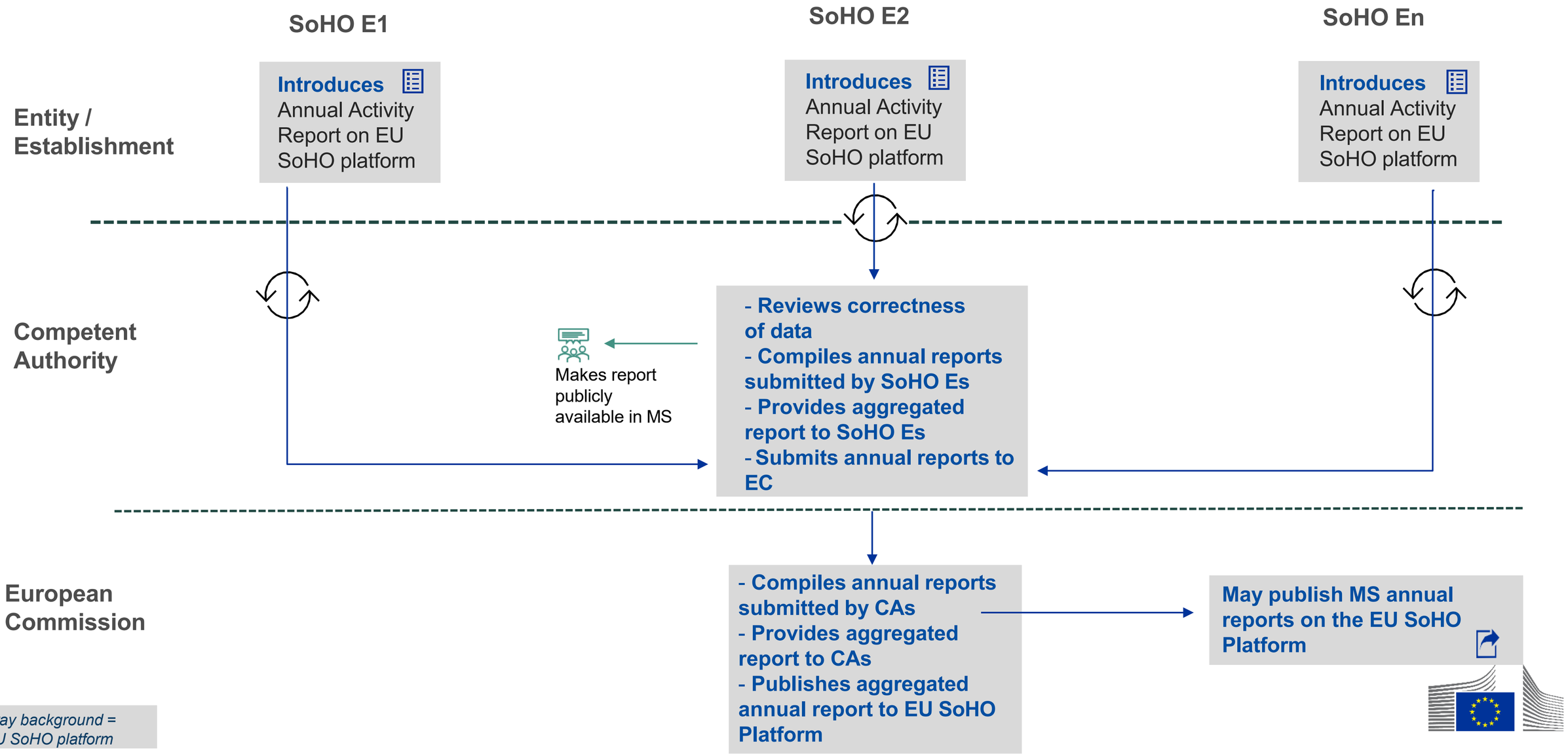
SoHO Platform

Article 41

- SoHO entities shall collect and report data relating to any of the following SoHO activities
  - (a) SoHO donor registration
  - (b) collection
  - (c) distribution
  - (d) import
  - (e) export
  - (f) human application

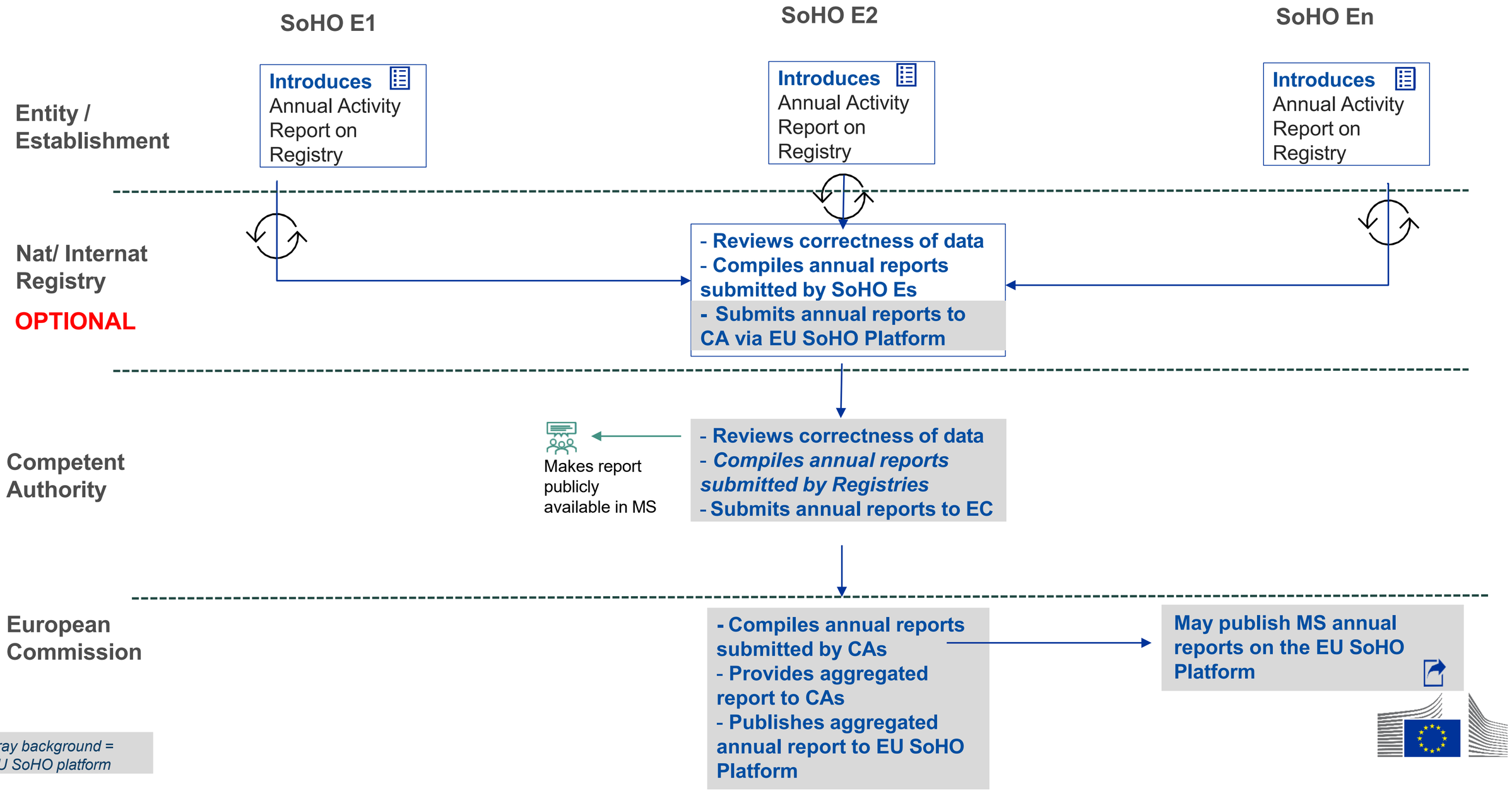
- Considerations:
  - EU-wide, all X,000 SoHO entities, per SoHO
  - annual exercise, possible use of registries, recycle existing data exercises

Digital flow entity/establishment (SoHO E) data submission



Gray background = EU SoHO platform

Digital flow entity/establishment (SoHO E) data submission



Gray background = EU SoHO platform

Thank You

rita.PITEIRA@ec.europa.eu

Thank you!

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European Society of Human Reproduction and Embryology

Session 4:
Final Remarks

EuMAR
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European Medically Assisted Reproduction registry Final Dissemination Conference

Final remarks

Carlos Calhaz-Jorge

EuMAR by ESHRE

Co-funded by the European Union.
Project: 101079865 — EuMAR — EU4H-2021-PJ2

Final remarks

EuMAR

a pan-European cycle-by-cycle MAR registry

- Will rely on the participation of CA, professionals and patients
- Will empower patients
- Will be a crucial contribution for improving clinical care

EuMAR by ESHRE

EuMAR policy recommendations

Improve equitable access to fertility care	Collect MAR Equality data	Ensure national mandatory reporting from all clinics	For MS
Provide dedicated funding for EuMAR reporting	Develop a legal framework for a gamete donor registry	Make cycle-by-cycle MAR registries mandatory	For EU
	Raise patients' awareness on MAR data		For EU & MS

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