HEALTH INFORMATION SYSTEMS

HEALTH INFORMATION SYSTEMS IN MALTA – PAST, PRESENT AND FUTURE

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ABSTRACT

It is well documented and recognized internationally that good quality health information is essential to public health in its endeavor to protect and promote the health of a nation. The need for dedicated health information systems within the Ministry for Health in Malta was felt more than 30 years ago, when the Chief Government Medical Officer at the time called for the introduction and implementation of a health service information system. This led to the development of a dedicated unit with the aims of providing basic statistical and epidemiological information, conducting surveys and evaluating health programmes. Over the years, this unit has developed into the current Directorate for Health Information and Research which is now responsible for maintaining ten population-based Health Registers and a five yearly National Health Interview Survey, in addition to other ad hoc research. This article traces the development of health information systems in Malta from their inception in the early 1980s to date.

Background

"Nothing exists until it is measured." [1] This famous statement made by the acclaimed Danish physicist Niels Bohr back in 1930 is acutely relevant to public health. Nowadays it is well recognized that appropriate decision-making for public health is dependent on the availability of timely and accurate data. It is the function of health information systems to provide and make sense of such data.

History is replete with examples that highlight how health information data has contributed immensely to the protection of population health. Early use of health information to influence policy and practice is evidenced in the mid-1800s with John Snow's work during the cholera epidemics of London, when the eminent English physician was able to identify the source of infection using information on deaths and addresses of each cholera victim[2] The Great Smog of London in 1952 was yet another early instance when health information was pivotal to protecting public health: information on deaths, causes and distribution identified air pollution as the cause of increased mortality.[3],[4]

More recently, health information systems have been crucial in recognizing the health risks of specific exposures and behaviours including smoking, alcohol and certain lifestyles. They have also served in vital research into the association and causation of several major public health concerns including cancer, cardiovascular disease, birth defects and dementia, to name but a few.

Recognizing the importance of having timely, accurate health information, several countries have invested in the comprehensive registration and surveillance of causes of death, patterns of disease and chronic health conditions. Such registration continues to be developed globally and is most advanced in Western countries and parts of Asia. Efforts to better document health data in low income countries is ongoing through several international initiatives[5].

Over the years, health information systems have shifted from paper-based to computer-based processing and storage, and from departmental or institution-based to regional, national and even international systems. Similarly, users of such systems have also extended from health care professionals and administrators to now include health consumers (including patients and relatives), planners and researchers[6].

Today it is recognized that effective health information systems should address several domains, including demographics, health determinants (socioeconomic, environmental, behavioural and genetic factors), health system functions (inputs, processes, performance and outputs), health conditions and outcomes and health inequities[7]

Relevance, accuracy, completeness of ascertainment, timeliness and appropriate distribution and release of information are of essence for all health information systems[8]. Having quality information is not enough to justify its collection until it is put to effective use[9].

Other important uses of routine health information systems include epidemiological surveillance and research and comparisons between countries. For purposes of country-comparisons it is essential that data collection, processing and analysis is harmonized between countries to allow for meaningful comparisons and interpretation.

Health information systems therefore serve multiple functions at various levels; at the level of individuals and communities, information may contribute to improve clinical management and service provision. At higher levels, health managers and planners can make informed decisions on the functions of health facilities, and at the highest levels health information may direct strategic policy making and resource allocation[7]

This article aims to document and trace the development of health information systems in Malta, through the review of relevant Ministry for Health documentation and personal communications with public health officials who have worked within the field.

Historical Development of Health Information Systems in Malta

Establishing a dedicated unit

The importance of effective health information systems was recognized by the Chief Government Medical Officer (CGMO) in the early 1980s, who requested that a dedicated unit responsible for coordinating the collection, collation, analysis and reporting of health information within the Maltese Health Ministry be established.

This proposal was given very high priority by Dr Alfred Grech, the CGMO at the time, partly due to the locally felt need and partly in response to the data submission requirements by the World Health Organisation (WHO), as "Malta was committed to provide Health ndicators required by WHO by the year 2000" [10]. Initial impetus was given by the CGMO setting up a meeting on the 25 June 1982 with the Computer Project Manager (Mr. Emanuel Camilleri) of the Computer Centre of Swatar, Dingli. The agenda of this meeting was the implementation of a dedicated 'Health Services Information Unit' with the aim of strengthening and evaluating Health Services in Malta(10). The objectives proposed for this Unit were:

> *"1 – To provide in a systematic, analytical and useful manner basic*
> *information (statistical, epidemiological and otherwise)*
> *fundamental to the health services and their development*
> *2 – To conduct monitoring surveys; and*
> *3 – To ensure a critical evaluation of the development and*
> *implementation of health programmes and the relevance,*
> *formulation, efficiency and cost-effectiveness of such programmes,*
> *in the light of pre-determined health indicators and of the findings*
> *derived from the aforementioned surveys." [10]*

Subsequently, Mr Ernest Causon - the Head of Medical Records at St Luke's Hospital - was assigned to lead the project to develop health information systems within the Department of Health, and in this regard was given statistical and computer training placements at the Computer Centre in Swatar [10].

In March 1983 a Health Information Unit (HIU) was officially set up at No. 6, Harper Lane, Floriana with recruitment of several staff members. The first projects proposed were the implementation of a computerised immunisation programme and recording communicable disease cases.

In March 1984, a tender for computer equipment with a 'minimum 512KB Main Memory' and an 'operating system capable of supporting 10 jobs concurrently' was requested by the CGMO. This tender was subsequently issued through the Swatar Computer Centre in July 1984.10 This computer system would be housed in Swatar, Dingli and terminals made available at the Health Information Unit.

Collaboration with WHO

Further assistance in the development of this Unit was sought through consultations with 'a team (Computer staff and Medical Epidemiologist) from the World Health Organisation European Regional Office" who would give advice on equipment and training requirements and long-term development of the system. WHO would also provide much needed financial assistance[10].

A WHO consultation visit occurred in January 1984. A report was drawn up by the WHO consultant, Dr M Kataja, identifying diabetes as '*one major health problem in Maltese islands*' and suggesting that '*a registry on diabetes could be an example of the problem oriented way of thinking towards the goal of computerised medical records...The diabetes registry could be taken first...*'[10].

Unfortunately, at the time of writing, no national operational Diabetes Register exists, although it is envisaged that such a register will be developed in the near future.

Another visit in 1985 by WHO consultant Mr K Floisand resulted in a detailed report on the plan for further development of the 'National Health Information System for Malta' (December 1985). This report suggested that the involvement of medical staff in the process was crucial, and it was expected that 'two medical specialists will qualify in Community Medicine and Statistics' in 1986[10].

Short computer training courses were provided to key members of staff between October 1984 and January 1985. This included training in: COBOL programming, Management Techniques, Presentations and Communication Skills, Basic Programming Language, Fortran Programming Language and Systems Analysis and Design.

Move to St. Luke's Hospital

In 1985, plans to relocate and develop more appropriate premises for the Unit were undertaken. The ground floor of the 'Sisters Quarters' at St Luke's Hospital were identified, and the entire unit moved to these premises that year.

According to a summary of the functions and proposed developments of the Unit written up in August 1985, at this time ongoing registration included: birth registration for purposes of tracking immunisation, notifiable communicable disease registration, obstetrics, neonatal and gynaecological recording on patients admitted to maternity and gynaecological wards and work towards setting up a National Diabetes Register.

Ongoing projects and surveys included: a diabetes and pregnancy project, an occupational therapy survey, a diabetes survey, an asthma survey, a survey of smoking and alcohol habits in school children, a screening programme on scoliosis in school children and the MONICA (Multinational MONItoring of trends and determinants in CArdiovascular disease) project study.

The latter, was the first major health survey undertaken in Malta in collaboration with WHO, the aim being the monitoring of trends and determinants of risk factors associated with cardiovascular disease[11]. Projects proposed for development at that time included: 'a phased implementation of a fully computerised system of case histories' and a 'computerised "master index" of patients'[10].

In 1987, a situation report on health information services suggested that the Unit should acquire 'independent computer facilities,' moving away from the Central Government Computer System at Swatar. In 1988, Dr Julian Mamo, a qualified medical epidemiologist joined to lead the Unit and lamented that a 'personal computer capable of storing small database on which statistical analysis could be done was not yet available.'10 The first personal computer - a Wang PC funded by WHO - arrived more than a year later .

In May 1991, under the lead of Dr. Hugo Agius Muscat, the name of the unit was changed to "Health Information Systems Unit (HISU)" through a DH circular 84/91.10 In 1993, following public service reforms, the HISU became one of the line departments of the Health Division and was renamed Department of Health Information (DHI).

The introduction of personal computers and installation of an ethernet-based Local Area Network in the early 1990s provided an undeniable boost to the collection of national health data and development of national health registers and surveys. It allowed for increased possibilities and timeliness of data retrieval; meaningful analysis of the data gathered, and increased potential of release of data, information and reports.

The existing Mortality and Cancer Registers were computerised, and a new Congenital Anomalies Register was designed and set up. A National Obstetric Information System (NOIS) was also set up, inspired by the WHO OBStetrical Quality Indicators and Data collection (OBSQID) project[12].

In 1994, it was felt that a larger 'Health Data Centre' was needed to support the major computer related projects in the Health Division, and in 1997 the DHI moved from its offices outside St Luke's Hospital to its current larger premises at 95, G'Mangia Hill. In 2007, the name of the DHI was changed to 'Department of Health Information and Research' (DHIR) highlighting the work that was being done in relation to research and population-based surveys. A few years later, this department was designated as 'Directorate for Health Information and Research', as it is known today.

Supporting legislation

Amongst the first national health registers to be kept by the unit were: Births registration (namely to support immunisation requirements), Infectious Disease, Mortality and Cancer Registers. Notification of infectious disease, mortality and cancer were statutory at the time [13],[14],[15].

In 2003, the adoption of the Public Health Act - Cap. 465 (2003)16 gave the Superintendent of Public Health the right to request data collection in the interests of public health. The adoption of the Health Act in 2013 – Cap. 528 (2013), specifies that any Department established under the Health Act '*may request all information from patients, relatives, personnel, and professionals, and from public and private healthcare providers, and such data shall be given to it in cases of emergency, for reasons of public health and to safeguard the vital interest of the patient or a third person*'[17]

It is under these legal frameworks that current data collection occurs. Subsidiary legislation to better implement the provisions of the General Data Protection Regulation is currently begin developed at the time of writing of this article.

Current functions of the DHIR

The DHIR now routinely manages ten population based National Health Registers and runs a National Health Interview Survey every five years. The National Mortality Register, one of the older registers, collects information and analyses the causes of death in the population. The Malta National Cancer Registry provides information on cancer incidence, mortality and survival. The National Obstetric Information System has depicted the changes in birth rates and maternal and perinatal health over the past years.

Furthermore, the Malta Congenital Anomalies Register registers congenital anomalies occurring in births in Malta and Gozo and the Cerebral Palsy Register records all children diagnosed with this condition. Other sources of morbidity data are the National Hospitals Information System, the Rare Disease Register and the Dementia Register. The Injury Database collects data from emergency departments and provides information on injuries sustained by the population. The Organ Transplant Register keeps information on organ transplants. Last but not least, the Health Interview Survey is an important source of information about the lifestyles of Maltese society. Without such information, the development of policies and action for the improvement of the health of the population would not be possible. All Registers and Surveys are now well established and internationally recognised, participating in European and global organisations and projects.

All health information collected by these systems is kept in accordance with the governing data protection legislation. Management and overall responsibility for the registration of infectious diseases moved to the Infectious Disease Control Unit in the mid-1990s.

Details of the functions of the current health information systems at DHIR can be found as online supplementary information on the Directorate's website at :
https://deputyprimeminister.gov.mt/en/dhir/Pages/Introduction.aspx.

Leadership

Since its inception, the DHIR has been under the lead of several Senior Civil Servants, Medical Officers, Consultants, Acting Directors and Directors. These were:

Mr Ernest Causon (1983-1985),
Mr Paul Farrugia Gonzi (1985-1988),
Dr Julian Mamo (1988-1990),
Dr Hugo Agius Muscat (1990 - 2000),
Dr Renzo Pace Asciak (2001- 2006),
Dr Miriam Dalmas (2007)
Prof Neville Calleja (2007 to present).

Conclusion

The developments leading to the current Directorate for Health Information and Research show a successful and significant growth of a unit over the past three decades, from its humble but far-sighted beginnings in 1983 to its now major role within the Ministry for Health as a Directorate.

It is recognized as the official national health data source both locally and internationally, supplying health data to several organisations including EUROSTAT, WHO Health For All and OECD (Organisation for Economic Co-operation and Development) amongst others. The addition of technology and computerisation has led to significant changes in the modus operandi; information technology has given a totally different perspective to the way data is collected, processed, analysed and ultimately released.

Are we where we want to be yet? Definitely not. Health information requirements, both locally and internationally, are dynamic and continue to evolve and grow over time, hence the importance of ongoing support and resourcing from the Department for Policy in Health.

There is scope for further development of health information on several fronts. Health professionals' awareness and notification of cancer, congenital anomalies, rare disease and cerebral palsy through the DHIR web notification form still leaves a lot to be desired.

Furthermore, Malta lacks comprehensive national registration of major health conditions of concern, including diabetes and cardiovascular disease. Our Health Interview Surveys need to also include regular health examination components. Health ministry policy and planning needs to support the development of strategic health information system plans which include exploring of new architectural health information systems, new types of data collection and technologies.

Policy development is not always based on accurate local information either because such information is not sought, or because it is not available. On a global level, the Millennium Development Goals and health-related Sustainable Development Goals all highlight the need for stronger health information systems which can then feed into evidence based decision-making[18],[19] .

It is therefore crucial that the DHIR functions will continue to receive the necessary support, resourcing, development and education required. It is augured that over the next decade(s) the MAPHM will report on the continued growth and development of health information systems in Malta.

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References

1. Neils Bohr. New World Encyclopedia (2018).
2. Snow, J. On the mode of Communication of Cholera. London: John Churcill (1849). Available at: https://collections.nlm.nih.gov/ext/cholera/PDF/0050707.pdf. (Accessed: 9th February 2019).
3. Logan, W. P. D. Mortality in the London Fog incident, 1952. Lancet 336–338 (1953).
4. Scott, J. A. Fog and Deaths in London, December 1952. Public Health Rep. 68, 474 (1953).
5. Mphatswe, W. et al. Improving public health information: a data quality intervention in KwaZulu-Natal, South Africa. Bull. World Health Organ. 90, 176–182 (2012).
6. Haux, R. Health information systems. Int. J. Med. Inform. 75, 268–281 (2006).
7. AbouZahr, C. & Boerma, T. Bulletin of the World Health Organization - Health information systems: the foundations of public health. Bull. World Health Organ 83,578-583 (2005).
8. Lippeveld, T., Sauerborn, R. & Bodart, C. Design and implementation of health information systems Edited by. WHO 280 (2000).
9. Aqil, A., Lippeveld, T. & Hozumi, D. PRISM framework: A paradigm shift for designing, strengthening and evaluating routine health information systems. Health Policy Plan. 24, 217–228 (2009).
10. DH 1086/82 'Setting up of a health service information unit', Ministry of Health file.
11. WHO MONICA Project Principal Investigators. The WHO MONICA Project (monitoring trends and determinants in cardiovascular disease): A Major International Collaboration. J. Clin. Epidemiol. 41, 105–114 (1988).
12. Johansen, K. S. & Hodd, M. Quality development in perinatal care - the OBSQID project. Int. J. Gynecol. Obstet. 64, 167–172 (1999).
13. Prevention of Disease Ordinance (Cap.36). (Laws of Malta, 1908).
14. Public Registry Act (Cap. 56). (Laws of Malta, 1927).
15. Notification of Cancer Act (Cap. 154). (Laws of Malta, 1957).
16. Public Health Act (Cap. 465). (Laws of Malta, 2003).
17. Health Act (Cap. 528). (Laws of Malta, 2013).
18. MDGs. Millenium Development Goals. Available at: http://www.mdgfund.org. (Accessed: 10th March 2019).
19. SDGs. Sustainable Development Goals. Available at: https://sustainabledevelopment.un.org/. (Accessed: 10th March 2019).