Chapter 1
Introduction

1.1 Motivation and Objective of the Book

Which technologies are appropriate for building *health information systems*? How can they be managed? How to assess their *quality*? The objective of this book is to provide answers to these questions.

Health is one of the key components of our lives. And good health care is an important prerequisite for good health. Well-built and well-managed health information systems constitute an essential part of providing good health care. Health care is delivered for people by people. Health care starts when people are born (even earlier) and ends when people pass away. Sometimes, the relative share of health care in our lives appears negligible, for example, when we are in good health, living our "normal daily lives." Sometimes, the relative share of health care is intensive, for example, for persons suffering from a severe acute disease and as inpatients in hospitals. Sometimes, it is in between, for example, for persons with chronic diseases needing medication or other therapeutic measures on a regular basis.

The authors of this book have been involved in managing health information systems for many years, some of us for decades. Managing *information systems* also includes building and assessing components of such *systems*, as will be explained later. We do this mainly in research and education, but always with close links to practice. We also advise health care facilities as well as governments and other authorities. During all these years, we have seen information systems that contribute well to the diagnosis and therapy of patients by providing good support to *health care professionals* as well as to the patients themselves. We have also seen information systems that produce an unnecessary workload for physicians and nurses or fail to appropriately deliver *information* that would have been relevant for good decisions.

We, the authors of this book, believe that managing health information systems in the current era of digitization must be approached differently than in the past. In particular, in order to provide answers to the questions raised at the beginning, we

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need an understanding of how information systems in the context of health and health care relate to the various *life situations*.

This is why this introductory chapter is on such life situations and on the (sometimes contradicting) stakeholder requirements. *Stakeholders* in this context include the patients themselves as well as health care professionals and, for example, management staff in health care facilities and governmental bodies.

We are convinced that being aware of these life situations, of the stakeholder requirements, and of the basic concepts and terms introduced in Chap. 2 is of great importance. These two chapters will give you, the reader, a better understanding of the following chapters of this book: Chap. 3 on technology perspectives, Chap. 4 on management perspectives, and Chap. 5 on quality. These more generic chapters will be rounded out by Chap. 6 on specific health information systems for certain life situations and *health care settings* such as, for example, *hospital information systems* and information systems in personal environments.

After reading this chapter, you should be able to

- recognize the relevance of health information systems,
- understand the motivation and objectives of why this book was written,
- view life situations in the context of health, health care, and health care settings, and
- explain the various stakeholders' requirements of health information systems in this context.

1.2 Life Situations

As mentioned before, health care starts when people are born (even earlier) and ends when people pass away. Sometimes, the relative share of health care in our lives is small, sometimes it becomes higher. This section provides an overview of some typical life situations.

Health care organization and health-related processes can vary from country to country; however, these life situations seem ubiquitous. We focus on life situations related to health care. This view may be limited, as life is much more, but it is useful for our topic of health information systems.

1.2.1 Prevention

The World Health Organization's constitution defines health as a state of complete physical, mental, and social well-being [1]. Living in good health is by no means a given; it must be achieved or preserved by respective measures. In health care, many of these measures can be subsumed under the term "prevention" or, more precisely, primary *prevention*. In addition to primary *prevention* (prevention of diseases), the terms secondary *prevention* (early detection and timely treatment of diseases) and tertiary *prevention* (reduction of negative implications of long term, usually chronic

diseases) are well established and used. *Prevention* mostly takes place in our normal daily lives, for example, at the locations where we live and work. Tertiary *prevention* may also coincide with rehabilitation.

1.2.2 Wellness

Wellness is a term related to *prevention*, as it also focuses on living in good health. In the context of wellness, the term "fitness" can also be found. Wellness and fitness activities usually take place in our normal daily lives and at the locations where we live and work. Sometimes, wellness activities are done at wellness centers (e.g., hotels that are specialized in this field). Sometimes, fitness activities are done at sports centers and recreational parks.

1.2.3 Emergencies

Emergency situations such as acute heart attacks or severe traffic accidents are completely different life situations. Persons suffering such emergency situations frequently require immediate assistance. As patients, they are usually brought to the emergency units of hospitals, where they are diagnosed and treated by health care professionals.

1.2.4 Acute Diseases

Persons suffering from acute diseases also step out of their normal daily lives, at least to some extent. With respect to these diseases, these persons have become patients. Depending on the kind and severity of such an acute disease, patients may, among other things, be treated as outpatients in medical offices or as inpatients in hospitals. For outpatients, diagnosis and therapy may take place within these offices or at the locations where the patients live. If diagnosis and therapy are performed at a distance, these activities are usually subsumed under terms "telehealth" and "telemedicine."

1.2.5 Chronic Diseases

The life situations of patients suffering from chronic diseases can be more or less viewed similarly to those described for patients with acute diseases. In chronic situations, long-term treatment and long-term care is needed, and health care monitoring becomes more important here. If this monitoring is done at a distance, these activities are usually also subsumed under the term "telemonitoring."

1.2.6 Care

Life situations primarily related to care but not necessarily related to treating diseases are often characterized by physical and mental functional deficits of the affected persons that could lead to frailty, for example. These are often, but not exclusively, senior citizens at an advanced age. Care may be provided at these persons' private homes, at homes for the elderly, at nursing homes, or, for palliative care, at hospices.

1.2.7 Rehabilitation

In particular after treatment episodes for inpatients, rehabilitation episodes may sometimes follow in order to cure or alleviate diseases. As already mentioned, these rehabilitation activities can often be subsumed under tertiary *prevention*. Rehabilitation may take place at inpatient units or may be supported by outpatient rehabilitation centers. With acute and chronic diseases, this can be done within such centers, or perhaps at a distance through telerehabilitation activities.

1.2.8 Research for Life

Another life situation must be mentioned here that to some extent differs from the ones described above, as it is also of considerable importance for health information systems: the life situation of persons in the context of biomedical research. Patients, or even healthy persons, may participate in research activities. For example, patients may be asked to participate in randomized clinical trials. Or, as another example, *data* on patients may be stored in disease registers to better understand diseases and their diagnosis and therapy in order to improve treatment for future patients.

1.3 Stakeholders' Requirements

As mentioned in the introduction, health care is delivered for people by people. Also mentioned was that stakeholder in this context refers to the patients themselves, as well as health care professionals, the management staff of health care facilities, or

even governments. This section lists some of the essential requirements that important stakeholders have regarding health information systems.

Being aware of these stakeholders and their requirements of health information systems is important for adequately managing health information systems. We will list here major stakeholders, either introduced as persons or as bodies. This is not an exhaustive list. The requirements listed here for these stakeholders are important requirements with respect to health information systems. These lists will highlight some important requirements, but by no means all of them.

1.3.1 Requirements of Patients

The patients' objectives are usually to receive good and affordable health care, to be informed and empowered regarding all decisions related to health care and, if possible, to receive this care without having to change their normal daily lives too much, with social participation and dignity as important properties.

Requirements that patients have of health information systems are, mostly, (1) to be informed (e.g., about appointments with their physicians at medical offices, about diseases, about possible diagnostic and therapeutic strategies and their risks, or about positive or negative aspects of medication), (2) to be able to communicate with health care professionals and their facilities (e.g., asking for an appointment, asking for advice), and (3) to be able to provide data or to report (e.g., on unexpected events that may be important to know in the context of their diseases), and (4) to feel sufficiently informed and involved when decisions about their individual health care are being taken.

Patients also want to be informed about the qualification and reputation of their health care professionals and of their health care facilities. When receiving direct advice on health care matters, for example, through the internet or via health apps, they also want to know about the quality of the care.

Regardless of the persons and facilities providing the care, patients expect all caregivers to have access to all necessary data in their health record (provided the patients give their permission). They also expect data privacy and data confidentiality to be safeguarded.

Finally, patients expect health information systems to support not only themselves but—perhaps even more importantly—to also support their health care professionals and sometimes their informal caregivers and that this support is comprehensive, trustful, and lean.

Fig. 1.1 Health information systems constitute an essential part of providing good health care. Decisions are made during a ward round in pediatric intensive care. (Courtesy of Karin Kaiser/MHH)

1.3.2 Requirements of Health care Professionals

Health care professionals usually are physicians and nurses but may also be pharmacists, physiotherapists, and midwives, just to mention a few. Their objective is to provide good health care for their patients.

Requirements that health care professionals have of health information systems include that these systems support them in doing their work efficiently and in good quality. This often involves providing easy and comprehensive access to information in order to make good decisions, with organizational support and with reduced documentation efforts while maintaining good documentation quality (Fig. 1.1).

Having access to all the patient data relevant for adequate diagnostic and therapeutic decisions, for example, is of great importance. If relevant data are missing or if data are difficult and time-consuming to obtain, this would risk reducing the quality of care and could increase costs.

Additional requirements include being able to efficiently record and communicate decisions at the time and place where they were made, receiving decision support, and having access to knowledge on diseases and on how to treat them.

1.3.3 Requirements of Informal Caregivers

Informal caregivers are often spouses or close relatives of the patients. Although they are usually not trained health care professionals, their contribution to caring for patients can be of enormous importance for the quality of health care.

Requirements that informal caregivers have of health information systems primarily include being informed of the treatment provided by health care professionals, having access to the patients' health records (provided the patients give their permission), having the opportunity to communicate with health care professionals, and recording observations.

1.3.4 Requirements of Researchers in Biomedicine

Many researchers in biomedicine need patient data for their research. Provided that patients give their permission or that this is allowed by law, the researchers' objective is to access and use these data for their research. This can be routine data recorded during *patient care* at one or several health care facilities.

Sometimes these data can be aggregated, anonymized data. Biomedical research related to patient data is often conducted as part of studies, for example, clinical trials or observational studies, with a study plan, elaborated before collecting data, and approved by ethics committees.

Requirements that researchers in biomedicine have of health information systems include being supported in doing their work efficiently and in good quality, for example, to be able to access, store, and analyze such data with reasonable effort and with the potential of attaining good outcomes for medical progress.

1.3.5 Requirements of Management Staff

Persons involved in managing health care facilities have certain responsibilities related to running their facilities efficiently and in good quality with regard to their facilities' objective of providing health care. For this purpose, these persons must document procedures for reimbursement and to ensure the availability of data for *controlling*, this with respect to the sometimes-various levels of health care management.

Requirements that management staff have of health information systems include being supported in doing their work efficiently and in good quality. This often involves having timely access to controlling data and being able to efficiently use analytics tools in the context of data warehousing.

1.3.6 Requirements of Insurance Companies

At this point, we will shift our view from persons to facilities. Health care insurance companies want to spend the money obtained from their members to provide these members with good and efficient health care when needed. This can involve providing timely payment to health care facilities and *controlling* whether payments have been adequate. This may also comprise informing their members on health care matters and exploring and promoting new, improved health care processes.

Requirements that insurance companies have of health information systems include being able to carry out these tasks efficiently and in good quality. Insurance companies want to be able to verify whether payments that were made were actually used for "their" members and that these members were actually insured at the time of treatment.

1.3.7 Requirements of Governmental Bodies

Governmental bodies with tasks related to health care often involve ministries or departments of health. The objectives of such governmental bodies are to provide a legal framework for the health care of the people living in a certain state or region. Sometimes, they are involved in the practice of health care themselves.

Requirements that governmental bodies have of health information systems are that these *information systems* support good health care for the people of their state or region with reasonable costs and that the *information systems* provide data and *key performance indicators (KPI)* about the health status of people in the region or nation.

1.3.8 Requirements of Sponsors

Health care, health care facilities, and the people providing health care need to be financed. Financers of health care and of health care facilities will here be called sponsors. Sponsors may be states using taxes paid by their citizens or insurance companies using the premiums paid by their members. Sponsors (private companies, cities, states, etc.) can also own health care facilities such as hospitals.

Sponsors usually expect their facilities or *services* to efficiently provide health care that is competitive to facilities delivering related health care and

which is financially sound. For non-profit sponsors, this can mean running a *health care facility* without financial deficits. For commercially oriented sponsors, this can mean that health care facilities should work with a profit for the sponsors' stakeholders.

Requirements that sponsors have of health information systems are that these information systems support the objectives mentioned above for the respective health care facilities and that they provide the data needed for controlling investment costs and running expenses.

1.3.9 Requirements of Vendors

Vendors in this context are companies that offer hardware and software or consulting services for information systems of health care facilities. Vendors may also offer tools or services (on *prevention* and wellness) directly for healthy persons as well as for patients and their informal caregivers (e.g., through the internet and via health apps) and their settings.

The objective of vendors is to sell such tools or services and to be competitive within their respective markets. In addition to providing good products and services, customer retention can also play an important role.

Here requirements of health information systems are rather indirect, as vendors are not users of such systems themselves.

1.3.10 Requirements of Housing Companies

In the new era of digitization, the personal home environment can also play a significant role in supporting health care. This is particularly true for persons living at home who receive health care as outpatients, for example, with chronic diseases or as senior citizens with age-related deficits. Housing companies offering the opportunity to use sensor and actor infrastructures within the homes for health care purposes could be more competitive in their market.

Requirements that housing companies have of health information systems are that these information systems support the objectives mentioned above for the respective health care facilities and that they provide opportunities to receive and send data from and to health care facilities and to residents' apps.

1.3.11 Coinciding and Contradicting Requirements between Stakeholders

The requirements of the different stakeholders are sometimes similar and therefore coincide. Other times, however, they tend to conflict and may even become contradictory. Being well-aware that requirements of different stakeholders may sometimes vary and may even contradict is helpful when managing health information systems.

The patient-centered objectives on care of governmental bodies, for example, may to some extent contradict the institution-centered objectives of health care facilities and their professionals working in health care and management. The objectives of health care professionals within a health care facility will tend to focus on providing the best health care possible, while managers at the same facility will have a focus on cost efficiency and obtaining well-documented data for reimbursement and *controlling*. Sometimes, these contradicting requirements may even exist within the same person, for example, within a family physician at a small medical office who is responsible for both health care and management.

1.4 Example

The following example will be used in many parts of this book. Although the situations described here are realistic, all persons in this example are fictitious and do not exist.

The Russos live in a flat in a small town on the edge of the commuter belt of a large city. Mrs. Russo, a former optometrist, is 68 years old and—following a fall in the bathroom last year with a fracture of a leg and some complications—suffers from lasting limitations of her movement capacity, affecting her ability to perform some of her activities of daily living (e.g., taking a shower, shopping, meeting with friends). She was also diagnosed with a mild case of depression along with an anxiety disorder. Mr. Russo, a former software consultant, is 72 and, following a myocardial infarction 15 years ago, was diagnosed with heart failure 3 years ago. The Russos' general practitioner (GP), Dr. Andersson, has furthermore diagnosed him with hypercholesterolemia (elevated blood cholesterol) and diabetes and has put him on medication with several drugs. Dr. Andersson also advised Mr. Russo to take up mild physical activity and lose some of his excess weight, but—following a brief episode of motivation and a Nordic walking course—he has found it impossible to follow her advice and sustain regular physical activity, in part because he increasingly needs to help his wife in performing her daily activities.

One morning, Mr. Russo wakes up early in the morning from severe shortness of breath. Although he has experienced this symptom before in a milder form, he immediately senses that something is wrong and calls his GP. Dr. Andersson comes for a home visit and finds him in bed with low blood pressure, elevated heart rate, and pulmonary edema. She diagnoses him with an exacerbation of heart failure, strongly advises him to be admitted to Ploetzberg Hospital university medical center, and subsequently calls an ambulance. The paramedics arrive and perform a resting 12-lead electrocardiogram (ECG), and the emergency physician puts Mr. Russo on oxygen. After arrival at Ploetzberg Hospital, Mr. Russo is admitted to the cardiology ward and treated with drugs. Blood samples are taken and an echocardiography is performed. His condition improves over a week, but an intracardiac catheter examination (coronary angiography) shows a severe stenosis of a main coronary artery, which is treated immediately. Two weeks later, Mr. Russo is discharged from the hospital and, following a brief stay at home, begins rehabilitation at the Kreikebohm Rehabilitation Centre. Meanwhile, Mrs. Russo's children have organized a home nursing service for her that comes twice a day to support her while her husband is away, along with a domestic help to assist her with the housework.

Dr. Andersson receives discharge letters from both Ploetzberg Hospital as well as the Kreikebohm Rehabilitation Centre. She adapts his medication according to the cardiologists' advice. Along with his wife, Mr. Russo enrolls in a support program arranged by his health insurance company where he uses an app on his mobile phone to enter data on his physical and mental well-being and his weight. Furthermore, he receives an activity tracker that also measures his heart rate. Among other things, Dr. Andersson uses this data to manage the course of his disease and for adapting her treatment. Researchers from Ploetzberg Hospital ask Mr. Russo whether he would participate in a scientific study to investigate the effect of close-knit home monitoring on rehospitalization in patients with heart failure, to which he agrees. He can observe his monitoring data on his smartphone.

1.5 Exercises

1.5.1 Life Situations

Consider a recent health-related situation you were involved in. Which life situation (Sect. 1.2) does it correspond to and what was your role in this life situation (Sect. 1.3)? List some of the requirements you had in this role and in this life situation.

1.5.2 Requirements of Various Stakeholders

Consider the requirements of various stakeholders when it comes to health information systems supporting various life situations. Can you imagine situations where the requirements of two stakeholder groups differ or even contradict each other? What does this imply when building health information systems?

Reference

1. World Health Organization (WHO) Constitution. (1946, July 22). https://www.who.int/about/governance/constitution. Accessed 15 Jan 2023.