10 *Health Information* NURAIDAH M. MARZUKI, FAZILAH S. ALLAUDIN, SUPATHIRATHEAVY RASIAH AND JO. M. MARTINS

10.1 Introduction

Earlier chapters discussed how health development in Malaysia has been part of a systematic approach to socio-economic development since independence. This chapter elaborates on how information has supported this process. Like most developing countries, Malaysia faced challenges in generating adequate, accurate and timely information to support health development. This chapter illustrates the strategies Malaysia adopted to address those challenges. The chapter also illustrates how components of the health system such as governance and healthcare services stimulated the incremental development of the health information system.

10.2 Nature of Information and Main Sources

The information Malaysia used in supporting health development included health information collected primarily for the health sector and information collected for more general purposes such as population censuses and vital statistics. In this context, the World Health Organization (WHO) has suggested that health information involves the production, analysis and dissemination of information on three major dimensions of health (World Health Organization, 2007):

- Determinants of health
- Performance of the health system
- Health status

The main sources of information are:

- Censuses of the population
- Household surveys

- Civil registration of vital events
- Public health surveillance
- Medical records
- Data on health services
- Data on health systems resources in the nature of human resources, health infrastructure and financing

Additionally, there are data on materials such as vaccines and drugs, as well as findings from health systems research. Over time, although in a generic sense the dimensions of the health system and the methods of collection have remained substantially those mentioned above, the instruments used have advanced with the evolution of information technology (IT) and the evolution of health concerns as the country has experienced socio-economic and epidemiological transitions.

10.3 The Era of Rapid Development (1960s–1970s): Health Information Helped Address Health Concerns

During this phase of development, data collection and compilation were mostly manual, resulting in slow, sometimes incomplete data and limited analysis. Data flowed from health facilities to district health offices, where it was compiled and transmitted to state health departments, which in turn did further compilation before transmitting it to the Ministry of Health (MoH) at national level. Each MoH programme had its own data collection system, occasionally resulting in conflicting information. Systems for checking data comprehensiveness were limited. Additionally, there was no central compilation and analysis of information from other agencies such as local authorities, the Ministry of Defence and the Ministry of Education (MoE), as well as private sector health services. Annual reports, such as those of the MoH and the Department of Statistics (DoS), were the most readily available sources of information.

10.3.1 People and Their Health

During the immediate post-independence years, the MoH used a range of information that was already available to develop health priorities and to monitor the implementation of health interventions. For example, empowered by the relevant legislation, the DoS conducted population censuses through household surveys that provided basic information on the number, location and characteristics of the people in the country. The DoS also collected data on births and deaths; police throughout the country, together with hospitals, were responsible for registering and reporting births and deaths. Thus the 1957 census showed that three-quarters of Malaysian people lived in rural areas (Department of Statistics, 1960), and the DoS provided annual population estimates between censuses using data from the existing system of registering births and deaths. Additionally, registering births and deaths provided annual information on fertility and infant mortality. For example, fertility was about three times the replacement level, and infant mortality was high and the associated life expectancy was relatively low (Fernandez et al., 1975).

The MoH also collected and compiled data from hospitals on causes of admission and of death. Deaths registered by the police were not usually medically certified. However, the limited available information indicated that most mortality was related to infectious diseases such as malaria and tuberculosis (Roemer, 1976). Surveys of education status showed that about three-quarters of the adult population (\geq 15 years of age) were illiterate (Ministry of Education Malaysia, 1967). Similarly, household budget surveys showed that most people in rural areas lived below the poverty line (Roslan, 2001). Concerns about toddler mortality rates (1–4 years of age), known to be associated with malnutrition, led to a joint applied nutrition programme by the MoH and other ministries (education, information and agriculture). An evaluation study performed in 1979 showed enhanced child nutrition practices and weight gains (Ministry of Health Malaysia, 1982; Chapter 4).

Legislation required the reporting of dangerous and infectious diseases to the MoH, and such information provided the basis for the disease control measures described in Chapter 6. Once the various disease control programmes had been developed, each established its own information system, including the monitoring of disease and deaths and programme activities (Chapter 6).

Household surveys, such as those for 1957–1958 and 1973–1974 (Young et al., 1980), also yielded an assessment of household use of health services and their distribution among different income groups.

10.3.2 Health Workforce

Legislation required the registration of nurses, midwives, doctors, dentists and pharmacists in both the public and private sectors (Chapter 8; Federation of Malaya, 1957), providing annual estimates of the distribution of health professionals. For example, the number of nurses and doctors per head of population was relatively low. Also, while healthrelated information showed that the major determinants of health were related to the poor living conditions in rural areas, information from the registration of health professionals indicated that most nurses worked in public hospitals, while more than half of the doctors were in the private sector (Department of Statistics, 1964; Chapter 3; Chapter 8). Such information guided the formulation of policies related to human resources (Chapter 8). Annual registration data enabled monitoring of the progress made to increase low numbers in relation to the growing population. In addition, an annual census of doctors and dentists in the private sector carried out since the 1970s (e.g. Department of Statistics, 1975) enabled assessment of the public-private distribution of the health workforce and guided the mobilisation of scarce health professionals, especially for rural areas.

10.3.3 Health Facilities and Services

The MoH routinely collected information on public sector health facilities and their basic activities, such as number of admissions and ambulatory patient encounters. This information indicated that most hospitals and clinics were located in urban centres and that most hospitals in the private sector were relatively small and most were concerned with maternity services. Such information guided planning for expanding the rural health service and strengthening the public hospital network (Chapters 4 and 5). For example, there were an average of two public sector beds per 1,000 people (excluding special institutions) (Federation of Malava, 1959). This would be considered a relatively high ratio for a young population, although some beds were reserved for patients with tuberculosis and other infectious diseases. At that time, data collected from hospitals were rudimentary, such as number of admissions and patient encounters. It did not permit the evaluation of functions. About 20 years after independence, a purposedesigned survey of hospitals showed low occupancy rates in small

hospitals but very high occupancy in larger hospitals in the greater urban centres (Chapter 5; Institute for Public Health, 1983), triggering several initiatives for improving services in smaller hospitals.

In rural areas in 1960, there was only one main health centre per 600,000 people, one sub-centre per 320,000 people and one midwife clinic per 120,000 people (Ismail, 1971). Data were also collected on the number of visits to health centres for maternity and child health and on public hospital outpatient services. Such information mainly supported decisions related to staff deployment and the supply of medical products, including vaccines, to public sector facilities. After 17 years of rigorous expansion of the rural health service, the MoH conducted a household survey: a high proportion of villages were 'underserved', and this finding triggered the re-vamping of the rural health service (Chapter 4) to rapidly increase access to front-line staff through revised staffing patterns and mobile clinic services. In 1968, an environmental sanitation survey in selected rural areas indicated that only 4% of the population was served with piped water, and the remainder obtained water from either unprotected wells or untreated surface water (Ministry of Health Malaysia, 1982), and this triggered a re-vamped approach to rural sanitation (Chapter 7). Annual data compiled and analysed by the MoH enabled the government to monitor progress in comparison to the targets, as discussed in Chapters 4-8.

10.3.4 Health Financing

During this phase of development, information available on health financing was mostly from the government's financing of health services and their administration in the public sector. At about the time of independence, public sector expenditure on health amounted to about 1.4% of the gross domestic product (GDP) (Federation of Malaya, 1957; 1959; 1961; Department of Statistics, 1999; Chapter 9). Since the 1970s, the annual census of private doctors, dentists, maternity homes and hospitals also reported revenues of, and expenditures incurred in, related private practice (Department of Statistics, 1975). Central government agencies used this annual census mostly to monitor growth in private health sector employment and economic activity. Household expenditure surveys such as that for 1957–1958 yielded an estimate of households' health-related expenditures (Roemer, 1976; Chapter 9).

10.3.5 Information Supported the Assessment of Progress

10.3.5.1 Effectiveness

Household surveys indicated that although still high, poverty, closely associated with health status in Malaysia, had declined by 1980 to 37% of the population (46% in rural areas) (Chapter 3). Registers of communicable diseases indicated that substantial progress had been achieved in the incidence of diseases usually associated with childhood, such as mumps and whooping cough (Chapter 6; Ministry of Health Malaysia, 1982). This progress was reflected in the fall in communicable diseases as a cause of death in mortality statistics compiled by the DoS and in infant and maternal mortality during the period (Department of Statistics Malaysia, 1991; Chapters 3–7).

10.3.5.2 Costliness

Information on the annual expenditure on health service delivery and administration was available only for the public sector. The government used such information as part of the annual review process, and the evaluations were associated with the preparation of the Malaysia Plans and their mid-term reviews. Also, although the DoS collected some limited information on the private practices of doctors, dentists, hospitals and maternity homes, this was not aggregated to obtain an overall picture nor used in planning. Estimates indicate that overall annual expenditure was under 2% of the GDP for the substantial health improvements recorded during the 1960s and 1970s.

10.3.5.3 Equity

Malaysia used a variety of instruments and data sources to produce a useful assessment of equity in the distribution and access to health services, outcomes and financial burden. Disaggregation and analysis of the various types of data for demonstrating trends in differences between urban and rural areas and between population groups provided evidence on progress towards the goal of reducing inequity illustrated in Chapters 3–7. Physical access to healthcare improved in rural areas. Household surveys indicated that spending on public healthcare benefited mostly those living in poverty and with lower household incomes (Young et al., 1980).

10.4 The Era of Transition and Consolidation (1980s-1990s)

In the two decades of the 1980s and 1990s, Malaysia experienced a major socio-economic transition, with most people becoming urbanbased, a lower proportion of dependent children and a larger proportion of young adults. The success in the prevention and management of communicable diseases also led to an epidemiological transition. These changes drove the need for better health-related information. International development in IT and the growing capacity and competence in the MoH for managing healthcare services (Chapters 4, 5 and 8) facilitated and supported the further development of health-related information.

10.4.1 People and Their Health

The population censuses, vital statistics, disease registers and surveys of internal migration continued to provide information on population growth and characteristics as well as disease occurrence. The MoH used this information to assess the population covered by services such as immunisation and to assess the progress made in reducing mortality and disease incidence. Household living condition surveys indicated that poverty was substantially reduced during the 1980s and 1990s (Chapter 3). Nevertheless, continuing concerns regarding possible lags in reaching the poor and their health led to health assessments of the very poor to ascertain the appropriate support to be provided (Ministry of Health Malaysia, 1992).

However, changing disease patterns drove the need for better information. For example, non-communicable diseases were not notifiable, and the only available data were those collected from admissions and deaths in public sector hospitals. Similarly, dental health data were limited to the provision of dental service. The need for communitywide information led the MoH to initiate large-scale population-based surveys that were to become a regular feature in the future. An example is the first National Health and Morbidity Survey in 1986–1987, a comprehensive household survey on access and use of health services, health-related behaviour and morbidity from non-communicable diseases such as hypertension and diabetes mellitus (Institute for Public Health, 1988). The survey was repeated in 1996 (Institute for Public Health, 1999) and more frequently in subsequent decades. Other examples include oral health surveys of six-year-old school children (Dental Division, 1972a) and of adults (Dental Division, 1972b), which provided data on oral health and the need for services. Such surveys subsequently formed a regular surveillance system on oral health.

Another aspect of health information was health systems research (HSR). The driver motivating the development of HSR was the thrust to improve management within the MoH to respond better to the national policy of improved effectiveness and efficiency (Chapters 4 and 5). Beginning with a small unit within the Institute for Public Health, which at the time was mainly a training institution, HSR proved its value to the MoH and was soon developed into a major programme with international credentials, subsequently meriting its own institution.

10.4.2 Health Workforce

During this phase of development, new legislation commenced requiring the registration of additional categories of personnel assistant medical officers, opticians and optometrists - thereby increasing the human resources information database. However, as the numbers of health professionals increased, the system's capacity for updating the database regularly was limited (World Health Organization, 2014). Therefore, the registers maintained by the respective boards became less valuable as a source of information for planning and policies regarding the health workforce. Mainly, the boards used the information to regulate professionals (Chapter 12). Meanwhile, information required for health workforce planning was deficient, contributing to gaps in planning. For example, the progressive transfer of health personnel education from the MoH to the MoE resulted in information lags between the two ministries, creating a barrier to forward planning by the MoH, the main user of health personnel. Furthermore, the MoE did not obtain data from all sources that produced health personnel, namely private sector institutions and foreign institutions. The time lag and incomplete data later resulted in serious problems of employment, as discussed in Chapter 8 and Case Study 8.1.

Box 10.1 illustrates the initial development of HSR in Malaysia.

Box 10.1 Health systems research provided information for managerial decision-making

Prior to 1980, the general perception was that research was the prerogative of researchers in research institutes who published results in journals, and health system managers had little interest in or access to such information. The Fourth Malaysia Development Plan (1981–1985) adopted health systems research as a tool to provide appropriate focused information to address the problems experienced in implementing programmes (Pathmanathan, 1988). Few researchers were available or had the competence to perform such research.

A small group of staff at the Public Health Institute developed short training programmes specifically designed for multi-disciplinary teams of staff who managed health districts, hospitals and state-level health programmes. This training programme eventually gained international recognition and was replicated in several countries (Varkevisser et al., 2003). The programme aimed at providing basic research competence to a wide array of health staff and at encouraging the use of information in decision-making at every level in the health system. Examples of the programme's outputs included measles immunisation coverage in a local area improving from 44% to 66%, reduced instances of non-availability of prescribed medication at dispensing counters through improved local record-keeping of medicine stocks, and reduced waiting times at hospital outpatient clinics by redeployment of staff and re-scheduling of their work programmes.

Lessons arising from the experience included the need to discourage beginner teams from selecting complex problems. For example, an attempt to compare the cost-effectiveness of the 'flying doctor' services versus static clinics for remote population groups resulted in frustrating and inconclusive findings. Conversely, successful projects such as the measles immunisation spurred statelevel managers to expand the initiative state-wide and seek means of ensuring that every client contact with the health system, whether in a hospital or a private clinic, would be an opportunity to encourage immunisation.

Thirty years after its initiation, the programme continues to flourish, largely because healthcare managers at every level of the system appreciate its usefulness and have adapted it in various forms to suit their particular needs and constraints.

10.4.3 Health Facilities and Services

Information from the sources described earlier in this chapter continued to provide data that showed, for example, that although the number of total hospital beds increased, the beds-to-population ratio in the public sector declined, partly compensated by the substantial rise in private sector beds (Chapter 5). Data showing the rising prevalence of small private hospitals was a factor in triggering the formulation of new legislation to regulate private hospitals. Similarly, data showing the increased utilisation of health centres in the public sector for ambulatory care contributed to the transfer of outpatient services from hospitals to health centres (Chapter 4). The introduction of the quality assurance programme (QAP) in several MoH programmes contributed to better data quality, such as in the accuracy in International Classification of Diseases (ICD) coding of deaths or discharges from hospitals. It also resulted in better use of information, as the QAP required evidence of remedial measures by institutions, whose performance on selected indicators suggested the need for immediate improvement (Chapter 5).

10.4.4 Health Financing

As described earlier, information on health expenditure was limited to that in the public sector, and there was uncollated and limited information on the private sector. Rising concerns about the sustainability of the healthcare financing system prompted the need for more comprehensive information on health expenditure. The first major assessment of healthcare financing was carried out in the 1980s by external consultants (Westinghouse Health Systems, 1985) in conjunction with the study of the possible introduction of social health insurance in Malaysia (Chapters 3 and 9). The study provided sufficient information for a policy decision not to implement social health insurance. A household health expenditure survey provided information on out-ofpocket expenditure on health for 1996 (University Malaya, 1999). This led to awareness of the need to gain better understanding of the financial implications of the structural changes taking place to households and the financing of public and private health services. The MoH has undertaken recent estimates on health financing of both the public and private sectors for the late 1990s and consequent years (Malaysian National Health Accounts Unit, 2017). These studies indicate that health financing as a proportion of the GDP rose from 1983 to 2000, with an increasing proportion from the private sector (Chapter 9). This information shows that the government policy of placing greater emphasis on the provision of private health services has a price, and there is a need to provide public sector services as part of the social safety net.

10.4.5 Information Technology Development

Struggling with the increasing amount and varied quality of data generated by the different programmes, the MoH took a significant step towards improving the accuracy and comprehensiveness of health information. It established a central information documentation unit responsible for routinely collating information on all programme activities; checking comprehensiveness and accuracy; and analysing and publishing information on health status, human resources and health service delivery, using DoS information as the denominator. These publications became the source of official information, replacing the several different reports published by individual programmes (i.e. Information and Documentation System) (Ministry of Health Malaysia, 2001; Selvaraju, 2006). The rising availability of computerisation supported the implementation and effectiveness of this initiative to centralise and standardise data generated by the MoH. Progress was incremental, dictated by the cost of new technology and the capacity for training staff at district and state levels to acquire computer literacy.

Another important development was the proposal to establish a telehealth programme, beginning with a Telehealth Pilot Project (Ministry of Health Malaysia, 1997; Suleiman, 2001) to increase IT use to promote the integration of the collection of health information from a variety of sources. Three major modes were envisaged:

- Lifetime health plans
- Teleconsultation
- Information and education

The first was to provide a lifelong personal health record linked to an electronic medical record. The second was to consist of a multimedia network for face-to-face consultation of individuals and health professionals or among healthcare providers to enhance clinical support. The

third was to establish knowledge databases and interactive training programmes and make health information available to the public and to health professionals. By 2000, several projects had been initiated, such as the Medical Care Information System for collecting patient information in MoH hospitals, the Communicable Disease Control Information System for collecting information for the surveillance and management of communicable diseases, and the Maternal and Child Health System for collecting and analysing information from MoH services (Ministry of Health Malaysia, 2002).

As one of the pioneering efforts in telehealth globally, the Telehealth Pilot Project encountered numerous implementation challenges and was stopped for re-evaluation in 2000. Subsequently, the scope and financing of telehealth implementation was scaled back. The Information Management Division remains responsible for telehealth as a whole; however, in practice, the various projects emerging from the original initiative have been taken over by the relevant MoH divisions, which determine the pace, scope and objectives in their implementation.

As discussed in detail in Case Study 10.1, systems interoperability was a key obstacle to implementing and scaling up the telehealth project. This continues to be a challenge, with no overall interoperability standard defined yet. At present, interoperability issues are being addressed on a case-by-case basis based on the needs of a particular application or system. The Health Informatics Centre (HIC) has been working to develop and promote the adoption of standards and terminology for the healthcare industry in Malaysia and to audit documentation to ensure data quality. While adherence to standards set by the HIC has been good, data quality remains a work in progress.

10.4.6 Assessment of Progress in Health Outcomes

10.4.6.1 Effectiveness

Household surveys indicated that poverty, a major factor associated with health, declined from about 37% in 1980 to 9% in 1999 (Chapter 3). The registration of births and deaths provided evidence that health service interventions were most successful in reducing infant, maternal and adult deaths. When death rates reached low levels, concerns about data accuracy and comprehensiveness began to surface. For example, as less than half of the deaths were medically certified,¹

there was insufficient information on the causes of death. The MoH established a system of confidential enquiry into maternal deaths to provide sufficient information to institute preventive measures for the future. These enquiries also led to the recognition that misclassifications of the cause of death were distorting the disease profiles constructed from this data source. Registers of notifiable diseases showed a continuing decline in the incidence and mortality of the major communicable diseases, while hospital statistics suggested increased morbidity and deaths from non-communicable diseases (Chapters 3 and 6). Household health surveys (Institute for Public Health, 1988; 1999) provided evidence of the growing importance of non-communicable diseases and related behaviour and led the MoH to establish Healthy Lifestyle programmes (Chapter 6).

10.4.6.2 Costliness

Concerns about healthcare financing continued during this phase of development. Studies indicated that Malaysia's total expenditure on health was relatively low compared to its GDP. Recognising the need for more comprehensive information on healthcare expenditure, the MoH developed the National Health Accounts (NHA) programme. The NHA uses standardised international NHA methodology to provide annual information on health expenditure. The data cover public and private sectors, are adjusted for inflation to support trends analysis, and include aggregated and sufficiently disaggregated information on the sources of funds and expenditure to support policy and planning decisions (Malaysian National Health Accounts Unit, 2015). The data provided by the NHA continued to support efforts to re-organise the country's healthcare financing system.

10.4.6.3 Equity

The information available for both service coverage and health outcomes of the population in different states indicated that access and use of services continued to improve in those states with the greatest need. Differences continued to prevail, but they became smaller (Chapters 3– 7). Household surveys also showed that exempting the poor from fees for public health services lessened the financial burden for the poorer people (Chapter 9). **Box 10.2** System observations: closing the feedback loop to improve data collection

Health information systems are crucial to creating learning feedback loops that enable health system strengthening. However, the actors who collect the data may not recognise its value, resulting in poor data quality. In developing this volume, we came across several accounts in which data collection and entry were low priorities for both hospital administrators and ground-level medical personnel, who were motivated by tasks that had direct impacts on patient outcomes. When data were used to evaluate and improve hospital performance, however, hospital administrators responded by making proper data entry a high priority and communicated that to the hospital workforce (Figure 10.1).



Figure 10.1 Reinforcing loop showing how compliance with data collection improves the quality of data, enabling positive impacts on health outcomes. When health system personnel are able to observe these impacts, the intrinsic motivation improves the level of compliance in data collection. Conversely, when this connection is not made, data collection can be perceived as a box-ticking exercise, compromising the quality of data collected.

10.5 Health Information in the 2000s

10.5.1 People and Their Health

The decennial census of population and inter-census estimates continued, and they showed that the majority of people lived in urban Box 10.3 System observations: use of health information for single- and double-loop learning

Health information can be used to improve the implementation of health strategies towards existing goals (single-loop learning). Such learning seeks to improve the performance of the health system within existing paradigms and is important for health system strengthening. The role of household health surveys in the establishment of 'Healthy Lifestyle' programmes provides a different example in which health information catalysed a paradigm shift. Here, health information was used to determine whether the existing goals of the health system were appropriate and adequate (double-loop learning)

areas, with the possible exception of Kelantan (Department of Statistics, 2011). The proportion of registered deaths that were medically certified increased from 39% in 2000 to 51% in 2014. However, the quality of data on the cause of death remained inadequate for policy and planning. For example, in 2013, the cause of death classification for 30% of deaths was unacceptable. Among the medically certified deaths, 12.5% were assigned to 'symptoms, signs and ill-defined conditions'; among the non-medically certified deaths, 60% were assigned to 'old age' (Omar et al., 2019). The continued use of household health surveys provided more abundant information on health-related behaviour and the characteristics of the users of services, while some surveys focused on specific health aspects such as adult nutrition (Institute for Public Health, 2014), non-communicable diseases (Institute for Public Health, 2015), maternal and child health (Institute for Public Health, 2016), and adolescent (Institute for Public Health 2018) and elderly health (Institute for Public Health, 2019). This information supported the refinement of health strategies and programmes in specific areas discussed in Chapters 4-6.

10.5.2 Health Workforce

Institutional re-organisation transferred responsibility for the pre-service education of most categories of health personnel to the MoE (Chapter 8). As a result, within the MoH, all aspects of human resource

management became the purview of the civil service arm of the MoH. As discussed in Chapter 12, the consequence was policies and management focused on MoH staff but not on the health workforce of the country. Information aspects of the health workforce that were essential for policy and planning were dispersed between various ministries and between departments within the MoH. Examples of such information include entry and output from training programmes, entry and exit from the workforce, geographic- and discipline-specific deployment and ratios between various categories. No single agency is responsible for collating, aggregating and analysing nationwide information. Spurred by a WHO effort to construct the health workforce profiles of member countries, the MoH initiated a major study (World Health Organization, 2014) to compile nationwide information that provided sufficient information for identifying key gaps in policies and impending problems in the workforce, some of which are illustrated in Chapter 8. Efforts are ongoing to institutionalise the routine collation and analysis of such information and to strengthen policy and planning by using it to make estimated projections for workforce requirements and supplies for the future.

10.5.3 Health Facilities and Services

The MoH maintains an inventory of health facilities in the public and private sector that enables it to monitor trends in the number of and the capacity of public and private facilities per head of population. This information supports policies and planning, for example, for expanding hospitals or clinic networks (Chapters 3–5). However, information on services availability in health facilities is limited to the public sector. The MoH conducted facility surveys through its Clinical Research Unit (Clinical Research Centre, 2014) in the private and public sector for a few years, creating a comprehensive picture that enabled the analysis of gaps and utilisation patterns, particularly of specialised services in hospitals and clinics. However, in subsequent years, although the private sector provided much of the information required by new legislation, the MoH did not institutionalise mechanisms for collating and analysing such information. The quality of services provided by health facilities in the public and private sectors became available from the quality accreditation programme (Malaysian Society for Quality in Health, 2018; Chapter 12).

Growing management competence in the MoH and international emphasis on evidence-based decision-making in healthcare produced a thirst for a wide variety of information. For example, several clinical specialist groups established disease registers for their specialities to provide evidence of the effectiveness of clinical interventions. In response to requests from MoH programmes, the National Institutes of Health (NIH) conducted an increasing number of studies to evaluate interventions or analyse problems. Examples include evaluation of the cluster hospital concept (Institute of Health Management, 2016), analysis of healthcare demand (Health Policy Research Associates et al., 2013) and attitudes towards tobacco smoking (Tee et al., 2012). Similarly, local universities produced increasing numbers of studies related to the Malaysian health system and its programmes. There is a growing challenge in keeping track of such outputs and providing convenient access to researchers and managers.

10.5.4 Health Financing

The NHA programme started by the MoH in 2001 (Ministry of Health Malaysia, 2018) made a major difference to the information available and the periodic assessment of health financing in both the public and the private sector and their relative evolution since 1997 (e.g. Malaysian National Health Accounts Unit, 2017). NHA data are quoted widely in reports and discussions, demonstrating that it has raised wide awareness of the issues related to health financing. Analysis of health expenditure showed substantial growth in health expenditure as a proportion of the GDP, from 3.3% in 2000 to 4.6% in 2015, and the relative importance of private health expenditure, which amounted to almost half (48.5%) of the total (Chapter 9).

10.5.5 Medical Products

In addition to information related to the regulation of pharmaceutical products in Malaysia and the use of pharmaceutical products and medical devices, the MoH has conducted surveys since 2004 on the use and prices of medicines (e.g. Ministry of Health Malaysia, 2006) and also later on medical devices (e.g. Ministry of Health Malaysia, 2009). Price negotiations for the procurement of medicines for the MoH use some of this information (Chapter 11).

10.5.6 Information Technology Development

The initial proposals for the greater use of IT in MoH information systems (Ministry of Health Malaysia, 1997) were further developed in proposals for a Malaysian Health Data Warehouse (MyHDW) (Ministry of Health Malaysia, 2013). This continues to be under development, with all the constraints usually encountered with IT systems development of a very comprehensive nature. By 2016, progress had been achieved in the collection, storage and processing of information on each hospital inpatient and in the production of related reports (Ministry of Health Malaysia, 2018).

The growing interest in producing and using information from research led the MoH to take the lead in establishing a national process to identify research priorities that guide public sector funding for research in Malaysian academic institutions as well as the NIH under the MoH (Suleiman & Merican, 2000). The rapid escalation in the volume of information from different systems created the need to create and maintain websites providing convenient access. It also required discussion forums to disseminate information. The NIH took the lead in collaborating with local and international academic institutions to provide regular forums for disseminating information and encouraging discussion. While this is evidence of progress, many institutions continue to struggle with issues of systematic cataloguing of research and providing access to research products. Another aspect of access to information is that while the MoH has a wealth of data from various sources, researchers outside the MoH system experience difficulty accessing it. Processes for making the data more accessible without compromising integrity are in the developmental stages.

10.5.7 Health Outcomes

10.5.7.1 Effectiveness

Chapters 3–7 demonstrated the substantial gains in health status but also the more recent plateau in infant and maternal mortality and in diseases such as dengue and tuberculosis, and the rapid increase in ill health due to non-communicable disease. Recent studies also indicate potential lacunae in the health information system. For example, a recent multi-dimensional study on urban child poverty shed light on childhood undernutrition, with high levels of stunting and maternal anaemia in the urban poor, which exists side by side with the problem of obesity among children nationwide (UNICEF, 2018). Another study indicated higher levels of avoidable mortality than in comparator countries of the Organisation for Economic Co-operation and Development (OECD) (Ministry of Health Malaysia & Harvard T. H. Chan School of Public Health, 2016). The output of studies such as these served to stimulate the Malaysian health system into making course corrections (Chapter 12).

10.5.7.2 Costliness

Information from the NHA programme (Malaysian National Health Accounts Unit, 2017) provided significant insights into the cost of health services in the public and private sectors, which increased by 1.3% of the GDP during the 15-year period of 2000–2015. This information also gave an indication of the service specialisation of the private sector in medical services and its costliness and increasing share of health expenditure (about 49% in 2015) (Chapters 3 and 9).

A major feature of the health system is technological change in medical care. While the MoH produces studies assessing new technologies and their cost-effectiveness, the use of such information is limited to MoH facilities and insurance agencies (Chapter 5).

10.5.7.3 Equity

Surveillance of poverty levels in Malaysia has shown a continuing fall in poverty levels in all states. However, although the gap has narrowed, there continues to be a higher proportion of people living below the poverty line in states with a higher proportion of people in rural areas (Chapter 3). Some concerns have been raised about the use of the current poverty line and the assessment of poverty in Malaysia (Ravallion, 2019), and suggestions have been made for alternative assessment methods that would better reflect current conditions. Information on estimated life expectancy at birth reflects the continuing difference among states in most cases (Department of Statistics Malavsia, 2017). As far as equity in access is concerned, household surveys show that health services in the public sector provide a degree of access to people in rural areas for most essential services, but the usual disadvantage of distance and travel remains. Although there is a financial burden associated with high out-of-pocket disbursements by those who use medical services in the private sector (Ministry of Health Malaysia & Harvard T. H. Chan School of Public Health, 2016), services supplied almost free by the public sector tend to diminish the financial burden and improve financial access for those most in need.

10.6 Lessons from the Malaysian Experience

Health information systems developed in incremental stages, spurred by growing demands from policymakers and managers from different levels in the healthcare system. The growing managerial competence and increasing complexity of healthcare services contributed to the growing demand for information. Conversely, information provided by the health information systems contributed substantially to the development of the healthcare system and provided evidence for making corrections in the direction of development. User demand contributed to improving the quality and timeliness of information. Digitalisation contributed immensely to the development of the health information system but also presented serious challenges related to governance and human and financial capacity.

During the development process, several information sub-systems grew in response to specific needs. A continuing challenge for the health information system is to co-ordinate and harmonise information generated by different sub-systems. Another continuing challenge is to provide adequate and timely access to information without jeopardising the integrity of various healthcare services.

10.7 Key Messages from Malaysia's Experience

10.7.1 What Went Well?

- Spurred by demands from increasingly competent managers and clinicians, the health information system, in incremental steps:
 - $\circ\,$ used information from health and non-health sources (census, income),
 - steadily improved the timeliness and quality of data, and
 - embraced initiatives that added analytic and evaluative information (health systems research, quality improvement, disease registries, technology assessment, NHA).

- The utilisation of data and information spurred improvement in data quality.
- Continuing efforts are needed to harmonise and standardise data generated by different information sub-systems that evolve with growing healthcare systems.

10.7.2 What Did Not Go So Well?

- Inadequate infrastructure, managerial capacity and demands on financial and human resources hampered ambitious digitalisation plans.
- In the interests of safeguarding confidentiality, academicians and researchers outside the MoH have inadequate access to health information.
- There is inadequate collated, analysed information on private sector healthcare and on occupational and environmental health.

10.7.3 Trends and Future Challenges

Increasing digitalisation is expected to bring great benefits if the system is able to address the difficult challenges of platform interoperability and concerns about confidentiality in relation to legal requirements, personal privacy and commercial interests.

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System Analysis Case Study 10.1: Challenges in Introducing Telehealth

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Introduction

Telehealth uses ICT for a wide range of applications in healthcare, ranging from information management to remote care. Many benefits from ICT use are scale-dependent. For example, integrated electronic patient records for a patient are only dependable if all the health providers for that patient are part of a common information system. When a telehealth standard is in common use, the benefit of adopting that standard is high, reinforcing interoperability (Figure 10-A, R1 loop). However, when there is no prevailing standard in practice or in policy, incompatible practices can proliferate (Figure 10-A, R2 loop).

Background to Telehealth in Malaysia

The push for telehealth in Malaysia was part of a national strategy, known as the Multimedia Super Corridor programme, for accelerating ICT use and moving toward a knowledge-based economy. Telehealth implementation was meant to follow a roadmap from 1997, beginning with a fiveyear Telehealth Pilot Project with four components: Teleconsultation, Mass Customised and Personalised Health Information and Education, Lifetime Health Plan, and Continuing Medical Education. A total of RM 100 million was allocated for this phase of telehealth implementation (Economic Planning Unit, 1996; 2001).

The move towards telehealth was widely welcomed in the healthcare sector, as it was perceived to address many health system needs by improving the coverage and quality of service delivery, including the equitable distribution of specialised care. It would also improve the health information system, thus providing the data necessary for better use of medical products, health financing and policymaking (Suleiman, 2001).

Telehealth was implemented in a top-down manner. This push from the top was necessary to create co-ordinated action across the MoH for the systemic changes needed to implement telehealth. Unfortunately, the knowledge and exposure regarding the need for health



Figure 10-A For telehealth functions that cut across health facilities, the more health facilities adopt and operate within a particular interoperable telehealth standard, the greater the benefit for other facilities to adopt that standard, creating a reinforcing cycle (R1 loop). However, when there is not a critical mass of health facilities operating to a single standard, the proliferation of incompatible telehealth standards can occur, as facilities seek to set the definitive standard or simply meet locally relevant needs with locally available resources.

interoperability was rather scarce in the 1990s, resulting in the insufficient establishment of standards that would ensure interoperability. This problem was exacerbated by varying levels of IT infrastructure and perceived needs across health facilities. As a result, the push for telehealth adoption did not create a critical mass of health facilities operating to the same standards. Instead, a range of telehealth systems proliferated without strict conformance to standards, undermining interoperability (Figure 10-B).

Persistence of Incompatible Standards

Malaysia's attempt to adopt telehealth was one of the earliest efforts globally. As such, a range of unforeseen challenges emerged and the



Figure 10-B The push for the adoption of telehealth could increase the number of facilities adopting an interoperable telehealth standard or lead to the proliferation of incompatible standards. Due to the lack of technical guidance and enforcement, a proliferation of incompatible standards occurred.

targets intended for the Telehealth Pilot Project were not achieved. The national push for telehealth was revised pending re-evaluation and new directions. Although unsuccessful, the pilot project provided valuable lessons and experience and increased expertise that could be built upon.

One of the key obstacles was the fragmentation of telehealth systems and practices that emerged in the Telehealth Pilot Project. With a variety of disparate systems in operation, enabling system interoperability would have incurred additional costs, as facilities that had already launched telehealth would have to be upgraded to new ICT systems and infrastructures (Figure 10-C, R3 loop). This would be both costly and disruptive. For health facilities that had not yet strongly



Figure 10-C The proliferation of incompatible telehealth standards actually increases the cost of adopting interoperable standards (R3 loop) due to health facility operations and structures coming to rely on incompatible telehealth software.

invested in telehealth, the limited number of facilities with which they could achieve interoperability limited benefits, while uncertainties regarding the future of interoperability standards increased risks (Figure 10-D, R4 loop).

Systems Lessons

Systems analysis of the experience of telehealth in Malaysia illustrates the importance of path dependence and lock-in in the development of information and communication technology (ICT) in healthcare. Malaysia's pioneer efforts with telehealth were timely and foresighted, even though they did not yield the desired results. However, the proliferation of telehealth practices has created a



Figure 10-D The lack of a critical mass of health facilities operating on the same telehealth standard reduces benefits for certain functions, such as health information exchange. The lack of immediate benefits to health facilities discourages the adoption of telehealth, which in turn makes it difficult to achieve a critical mass (R4 loop).

persistent problem for interoperability. It is important to design health system experiments to 'fail forward' when lock-in is a real possibility. In such cases, it may be more important to avoid unacceptable outcomes than to aim for full-scale success in implementation.

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Note

1. Medically certified deaths are those that are certified by physicians and include cause of death. Other deaths are certified by local police, who provide a 'lay' opinion on the cause of death reported by relatives.