

A web-based support system of the Belgian Register for Assisted Procreation

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KEYWORDS

Web-based System; E-Health; Database; Assisted Reproductive Technology

1. INTRODUCTION

“Assisted reproductive technology (ART)” is defined as all treatments or procedures that include the in vitro handling of both human oocytes and sperm or of embryos for the purpose of establishing a pregnancy. “In vitro fertilization (IVF)” is a quite complex ART procedure involving extracorporeal fertilization [1]. Sometimes, non-IVF techniques with lower technological involvement can be tried such as intrauterine insemination (IUI) or ovulation induction. Nevertheless, the ART process always entails a little more risk in comparison to spontaneous pregnancies for both mothers and children. Possible risks associated with the process of ART include multiple pregnancy or complications such as infection or bleeding [2].

In 1978, the world's first baby successfully conceived through IVF was born in Great Britain. Belgium was also one of the first countries to deal with medically assisted reproduction (MAR). The first Belgian baby resulting from an in vitro fecundation was born in 1983. From that moment on, the use of such techniques became more and more frequent. In 2012, 5787 and 1344 babies were born in Belgium thanks to IVF and non-IVF techniques, respectively [3].

Faced with the growing management of data and information collected from ART procedures, there was a need for a system to collect, control and regulate these treatment cycles in view of minimising the potential risks.

Since 1989, MAR data were recorded by BELRAP (Belgian Register for Assisted Procreation). In 1999, the Ministry of Public Health installed the national College of Physicians for Reproductive Medicine. It was given the mission to carry out quality control and registration of MAR activities in Belgium. The College was in charge of setting up a registration system able to provide reliable statistical information on activities and outcome but also to focus on new research questions and to perform quality control and assurance. Moreover, in July 2003, a new law enabled reimbursement of ART laboratory costs limiting the number of embryos that could be transferred. The goal was to reduce the multiple pregnancy rate by 50% [4]. Registration is mandatory for all IVF cycles since 1999 and since 2006 for all non-IVF cycles stimulated with gonadotropins.

From 2003 to June 2009, the ART centres were requested to send their data periodically to a contact point mandated by the College where they were stored into an Access database. However this procedure rapidly revealed its limitations, in particular major delays were pointed out in statistical reporting but also in error reporting and feedback to the centres. As a consequence, the lack of involvement of the centres in the process of data collection led to a shortage of real participation of the centres.

In this study, the development and functionalities of a new system that has replaced this procedure is described and discussed.

2. METHODS

2.1. Objective

The aim of the new system is to facilitate the use and control of the data. It has to be bi-lingual (Dutch and French), the ART centres need to be able to send in their data and receive feedback about the quality of the data and finally, it must allow the College to generate a list of reimbursable cycles.

2.2. Development

A web-based system (Figure 1) was developed and deployed (www.belrap.be) in which ART centres can directly upload (in case they have for example their own application to manage their data) or fill in their data on a cycle basis. They immediately receive a quality report indicating errors, inconsistencies and missing data. Each ART centre is also able to review the status of its data and to access global and individual statistical reports of the past years. The information is stored in a database (DB) allowing statisticians to extract data to produce yearly reports. Finally the system allows the College to generate the list of reimbursable cycles.

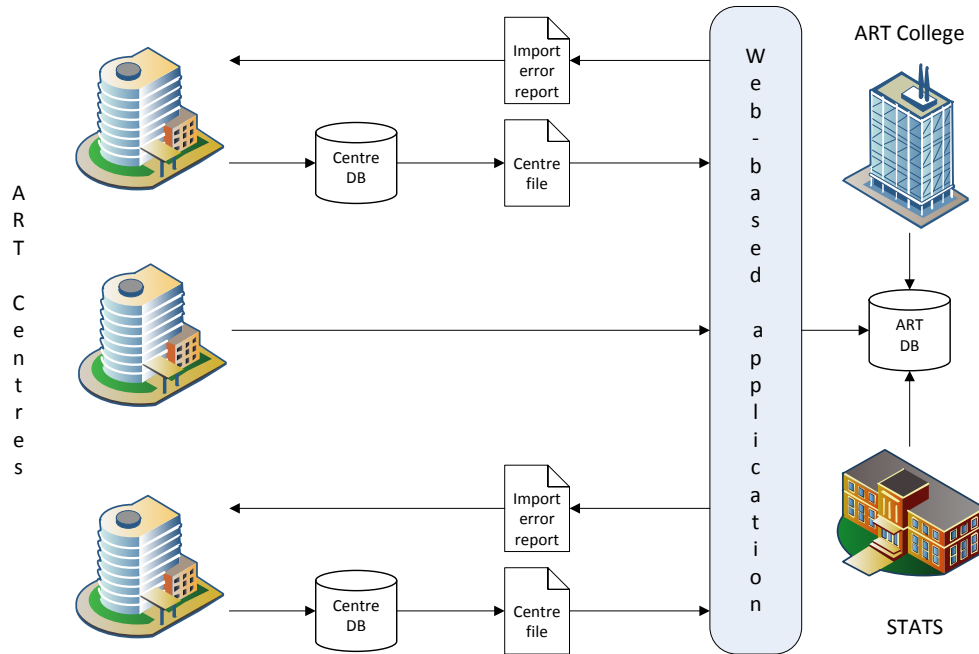


Figure 1: Application architecture

2.3. Access

Five different privilege level profiles are available. The System Administrator can access all the functionalities of the website. College Members can access reimbursement functionalities. The Statistician can upload the report. The Centre User can manage the cycles' data. In addition, the Centre Administrator can also manage the user profiles of the ART centre and access the centre specific statistical reports.

3. RESULTS

This web-based application, where web pages are created dynamically and interact with the database, offers several advantages: The application can be accessed from anywhere without requiring installation of the software; All data are centralized in one remote and secured database; Every update is immediately available to all users. The software uses the ASP.NET 3.0 (Active Server Page) technology from Microsoft and was developed with the Microsoft Visual Studio 2010 software. The application is built upon an SQL Server 2010 database. The site is hosted on a Web server running Windows Server 2003 R2 with Internet Information Server 6.0. It is hooked to the Internet by means of a T1 connection.

3.1. Security

A SSL (Secure Socket Layer) certificate was installed on the server for 128 bit encrypting of the transmitted data.

Each user needs a login to access the private part of the web application. The privilege level will determine which functionalities the user can access on the website (creation, modification, validation). When a user logs into the application, a "Session" is automatically opened. After 20 minutes without user activity, the session expires.

The web application and the database are stored on two hard drives in disk mirroring configuration. A backup server automatically saves a copy of the data once a day. Backup tapes are stored in a fire resistant cabinet. The servers are located in a secured room. Finally, an uninterruptible power supply can provide power to the servers in case of outage.

3.2. Data Types

Since 2008, the terminology used is based on the ART Glossary published by the International Committee for Monitoring Assisted Reproductive Technology (ICMART) [1]. An IVF cycle record contains 124 fields such as “Date of birth of the patient”, “Labo rank” or “Pregnancy outcome”. A non-IVF cycle record contains 46 fields such as “Intrauterine insemination”, “Ovarian stimulation” or “Date of delivery”.

3.3. System Description

The public part of the website is accessible by everyone. It contains information about the national College of Physicians in Reproductive Medicine and its activities. Note also that the annual Belgian reports can be consulted for free as well as the list of ART centres.

Only authenticated users can access the private part.

Before any new cycle is started, the ART centre needs to ask for a unique number, the so-called BELRAP identification number, to identify the cycle for the data transfer. First, the user has to choose whether the number will be used for an IVF or non-IVF cycle. Then, the user can enter an internal identification number, the date of birth of the woman, the date of last menstrual period or date of first stimulation, the Social Security Identification Number (SSIN) of the woman and her partner (if available) and finally another centre that could collaborate on this cycle, if necessary.

There are two ways to manage IVF and non-IVF cycles and baby's data: the centre can upload an Excel file with the data or the centre can also use the web pages developed to manage the data online. The data are divided into logical sections and each section corresponds to a web page. Each centre can export its cycles and baby's data to an Excel file.

3.4. Quality Control

The IVF and non-IVF data have to follow some codification rules. There are four kinds of rules and each one is associated with a specific colour: “Red” is dedicated to the Error rules which are generally related to the format of the data. “Orange” is dedicated to the Missing rules. “Blue” is dedicated to the Inconsistency rules between several fields. “Yellow” is dedicated to the Other rules. The data must comply with the Error, Inconsistency and Other rules while the Missing rules are only informative. Codification rules are revised annually.

When an IVF or non-IVF file is uploaded, the application automatically checks every record with the codification rules. An import report indicating the possible problems can be downloaded immediately by the centre. All problems are highlighted according to the above colouring scheme.

The statistics page provides the centre an overview of the cycles' status, year by year. The remaining open issues are shown in red. The system administrators periodically send emails to the centres with some explanations on how to validate and correct the data.

3.5. Ethics

Every user is bound to adhere rules such as strictly maintain the confidentiality of the data, view only the data necessary for his/her work, ensure the quality and completeness of the information contained in the medical record.

For privacy and confidentiality reasons, the SSIN which uniquely identifies individuals in the Belgian healthcare system is encrypted in an irreversible way before being stored in the database. The number (message) is cyphered with a hash function which returns a value (digest). One SSIN always returns the same cyphered value but it is impossible to retrieve the original SSIN from that value.

3.6. Data analysis

The collected data are analysed on a yearly basis and an annual report is published online. Moreover, each ART centre receives since 2007 an individual report to compare itself to the overall statistics and to localize itself to the other centres in an anonymous way.

4. DISCUSSION

The development of the website took around 9 months. The major difficulties encountered were the cleaning and importation of the historical data and the uploading of files that may contain a huge number of records with a lot of fields.

Since 2009, 200 user accounts have been created on the web application. Currently, they have generated about 330,000 BELRAP numbers. The system also contains information about 185,000 IVF cycles, 110,000 non-IVF cycles and 30,000 babies (IVF and non-IVF).

The system and the data collected can serve several purposes.

Researchers can use the data collected in their studies. As an example, De Neubourg et al. (2013) [5] analysed the evolution of multiple deliveries in Belgium. Data are also sent to European and International organisations that are monitoring ART (i.e. European IVF Monitoring (EIM) [6], ICMART [7]).

A public health objective could also be met. In order to reduce the multiple delivery rate, the Ministry of Public Health decided in 2003 to reimburse laboratory costs of IVF cycles under certain conditions. The web application hosts an algorithm that automatically generates the list of reimbursable cycles every year.

ART centres are directly involved in the data collection procedure. The checks implemented in the system allow them to control the quality and consistency of their data while the individual reports give them the opportunity to compare their results with the other centres.

Some limitations of the current system are: 1) A lot of items are registered. A simplification of the registration will further increase the quality of data registered. 2) The current import and export procedures are relatively slow when dealing with a huge number of records. Better procedures will increase the usability of the system.

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