

# HISTORY OF MEDICAL DATA COLLECTION IN THE MALTESE ISLANDS

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The collection of medical information is today an essential administrative tool, allowing the state, department or the individual practitioner to audit the prevalent practice and to assess the level of health care, identify problems and focus on priorities for improvements. These objectives can be reached by the collection of event-oriented databases that can have several levels, each with its utility status. These levels may include (1) demographic data and vital event registration, and (2) clinical event-oriented data. The move towards the collection of person-oriented medical data ensures that the collected database can be extended to better serve the medical needs of the individual patient.

## *Demographic and Vital-event Data*

The concept of assessing population size and growth of a community has a long history with known population counts being recorded in Babylon, China and Egypt between 2800 and 2200 BC. These counts were aimed at assessing the strength and wealth of the country. It has been recorded that the first count of population in Malta was carried out by the Emir Yusuf-al-Futah in the year 991 for the purpose of securing certain privileges for the inhabitants, while subsequent medieval counts were made by the Bishop of Strasbourg in 1175 and Abbot Gilibertus in 1241. These latter counts were concerned with taxation. Population counts made during the period of the Knights of St. John were conducted in connection with the importation of grain from Sicily free of export duties<sup>1</sup>.

The ecclesiastical authorities were also required to conduct population counts in order to known how many souls were under the Bishop's care, and the 'status animarum' contains information about population size. The Synod of Augsburg held in 1548 prescribes four books to be kept by the parish priest "Primum in quo baptizatorum; secundum confitentium et communicantium; tertium, in quo eorum, qui matrimonium in facie ecclesiae contraxerunt; et quartum in quo mortuorum...nomina et cognomina....descibantur." The formal universal prescription was extended to five parochial registers in 1614 by Paul V in the Rituale Romanum. The five registers included (1) Liber Baptizatorum, (2) Liber Confirmatorum, (3) Liber Matrimoniorum, (4) Liber Defunctorum, and (5) Liber de Statu Animarum. The same norm has remained unchanged, though in the 1983 revision of the Codex Juris Canonici, the Liber de Statu Animarum no longer features among the Libri Paroeciales. In Malta, long before the official declarations, parish priests had been keeping their own records. In fact, the Mdina Baptismal registers start from 1539, while the missing first 38 folios suggest that the original records started in 1528. The preserved records from Naxxar date to 1546, those of Birgu from 1552 and of Birmiftuh from 1556<sup>2</sup>.

Civil registration of births was introduced in Malta by Napoleon Bonaparte by decree of 24 August 1798 which made it obligatory for the doctor or midwife assisting at a birth to present certificates of the birth within 24 hours to the municipality under penalty of suspension from prac-

tice and infliction of a fine and imprisonment<sup>3</sup>. Subsequent regular civil registration of vital event data in Malta can be traced to 1863<sup>4</sup>. Ordinance II of 1870 required that prior to burial in cemeteries, a certificate showing the cause of death was required<sup>5</sup>. Mortality statistics by cause of death started to be published regularly by the Chief Police Physician in May 1872. These fortnightly reports gave the number of deaths by cause, sex and district. The causes of death were classified into: Zygomatic, Constitutional, Local, Developmental, and Violent Death<sup>6</sup>. After April 1873, further information pertaining to age at death was also included. The first annual report on a regular basis was published in 1896<sup>7</sup> and continued throughout the twentieth century. The first regular census in a series of decennial censuses was carried out on 21 March 1842<sup>8</sup>. Demographic data remains the responsibility of the Central Office of Statistics.

## *Clinical Event-oriented Data*

The concept of collecting medical statistics was introduced by John Graunt of London in 1662 with his work "National and political observations upon the bills of mortality", wherein he showed among other things that the maternal mortality was one in two hundred and that one-third of infants perished before the age of three years. It was only in the nineteenth century that regular statistics were collected with the scope of identifying medical and social problems to enable measures to be taken to control population health. In the United Kingdom, the Registrar General's Office in 1837 started to keep accurate records of all births, stillbirth and maternal deaths. In that same year, the

Presidents of the Royal Colleges of Physicians and Surgeons asked the medical profession to submit certificates of deaths stating if possible the cause. These regulations were also taken up by the British Naval authorities, who in 1825 required the Naval Surgeon to submit regular nosological tables. One British Naval surgeon who worked in Malta in the early decades of the nineteenth century published detailed clinical reports of the cases treated at Bighi Naval Hospital in Malta during 1842-1844<sup>9</sup>.

The Civil authorities in Malta started requesting the certification of disease and cause of deaths in 1870-1871. The first Ordinance published in 1870 was that respecting cemeteries, whereby a death certificate became a requirement for burial - this to have the date of death, the name, surname and profession of the deceased, and the cause of death<sup>5</sup>. A subsequent Government Notice issued in 1871 required all physicians and surgeons to submit information to the Superintendent of Police of any communicable disease. The list of reportable infectious disease was revised in 1899<sup>10,11</sup>. Fortnightly publication of the collected data was initiated in May 1872, while annual reports were initially published in 1896<sup>6,7</sup>.

Previous to these ordinances, the Civil Hospitals had maintained an admissions register that included an admission diagnosis. The earliest register viewed by the author pertains to the Hospital of St. John the Baptist at Rabat, Gozo and covers the period 31st December 1841 to 31st August 1851. Maternity data is included in this register. In later decades maternity data was amplified by the introduction of a Lying-in register. The second volume of Registers of Lying-in Women for the Gozo civil hospital covers the period 29th March 1876 to 11th April 1884. Presumably the first volume approximately covered

the previous decade<sup>12,13</sup>. The maintenance of admission registers of the various Government Charitable Institutions was formalised by the 1851 regulations<sup>14</sup>.

While the national data was collected by the Public Health Department and could be utilised for public health measures, the hospital clinical data was managed and collected by the Commissioner for Charitable Institutions whose concern towards data collection was purely administrative and budgetary. The situation changed after 1937 when the Public Health Department and the Charitable Institutions Department were amalgamated in the Medical and Health Department. This allowed the medical administrators to audit clinical data and assess medical management in the various hospital clinical departments. The annual reports after 1937 contain appendices detailing audits of clinical departments, besides reports from various support services<sup>15</sup>.

In the second part of the twentieth century, the advances in medical sciences and public expectations, and new trends in administration placed increasing pressure for more and for better medical information. In Malta, the Department of Obstetrics and Gynaecology has been in the forefront of this development, and its history can serve as a model for that of other departments. The first annual clinical report for the obstetric department in the main State Hospital was published in 1937<sup>16</sup>. There has been since a regular series of annual reports issued from the department, reports that unfortunately have not always been published formally. The annual clinical reports were laboriously assembled by hand from the Labour Ward Birth Registers (in use since the mid-19th century) and the case records of patients with a bad obstetric outcome. While these reports are

interesting to the clinicians and the hospital administrators, they are of limited utility epidemiologically since they gave information only about abnormalities and did not provide national standards for comparison. It was realised that the volume of data that requires to be processed on an annual basis can only be suitably managed by the use of computers.

Data collection using computer services was initiated in conjunction with the International Fertility Research Programme (USA) in 1981. The purpose of this programme was to collect, analyse and report data relating to obstetric delivery in a standard manner for all contributors to the programme. For the Department, the experiment served as a feasibility study of data collection of circa 5000 maternities. The data was transcribed onto standard data sheets by a trainee obstetrician and the data sheets forwarded to the IFRP where the data was handled electronically<sup>17</sup>.

During 1982, arrangements were made through the Department of Health with the Government Computer Centre (Malta) for the initiation of local electronic handling of clinical data of all obstetric deliveries occurring in the main State Hospital. The program, based on the experiences with the IFRP system, was finally initiated in January 1983. This event-based data collection continued until the end of 1986 (Table 1). The data was transcribed from the patients' files onto a series of three obstetric-related Data Forms [Obstetric Coding Sheet; Multiple Birth Record; and Neonatal Coding Sheet] by a midwife under the overall supervision of an obstetric registrar responsible for the Department's audit program. An Instruction Manual defining specific problems was prepared. The collected information facilitated the preparation of a series of detailed annual clinical re-

ports, the evolution of a number of epidemiological studies which helped to identify particular obstetric risk groups in the Maltese situation, and served as a basis of clinical practice audit in the Department<sup>17,18</sup>.

Similar progress in clinical event-oriented data collection was made in Cancer Registration. Following the Cancer Noti-

Year	State Hospital (Malta) No. of maternities	Computer recorded maternities	%	System in use
1981	5212	4619	89.0I	FRP (USA)  Comp.Centre (Malta)
1983	5286	5286	100	
1984	5083	5031	99.0	
1985	5014	4968	99.1	
1986	4789	4787	99.9	

Table 1: Data Collection Efficiency

fication Act of 1957, registration of cancer cases was initiated by the oncological department at St. Luke's Hospital. This was taken up in a computerized form by the Department of Health Information in 1984 and is still maintained today.

#### Person-Oriented Database

An event-oriented database is only of general value assisting health planning and hospital resource management. It gives no direct benefits to the individual patient. During 1986, the Department of Health in conjunction with the World Health Organization introduced a computer-based INDIVIDUAL HEALTH PROFILE aimed as a person-based record for all patients who encountered government medical services with the aim of providing readily available clinical information to medical practitioners on the patients they were treating, of scheduling appointments and follow-up procedures, of managing immunization and other preventive programs, and of conducting surveys and research. The INDIVIDUAL HEALTH PROFILE included socio-medical information about each patient and the medical diagnosis at each encounter<sup>19,20</sup>. This profile was eventually termed the Patient Master Index.

This has now evolved in the Patient Administration System [PAS] still in use today.

The system used initially was the CMG-COSTAR [Computer Stored Ambulatory Record] as modified by the Central Medical Group of Imperial Chemical Industries. The system was basically a highly structured medical case record designed for use

oriented one, thus necessitating a number of encounter forms [Initial Encounter Form; Antenatal Examination Form; Intrapartum Data Form; Infant Characteristics Form; Postpartum Care Form] to be devised for data collection<sup>21</sup>.

It was initially planned that the relevant encounter forms will be completed by the attending physician who was also responsible for the manual Medical Record. However, after a feasibility study, this was found to be impractical in view of the large numbers of patients attending the antenatal clinics at Karin Grech Hospital and the reluctance of the physicians<sup>18</sup>. A system was thus organized whereby data transfer from the manual medical record onto the encounter forms was done by a team of two part-time midwives and a health assistant clerk. The completed forms are then sent to the Health Services Information Unit where the data is transferred to the computer by trained personnel. The system of using a team of data collectors was found to be more reliable and efficient than when data was collected by medical personnel. The team became very used to the notes and could find their way through these quickly. They were made to feel a part of the medical team and had free access to the doctors for any queries. The data capture rate of the system during 1987 approximated 91% (Table 2).

The transfer of information from the manual medical record to the data collection forms and eventually onto computer al-

DATA FORMS	Computer Data	Hospital Records	%
Initial Encounter Forms	4474	4834	92.6
Antenatal Examination Forms			
a] Hospital Follow-ups		15217	
b] Health Center Follow-ups		5047	
c] Ward Admissions		2378	
Intrapartum Data Form	4470	4899	91.2
Infant Characteristics Form	4451	4952	89.9
PostPartum Care Form		340	

Table 2: Data Capture - 1987

lowed for the possibility of transcription errors, especially where text was involved. The case record data sheets were structured with this possibility in mind and information items were clearly defined whenever possible. Another problem associated with the system was breakdown of confidentiality. Security and confidentiality of patient information were inherently ensured by the CMG-COSTAR System if a dedicated computer was used. The only possible breakdown in confidentiality that could occur was during the period between data collection and its processing onto computer. However by encouraging the use of the national Identity Card Number, the risk was considered to be not greater than access to the Manual Record. The scope of this person-oriented program, besides facilitating statistical analysis, was to make easily available the individual patient records to the practitioner. The data could be arranged by the computer in flow-chart format mimicking the manual medical data record with which the practitioner was familiar. Four obstetric flow charts were designed. The first chart identified obstetrical important socio-biological characteristics, the past medical history and the general examination of the patient. The second chart outlined the antenatal obstetric observations in chronological order, while the final chart tabulated in chronological order the antenatal investigations.

The hardware used for the system consisted of two Burroughs mainframes which held the Master Index and the record files. A Wang 380 personal computer was linked via dedicated telephone lines to the peripheral centres in the Hospital and the Primary Health Care Centres. The system was accumulative, and within a few years the Master Index and record files became inundated with information and unwieldy to use effec-

tively as medical case records or for statistical evaluation.

The Department of Obstetrics & Gynaecology in liaison with the Department of Health Information in 1991 returned to an event-oriented system entitled Maternity Information System. Data collection for the MIS commenced once the mother delivers her child.

for over 80% of maternities occurring in the Islands. The data has been validated since 1993, initially whenever obstetric information was requested, but after 1995 more regularly with an annual report being issued by the DHI (Table 3)<sup>22</sup>.

In 1998 after exposure to the WHO-Euro OBSQID project, the data sheets were reviewed in the

MATERNITY INFORMATION SYSTEM	1995	1996	1997
TOTAL BIRTHS Karin Grech Hospital	4482	4212	3977
TOTAL REGISTERED BIRTHS Maltese Islands	4613	4944	4835
% DATA CAPTURE	97.2	85.2	82.3

Table 3: Data Capture

Information regarding the course and outcome of pregnancy is recorded onto a standard maternity information sheet, comprised of four sections [MATER - maternal identification; BOOKDEL - antenatal booking data; DELNEW - delivery data; and INFANT1 - infant data]. The main objective of the system is to provide information to clinicians and management personnel on obstetric care and outcomes in the hospital. The data collection is performed by two nurses stationed in the Post-Natal Ward with data being gathered from the Patients' Maternity Co-operation Card, Nursery Infant Notes, and the Labour Ward Registers. The completed data sheets are eventually passed on to the data entry operators at the DHI who validates the maternal identification information with the Patient Master Index. The latter is part of a comprehensive Healthcare Information System that holds demographic details on all residents on the Islands. The medical data in the sheets are then coded according to the International Classification of Disease (ICD-9), and once coded are entered into a dBase IV program. Data capture has reached 100% efficiency for the main State Hospital, accounting

light of the OBSQID-BIS. The presently used data sheets were found to lack information about a few specified data items. The MIS database was thus adapted to conform with the requirements of the OBSQID project and the new database - the National Obstetric Information System - initiated in 1999. In addition, the maternity information was extended to all the other state and private run maternity hospitals which increased their role in the maternity services of the Islands, their contribution rising from about 3% of the total deliveries on the Islands in 1995 to 18% in 1997.

Another unit which availed itself of the person-oriented COSTAR system in 1986 was the Diabetes Clinic of the Department of Medicine where data was inputted directly on terminals placed at the clinic<sup>20</sup>. This was after 1989 replaced by the DiabCare computer program launched by the St. Vincent's Declaration. This later program enables health care personnel to record and analyse data from a large number of patients and to compare results with those of other centres. By 1999, a total of 14300 diabetic patients were registered in the Clinic's computerised management system<sup>23</sup>. The DiabCare project has

been extended to diabetes during pregnancy – DiabPregCare – which has been adopted by the Diabetic Pregnancy Joint Clinic at St. Luke's Hospital.

The COSTAR system was also piloted for the management of clinical data collection from the Floriana Health Centre, with plans to extend these to all the health centres by 1990. This system however became defunct with the abandonment of the COSTAR System in the early 1990s<sup>20</sup>. Several data programs have been proposed locally for general practice, and the number of general practitioners who utilise information technology systems to maintain their practice is steadily increasing. IT systems in health care are the way forward, not only for better management of hospitals and general practice but also for better individual patient care. Attempts should be made to link the hospital clinical data, such as major diagnosis and treatment prescribed, with primary health care. This can be facilitated through the introduction of smart cards containing important clinical data about the individual. These cards, issued and updated by the hospital, are then given to the individual to be presented to medical practitioners whenever necessary.

## REFERENCES

1. Census '85: Vol 1 - A demographical profile of Malta and Gozo, Central Office of Statistics, Malta, 1986, p.3-9
2. Fiorini S. Status Animarum I: A Unique source for the 17th and 18th Century Maltese Demography. *Melita historica*, 1983, viii(4):p.325-343
3. Collezione di bandi prammatiche ed altri avissi ufficiali pubblicati del Governo dell'Isola di Malta e se dipendenze. Dal 17 Luglio 1784 al 4 Ottobre 1813. Government Press, Malta, 1840, p.41-43
4. Ciappara F. Marriage in Malta in the late eighteenth century, Assoc News Ltd, Malta, 1988, p.33
5. Ordinance II of 1870. Malta Government Gazette, 26 July 1870, 2448:p.221
6. Malta Government Gazette, 31 May 1872, 2522:p.181
7. Pisani S.L. Annual Report on the health and sanitary condition of these Islands in 1896. Malta Government Gazette suppl., 27 November 1897, 3959:p.i-xv
8. Malta Government Gazette, 31 December 1842, 1551:p.57-59
9. Savona-Ventura C. The naval career of Sir Thomas Spencer Wells in the Mediterranean: 1842-185. Maltese Medical Journal, 1998, 10(2):p.41-46
10. Malta Government Gazette, 1871, 2469:p.19; 2482:p.111-113
11. Malta Government Gazette, 6 June 1899
12. Register of Admissions. Hospital of St. John the Baptist, Rabat, Gozo. 1 December 1841 to 31 August 1851. Manuscript previously held at Gozo General Hospital.
13. Savona-Ventura C. A Maternity Unit in Gozo a hundred years ago. Maltese Medical Journal, 1995, 7(1):p.55-61
14. Establishments of the Government Charitable Institutions of the Islands of Malta and Gozo. Government Printing Office, Malta, 1851, p.10
15. Annual Report on the Health Conditions of the Maltese Islands and on the work of the Medical and Health Department for the year 1937. Government Printing Office, 1938, Malta
16. Ellul J., Stilon V., Mattei S., Zammit C. Clinical Report of the Maternity & Gynaecological Subdivisions of the Central Hospital, Malta for 1937. Lux Press, Malta, 1938.
17. Grech E.S., Savona-Ventura C., Fenech Gonzi P. Computerization of Obstetric Data. In: Grech E.S., Savona-Ventura C., eds. Proceedings: European Study Group on Social Aspects of Human Reproduction. Vth Annual Meeting, Malta. September 1987. Government Press, Malta, 1988.
18. Grech E.S., Savona-Ventura C. The Obstetric and Gynaecological Service in the Maltese Islands. Department of Obstetrics and Gynaecology, Malta, 1988.
19. D.O.H. Health Services Development Plan - Malta 1986-1990. Department of Health, Malta, 1986
20. Mamo J., Agius Muscat H., Ellul M., Lenicker R. Development of a Health Information System for the Maltese Islands. Medi-Scope 1989, 13, 1-2,6
21. Savona-Ventura C., Grech E.S., Grech A., Fenech-Gonzi P. Computerization of data: a person-based medical record system. *Int. J. Gynecol. Obstet.* 1990, 32, 247-54
22. Savona-Ventura C, Janulova L. The computerization of maternity information in a small island community. The Malta Experience 1981-1997. Handout given to the W.H.O. Fifth Workshop on Quality Development in Perinatal Care, Nof Ginosar, Israel, 29-31 October 1998
23. Azzopardi J. The St. Vincent Program in Malta. Abstracts. Diabetes Care and research in Europe. St. Vincent Declaration ten years on. The Target, The Progress, The Vision. Diabetes Nutrition & Metabolism, 1999, 12(3):p.224