The ICMART Tool Box for ART Data Collection

Version 1.

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Note that these documents will be updated on a regular basis to reflect any changes in ART monitoring procedures.

Check the online version at http://www.icmartivf.org/ for any amendments.

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Welcome Letter from the Chair of ICMART

Dear current and future contributors to national and international ART data collection efforts!

Access to infertility treatments and an appropriate balance among effectiveness, safety and quality of ART treatments are dynamic entities that need to be monitored. One of the goals when monitoring ART treatments is to facilitate comparisons over time and to examine the impact of national and regional regulations on the outcome of these treatments. Building confidence in the global state of ART is needed by consumers and required for optimal development at all levels and for all stakeholders.

ICMART continues to develop a system for the collection of relevant information from patients to clinics, to national registers, to regional registers and finally to the ICMART global ART register. In doing so, standardisation of definitions and data collection strategies is necessary. The data collected are a reflection of scientific and technologic developments and also a reflection of the interests of patients and other stakeholders.

To meet strategic objectives, ICMART is now offering *The ICMART Toolbox for ART Data Collection* containing a number of aids / instruments / tools to assist professionals involved in ART data collection efforts all around the world. The Toolbox is freely available through this ICMART website and will be revised periodically.

We trust that The ICMART Toolbox for ART Data Collection is a useful addendum to global ART monitoring.

On behalf of ICMART,

David Adamson, MD
ICMART Chair

Introduction

What is ICMART?

The International Committee for Monitoring Assisted Reproductive Technologies (ICMART) is an independent international nonprofit organization that has taken a leading role in the development, collection, and dissemination of worldwide data on assisted reproductive technologies (ART). ICMART provides information on availability, effectiveness, and safety to health professionals, health authorities, infertile people and to the public.

Since 2009, ICMART has been recognized as a Non- Governmental Organization (NGO) in official relations/affiliated with the World Health Organization (WHO). NGOs have more recently been included in the term Non-State Actors (NSAs). In collaboration with WHO, the ICMART/WHO glossary of ART terminology was developed to facilitate the collection and dissemination of ART data through a set of standardized definitions. These definitions are also used in the most recent ICMART World Report on ART. The ICMART/WHO glossary provides a conceptual framework for international terminology as well as ART data development.

Vision

ICMART's vision is to be the professional organisation that provides comprehensive data on all ART cycles performed in the world, and to assist ART stakeholders in the establishment of registries to optimise access, availability, safety, effectiveness, and quality of ART services.

Mission Statement

ICMART's mission is to contribute to the formation of national and regional ART registries in order to collect, analyse and disseminate validated international data and to assess worldwide trends in ART performance. Additionally, ICMART leads research and promotes international development of standardised definitions on infertility and fertility care.

Development of data collection strategies

ART is increasingly available to infertile individuals worldwide. Correspondingly, the sophisticated treatment regimens associated with assisted reproduction are being applied to an expanding population of infertile individuals.

However, questions have been raised on the effectiveness, safety, availability, and costs of ART procedures, as well as on the many ethical and legal aspects of their use. Initial reports of ART procedures and outcomes from individual clinical centers were based on relatively small numbers of patients, making the extrapolation from such small numbers of highly selected patients to the general population problematic.

Therefore, during the last decade, a 4-level system of ART cycle data collection has been devised by ICMART where clinics report either to National registers which then report to Regional registers, or directly to Regional registers, and then finally to the ICMART global register. While the system is still being established worldwide, Regional registers have already been set up in North America, Latin America, Australia-New Zealand, Europe and the Middle East.

It is important to acknowledge that data collection systems, comprehensiveness and data quality vary among countries and regions reported by ICMART. Additionally, patients, healthcare systems, cultural, socioeconomic and other factors vary greatly among countries and regions. Therefore, these data must be interpreted cautiously when assessing similarities and differences among countries and regions.

Data Collection Rationale

The collection of data on the outcomes of ART can assist:

1. **Patients** seeking medical assistance for their infertility by allowing them to make informed and appropriate decisions concerning their own treatment options.

2. The **Medical Profession** and **Laboratory Professionals** in providing optimal patient care by advancing the research and development of more effective forms of treatment while documenting the effectiveness and safety of currently available techniques.

3. **Public Health Authorities** responsible for assuring public safety, developing health care delivery policies, and ensuring cost reimbursement.

4. The **Public** in understanding better the assisted reproductive technologies and their role and value in helping people with infertility and other medical problems.

What is the purpose of The ICMART Tool Box for Data Collection?

The ICMART Tool Box for ART Data Collection is a package to facilitate the monitoring and data collection of ART cycles and outcomes. It is meant as an introductory package for countries and/or regions that use ART but have not yet established monitoring of the treatments and/or of the maternal and perinatal outcomes. The package may also serve as a reference for countries and/or regions that already monitor ART to ensure that they are applying standardized methodology and definitions to their data collection. Finally, it can also be used by fertility clinics to gather the minimal information necessary to evaluate their ART activity.

Instructions for completing The ICMART Tool Box for Data Collection forms at National and Regional levels

ICMART annually monitors ART cycles performed internationally through the collection of data on standardized forms provided by National and/or Regional registers. The data requested on these forms concerns all of the reported ART cycles that National and/or Regional registers received from fertility clinics annually and provides an overview of outcomes at the National and/or Regional levels. Below is an outline of important instructions to be followed when completing the forms to ensure that data are captured as accurately as possible. Please use the ICMART/WHO glossary of ART terminology (Zegers-Hochschild et al., 2009) at the end of this package to ensure consistent use of definitions between countries and regions.

General considerations

- The forms reflect ART cycle activity for a single year and include:
    - The cycles with aspirations performed (including aspirations without oocytes retrieved)
    - The cancelled cycles for which an aspiration was intended to be performed for the year being reported
    - Frozen embryo transfers performed or intended to be performed for the year being reported
    - All pregnancies that resulted from ART cycles performed for year being reported.
- Complete the forms by filling in each form carefully, leaving as few questions unanswered as possible. However, if data are not available for some sections of the forms these sections should be left blank.
- Carefully read the specific instructions at the bottom of the forms before filling in the forms.
- Use the definitions in The ICMART/WHO Glossary of ART Terminology which is included at the end of this package.
- If your register does not use the same or very similar definitions as those in the ICMART/WHO register and in these tables, complete the table with the definition used in your country, and indicate the definition you use in your country register in a footnote.
- If a table does not fit with your register data, complete it with your available data and indicate any differences in a footnote.

Specific instructions for completing the forms

Form 1: Organization of national ART registers

- Put numbers in the boxes as required.
- Place a check mark in the box for Yes/No questions.
- The number of cycles is the sum of all the cycles initiated with the intention of performing an oocyte recovery, including Preimplantation Genetic Diagnosis (PGD)/Preimplantation Genetic Screening (PGS) cycles, oocyte donation (OD) cycles and gamete intrafallopian transfer (GIFT) cycles, plus all the cycles initiated with the intention of performing an FET.

Forms 2 to 6:

- Exclude PGD / PGS (reported on Form 7) and oocyte donation (reported on Form 8).

Form 2: Number of treatments and pregnancies

- This is the only table where GIFT cycles will be reported because the frequency of GIFT is very low and declining.
- FET cycles are reported regardless of the fertilization technique (IVF or ICSI), but excluding PGD and OD.
- Assisted hatching (AH) and in vitro maturation (IVM) should be included in the column of the relevant fertilization technique (IVF **or** ICSI).
- For cycles in which both conventional IVF and ICSI were used, report cycles in the column of the technique that resulted in the transferred embryos. If both types of embryos were transferred, count as ICSI. This applies to all the forms when both IVF and ICSI were performed in a single cycle. If both fresh and frozen embryos are transferred in a single cycle, report as a fresh embryo transfer cycle.
- In countries in which surrogacy is performed, report surrogacy cycles the same as non-surrogacy cycles according to the fertilization technique (IVF **or** ICSI) that was used, without specifying that it was a surrogacy cycle on all the forms except Form 9. Specific questions and data regarding surrogacy are reported at the bottom of Form 9.
- Report oocyte freezing if performed.
- If possible, report summarized information on cross boarder cycles performed in your country. This information should also be reported in the general procedure with all the other cycles.

Form 3: Results by women's age and ART technique

- For Forms 3a and 3b

- Deliveries: if the health status at birth is not available, put the number of deliveries and indicate the definition used in a footnote.

- Form 3b only
  - If the origin of frozen embryos is not available in your register, fill in the information on the 3 columns 'After both IVF and ICSI'.

Form 4: Results by number of transferred embryos

- The number of elective transfers of 1 and 2 embryos is very useful for the report but, if you do not have this data, fill in the column labelled 'All'.
- A transfer of 1 embryo is elective when more than 1 viable embryo was obtained, regardless of its quality.
- A transfer of 2 embryos is elective when more than 2 were obtained, regardless of their quality.

Form 5: Gestational age by treatment and multiple deliveries

- Gestational age calculations: completed weeks of gestation, by adding 14 days (2 weeks) to the number of completed weeks since the fertilization.
  - Fresh cycles: calculate the number of days between oocyte collection and delivery, add 14 days, divide the sum by 7 and use the integer.
  - FET cycles: calculate the number of days between transfer and delivery dates, add the embryo age at transfer (sum of the embryo age at freezing and the number of culture days at thawing, generally 2 to 6 days), add 14 days, divide the sum by 7 and use the integer.

Form 6: Neonates outcome in relation to treatment

- Use the ICMART/WHO glossary as carefully as possible and indicate all the deviations, if any, from these definitions.

Form 7: Preimplantation Genetic Diagnosis (PGD) and Preimplantation Genetic Screening (PGS)

- Use the ICMART/WHO glossary as carefully as possible and indicate all the deviations, if any, from these definitions.

Form 8: Oocyte donation

- Part A concerns the ***donor***. Parts B and C concern the ***recipient***.

Form 9: Complications of treatment

- If a woman had two occurrences of the same complication in 2 different cycles, count her twice. If two of the same complications occur during the same cycle, count her once.

- If a woman had two different complications, count her in both of them.

Form 10: List of congenital anomalies (malformations and genetic abnormalities)

- This form includes information on all the fetuses / newborns with anomalies.
- Anomalies consist of malformations and genetic abnormalities.
- All the congenital anomalies must be reported for all spontaneous abortions, medical abortions, stillbirths, and live births.

Form 11: Intrauterine insemination (IUI)

- Complete this form if information is available on this technique.

World Report on ART, National Form, Reporting Year

_____

Form 1. Organization of National ART Registers

Country name		
Contact person:	Full name	
	Institution	
	Address	
	Tel. Fax	
	Email	
Number of ART clinics in the country:	Total	☐☐☐
	Total included in this report	☐☐☐
Size of all country ART clinics.	Number of clinics with, per year:	
	< 100 cycles	☐☐
	100 – 199 cycles	☐☐
	200 – 499 cycles	☐☐
	500 – 999 cycles	☐☐
	≥ 1000 cycles	☐☐
Estimation of the total number of cycles for reporting year (this includes cycles that have been both included and not included in this report). The number of cycles per year includes all the initiated ("intention to treat") cycles for the purpose of IVF/ ICSI (including PGD/PGS and OD) plus FET (See instructions.)		☐☐☐☐☐☐
Reporting requirement: 1. Compulsory; 2. Voluntary; 3. Other (please describe)		☐
Responsibility for the register: 1. National Health Authority; 2. Medical Organization; 3. Other (please describe)		☐
Reporting methods:		
Cycles: 1. Individual cycles; 2. Summaries of cycles reported by the clinics		☐
Deliveries: 1. Individual cycles; 2. Summaries of deliveries reported by the clinics		☐
Link to other registers		
Birth register:		☐ No ☐ Yes
Congenital anomalies register:		☐ No ☐ Yes
Cytogenetic register:		☐ No ☐ Yes
Pre-implantation Genetic Diagnosis (PGD) register:		☐ No ☐ Yes
Disease register:		☐ No ☐ Yes
Other register: Please describe:		☐ No ☐ Yes
Total numbers of deliveries for reporting year (if available)		
Total numbers of babies born in reporting year (if available)		

In the country ART register (or in linkable register), is information available on:

	In general,	By technique,	By multiplicity
- Prematurity	☐ No ☐ Yes	☐ No ☐ Yes	☐ No ☐ Yes
- Perinatal mortality	☐ No ☐ Yes	No Yes	No Yes
- Malformation	No Yes	No Yes	No Yes

If Yes, could these data be sent to the ICMART register? No Yes

If Yes, ICMART will contact you at a later date.

Comments

Form 2. Number of Treatments and Pregnancies

2a. General procedures

	Fresh cycles*			FET**	Thawed oocytes***
	IVF	ICSI	GIFT	All	Thawings
Initiated cycles					*Thawings*
Aspirations				*Thawings*	
Embryos frozen without transfers				----	----
Transfers					
Pregnancies					
Deliveries: Total					
With live birth					

Include*: *GIFT cycles and cycles for foreign patients.* ***Exclude*: *PGD, PGS, OD and cycles with oocyte freezing. (PGD and PGS results will be reported in Forms 7a and 7b. OD results will be reported in Form 8.)*

Information on FET cycles regardless of the fertilization technique (IVF or ICSI), but* ***exclude *PGD, PGS and OD. Record the numbers of cycles where frozen embryos were thawed for use in the box for Aspirations.*

***Cycles specifically performed with thawed oocytes.

Additional information:

- ***Assisted hatching and in vitro maturation*** *have to be included in the column of the relevant fertilization technique (IVF or ICSI).*
- *Where both conventional (standard) IVF and ICSI were used, report the technique that resulted in the transferred embryos. If both types of embryos were transferred, count as ICSI.* ***This will apply to all the forms when both IVF and ICSI are performed in a single cycle****. If both fresh and frozen embryos are transferred in a single cycle, report as a fresh embryo transfer cycle.*
- *In countries where surrogacy is performed, report surrogacy cycles with the fertilization technique (IVF or ICSI) that was used, without specifying it on all the forms. There are specific questions regarding surrogacy at the bottom of Form 9.*

2b. Report on oocyte freezing*

Total number of cycles	Freezing during an ART cycle	Cycles performed for fertility preservation only	
		Medical reason**	Social reason

** Only report the numbers of cycles with freezing*

*** Cancer or other major medical disease*

IVM	Aspirations	Transfers	Pregnancies	Deliveries

See instructions specific to this form and use definitions in The ICMART/WHO Glossary.

2c. Cycles performed for cross-border patients*

a. Summary of cycles

	Woman's own oocytes				Oocyte Donation	
	IVF	ICSI	GIFT	PGD	Anonymous	Known donor
Initiated cycles						

b. Countries of patients' origin and main reasons for cross-border travel for treatment

Main Countries of origin**		
	Country	Cycles
1.		
2.		
3.		
4.		
5.		
6.	Others (total number)	

Reason		Cycles
Legal	Illegal technique in home country	
	Illegal patients characteristics***	
Access	Care more expensive in home country	
	Distance, waiting list	
Quality	Previous failures	
Other		

* Patients who live in a different country from the one in which they had their ART treatment.
** *Indicate the 5 main countries of patients' origin and give the number of cycles for each of them. Give the total number of cycles for all others.*
*** *For example age limitation, legal couple status, sexual orientation, etc.*

See instructions specific to this form and use definitions in The ICMART/WHO Glossary.

Form 3. Results by Women's Age and ART Technique

3(a). Fresh cycles

	After IVF			After ICSI			After both IVF and ICSI		
Women's age	Aspirations	Pregnancies	Deliveries*	Aspirations	Pregnancies	Deliveries*	Aspirations	Pregnancies	Deliveries*
≤ 34									
35-39									
≥ 40									

Note: This table excludes PGD, PGS and OD, which will be reported in Forms 7a, 7b and 8, respectively.

3(b). Frozen embryo transfers

	After IVF			After ICSI			After both IVF and ICSI		
Women's age	Thaws	Pregnancies	Deliveries*	Thaws	Pregnancies	Deliveries*	Thaws	Pregnancies	Deliveries*
≤ 34									
35-39									
≥ 40									

Note: This table excludes PGD, PGS and OD, which will be reported in Forms 7a, 7b and 8, respectively.

***Initiated cycle**: An ART cycle in which the woman receives specific medication for ovarian stimulation, or monitoring in the case of natural cycles, with the intention to treat, irrespective of whether or not follicular aspiration is attempted*

***Aspirations**: Include attempted aspirations in which no eggs were recovered.*

***Pregnancy**: Evidence of pregnancy by clinical or ultrasound parameters (visualization of a gestational sac). It includes ectopic pregnancy. Multiple gestational sacs in one patient are counted as one clinical pregnancy.*

***Delivery**: The expulsion or extraction of one or more fetuses from the mother after 20 completed weeks of gestational age*

See instructions specific to this form and use ICMART/WHO definitions in glossary.

Form 4. Results by Number of Transferred Embryos

4(a). All IVF and/or ICSI fresh cycles

	Number of transferred embryos							
	1		2		3	4	≥ 5	Total
	All	Elective*	All	Elective*				
Transfer cycles								
Clinical pregnancies								
Pregnancy losses**								
Deliveries: Total								
Singleton								
Twin								
Triplet +								
Lost to Follow-up								

Note: This table excludes PGD, PGS and OD, which will be reported in Forms 7a, 7b and 8, respectively.
** If possible, indicate the number of elective single and elective double embryo transfers.*
*** Abortions (spontaneous miscarriages and induced elective pregnancy terminations) and ectopic pregnancies.*

4(b). All FET cycles (resulting from IVF and/or ICSI)

	Number of transferred embryos							
	1		2		3	4	≥ 5	Total
	All	Elective*	All	Elective*				
Transfer cycles								
Clinical pregnancies								
Pregnancy losses**								
Deliveries: Total								
Singleton								
Twin								
Triplet +								
Lost to Follow-up								

Note: This table excludes PGD, PGS and OD, which will be reported in Forms 7a, 7b and 8, respectively.
** If possible, indicate the number of elective single and elective double embryo transfers.*
*** Abortions (spontaneous miscarriages and induced elective pregnancy terminations) and ectopic pregnancies*

See instructions specific to this form and use definitions in The ICMART/WHO Glossary.

Form 5. Gestational Age by Treatment and Multiple Deliveries

5(a). Fresh cycles (total aspiration cycles following IVF and/or ICSI)

	Gestational age (calculated completed weeks of amenorrhea)						
Deliveries*	**All**	**20-27**	**28-32**	**33-36**	**37-41**	**42 +**	**Unknown**
Singleton							
Twin							
Triplet							
Quadruplet or higher							
Unknown							
Total							

Note: This table excludes PGD, PGS and OD, which will be reported in Forms 7a, 7b and 8, respectively.
**Deliveries: the expulsion or extraction of one or more fetuses from the mother after 20 completed weeks of gestational age*

5(b). FET cycles (total transfer cycles using only frozen embryos following IVF and/or ICSI)

	Gestational age (calculated completed weeks of amenorrhea)						
Deliveries*	**All**	**20-27**	**28-32**	**33-36**	**37-41**	**42 +**	**Unknown**
Singleton							
Twin							
Triplet							
Quadruplet or higher							
Unknown							
Total							

Note: This table excludes PGD, PGS and OD, which will be reported in Forms 7a, 7b and 8, respectively.
**Deliveries: the expulsion or extraction of one or more fetuses from the mother after 20 completed weeks of gestational age*

Gestational age calculation:

- ***Fresh cycles:*** *calculate the number of days between oocyte collection and delivery, add 14 days, divide the sum by 7 and use the integer.*
- ***FET cycles:*** *calculate the number of days between transfer and delivery date, add the embryo age at transfer (generally 2 to 6 days), add 14 days, divide the sum by 7 and use the integer.*

See instructions specific to this form and use definitions in The ICMART/WHO Glossary.

Form 6. Neonates Outcome in Relation to Treatment

6(a). Fresh cycles (total aspiration cycles following IVF and/or ICSI)

Number of babies	Health Status in the Perinatal Period Number of neonates				
	Total	Stillbirths	Live Births	Early Neonatal deaths*	Unknown
Singleton					
Twin					
Triplet					
Quadruplet or higher					
Unknown					
Total					

Notes: This table excludes PGD, PGS and OD, which will be reported in Forms 7a, 7b and 8, respectively.

Forms 6a and 6b report number of neonates (2 for twins, 3 for triplets, etc.).

**Early neonatal death: Death of a live born baby within 7 days of birth.*

6(b). FET cycles (total transfer cycles using only frozen embryos following IVF and/or ICSI)

Number of babies	Health Status in the Perinatal Period Number of neonates				
	Total	Stillbirths	Live Births	Early Neonatal deaths*	Unknown
Singleton					
Twin					
Triplet					
Quadruplet or higher					
Unknown					
Total					

Notes: This table excludes PGD, PGS and OD, which will be reported in Forms 7a, 7b and 8, respectively.

Forms 6a and 6b report number of neonates (2 for twins, 3 for triplets,. etc.).

- *Stillbirths : ≥ 20 weeks*
- *Live births : ≥ 20 weeks*
- *Early neonatal death: Death of a live born baby within 7 days of birth.*

See instructions specific to this form and use ICMART/WHO definitions in glossary.

Form 7a. Pre-implantation Genetic Diagnosis

	Women's age				
	≤ 34	35 – 39	≥ 40	Unknown	Total
Initiated cycles					
Aspirations					
Transfers					
Embryos examined					
Embryos normal					
Embryos transferred					
Pregnancies, clinical					
Deliveries : Total					
Singleton					
Twin					
Triplet or higher					
Unknown					
Babies born : Total					
Stillbirths					
Live births					
Early neonatal deaths					
Unknown					

Note: Regardless of fertilization technique.

- *Live births : ≥ 20 weeks*
- *Stillbirths : ≥ 20 weeks*
- *Early neonatal death: Death of a live born baby within 7 days of birth.*
- *Preimplantation Genetic Diagnosis (PGD): analysis of polar bodies, blastomeres, or trophectoderm from oocytes, zygotes, or embryos for the detection of specific genetic, structural, and/or chromosomal alterations.*

See instructions specific to this form and use definitions in The ICMART/WHO Glossary.

Form 7b. Pre-implantation Genetic Screening

	Women's age				
	≤ 34	35 – 39	≥ 40	Unknown	Total
Initiated cycles					
Aspirations					
Transfers					
Embryos examined					
Embryos normal					
Embryos transferred					
Pregnancies, clinical					
Deliveries : Total					
Singleton					
Twin					
Triplet or higher					
Unknown					
Babies born : Total					
Stillbirths					
Live births					
Early neonatal deaths					
Unknown					

Note: Regardless of fertilization technique.

- *Live births : ≥ 20 weeks*
- *Stillbirths : ≥ 20 weeks*
- *Early neonatal death: Death of a live born baby within 7 days of birth.*
- *Preimplantation Genetic Screening (PGS): analysis of polar bodies, blastomeres, or trophectoderm from oocytes, zygotes, or embryos for the detection of aneuploidy, mutation, and/or DNA rearrangement*

See instructions specific to this form and use definitions in The ICMART/WHO Glossary.

Form 8. Oocyte Donation

8(a). Aspiration cycles (donor)

	Women's age (donor)				
	≤ 34	35 – 39	≥ 40	Unknown	Total
Initiated cycles					
Aspirations : Total					
Specific donors					
Egg sharing					

8(b). Oocyte donation transfer cycles in recipients (fresh cycles)

	Women's age (recipient)					
	≤ 34	35 – 39	40 – 44	≥ 45	Unknown	Total
Transfers, total						
1 Embryo						
2 Embryos						
3 Embryos						
4 Embryos						
≥ 5 Embryos						
Pregnancies, clinical						
Deliveries: Total						
Singleton						
Twin						
Triplet						
Quadruplet or higher						
Unknown number						
Babies born : Total						
Stillbirths						
Live births						
Early neonatal deaths						
Unknown						

Note: Regardless of the fertilization technique.

- *Live births : ≥ 20 weeks*
- *Stillbirths : ≥ 20 weeks*
- *Early neonatal death: Death of a live born baby within 7 days of birth.*

See instructions specific to this form and use definitions in The ICMART/WHO Glossary.

8(c). Oocyte donation transfer cycles in recipients (FET cycles)

	Women's age (recipient)					
	≤ 34	35 – 39	40 – 44	≥ 45	Unknown	Total
ınsfers: Total						
1 Embryo						
2 Embryos						
3 Embryos						
4 Embryos						
≥ 5 Embryos						
ɡnancies, ıical						
ıiveries: Total						
Singleton						
Twin						
Triplet						
Quadruplet or higher						
ɒies born : Total						
Stillbirths						
Live births						
Early neonatal ıdeaths						
Unknown						

Regardless of the fertilization technique.

- *Live births : ≥ 20 weeks*
- *Stillbirths : ≥ 20 weeks*
- *Early neonatal death: Death of a live born baby within 7 days of birth.*

See instructions specific to this form and use definitions in The ICMART/WHO Glossary.

Form 9. Complications of Treatment

9(a). Women's complications with admission to hospital or medical intervention

	Number of cases*
Ovarian hyperstimulation syndrome (OHSS)	
Complications of oocyte retrieval: All	
Bleeding**	
Infection***	
Maternal death (documented)	

**If a woman had two occurrences of the same complication, in 2 different cycles, count her twice. If a woman had two different complications, count her in each of them.*
***Report bleeding if patient required a blood transfusion and/or was hospitalized.*
****Report infection if patient required intravenous/intramuscular antibiotics and/or was hospitalized.*

9(b). Congenital anomalies

Technique	Number of neonates / fetuses with congenital anomalies*				
	Total**	Delivered***	Fetal losses		
			Spontaneous	Induced	Total
IVF fresh cycles					
ICSI fresh cycles					
FET (IVF and/or ICSI)					
Oocyte donation					
PGD					
PGS					
GIFT					
TOTAL					

** Malformations and genetic abnormalities.*
*** Delivered neonates include stillbirths and those with unknown health status at birth*
**** Including stillbirths and those with unknown health status at birth.*

If possible, report individual information on each malformed neonate or fetus on Form 11.

Additional questions

1. Is in vitro maturation performed in your country: If yes, indicate the number of cycles.	No Yes
2. Is fetal reduction allowed in your country: If yes, indicate the number performed for ART pregnancies.	No Yes
3. Is maternal surrogacy allowed in your country: If yes, indicate the number of ART aspiration cycles for surrogacy. If yes, indicate the number of cycles with deliveries, with at least one live birth from surrogacy.	No Yes
4. Is sperm donation performed in your country? If yes, indicate the number of cycles.	No Yes
5. Is embryo donation performed in your country? If yes, indicate the number of cycles	No Yes

Form 10. List of Congenital Anomalies
(Malformations and Genetic Abnormalities)

Baby	Congenital anomalies (Describe all anomalies found in each baby)	Woman's Age*	ART		Gestational age at birth/abortion*** *	Status**** *
			Technique* *	Semen / sperm***		
1.						
2.						
3.						
4.						
5.						
6.						
7.						
8.						
9.						
10.						
11.						
12.						
13.						
14.						
15.						
16.						
17.						
18.						
19.						
20.						
21.						
22.						
23.						
24.						
25.						

**Woman's age at conception.*
***ART technique: IVF, ICSI, FET (IVF or ICSI), oocyte donation, GIFT.*
****ART semen/sperm: ejaculated (spouse / donor), TESE, MESA, fresh or frozen.*
*****Gestational age: completed weeks of amenorrhea (see the comment on form 5).*
******Status: Spontaneous abortion (miscarriage), Induced abortion/elective termination, Stillbirth, Live Birth, Early neonatal death.*

Copy and use additional pages as necessary.

See instructions specific to this form and use definitions in The ICMART/WHO Glossary.

Form 11. Intrauterine insemination (IUI)

IUI-H (Husband/partner sperm)

	Woman < 35 years	Women 35-39 years	Woman ≥ 40 years	*Total*
Number of IUI-H cycles				
Pregnancies*				
Deliveries: Total				
Singleton				
Twin				
Triplet +				

***** *Includes all IUI with or without ovarian stimulation.*

IUI-D (Donor sperm)

	Woman < 35 years	Women 35-39 years	Woman ≥ 40 years	*Total*
Number of IUI-D cycles				
Pregnancies*				
Deliveries: Total				
Singleton				
Twin				
Triplet +				

***** *Includes all IUI with or without ovarian stimulation.*

See instructions specific to these forms and use definitions in The ICMART/WHO Glossary.

Comments:

Setting up monitoring of ART at the fertility clinic level

The following two forms are used for monitoring ART treatments at the fertility clinic level.

The first form requests information on the patient, the type of ART treatment received, as well as the outcome of the pregnancy for both the infant and the mother. This form is to be filled out for each patient who utilizes ART treatment at any clinic within the country.

The second form requests patient information on infertility treatments which is restricted to intrauterine insemination (IUI) with or without ovarian stimulation (OS), which is performed in the European IVF-monitoring (EIM) report, and is to be completed only for patients who have this procedure as part of their medical assisted reproduction (MAR) treatment. There is no international agreement on what and how to report these MAR treatments. However, since IUI is now reported in a growing number of countries, ICMART has decided to create a register so that these data can be collected and reported where possible.

On an annual basis, these forms are forwarded to the designated country or regional level organization so that data may be compiled and sent to ICMART for tabulation in the annual ICMART World Report on ART.

Identification: Centre and Patient

Centre: name

Patient identification: (Last name, First Name or Unique Identifying Number)

Woman's date of birth (recipient's date of birth in case of egg donation): day, month, year

Country of residency:

If foreign country, reason for crossing-borders: 1. Illegal technique or procedure (e.g. egg donation); 2. Illegal patient conditions or characteristics (e.g. age); 3. Less expensive; 4. Closer distance; 5. Previous treatment failure; 6. Other

If other reason, specify: _____

ART type: 1. IVF; 2. ICSI; 3. GIFT; 4. FET; 5. Oocyte thawing; 6. PGD; 7. PGS; 8. Surrogacy

If Egg donation: Donor's age

Donation cycle: 1. Specific donor for one recipient; 2. Egg sharing ; 3. Unknown

CYCLE

Cycle starting date (thawing date for FET and thawed oocytes): day, month, year

Aspiration (for fresh cycles only, and including donation cycle): 0. No (cancellation); 1. Yes

If yes, aspiration date: day, month, year

Number of oocytes collected

Gametes' origin

Semen: 1. Male partner; 2. Anonymous donation; 3. Known donor

Oocyte: 1. Female partner; 2. Anonymous donation; 3. Known donor

Oocyte freezing

0. No; 1. Yes, during regular ART cycle; 2. Yes, cycle specifically for oocyte freezing

Oocyte freezing reason: 1 Medical; 2 Social

In vitro maturation: 0. No; 1. Yes

Embryos obtained:

Total number (transferred + frozen + non-viable embryos discarded)

Number frozen (including 2PN zygotes)

If PGD or PGS:

Number of embryos examined

Number of embryos genetically normal and viable

Number of embryos genetically normal but non-viable and discarded

Number of embryos genetically abnormal but viable and discarded

Number of embryos genetically abnormal and non-viable and discarded

Transfer: 0. No; 1. Yes

Number of transferred embryos

Cycle outcome: Pregnancy: 0. No; 1.Biochemical Pregnancy 2. Clinical Pregnancy (sac at ultrasound or ectopic).

Pregnancy Outcome: 1. Delivery; 2. Miscarriage 3. Ectopic pregnancy
4. Induced abortion); 5. Lost to follow-up
Embryo/fetus reduction 0. No; 1. Yes

Date of outcome, if known: day, month, year

Date of loss to follow-up if outcome date unknown: day, month, year

Number of delivered babies

Health status: 1. Live birth; 2. Stillbirth; 3. Early neonatal death; 4. Unknown

Congenital anomalies: 0 No; 1 Yes; 2. Unknown

Describe anomaly:_____

Pregnancy issue of the malformed fetus(es)/baby(ies):
1. Miscarriage (spontaneous abortion); 2. Induced abortion; 3. Stillbirth;
4. Live Birth; 5. Early neonatal death.

	Baby 1	Baby2	Baby 3	Baby 4
Health status				
Congenital anomalies				
Pregnancy issue				

Maternal complications

Ovarian hyperstimulation syndrome (with hospitalization) : 0. No; 1. Yes

Retrieval complication: 0. No; 1. Bleeding; 3. Infection; 4. Both 5. Other

Maternal death: 0. No; 1. Yes

IUI Individual Form

Identification: Centre and Patient
Centre: name

Patient identification: (Last Name, First Name or Unique Identifying Number)

Woman's date of birth: day, month, year ☐☐ ☐☐ ☐☐

Country of residency:

If foreign country, reason for crossing-borders: 1. Illegal technique or procedure (e.g. sperm donation illegal); 2. Illegal patient conditions or characteristics (e.g. age); ☐

3. Less expensive; 4. Closer distance; 5. Previous treatment failure; 6. Other

If other reason, specify: _____

CYCLE

IUI date: day, month, year ☐☐ ☐☐ ☐☐

Semen origin: 1. Spouse; 2. Anonymous donation 3. Known donor ☐

Cycle outcome: Clinical pregnancy: 0. No; 1. Biochemical pregnancy 2. Clinical pregnancy (sac at ultrasound or ectopic). ☐

Pregnancy outcome: 1. Delivery; 2.Miscarriage 3. Ectopic pregnancy
4. Induced abortion); 5. Lost to follow-up ☐

Embryo/fetus reduction 0. No 1. Yes ☐

Delivery date: day, month, year ☐☐ ☐☐ ☐☐

Number of babies delivered ☐

Starting a National Registry and Software Availability

Although the technology for registering ART procedures is available from many sources, the ability of different organizations/entities and institutions within a country to agree on a standard system of collecting national data has proved to be very difficult. This is especially so in developing countries where registration is not mandatory.

ICMART, through its participating institutions, has been pivotal in facilitating collaboration among already existing national and regional registries and those countries willing to start programs of their own. So far, South Africa has developed its own national registry with the collaboration of the Latin American ART registry (REDLARA), and both Egypt and India are in advanced phases of implementing their national registries in collaboration with and using the software developed by the Society for Assisted Reproductive Technology (SART), USA.

ICMART has the capacity to work together with local professional organizations and help them establish national registries. This includes facilitating collaboration among ART centers in order to reach common goals and developing simplified software or adapting already existing software to their specific needs.

The ICMART-WHO Glossary of ART Terminology:

Reprints from Fertility & Sterility and Human Reproduction

- Attached are two identical and simultaneous publications of the ICMART-WHO Glossary of ART Terminology

Zegers FZ, Adamson GD, Dyer S, Racowsky C, de Mouzon J, Sokol R, Rienzi L, Sunde A, Schmidt L, Cooke ID, Simpson JL, van der Poel S. The International Glossary on Infertility and Fertility Care, 2017: Led by ICMART in Partnership with ASRM, ESHRE, IFFS, March of Dimes, AFS, GIERAF, ASPIRE, MEFS, REDLARA, FIGO. *Hum Reprod* 2017;32(9):1786–1801. (contemporaneous publication with *Fertility and Sterility*)

Zegers FZ, Adamson GD, Dyer S, Racowsky C, de Mouzon J, Sokol R, Rienzi L, Sunde A, Schmidt L, Cooke ID, Simpson JL, van der Poel S. The International Glossary on Infertility and Fertility Care, 2017: Led by ICMART in Partnership with ASRM, ESHRE, IFFS, March of Dimes, AFS, GIERAF, ASPIRE, MEFS, REDLARA, FIGO. *Fertil Steril.* 2017 Sep;108(3):393-406. doi: 10.1016/j.fertnstert.2017.06.005. Epub 2017 Jul 29. (contemporaneous publication with *Human Reproduction*)