

The ICMART Tool Box for ART Data Collection



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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.



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 Tool Box 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 Tool Box is freely available through the ICMART website and will be revised periodically.

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

On behalf of ICMART

Karl Nygren M.D.

ICMART Chair



Introduction

What is ICMART?

The International Committee 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 technology (ART). ICMART provides information on availability, efficacy, 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). 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

The vision of ICMART is to be the professional organization that disseminates accurate and comprehensive ART data from all ART cycles performed in the world so that all individuals interested in ART can examine access to ART, effectiveness and safety of ART services around the world.

Mission Statement

The mission of ICMART is to collect, validate, analyze and disseminate comprehensive international data on ART that is useful to all ART stakeholders, to publish results of research on this data, and to promote the international development of data collection capabilities using standardized definitions and ART registries.



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.