Preface

In recent scientific and policy debates at global and national levels, it has been frequently highlighted that demographic change, rising incidence of chronic disease, and unmet needs for more personalized care are trends demanding a new, integrated approach to health and social care. In an ideal world, integrated care encompasses continuity of care, shared care, holistic care of co-morbidity, and seamless delivery of care. In integrated care, professionals from different organisations work together in a team-oriented way towards a shared goal with coordinated resources to deliver, via an integrated service delivery process, the formal responses to all of a person’s care requirements in a way that also complements and treats as partners the informal care providers. This requires high-quality collaborative working relationships, clarity and commonality of objectives and care plans, effective communication among team members, a clear understanding of, and respect for, individual roles and skills within the team, a transparent incentive structure, and the general flexibility of practitioners.

ICT presents a major opportunity to enable or support care integration across social care and healthcare, superseding today’s chain of disjoint responses to discrete threats to health and social care needs. With the issue still being very much at a concept stage, much remains to be learned about how it can be made a reality, how framework conditions have to shift to accommodate new necessities, and how service and business models have to be built to get support from all stakeholders involved. However, an increasingly solid evidence base is emerging, indicating that ICT can be used effectively to respond to the growing call for improved care. At the same time, real-life examples of integrated eCare are emerging across the globe and can provide useful lessons.

Thus, we think that the time has come to take stock of what alreadyexists in the area of integrated eCare and give people active in the field the opportunity to publish their knowledge and experiences in this book, allowing others to learn and built upon existing experiences more easily.

First, we take a step back, reflecting a bit about what integrated care means across Europe and what conceptual approaches to integrated eCare exist, a topic taken up by the authors of the first three chapters in this book in Section 1, “Conceptual Approaches to Integrated eCare.”

Integrated care is anything but new. The call for better joined-up service delivery, particularly for those suffering from chronic conditions, traces back as far as into the 1950s. In fact, it is simply a return to the core care delivery philosophy espoused by Hippocrates, as Chapter 1, “The Core Vision of Person Centred Care in a Modern Information-Based Society,” by Michael Rigby starts off with. The new enablement though is the digital era, which can provide a return to an integrated approach after centuries
of increasing specialisation created increasing provider-dominated fragmentation. This fits both the modern idiom of consumer-orientation in an increasingly informed society and the need for increased efficiency in a rapidly ageing demography.

Integrated eCare is one phrase with several meanings, as is shown in Chapter 2, “Do All Roads Lead to Rome? Models for Integrated eCare Services in Europe,” by Lutz Kubitschke and colleagues. In general, one can observe two larger definition streams within the integrated care discourse. On the one hand, there have been developments starting within the healthcare realm, in particular the “man-aged care discourse” and the “public health discourse.” On the other hand, there is a broader approach putting increasing emphasis on real person-centred care, leading to the call for integration across social care, healthcare, and other relevant sectors. Integrated care is a mission and a journey, involving new services and service re-engineering, but to be achieved without losing the expertise of the present. It needs more than simply bringing together the stakeholders and adding ICT to end up with better care.

Integrated care, and especially ICT-supported integrated care, has become a key commitment across Europe as a service redesign principle. For example, the European Commission is actively promoting such change and innovation through its European Innovation Partnership on Active and Health Ageing initiative, in particular by means of its B3 Action Group on Integrated Care. The purpose of the group is to stimulate a forum of evidence and exchange for the practical adoption, replication, and scale-up of integrated care. It aims to make available programmes for chronic conditions/case management in at least 50 regions, for at least 10 percent of the target population by 2015 and to scale-up and replicate integrated care programmes supported by innovative tools, and services at least 20 regions in 15 Member States based on validated, evidence-based cases (2015-2020). Chapter 3, “Implementing and Scaling Up Integrated Care through Collaboration,” by B3 Action Group leader George Crooks and Donna Henderson highlights the common bottlenecks and barriers identified in a high-level survey of 27 B3 Action Group members from regions and delivery organisations across Europe to determine their state of readiness for the delivery of integrated care services. The authors also explore the key components that support the successful integration of services, including incentives and levers for change, and technology-enabled service solutions.

ICT can play an important, functional and supportive role in today’s care delivery and is regarded as an essential component to the successful operation of integrated systems of care. Yet, evidence suggests that the use of ICT is beset by significant barriers. For some, the emerging sophistication of ICT—for example, through mHealth or decision-support systems that can transfer data instantaneously—represents a set of disruptive innovations that will drive care systems to think and act differently. The truth, however, is often more prosaic in that the adoption of ICT innovations is only part of the wider challenges in the reform of care systems that play out across a broad spectrum of political, regulatory, organisational, professional, and cultural issues. Discussions around benefits and challenges of technology to arrive at better and more holistic care are being dealt with in three chapters in Section 2, “Technologies for Integrated eCare.”

The potential of ICT in integrated care delivery and risks and challenges that come along with it are critically reflected in Chapter 4, “Understanding Integrated Care: The Role of Information and Communication Technology,” by Nick Goodwin and Albert Alonso. Indeed, a recent systematic review of integrated primary and secondary care strategies found ICT cited as a key enabling factor (in some cases a prerequisite) in 17 of 21 articles. Implementing an appropriate ICT infrastructure across health
and social care was seen to improve planning of services and resource use, monitoring outcomes and cost-effectiveness, as well as a method for identifying and targeting people in need of care. ICT, then, helps to provide the necessary tools for “functional integration” that enables information to be shared between organisations and care professionals in order to promote inter-professional working and the better coordination of services around people’s needs. Yet the role of ICT is more ubiquitous than this since it can, at the interface between patients and care providers, enhance approaches to prevent ill-health (e.g. through forms of supported self-care), improve diagnosis and treatment (e.g. through the use of decision-support tools), and enable the real-time monitoring and management of a patient’s risk factors as a way to influence health and lifestyle. Hence, ICT has the potential to play many roles in supporting the effective realisation of integrated care in practice.

Many technologies, ranging from house automation, telemonitoring equipment, and service platforms to robots and smart textiles offer opportunities to support healthy, active, and dignified living. Online medical records allow exchange of relevant health- and care-related information between all involved parties. In addition, social media, online communities, and other services can assist informal carers and help them to better cope with carer burden. Other technologies like surveillance equipment, online follow-up, and video-call functionality increase the level of perceived safety for both the care recipient and the informal carer. Chapter 5, “Technology for Integrated eCare,” by Wil Rijnen and colleagues analyses technological developments relevant for integrated care service delivery and reflects ICT that made its way to the market. The authors conclude with a methodological roadmap towards the optimum solutions.

However, the mere existence of a multitude of ICT applications does not make care delivery better per se. The devil is as always in the details. ICT development for integrated care requires methods to deal with the complexity of the care environment and its different stakeholders and at the same time to deliver technically implementable specifications. To provide correct, understandable, and timely information at the point of need and to facilitate communication and decision support for a network of actors with different prerequisites and needs are some of the big challenges of integrated care. Chapter 6, “Informatics and Socio-Technical Challenges when Designing Solutions for Integrated eCare,” by Sabine Koch and colleagues therefore focuses on the specific challenges related to informatics and socio-technical issues when designing solutions for integrated eCare. Methods for requirement elicitation, evaluation, and system development using user-centred design in collaborative environments involving a variety of stakeholders are presented. Case studies in homecare of older patients, in the care of stroke patients, and regarding citizen eHealth services in general illustrate the application of these methods. Possible solutions and pitfalls are discussed based on the experiences drawn from the case studies. To address the main informatics and socio-technical challenges in integrated eCare, namely informatics-supported collaborative work, and to provide coordinated continuity for the patient, top-down activities such as health informatics standardisation and bottom-up activities resulting in the definition of concrete patient journey descriptions, interaction points, information needs (that can be transformed into standardized data sets), as well as visualization and interaction patterns need to go hand in hand.

Evaluation of integrated eCare services and the development of sustainable business models are key to implementation and widespread use, as reflected in Section 3, “Evaluating Integrated eCare Services.” Making the case for investment in these services and applications requires better marshalling of existing evidence, not only to show that integrated eCare works, but also to show where—and in what organisational context—it will work. Financial flows in social and healthcare systems must be critically assessed
for their ability to act as incentives or disincentives for integrated eCare service provision. Innovative business models are required, acknowledging that the business case for these complex interventions is often very different for the different players.

In Chapter 7, “Socio-Economic Impact Assessment and Business Models for Integrated eCare,” Reinhard Hammerschmidt and Ingo Meyer describe an approach to assessing the costs and benefits of integrated eCare services during their development and early operation under circumstances of uncertainty. They describe tools and methods to improve the service design through an iterative assessment of its socio-economic impacts. The final aim is to transfer pilot applications into sustainable routine services.

The evaluation of integrated eCare services must be thorough and include research methods from multiple different research traditions simultaneously, since it has to deal with a range of stakeholders and with interventions of high complexity. This implies a necessity of knowledge from different research paradigms and understanding of proper reporting. Chapter 8, “Evaluating Integrated eCare: Discussions and Guidance of a Diverse Field,” by Anne-Kirstine Dyrvig provides guidance for evaluating integrated eCare based on the MAST methodological model, along with discussions of advantages and disadvantages related to certain decisions that must be made during the research process. As an aid for understanding, real-life examples of evaluation are provided to illustrate challenges and possible solutions throughout the chapter.

However, having reflected on the important theoretical background and approaches to integrated eCare, the most important goal is to get the services to the people who need them as a mainstream and sustainable service. This is why the final section, Section 4, “Integrated eCare Services in Practice,” of our book deals with real-life implementations of integrated eCare services in different countries and regions across Europe.

Chapter 9, “Telemedically Augmented Palliative Care: Empowerment for Patients with Advanced Cancer and their Family Caregivers,” by Romina Nemecek and colleagues starts off with summarising the evaluation design of a controlled pilot study where a user-friendly telepresence system was developed and evaluated. The service enabled patients and family caregivers to send a direct request to a palliative care team. Patients with advanced cancer have a substantial symptom burden, which deteriorates their quality of life. Palliative care improves well-being of patients and their family caregivers. Additionally, a specially tailored database was developed, which contains up-to-date patient information. In the pilot, patients with advanced non-small cell lung cancer were consecutively assigned in a control and an intervention group.

A successful system that allows caregivers to assess the condition of a frail older person in a multidisciplinary way and to exchange information between providers in different organisations in a secure way, anywhere and at any time, was developed in Belgium. Chapter 10, “The Development of BelRAI, a Web Application for Sharing Assessment Data on Frail Older People in Home Care, Nursing Homes, and Hospitals,” by Dirk Vanneste and Anja Declercq describes the BelRAI Web application, which has been developed to support the use of interRAI assessment instruments in a multidisciplinary way and to exchange client-centred information across care settings. The authors describe the particularities of BelRAI, the security aspects, the support tools, the gradual process of implementation, the dos and don’ts, the pros and cons, and the challenges for the future. The benefits seem to overrule the drawbacks, but it has also become clear that only a significant expenditure on resources with regard to adequate staffing in healthcare environments, appropriate information technology, and training facilities can contribute to a successful introduction, maintenance, and full exploitation of this innovative health information system.
As in many countries, integrated health and social care has been a missed goal in the United Kingdom for many years. In Chapter 11, “Making Integrated eCare a Reality in the UK: Past Failures, Current Successes, and Future Challenges,” Mark Gretton examines why this has been the case and what might be done to remedy this. He describes the inception of the welfare state in its historical context to provide clues as to why integration has proved difficult. Gretton then examines Wistow’s forensic analysis of the barriers to integration, focusing in particular on his emphasis on the difficulty of integrating the diversity of social care with the monolith of healthcare. Rigby’s analogy of technological road mapping as a model for integrating care and planning services is explored in detail, before explaining how this method was utilized in the INDEPENDENT project in Hull. The chapter concludes that the analogy of “technological mapping” is a useful guide for directing services and helping to integrate care, but that government too has a vital role to play.

The experiences made in three pilot projects in Greece are summarized in Chapter 12, “Integrating Social and Health Services in Greece: Implementation of Three Pilot CIP-PSP-ICT-Programs (ISISEMD, INDEPENDENT, RENEWING HEALTH),” by George E. Dafoulas and colleagues. This chapter analyses services developed in three European projects in terms of service design, implementation, evaluation, and exploitation. All three services have proven to be easy to use with a high level of user satisfaction, and the evaluation outcomes indicate a positive impact (including reduced stress levels and increased quality of life and degree of independence) on the users’ lives. Those impacts are consistent with the key objectives of the Public Social and Health reformation that is taking place in Greece and can be considered as an answer to the main peculiarities and problems in Greek health and social care.

One of the emerging integrated care services in Germany is described in Chapter 13, “From Agreement to Realisation: Six Years of Investment in Integrated eCare in Kinzigtal,” by Birgit Reime and colleagues. Gesundes Kinzigtal is a population-based integrated care approach organising care across all health service sectors and health needs. The authors describe the development of an electronic networking system in the project between 2006 and 2013. An IT system supplies physicians’ offices and other providers such as ambulant nursing care services and hospitals with time-saving services, providing a comprehensive set of information about the patient. Reime and colleagues conclude with an outlook on expanding the project to further healthcare sectors and raise ideas for future studies on self tracking and mobile health data from APPs as well as community resources and voluntary networks to join electronic patient networks.

In Chapter 14, “The eCare Network in Bologna: No Longer Home Alone,” Carla Fiori describes the experience in Bologna following the creation of an eCare Network for frail elderly people since 2005. This has been developed over the years as a network of citizens, associations, institutions, and professionals, providing a relational and support ecosystem to frail elderly people. The issue of financial sustainability of the health and social welfare system in the face of ongoing demographic change has stimulated the creation of a service that aims to encourage the permanence of frail elderly citizens at home to prevent the onset of frailty or dependence conditions and to improve their quality of life by fighting social isolation and through the use of appropriate IT technologies. Community-based voluntary associations also play a key role in the eCare Network for the frail elderly.

Chapter 15, “Integrated eCare in Dementia: The Irish Experience in the INDEPENDENT Project,” by Sarah Delaney concludes this book by describing the evaluation of the INDEPENDENT project as it was implemented in Ireland. Newly implemented services provide Service Managers and Care Coordinators at the Alzheimer Society of Ireland (ASI) with information from telecare packages installed
in the homes of people with dementia via a joint client database between ASI and Tunstall Emergency Response (TER). The joint database provides information on alerts and events generated by the telecare system to staff of ASI. This information is used to review and update personal care plans in response to changing client needs. The evaluation examined both the experiences of family carers of the telecare packages installed and the experiences of staff and key stakeholders in ASI and TER of the telecare packages and the Web portal.

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