


# Achieving Effective Integrated E–Care Beyond the Silos

Ingo Meyer  
*empirica, Germany*

Sonja Müller  
*empirica, Germany*

Lutz Kubitschke  
*empirica, Germany*



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Integrated care is seen as modern and exciting, but in fact, it is simply a return to the core care delivery philosophy espoused by Hippocrates. The new enablement of this is the digital era, which can provide a return to an integrated approach after centuries of increasing specialization has 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. The principal challenges are the necessary re-engineering of application of professional practices, the replacement of one strong set of governance processes with a new set, ensuring that technical system architects engage constructively and iteratively to meet the needs of all stakeholders, and ensuring a political and societal sponsorship, which is positive but not destructively naïve.

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The call for better joined-up service delivery, particularly to those suffering from chronic conditions, traces back as far as into the 1950s. However, a disjointed care provision split into multiple service silos prevails. In the present chapter, the authors present lessons from practice, particularly from two recent pilot projects, INDEPENDENT and SmartCare, to show what can be achieved through the use of ICT-supported, integrated care and to show how it can be achieved under given framework conditions. The guiding question is which roads will actually lead to Rome and which will not. By simply adding ICT to current care practices one will most likely not end up with better care. Rather, the authors argue that

a multi-pronged innovation approach needs to be pursued, one that simultaneously pays attention to the stakeholders involved, to the particular working models of the different care actors, and to the technologies to be employed. Using such an approach is shown to considerably increase the likelihood of achieving positive impacts on different levels, even if risks and uncertainty cannot be completely avoided.

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*Donna Henderson, NHS 24, UK*

Across the developed world, the majority of health and care systems are looking towards the integration of services within and across organisations to deliver efficiencies and enhance effectiveness and, by doing so, deliver service sustainability in an increasingly challenging environment, while a simple aspiration to articulate in reality the delivery of integrated care is proving challenging and in some cases elusive. In 2012, the European Innovation Partnership on Active and Healthy Ageing’s B3 Integrated Care Action Group carried out 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. This chapter highlights the common bottlenecks and barriers identified, before moving on to explore the key components that support the successful integration of services, including incentives/levers for change and technology-enabled service solutions.

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*Albert Alonso, Innovation Directorate of Hospital Clinic Barcelona, Spain*

This chapter provides a thorough grounding in the meaning and logic of integrated care and the role of ICT. It begins with an overview that describes why integrated care has become a central theme to the reform of health and social care in the face of mounting demographic and economic challenges that require a new way of thinking about how care can be more cost-effectively delivered. Following an in-depth analysis of what is meant by integrated care, including an interpretation of the various definitions and interpretations that have been provided, the chapter moves on to provide an understanding of the challenges faced when implementing integrated care programmes in practice and the key lessons in how systems of integrated care can be built. The role of information, communication, and technology as essential components for the success of integrated care is then considered together with an assessment of the future research agenda.

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*Pantelis Angelidis, Vidavo S.A., Greece*

Today, healthcare and social care services are often delivered independently. This can lead to inefficiencies, duplication of resources, and potentially to reduced levels of care quality. Older people are particularly affected by this situation, since they often need both types of services, such as support with daily living activities and chronic disease management. At the same time, the potential of Information and Communication Technology (ICT) to support integrated service delivery remains largely unexploited. Against this background, many are the technologies that might offer a suitable canvas for integrated care, particularly to more vulnerable social groups. The main goal of this chapter is to provide insight into the most promising technologies for facilitation of integrated care, such as Ambient Intelligence, Internet of Things, Robotics, Service Platforms, etc., and to discuss the potential of combined technologies to yield efficient and well-accepted solutions.

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The central role of eHealth to enable the successful implementation of integrated care is commonly acknowledged today. This is easier said than done. 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. This book chapter focuses on the specific challenges related to informatics and socio-technical issues when designing solutions for integrated eCare. Methods for requirements 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 standardised data sets), as well as visualisation and interaction patterns need to go hand in hand.

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Putting into place ICT-supported, integrated health and social care services means that a multitude of stakeholders are affected by changes to their working process and often to their economic performance. In this chapter, the authors describe their approach to assessing integrated eCare services to enable care integrators in making strategic decisions during development and early operation. The approach is founded on cost-benefit analysis. It stands out from other assessment frameworks in that it 1) allows identifying and addressing stakeholders that lose through the service and thus may become strong veto

players, 2) allows monitoring of the actual and prospective service development over time, 3) includes non-financial factors that in many cases have a major impact on the behaviour of a stakeholder, and 4) provides probabilistic methods for achieving rigorous results from data of varying quality. Following an exemplary integration case developed from one of their pilot projects, the steps of the assessment process are described, including an exemplary interpretation of the analytic results and their application in practice. The chapter concludes with an outlook on future work.

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Evaluation of projects on integrated eCare is key to implementation and widespread use. The evaluation must, though, be thorough and include research methods from multiple different research traditions simultaneously. This implies a necessity of knowledge from all research paradigms and understanding of proper reporting. In this chapter, guidance for evaluation of integrated eCare is provided, 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.

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*Romina Nemecek, Medical University of Vienna, Austria*

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*Barbara Hofer, Medical University of Vienna, Austria*

*Herbert Watzke, Medical University of Vienna, Austria*

*Christoph Zielinski, Medical University of Vienna, Austria*

*Michael Binder, Medical University of Vienna, Austria*

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. Within the scope of a controlled pilot study, a user-friendly telepresence system is developed, which enables patients and family caregivers to send a direct request to a palliative care team. Additionally, a specially tailored database is developed, which contains up to date patient information. Twenty patients with advanced non-small cell lung cancer are consecutively assigned in a control and an intervention group. The intervention group receives the telemedically augmented care, whereas the control group receives standard care. The primary goal of this chapter is to determine the usability and feasibility; the secondary goal is the assessment of the intervention's impact on quality of life and the number of unscheduled hospital admissions. To sum up, telemedically supported ambulatory palliative care may synergistically help to improve safety and quality of life.

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*Dirk Vanneste, KU Leuven, Belgium*

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As the complexity of caregiving rises and surpasses traditional models of care, the need for comprehensive and integrated assessment systems increases. The use of standardised and computerised data—available to those who must make decisions—has become paramount. In Belgium, the BelRAI Web application has been developed to support the use of interRAI assessment instruments in a multidisciplinary way and to exchange client-centred information across care settings. This chapter describes 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.

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*Mark Gretton, University of Hull, UK*

Integrated health and social care has been a missed goal in the United Kingdom for many years. This chapter examines why this has been the case and what might be done to remedy this. The inception of the welfare state is described in its historical context to provide clues as to why integration has proved difficult, before examining Wistow's forensic analysis of the barriers to integration in light of this, 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 utilised 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.

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*George E. Dafoulas, Independent Researcher, Greece*

*Christina N. Karaberi, Independent Researcher, Greece*

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*Kalliopi P. Liatou, Independent Researcher, Greece*

The Greek healthcare system incorporates principles of different organizational patterns characterized by many organizational, management, efficiency, and effectiveness problems. Integration of existing health services via the European Commission's ICT Policy Support Programme (ICT PSP) have proven to be economically advantageous for both patients and family members as well for the public health sector. Furthermore, the integration of existing services such as public help lines and health records promotes the main elements the Greek healthcare systems need for reformation of primary care via the establishment

of referral systems, the introduction of personal electronic health cards, and the adoption of clinical and pharmaceutical protocols. ISISEMD, INDEPENDENT, and RENEWING HEALTH are only three of the implemented CIP-PSP-ICT-programs that have been tested under realistic conditions integrating existing health services offered to people who suffer from chronic diseases as well as to their formal and informal caregivers. To be precise, ISISEMD tested under real conditions the impact of an intelligent system for independent living and self-care of seniors with cognitive problems. INDEPENDENT was a program based on both continued wellness of end users and organizational cooperation. The implemented INDEPENDENT services were built on existing health and social services. Lastly, RENEWING HEALTH aimed to evaluate the effect of tele-health on the quality of life of chronic patients. This chapter aims to give an analytic report of those three European programs in terms of service description, implementation, evaluation, and exploitation. Firstly, the authors introduce to the readers the main characteristics of the Greek healthcare system and the risks that it faces in regards to the major reformation and cut offs due to the economic recession, and then they explain how those risks could become opportunities to promote integrated services.

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*Birgit Reime, Gesundes Kinzigtal GmbH, Germany*

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*Christian Melle, Gesundes Kinzigtal GmbH, Germany*

*Monika Roth, Gesundes Kinzigtal GmbH, Germany*

*Marcus Auel, Gesundes Kinzigtal GmbH, Germany*

*Helmut Hildebrandt, Gesundes Kinzigtal GmbH, Germany*

Gesundes Kinzigtal is a population-based integrated care approach in Germany that organises care across all health service sectors and indications. This chapter describes the development of an electronic networking system in the project between 2006 and 2013. The IT system that was developed shall supply physicians' offices and other providers such as ambulant nursing care services and hospitals with time saving services providing the complete relevant information of the patient. The status of IT systems in practices at the start of the project and steps to achieve a mutual IT system and intersectoral cooperation are described. Pros and cons for small or large IT companies as partners and patients concerns on data safety and confidentiality are discussed. The chapter closes with an outlook on expanding the project to further healthcare sectors and raises 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.

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*Carla Fiori, CUP 2000 S.p.A., Italy*

This chapter describes the outcome of the creation of an eCare Network for frail elderly people in 2005. This was 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 phase of ongoing demographic revolution, 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 dependency and to improve their quality of life by fighting social isolation through



the use of appropriate IT technologies. Community-based voluntary associations also play a key role in the eCare Network for the frail elderly. Finally, in addition to a detailed description of the activities that have been put in place, the service outcomes, innovations, and prospects for further development are illustrated.

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This chapter describes the evaluation of the INDEPENDENT project as it was implemented in Ireland. The project in Ireland consisted of the collaboration of the Alzheimer Society of Ireland, a not-for-profit organization providing services for people with dementia and their family carers, and Tunstall Emergency Response (TER), a commercial telecare provider organization. A joint client database (referred to as a “Web portal” in the project) was developed that provided information on alerts and events generated by the telecare system to ASI staff. This information was used to review and update personal care plans in response to changing client needs. A multi-perspective and multi-method evaluation was undertaken in the INDEPENDENT project with family carers, staff in ASI, and TER and key stakeholders in ASI and TER. Thirty dyads (consisting of one person with dementia and one family carer) were evaluated at baseline. At 6-month follow-up, 12 dyads had dropped out due to mortality or entry into long-term residential care. ASI and TER staff and key informants were interviewed a year after the Web portal was implemented. Logged data were collected on telecare event and alert data, and on usage of the Web portal. Across the evaluation period, there were 1,661 telecare activations. The average number of activations per individual user was 24. A total of 1,800 logins were made to the Web portal by ASI staff. The telecare packages were given a high satisfaction rating by family carers, and this was borne out in interviews with staff, even though no change was observed in carer burden or proxy assessment of the quality of life of people with dementia. The main benefits identified were security, peace of mind, and reassurance. The Web portal was seen as beneficial, in that it provided close-to-real-time access to information on telecare alerts and events that could enhance care planning. However, staff regarded the portal as difficult to navigate and use. Key informants in ASI and TER both viewed the Web portal as enhancing the reputation of their organizations and felt that the benefits of the portal outweighed any difficulties encountered when implementing the project.

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## About the Contributors

**Ingo Meyer** is a senior research consultant at empirica. He holds a degree in Sociology, Political Science, and Theology from Bonn University. He has been working for empirica and in the field of ICT for health, care, and independent living since 2002. For the past six years, he has been focusing on issues of integrated care, preferably supported by the use of ICT tools. In this context, Ingo works on requirements-based service definition, the development of integrated health and care service processes, and their implementation in real-life environments. One aspect that he has been specialising in is the development of viable business models for integrated care, based on socio-economic impact assessment and cost-benefit analysis. Among other things, he has been and is involved in projects such as CommonWell ([www.commonwell.eu](http://www.commonwell.eu)), INDEPENDENT ([www.independent-project.eu](http://www.independent-project.eu)), SmartCare ([www.pilotsmartcare.eu](http://www.pilotsmartcare.eu)), and the recently started BeyondSilos project.

**Sonja Müller** is senior research consultant at empirica. She holds degrees in Geography, Urban Development, and Economic Sociology from Bonn University. Since joining empirica in 2001, her main fields of work are in the area of ICT for social care, independent living and integrated care. Sonja has strong expertise in requirements elicitation, service definition and process model development as well as managing large-scale pilots. She was strongly involved in the first pilot B on ICT supported integrated social care and healthcare services “CommonWell” and is currently working in the SmartCare ([www.pilotsmartcare.eu](http://www.pilotsmartcare.eu)) and the recently started BeyondSilos project.

**Lutz Kubitschke** is senior research consultant at empirica. He holds an interdisciplinary degree in Social Research, Economics, and Law (Diplom-Sozialwirt) from Göttingen University. Since he joined empirica in 1993, he has mainly been concerned with investigating the potentials generally provided by digital technologies for supporting vulnerable population groups and older citizens. He has a long standing track record in socio-technical and policy related research, and he has coordinated a range of high-profile projects in this field, the most recent one being a Europe-wide pilot project with a focus on better joining-up existing social and healthcare services with help of ICT ([www.independent-project.eu](http://www.independent-project.eu)). He is also involved in the ongoing SmartCare project ([www.pilotsmartcare.eu](http://www.pilotsmartcare.eu)) delivering integrated ICT-enabled care services to older citizens in ten European countries.

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**Albert Alonso** is a medical doctor trained at the University of Barcelona where he also developed his doctoral work obtaining his PhD degree in 1992. Additionally, he holds a postgraduate degree on

Management and Organisation of Information Systems by the University Pompeu Fabra (1996). Currently he works at the Innovation Directorate of Hospital Clinic as Head of Area of Care process efficiency and ICT integration. His main lines of work focus on the definition, evaluation and deployment of new models of health care provision with a special emphasis in integrated care models that use ICT; evaluation methodologies for integrated care and ICT and Health Technology Assessment. He has participated in numerous R&D projects since 1997. He is a regular lecturer in pre-graduate and post-graduate courses. He is Vice-chair, Secretary and founder of the International Foundation for Integrated Care and also Secretary of the Catalan Society for Clinical Documentation.

**Pantelis Angelidis** received his diploma in Electrical Engineering and his Ph.D. in Telecommunications Engineering from the School of Electrical Engineering, Aristotle University of Thessaloniki in 1989 and 1993 respectively. Since June 2002, he has founded VIDAVO. He has worked as a technology expert in the area of Telecommunications for the past 15 years. He has served as a project manager in more than thirty international projects. He has published over forty papers in international journals. He is a member of the permanent consulting committee of the Technical Chamber of Greece on telecommunications, a certified consultant on telecommunications of the Technical Chamber of Greece (Central Macedonia chapter) and of the Greek Courts (Thessaloniki), a member of the CEN TC224/WG6 technical committee.

**Marcus Auel** was born in 1965 in Giessen. He has studied medicine at the Ruprecht-Karls-University of Heidelberg, and at the University of Texas at San Antonio, Texas, USA. He has graduated at the Ruprecht-Karls-University of Heidelberg in 1991. From 1991 to 2004, he has specialized in internal medicine, cardiology and emergency medicine at the Klinikum Ludwigshafen, the Kreiskrankenhaus Dormagen and the Lukaskrankenhaus Neuss. From 2004 to 2005, he worked as an attending physician at the Klinik Bad Rippoldsau, where he has subspezialised in clinical nutrition and naturopathic medicine. Since 2005, he has been working as a physician in private practice in Hausach. He is member of the local physicians' network ("MQNK") and the "Gesundes Kinzigtal GmbH."

**Ilse Bierhoff**, Msc, is a research project manager at Smart Homes. She studied at the technical university of Eindhoven at the faculty Technical Innovation Science. Her expertise is applying knowledge from social sciences on problems related to the introduction of new technologies. Activities are the implementation of the user centred design approach with a focus on gathering of user requirements with innovative methods that allow an equal and creative interaction between user and experts, giving guidance to the process of actually installing smart home technology and the evaluation of those projects with all the stakeholders, and developing educational material on ambient assisted living.

**Michael Binder** is professor of telemedicine at the Medical University of Vienna. He is the supervisor of the telemedical research group at the Medical University of Vienna and vice chairman of the E-health service committee (Austrian Federal Ministry of Health). In 2002, he co-founded the Center of Excellence for Telemedicine at the Medical University of Vienna. He regularly organizes national workshops on telemedicine. His other scientific fields of interest are Medical Informatics, Artificial Intelligence in Medicine, Evidence Based Medicine and Dermatology (general dermatology, dermatooncology, pediatric dermatology). He has published more than 100 papers in peer-reviewed journals

## **About the Contributors**

and does scientific review himself (e.g. *British Medical Journal*, *Artificial Intelligence in Medicine*, *Journal of Investigative Dermatology*).

**Karaberi Christina** was born in 1978 in the town of Trikala. She studied Philosophy, Sociology and Clinical Psychology at the University of Crete, where she received her two Degrees: Degree in Philosophy and Sociology (1997-2001) and Degree in Psychology (2002-2004). She continued her studies on a post graduate level in “Healthcare Management MSc.” She is working as a private practitioner for the last 8 years and has also been involved in many tele-health, telecare, and e-government European projects. She has participated as a speaker in several conferences and workshops in national and European level.

**George Crooks** is currently the Medical Director for NHS 24 and Director of the Scottish Centre for Telehealth & Telecare. NHS 24 is the national provider of telehealth services for the whole of Scotland currently providing the majority of its services via telephony, the Web and digital television. He is responsible for the quality, safety and effectiveness of all clinical services and the development of new services in partnership with other NHS organisations. George was a General Medical Practitioner for 23 years in Aberdeen latterly combining that role as Director of Primary Care for Grampian. George was elected President of the European Health Telematics Association in February 2012 and is a Board member of the European Connected Health Alliance. He leads the Integrated Care Action Group on behalf of the European Commission within the European Partnership for Active and Healthy Ageing. He is Chair of the Scottish Digital Health and Care Innovation Programme Board, leading on the at scale delivery of telehealth and telecare services and also the Chairman of the Digital Health Institute in Scotland, a partnership between academia, industry and health and care delivery organisations delivering innovation in technology and design that can provide safe, effective and sustainable health and care solutions and create economic growth in Scotland. He was awarded an OBE in the Queen’s New Year Honours List 2011 for services to healthcare.

**George E. Dafoulas** is an Internal Medicine resident and the project coordinator of the clinical pilots for Central Greece of the EU co-funded scale trials “Renewing Health” ([www.renewinghealth.eu](http://www.renewinghealth.eu)) and “United for Health” (<http://www.united4health.eu/>) for the Health Technology Assessment of tele-health across EU member states. He is a medical consultant for the telehealth, telecare and EMR, EU co-funded projects for “e-trikala SA” a leading competence center of the Municipality of Trikala, in the e-health sector in Greece. Dr Dafoulas is also involved in research related with innovative tele-health services, working with the SANA group (<http://sana.mit.edu/>) after an internship in CSAIL-MIT, Cambridge-Boston, USA.

**Anja Declercq** is an associate professor at the Faculty of Social Sciences (Sociological Research Center) and project leader at LUCAS. She is specialized in research on care for older persons, with an emphasis on care for people with dementia. She also is an interRAI fellow ([www.interrai.org](http://www.interrai.org)), a member of the Instruments and Scales Development committee (ISD) of interRAI and a member of de Board of interRAI. Previous research projects dealt among others with innovative living arrangements for people with dementia, care pathways of older persons with cognitive and/or depression, and the implementation of the interRAI instruments in Belgium.

**Sarah Delaney** is a Senior Research Consultant with the Work Research Centre in Dublin. She holds an undergraduate degree in Social Anthropology from Queen's University Belfast and a Master degree in Applied Social Research from Trinity College Dublin. Sarah specialises in researching eHealth as applied to chronic disease management, mental health and psychiatry of old age. She is also experienced in the development and application of innovative approaches to research and evaluation.

**Carla Fiori** was born in Bologna (Italy) on June 21<sup>st</sup> 1957. She graduated in Political Sciences, course of Sociology, in 1981. From 1981 to 1987 she has been Researcher at the Department of Educational Sciences of the University of Bologna. Then, from 1987 to 1996, she has been employed by the Municipality of Bologna, with various functions: Project Manager for the realization of the first system for joint health bookings in Italy, and Project Manager for different European projects under several Framework Programs (GALA, PH-NET, CHARM, among others). From December 1997, she has been working for CUP 2000 S.p.A., first as Middle-level manager, and subsequently (from April 1999) as Executive Manager. She is presently Director of the International and Research Projects Office. In addition, she has been appointed by the President of CUP 2000 as Chief Executive Officer of the shared-capital company "T Erre e-Care Campania S.p.A." in the years 2006-2007. She has participated as speaker to numerous national and international conferences, and, as teacher, to several university courses and masters.

**Rafael Llarena Gómez** is the European Project Manager in Tunstall Healthcare, as well as the Head of the Telehealth Department in Tunstall Ibérica. He graduated in Computer Science in the University of Murcia and is MBA in the Instituto de Empresa (Madrid). Rafael has been involved in European Projects since 2004, starting as a researcher in the University of Murcia, moving then to Atos Origin where he worked as Project Manager for 4 years. In Tunstall, he has been coordinating EU projects at level group and he has been responsible of setting up a Telehealth monitoring centre to provide service to an international pharmaceutical firm.

**Nick Goodwin** is co-founder and CEO of the International Foundation for Integrated Care (IFIC), a not-for-profit membership-based foundation dedicated to improving the science knowledge and application of integrate care across the World ([www.integratedcarefoundation.org](http://www.integratedcarefoundation.org)). Nick also works as a Senior Associate at The King's Fund, London supporting its programme of research and policy analysis for integrating care. Nick's international commitments include the EU FP7 Project INTEGRATE ([www.projectintegrate.eu](http://www.projectintegrate.eu)) and the European Innovation Partnership on Active and Healthy Ageing. Nick is working with the World Health Organisation to support the development of a Global Strategy to develop person-centred and integrated care, and is on the Expert Advisory Team to WHO Regional Office for Europe's Framework for Action towards Coordinated/Integrated Health Services Delivery (CIHSD).

**Mark Gretton** is a Lecturer in Nursing at the University of Hull with a 25 year clinical background of acute hospital nursing. His principle interests are in the health and social care of older people, particularly those with dementia-related issues the care and management of people with acute and chronic cardiac problems, and ethical issues affecting end of life care and the autonomy of decision making. He is a Resuscitation Council (UK) Advanced Life Support Instructor and a member of the Hull Dementia Academy. He was the project leader of the Hull INDEPENDENT project and works clinically as a specialist nurse/lecturer in cardiac care at the Hull and East Yorkshire Hospital Trust.

## **About the Contributors**

**Maria Hägglund**, MSc, PhD, is a senior researcher at the Health Informatics Centre at Karolinska Institutet in Stockholm, Sweden. She defended her PhD thesis entitled “Sharing is Caring: Integrating Health Information Systems to Support Patient-Centred Shared Homecare” at Uppsala University 2009, and it focused on improving homecare of elderly patients through ICT. Her continued research focuses on user centered development of patient-centred information and communication systems to support collaboration within health- and social care as well as patient empowerment. She also has extensive experience of teaching and supervising at the Global Master’s Programme in Health Informatics at Karolinska Institutet. She has over 30 refereed publications and several invited presentations internationally.

**Reinhard Hammerschmidt**, MA, is senior research consultant at empirica specializing in business planning, evaluation and impact assessment of ICT-related healthcare services. He obtained a masters degree in Geography and Sociology from the University of Bonn (Dipl.Geogr.) and medical expertise from a training as a paramedic. He joined empirica in 2002 and has since then been engaged in a number of RTD and policy projects dealing with health and social care. He was co-investigator of EC-commissioned studies “eHealth Impact: The Economic Benefits of Implemented eHealth Solutions at Ten European Sites” and “EHR Impact: Economic Impact of Interoperable Electronic Health Records and ePrescription in Europe” developing and applying an economic impact assessment method based on cost-benefit analysis. Reinhard further developed this method in the ASSIST project for the European Space Agency where the assessment framework was refined and extended by a self-assessment tool for telemedicine projects aiming to become sustained services.

**Donna Henderson** trained as an Occupational Therapist and worked as an operational manager of a range of health and care services before moving into strategic planning for adult health and care services. She now specialises in supporting the development of telecare services in Scotland, in her role as Service Development Manager in Scottish Centre for Telehealth and Telecare. As part of NHS 24’s active engagement in European initiatives, she coordinates the European Innovation Programme on Active and Health Ageing’s B3 Action Group on Integrated Care.

**Helmut Hildebrandt** holds a master’s degree in pharmacy from the University of Marburg. He has worked intensively with the World Health Organization (Copenhagen) on health promotion and in health sciences with the University of Hamburg. During his 20 years of being founder and chair of a consulting firm to the health care industry he worked for leading hospitals, health insurances, physician’s networks, pharmaceutical, and biomedical companies. In 1999, he supported the federal ministry of health to introduce the possibility of managed care contracting into the German health care law. Since 2010, Helmut Hildebrandt concentrates exclusively on the development and management of integrated care (delivery) systems within his OptiMedis AG and Gesundes Kinzigtal GmbH is being headed by him. In 2013 he co-authored a report for a sustainable and efficient health care delivery reform for the Heinrich Böll Foundation. Helmut Hildebrandt is board member of the German Managed Care Association, has authored and co-authored several books, and has published more than 80 papers mainly on integrated delivery systems.

**Barbara Hofer** obtained her medical degree at the Medical University of Vienna, Austria investigating the latest developments in telemedicine/teledermatology with special emphasis on mobile applications



and its legal, digital picture processing and compression aspects, accuracy of telemedical results and economic facets. Additionally, she got her MSc (Sociology) at the department of Sociology, University of Graz, Austria. In combining her medical and sociological expertise her current research focuses on how to convey and communicate online risk information to patients and physicians to facilitate medical decision making. She concentrates her research on (telemedical) risk communication with a special interest how the general public and medical specialists use the Internet to obtain medical knowledge. Insights from this research are incorporated into online consumer health information tools and into physicians' continuing education tools.

**Patrick Huber** graduated 2012 at the Upper Austria University of Applied Sciences – Hagenberg Campus in Biomedical Informatics as MSc. His master thesis dealt with mobile wound management, in concrete with the standardization of a wound report using HL7 CDA. Currently he makes his PhD in Medical Informatics at the Medical University of Vienna, and also is employed as a research associate at the Telemedical Working Group of the Department of Dermatology at MUV. His scientific focus is telemedicine, EHRs, Interoperability and Standardization. Another part of his work requires knowledge of clinical decision support systems. He is interested both in Store-and-Forward and also Live-Interactive Telemedicine.

**Udo Kardel** was born in 1962 in Gengenbach, Kinzigtal. He holds a Master's degree in Economics from the Albert Ludwigs University of Freiburg. His minors were IT and software development. From a training program at the Siemens Nixdorf AG, he graduated as a system analyst. Between 1989 and 2007, he worked in several companies as an organization programmer, system analyst and software developer. Since 2008 he has been affiliated with the Gesundes Kinzigtal GmbH. Udo Kardel is responsible for linking the physicians' practices electronically, building the infrastructure in the practices and in the management office. Furthermore, he is in charge for the further development of software solutions, for the IT support of the practices and for the data safety and security. He is managing the cooperation with partnering IT companies and providers. Since 2012, he has been the head of the department of organization management and IT.

**Sabine Koch**, MSc, PhD, is the first professor of Health Informatics at Karolinska Institutet in Stockholm, Sweden and director of its Health Informatics Centre as well as the programme director of the Global Master's Programme in Health Informatics. She received both a MSc and a PhD degree in Medical Informatics from Ruprecht-Karls University Heidelberg, Germany. Her main scientific contributions were in the fields of dental informatics, and IT supported models for integrated health and social care applied in homecare of elderly citizens. Koch co-authored a recent research position paper (2013) of the European Science Foundation about "Harmonising Health and Social Care Delivery and Informatics Support to Ensure Holistic Care." She is the current treasurer of the International Medical Informatics Association (IMIA) and has about 80 refereed publications and more than 40 invited/keynote presentations internationally.

**Kalliopi Liatou** was born in 1984 in Trikala and studied Computer Science in the Department of Informatics of the Athens University of Economic and Business (AUEB), where she graduated from in 2007. In 2013, she received her Master of Science (MS), Computer Systems Networking and Telecom-

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munications from Staffordshire University, where she developed a “Citizen Responder Web platform for Crisis management” during her dissertation thesis. She worked in a private company in Athens as a Computer Programmer and in 2009 returned in Trikala where she started her cooperation with the e-trikala office in the Research and Development Department/EU Project Management Department. In this direction, she has also been involved in various telehealth, telecare and egovernment projects and workshops, participating as a speaker in several conferences in national and European level.

**Eva Katharina Masel** graduated 2009 at the Medical University of Vienna, Austria. Since 2010, she is working at the Clinical Division of Palliative Medicine of the Medical University of Vienna, which is the leading study centre of the Austrian Palliative Care Study Group (AUPACS). Her research focuses on palliative care of patients and families facing serious illnesses. Currently, she is doing her residency in Internal Medicine, her PHD in Mental Health and Behavioural Medicine, which focuses on psychiatric comorbidities in patients receiving palliative care and an University Course (Master of Palliative Care) at the Private Medical University Salzburg. Her research projects primarily focus on symptom management in palliative care. She is an active member of national and international palliative care associations.

**Christian Melle** holds a Master’s degree in Business Administration with a focus on healthcare management from Nuremberg University since 2007. He has a longstanding experience in implementing telemedicine structures in the inpatient, outpatient and home care sector by working for a telemedicine provider company in Nuremberg. He is currently employed with Gesundes Kinzigtal GmbH as a project manager in the department of health care management. Christian Melle has gained profound knowledge in development and management of integrated health care programs such as backpain or rheuma on local level. He also contributes to calls for proposals by the ministry of health on national and international level (e.g., related to ambient assisted living). Beside his work with Gesundes Kinzigtal GmbH he has started studying Health and Medicine Management at the University of Nuremberg – Erlangen in 2012.

**Romina Nemecek** graduated 2011 at the Medical University of Vienna, Austria. Since 2010, she is an active member of the telemedical research group under the supervision of Univ.-Prof. Dr. Michael Binder. Her research focuses on telemedicine, palliative care and dermatooncology. Currently, she is doing her residency and her PhD, which focuses on augmented palliative care for patients with advanced cancer and their family caregivers. Her other research projects deal with new skin imaging methods (laser-scanning microscope, multiphoton/optical coherence tomography), the management of chronic wounds and telemedicine in general. She is also an active member of the Evidenced-Based Medical Compliance Cluster (Ebmc<sup>2</sup>) of the Medical University of Vienna.

**Lamprini Ch. Oikonomou** is a Health Psychologist who specializes in the diagnosis and treatment of mental dysfunctions. Since December 2010, she has been privately involved in providing therapy to clients diagnosed with anxiety disorder, depression, emotional problems and addictions. She has also been involved in teaching of psychology at Public Institute of Vocational Training (IEK) and at the Military School of Permanent Officers of Greece (ΣΜΥ) and has been conducting research on telehealth and telecare field. More specifically, she participated in the ISISEMD (Intelligent System for Independent Living and Self-care of Seniors with cognitive problems). She also participated in the INDEPENDENT- ICT (Enabled Service Integration for Independent Living). She participated in the



publication of “Gerontechnology: Providing a Helping Hand When Caring for Cognitively Impaired Older Adults: Intermediate Results from a Controlled Study on the Satisfaction and Acceptance of Informal Caregivers,” *Current Gerontology and Geriatrics Research* (2012, <http://www.hindawi.com/journals/cggr/2012/401705/2012>). Through her lecturing, her written works, and her clinical research, she has sought to improve the care for people with mental dysfunctions.

**Stefanie Porkert**, MD, graduated at the Medical University of Vienna in 2009. Since 2011, she is dermatology resident at the Department of Dermatology, Division of General Dermatology, Medical University of Vienna. Additionally, she is working on her PhD thesis, focusing on chronic wounds. She is part of the telemedical project group of Prof. Binder and coordinates clinical studies focusing on teledermatology and wound management. Further scientific interests are CTCLs.

**Birgit Reime** is affiliated with Gesundes Kinzigtal GmbH as a public health expert and parallel as an acting professor of health promotion with Furtwangen University. She holds a Master’s and Doctoral degree in Psychology with a focus on medical psychology from the University of Marburg and a Master’s in Public Health with a focus on healthcare systems from the University of Ulm. She has 24 years of teaching experience in medical, nursing, midwifery and physiotherapy schools. During her time as a postdoctoral fellow at the School of Nursing at the University of British Columbia, Vancouver, Canada, Dr. Reime has gained profound experience in projects on health networks. She became an Adjunct Scientist in the Department of Healthcare Innovation and Improvement at the British Columbia Child and Family Research Institute in 2006. Her current work focuses on health promotion programs for vulnerable groups.

**Michael Rigby** commenced his career in the English National Health Service (NHS), in community services policy research. His first involvement in health informatics was in 1972, when he was involved in the design—and subsequently the running—of a child health EHR. His career then progressed to Service Planning Officer for an NHS region, responsible for planning of health services for 2.5 million population. He then transferred to an academic career, focussing on health service quality and use of information. He undertook work in many fields, including advice on electronic record developments in mental health in Plymouth as an English national project, and for a similar independent project in Ireland, and he ran or was involved in many projects in Europe and more widely. He is now retired from employment, and acts as expert adviser for *inter alia* the European Commission, European Science Foundation, and OECD.

**Wil Rijnen**, MSc, PDEng, works as a research project manager at Smart Homes, the Dutch expert centre for house automation and smart living. Since 2010, he is involved in various European research projects in the field of Integrated Care, Ambient Assisted Living and eHealth. Collaborating in these projects broadened his understanding of Europe’s care delivery, his expertise in care-related user research, and his insight into various user groups, including vulnerable elderly, COPD patients, chronic heart failure patients, etc. He holds a Master degree in Product Development from the Artesis University College of Antwerp (Belgium) and an additional post-master degree in User-System Interaction from the Eindhoven University of Technology (the Netherlands). His expertise is in User Research, User-Centred Design, Interface Design and Human Computer Interaction.

## **About the Contributors**

**Monika Roth** was born in 1968 in Gengenbach (Kinzigtal). She has studied nursing management at the Catholic University of Applied Science in Freiburg, and she has graduated from the doctoral program in Public Health at the UMIT in Hall, Tyrol, Austria. From 2000 to 2008, she worked in the management of an organization of long term care, at the Vinzentiushaus Offenburg GmbH. Since 2008, she has been working as a project manager of public health in the Gesundes Kinzigtal GmbH in Haslach, Black Forest, Germany. Since 2010, she is working as the head of the public health department in Gesundes Kinzigtal. Monika Roth is responsible for the primary prevention activities which are being offered in cooperation with sports clubs and the regional partners in the towns and villages in the Kinzigtal valley.

**Isabella Scandurra**, MSc, PhD, PhD thesis in medical informatics (2008), regards how to build usability into health informatics. Her major scientific interests comprise human-computer interaction in health and social care, mobility and home care, as well as usefulness and usability issues of ICT solutions in integrated care and other transitional settings. She was recently (2013) the project leader for a governmental initiative on how to improve the national eHealth strategy by incorporating usability in the eHealth action plans. Current research focus is on implementation, evaluation and interaction design of clinical information at the point-of-need in complex care situations where different care professionals collaborate and where the patient is engaged in the care. Key issues are patient-centred care, patient empowerment, ICT to support cooperation and multi-stakeholder participation in different processes. She has 45 refereed publications and she also works as a health informatics/usability expert outside academia.

**Sophie Schur** graduated from the Medical University Vienna in 2010. Since 2011, she is doing her PhD and residency at the department of Internal Medicine I/Clinical Division of Palliative Care at the Medical University Vienna. Her current research interest focuses on clinical research in palliative care and oncology with special interest on advanced cancer patients and their informal caregivers, the practice of palliative sedation and sarcoma and GIST patients. She further is an active member of the European Association for Palliative Care (EAPC) as well as the European Society of Medical Oncology (ESMO).

**Dirk Vanneste** holds a Bachelor in Nursing, a Master's in Medical Social Science (KU Leuven, Belgium) and a certificate of traditional Chinese medicine (Hubei University of TCM, Wuhan, P.R. China). He also studied data management at the Vrije Universiteit Brussel, the Universiteit Antwerpen and the Universiteit Gent. He worked in long term care facilities and ran his own home care organization for over 20 years. He currently has a private TCM practice. He also works at LUCAS (KU Leuven) as a doctoral researcher. His research mainly focuses on the conditions in which InterRAI instruments could be implemented at a national level in Belgium and the use of the interRAI instruments through online registration on the BelRAI Web application.

**Eleftheria Vellidou** is an Electrical Engineer (NTUA, GR), and holds an MSc in Digital Signal Processing (UMIST, UK) and an MSc in Management of Business Innovation and Technology (AIT, GR). She spent more than 15 years in the telecom industry and her professional experience ranges from product research and development to management of large-scale telecom projects implementation. She has participated in numerous European and National research projects mainly of the e-health and biotechnology domains. Her current research interests include medical informatics, telemedicine, vital signal

processing and diagnostic support systems. She leads the company's European collaboration activities. She is a member of the Technical Chamber of Greece.

**Herbert Watzke** is Professor of Palliative Care and Head of the Division of Palliative Care at the Medical University of Vienna, Austria, since 2005. His research activities are in the area of end-of life care for cancer patients and concern questions such optimizing diagnostic tools for symptoms in unconscious patients near the end of life and investigating new tools such as telemedicine which could help ascertain continuity of care when patients are dismissed from palliative care wards.

**Christoph Zielinski** is Professor of Clinical Oncology since 1992. He is head of the Department of Internal Medicine I at the Medical University of Vienna since 2004. From 2008–2010, he was Vice-Rector of the Medical University of Vienna. In 2010, he became the coordinator of the CCC (Comprehensive Cancer Center – a conjoint institution of the Medical University of Vienna and the General Hospital of Vienna). In 2013, he was appointed head of the CCC. His research focuses on clinical experimental oncology. He has published well over 100 papers in peer-reviewed journals.

## Chapter 13

# From Agreement to Realisation: Six Years of Investment in Integrated eCare in Kinzigtal

**Birgit Reime**

*Gesundes Kinzigtal GmbH, Germany*

**Udo Kardel**

*Gesundes Kinzigtal GmbH, Germany*

**Christian Melle**

*Gesundes Kinzigtal GmbH, Germany*

**Monika Roth**

*Gesundes Kinzigtal GmbH, Germany*

**Marcus Auel**

*Gesundes Kinzigtal GmbH, Germany*

**Helmut Hildebrandt**

*Gesundes Kinzigtal GmbH, Germany*

### ABSTRACT

*Gesundes Kinzigtal is a population-based integrated care approach in Germany that organises care across all health service sectors and indications. This chapter describes the development of an electronic networking system in the project between 2006 and 2013. The IT system that was developed shall supply physicians' offices and other providers such as ambulant nursing care services and hospitals with time saving services providing the complete relevant information of the patient. The status of IT systems in practices at the start of the project and steps to achieve a mutual IT system and intersectoral cooperation are described. Pros and cons for small or large IT companies as partners and patients concerns on data safety and confidentiality are discussed. The chapter closes with an outlook on expanding the project to further healthcare sectors and raises 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.*

### INTRODUCTION

A key problem of the German health service system is its institutional fragmentation, as in many other health systems: public health services, primary and secondary ambulatory care (outpatient care), and hospital (inpatient) care

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are organised and financed largely independently from each other. The separation between office-based (ambulatory) and hospital-based (inpatient) physicians is stricter than in other countries. This historical division of health services is connected to a reimbursement system without incentives for outcome-oriented health care or prevention so that quality- and value-based incentives have

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been virtually non-existent (Schlette, et al., 2009). Doctors in ambulant practices receive a kind of fee-for-service reimbursement. There are strong incentives for (technical) interventions. A cap which varies by the physician's medical specialty restricts the total amount of all such payments. The fee schedule is based on services actually provided and the payment caps are comparable to a salary with the intention that incentives for an (unnecessary) extension of services are being avoided (Busse and Riesberg, 2004).

The shortcomings of such a fragmentation into health care sectors have often been noticed (Amelung et al., 2012). Most prominent are the problems around insufficient communication between the different health professionals that work on the same patient. First it leads many providers to perform redundant services and, therefore, to unnecessary expenditures for ambulatory care, resources that are lacking for required care in other fields. For the patients concerned, these redundant services imply not only a waste of time but also – at least in situations such as X-ray – unnecessary risks (Schonfeld et al., 2011). Second, insufficient communication may cause harm directly because health professionals may give false advises and false or incorrect medication because of lack of information. Up to 5% of all hospital cases are estimated to be the result of wrong, too high or too low doses or of incompatible medications and around 25,000 deaths are calculated per year by the same reasons (Schrappe, 2005). Better and quicker communication delivered to each participant in the care process could help reducing this burden significantly (Hammersley et al., 2006).

The idea of implementing mutually compatible electronic means of communication and semi-automatically data processing for cooperating providers of different sectors of care has remained an utopia for German normal care up to now, with 68% of primary care physicians working in solo practice and another 31% in small group practice (Schlette et al., 2009) and more than 150 different IT-systems used in these practices. The same holds

true for the idea of creating a system of electronic patient records accessible to all providers treating a given patient (patients' informed consent provided). By facilitating the cooperation of all health care professionals, e.g. by jointly developed integrated care pathways, synchronising medications and by developing electronic patient records across the sectors of care *Gesundes Kinzigtal* aims to create the preconditions for a better-coordinated follow-up. This chapter will report on the experiences gained during the development and implementation of eCare into the integrated care model of health services in *Gesundes Kinzigtal*.

## **BACKGROUND**

Located in Southwest Germany, *Gesundes Kinzigtal* (in English: "Healthy Kinzig Valley") is the only population-based integrated care approach in Germany, which organises care across all health service sectors and indications and which is thoroughly scientifically evaluated on its medical outcomes compared to standard care, and which has a long-ranging contract basis with an adequate amount of investment (Seiler, 2007; Siegel et al., 2014). The system serves around half of the population of the region (around 33,000 insured of two statutory health insurances – AOK and LKK Baden-Wuerttemberg – out of 72,000 people living in *Kinzigtal*). It is free of charge for the insured of these health insurances. It is run by a regional health management company "Gesundes Kinzigtal GmbH", which has been founded through the cooperation of a local physicians' network ("MQNK") and a German health care management company with a background in medical sociology and health economics ("OptiMedis"). Details of the contractual basis and philosophy of the collaboration between health insurer, physicians and other health professions, healthcare institutions and the management company have been described in detail elsewhere (Herrmann et al., 2006, 2010, 2012a, 2012b). It

can be compared to the so-called accountable care organisations in the US, introduced by the Obama administration.

Summarising it can be said, that starting from 2006, *Gesundes Kinzigtal GmbH* is accountable for all the 33,000 insured people and their total costs of care and is rewarded for the relative gain that has been developed compared to the nationwide normal costs of care. The long term contract between the health insurances and *Gesundes Kinzigtal* and the thorough evaluation of over-, under- and misutilisation of care secures that *Gesundes Kinzigtal* is interested in investing into the health of this population and delivering the best possible prevention and care at the right time and in the right place (Hildebrandt et al., 2012a).

In contrast to many other integrated or managed care approaches *Gesundes Kinzigtal* serves the patients without any restriction regarding providers; that means the patients who enroll themselves into this program are free to choose any provider and are not restricted to use only those who belong to the project. Around 60% of all providers in the region take part and the number is rising. Their remuneration does not differ from the conventional way in Germany but the management company *Gesundes Kinzigtal* pays special surplus fees directly to the participating providers for additional intensified chronic care or educating services that are asked for by *Gesundes Kinzigtal* to improve the health status of the patients and strengthen their abilities to better manage and cope with their diseases.

Having started in 2006, the approach is an innovative model of integration in its combination of logistic reengineering of care processes, IT-integration, public health and prevention. The intervention includes about twenty preventive and health promotion programs for specific conditions. The primary goal of these programs is to improve patients' overall health status and increase their quality of life and thus to reduce interventions that would be necessary without the improved health status. In order to achieve maximum effective-

ness, *Gesundes Kinzigtal's* care and preventive programs target common chronic diseases with high impact on patients' health status and against which effective interventions are available.

The more effective trans-sector organisation of the local health care system and increased investments in well-designed preventive and health promotion activation programs are associated with a reduction in morbidity and mortality, and in particular with lower overall costs for the insured members of these "sickness funds". The results for one of the insurers show a substantial morbidity-adjusted efficiency gain for the years 2007- 2010, rising to more than 16% of total costs (included are pharmaceutical, hospital, nursing, emergency as well as physiotherapist and sick leave costs) compared to a control group of members of the same insurer (Hildebrandt et al. 2012b). A propensity-score matched control (n=4,596 each) between members of *Gesundes Kinzigtal* (IV) of the other insurer (AOK) and non-members (NIV) came to a significant reduction in mortality rates in the time frame of 10 months after enrolment (IV: 1.76% vs. NIV: 3.74%). Also after exclusion of the first two months after enrolment (an adjustment to avoid an indirect immortal time bias) the results remain stable (IV: 1.58% vs. NIV: 2.94%). After the intervention start the margin improved more in the IV than in the NIV too (margin difference over two years: 151 €). (Schulte et al. 2012)

At the core of the company's interventions are some basic prerequisites:

- Individual treatment plans and goal-setting agreements between physician and patient.
- Enhancing patient self-management and shared decision-making.
- Chronic care model (Wagner et al, 2001), patient coaching and follow-up care.
- Right care at the right time.
- System-wide electronic patient record.

The electronic patient record is the central element of many integrated care projects. In research



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on electronic patient records, an alignment is considered as being achieved when the process called ‘translation’ has finished. This process involves the four phases of problematisation (Callon 1986):

1. **Definition:** Defining a problem for which the electronic patient record is the chosen solution.
2. **Interessement:** Getting relevant stakeholders and health care providers to accept this problem-solution.
3. **Enrolment:** Defining the key roles and practices in the network.
4. **Mobilisation:** Engaging others in fulfilling the roles, performing the practices and linking with others in the network.

The consequences of implementing an electronic patient record have been investigated in many ways and by a variety of disciplines (Greenhalgh et al., 2009). In a broad-scale review of 37 previous reviews the authors found that while some primary studies and some systematic reviews showed positive benefits from the electronic patient record system, neither the nature nor the scale of benefits were consistent (Car et al. 2008).

It appears that context factors of electronic patient record systems have a strong impact on the extent of their benefits. The likelihood of success of an electronic patient record system is associated significantly with the question whether the system is locally “homegrown” (evolved in an ad hoc way by health care providers familiar with the operational level of key work applications) or whether it was developed “off the shelf” (developed as e.g., commercial products; Shekelle and Goldzweig 2009). “Homegrown” electronic patient record systems mostly emerged gradually at the speed of local need, energy and enthusiasm (Greenhalgh et al., 2009). As an example of a “highly efficient system associated with improved quality and safety of care” Greenhalgh and colleagues (2009) refer to the U.S. Department of Veterans Affairs, which introduced a paperless record system and

documented significant improvements in health outcomes following this process (Kupersmith et al. 2007). These effective solutions, however, are restricted to a distinct setting and are not widely generalisable. On the contrary, “off the shelf” electronic patient record systems often were purchased as an element belonging to a strategy for swift change (e.g., to solve an instant problem in the system). “Off the shelf” electronic patient record systems typically induced problems of fit with the requirements at the practice sites and often failed to meet expectations.

The development of the *Gesundes Kinzigtal* electronic patient record system was characterised by both sorts of characteristics, those of “home grown” and those of “off the shelf” systems. One of the central aims of the integrated care approach of *Gesundes Kinzigtal* is the best and easiest possible transparency for providers to the electronic patient records containing all diagnoses, treatments and prescription records of all providers taking part in the *Kinzigtal* system. When *Gesundes Kinzigtal* started, this was not at all the case. Each practice had only access to its own stored data, either paperbound or electronically stored. As observed elsewhere, if a general practitioner had sent a patient to a specialist, normally within several days but sometimes only within several weeks or even months s/he would receive a letter (or a fax) in return with the results of the specialists tests being made (Schabetsberger et al., 2006).

Today, all partnering physicians of *Gesundes Kinzigtal* have access to the information within the electronic patient records not only for data stored by themselves but also by the other providers. This requires a high level of trust among the network of health care providers. The very special situation: General practitioners as well as specialists may see this information within their own practice IT-system and don’t have to search for it in another data storage. All novel information is stored within the same day in a highly encrypted manner in a database in *Kinzigtal* and is then delivered to each provider who has got the written consent by the



patient, that s/he may get this information. The patient has to separately give written consent to each physician to allow access to his or her data once for a period of two years. For each patient a particular code is being constructed. After the patient gave his or her consent in the practice data access via the same specific code is enabled. Thus the patient is the owner of his/her data and has the exclusive right of disposal. Provided that patients consent a provider's access, the health care professional will have access to all relevant diagnoses and treatment information. This implies a swift and accurate data communication between providers which is an important precondition for increasing the quality of care by, e.g. reducing medication interactions and avoiding costly—and sometimes risky—redundant services. The chances for the physician to receive adequate information instead of asking the second or third time the same questions about patient's health status and treatments will rise. Not only for the physician (by saving valuable time) but also for the patient this is an important aspect in terms of getting a confidential relationship to his/her following two sections report on the pitfalls, benefits and lessons learned in terms of the development of the system wide electronic patient record. On the other hand the physician may fear that his potential failures in medication or treatment may be seen by his colleagues as well, therefore a special culture of cooperation and mutual quality improvement is a prerequisite for installing this kind of transparency.

## **ISSUES, CONTROVERSIES, PROBLEMS**

Since the initiation of the project *Gesundes Kinzigtal* in early 2006 the implementation of information technology and network building among the distinct project participants was one of three major tasks besides developing the health

management programs and enrolling patients and providers.

The plan was to establish a Data Ware House located at the management office of the *Gesundes Kinzigtal* project according to templates in the literature (Pirnejad et al., 2007). The health care providers would forward their patient data to the Data Ware House where the data would be maintained and prepared for exploration. Potential analyses related to a check of health care interventions conducted by the professionals, electronic transfer of lab work results and controlling. Last not least, the administration of the *Gesundes Kinzigtal* project should be supported in terms of billing with health care providers and with the statutory sickness funds.

First, the existing IT-systems (software and hardware) which were used in each physician office were documented. In November 2006, among 41 then participating physician practices 12 different IT-systems were in place and the best advanced technical communication process was a fax from one practice to the other (and then being stored as a pdf-document or a jpeg-document. No IT-system was able to be connected to the others so that physician A could see what physician B had done with the patient, what medication had been prescribed and what lab results had been stored.

The following requirements for a cooperative IT-system for Integrated Care had been developed in several workshops and intensive discussions in *Gesundes Kinzigtal* (De Clerq, 2008):

- Easy administration: All administrative processes with the insured people taking part in the Integrated Care project (becoming a member) must be documented electronically and exchanged within all participating health care professionals so easily that it is not a barrier to participation.
- Joint integrated care pathways: Chronic care pathways of multiple disciplines and new projects developed in *Gesundes Kinzigtal* must be able to be easily docu-

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mented by different providers within one electronic database but distributed to everybody participating in this pathway and to the central administration (Bertelsen et al., 2005). The IT-documentation must be easily changeable following the improvement cycles of the integrated care pathways (Kohl et al., 2008).

- Provider access to the data and securing data privacy at the same time: Patients have a right on their data and can decide who will get access. In the case of patient consent the optimal solution would lie in easy automatic access without complicated passwords and within the own practice-IT (Meslin et al., 2013).
- Information instead of data overflow: No provider wants to crawl through irrelevant data (Strachan & Kelly, 2011). Data has to be organised so that it becomes relevant information that really helps within the care process (for instance the newest diagnoses, what medication still is in use, the newest lab results).
- Avoidance of repetition: One entry (for instance for weight, blood pressure, medication) should be enough and no entry should need any repetition in another database (Debar et al., 2010). The central IT-system should be able to receive the relevant data from the practice IT-systems. This requirement applies not only to medical data but as well to economic data: Billing data from physician offices which signed up for the integrated care project *Gesundes Kinzigtal* should be developed automatically when the integrated care pathways are documented.
- Data exchange should start between central administration and physicians' practices but should not be restricted to these: In the long run the central electronic patient record should link physicians' practices with nursing agencies, with hospitals, physio-

therapists and all the other professionals within the health, nursing and social care field that are relevant for the optimisation of treatments and care processes. And furthermore: The patients should have access to this information but in a way that s/he may understand it via export in a personal health record accessible in a protected and secured way via internet.

- Information added: The IT-system should be able to add important information like lists of preferred pharmaceuticals and lists of correct reimbursement-relevant diagnoses.
- Affordability: The total costs of the development and the continuous maintenance of the integrated care IT-system should be economically within a good cost-benefit relationship.

Market research showed that some existing IT-systems in 2006 claimed to be able to fulfill some of the requirements but none could already demonstrate its proper functioning in real cases. One of the most prominent problems seemed to be the different practice IT-systems and their reciprocal sealing-off for export and import of data to other IT-systems.

After intensive discussions and several test sites using different IT-systems it became clear that the safest way for the establishment of a mutual approach and common IT-system for all practices would be to reduce dramatically the variance of IT-systems used in the practices of the partners of *Gesundes Kinzigtal*. In the end of 2006 the partners decided in full consensus

1. To change over a period of two years from the many different to one well known and well-reputed IT-system for as much practices as possible,
2. To contract a small IT-company from a nearby city to develop a new central IT-database, and

3. To contract another IT-company for developing the exchange processes between practices and the administration.
4. Gesundes Kinzigtal negotiating best prices and supporting the practices with the conversion and with the potentially required investments.

In April 2007, already 28 out of 41 physician offices had implemented the chosen practice IT-system. Around summer 2007 the first integrated care pathways were ready to be documented electronically so that some parts of the paperbound documentation could be reduced and first successes of the consensus were to be seen. Nevertheless the physicians and the staff in the central administration of Gesundes Kinzigtal felt from 2007 to 2012 like being part of a never ending construction site, without approaching the real value of what had been described in the requirements.

### **STANDARDISATION OF PRACTICES AND CONDUCT: WHAT WAS THE SITUATION AT THE BEGINNING? INTERSECTORAL COOPERATION**

After the detection of the actual state, a concept containing a minimum and a recommended target state has been developed. What was needed was a practical cross-border networking among practices, to enable communication in the physicians' network. For example, the target concept included different answers to questions such as additional memory (RAM modules), antivirus software and other software solutions, blackout-proof electronic power supply concepts, PC standards (Medical Devices Act) and backup concepts. Of course, the issues of data transmission (ISDN, DSL) were clarified. In close cooperation with the physicians, offers were obtained and evaluated in order to achieve an amicable solution at the end. In particular, multiple physicians replaced their

IT-systems so that after the first phase there was an 80 percent share of the same system in the practices. This was an important step because this facilitated the further procedure.

### **THE CENTRAL ELECTRONIC PATIENT RECORD: INTEGRATION OF GENERAL PRACTICE AND SPECIALIST PRACTICES**

The installation of a central electronic patient record has been driven by the joint decision of physicians to achieve the objectives of the Gesundes Kinzigtal project. But how should it look like and what solutions were considered? In a further selection process different providers, including major IT companies, but also smaller companies were included. The decision was made in favor of one smaller company in the region because their solution, based on the laboratory data transmission, offered quick and easy implementation independently of the respective IT system and the infrastructure in the particular practice.

Independently of the respective internal network a so-called "communication server" has been installed in every office, which focused only on the communication within the particular physician's office. This server protected the office towards the outside and it enabled the practice supervisor to get secure access to the internal physician's office network from the management office (remote maintenance). Each communication server was owned and maintained by the Gesundes Kinzigtal project. The particular computer was used only for the applications of the project. The utilisation by the physicians' offices for any other use was excluded in a Declaration of Privacy and Security in fall 2009.

By implementing the communication server it was now possible to connect all of the offices with each other independently of their respective IT systems and to get the central electronic patient record started. In a further step, it was agreed among the

physicians on the question what kind of information will be included in the common documentation in terms of non-directional communication (Meystre, 2007). This means the provider who enters data to the mutual system does not know who of the other providers will access these data next. A list of abbreviations which were used on medical records was compiled. For example, some offices used “d” or “diag” for “diagnosis”. It was arranged that this information was transferred to the central electronic patient record. Accordingly, the use of an undefined abbreviation in the local file did not trigger a transfer to the mutual file. In this way, an encrypted and unitary installation of the central patient records could be guaranteed (Goossen, 2006).

## **PATIENTS AND THE QUESTION OF CONFIDENTIALITY AND DATA PRIVACY AND SECURITY**

Projects of integrated care as well as office networks require a central electronic patient record for data exchange with each other and for the service evaluation and management functions in addition to local practice IT systems. Increasingly, there are demands for the involvement of the patient and, accordingly, the access of the patient on his or her health record must be considered carefully (van den Haak et al., 2002). On the other hand, several demands of patients and practices have been implemented already: a) to electronically request and receive appointments, b) to electronically request and receive repeated prescriptions, c) to conduct an online consultation.

Legal regulations regarding medical data transmission and data use differ from country to country (Ploem & Geysers, 2011). In Germany the patient has to give written consent for data use and data adjustment.

The question of Privacy Policy was taken into account in any decision and at each step: who has access to what kind of data? Where, centralised

or decentralised, and how, encrypted or unencrypted, the data is stored? Which documents must be signed, so that the data of the patient may be entered into the mutual documentation? These questions were discussed intensively with the board of patient representatives of *Gesundes Kinzigtal* (an advisory board elected by membership meetings) and with the data security company that is consulting and controlling all aspects of data privacy and protection within the *Kinzigtal* network. In a declaration of participation and Privacy Policy the patients of *Gesundes Kinzigtal* were made aware of the data processing within the physicians’ network. Furthermore, in membership meetings the enrolled patients were informed about the design and the privacy policy of the network and the central electronic patient record. By signing the documents, the patients approved the further processing of data within the project, including access to the data for other attending physicians.

In 2008 a chip card was introduced. Using this card enabled the decryption of the central electronic patient record in a physician practice. Additional to the card reader for the health insurance smartcard this required a second reader to decode the other smartcard, called health passport (Graph 1).

The patients agreed to the central patient record unconditionally and valued its implementation as an improvement of care. Surely, the solution of how to use the smartcard called “health passport” contributed to this acceptance also. Only by reading the smartcard, which had to be imported via the above mentioned second card reader, the respective practice was enabled to access the encrypted data, which could then be decrypted using the smart card. Therefore, the patients strongly felt that the sovereignty of the data was “in their own hands”. Thus, the central patient record, that is the mutual documentation of primary care physicians and specialists, was welcomed with high confidence in data security and data protection by the subscribed patients.

*Figure 1. A patient's "health passport"*



### **PROS AND CONS FOR SMALL AND FOR LARGE IT COMPANIES AS PARTNERS**

After evaluating the offers and ideas of network solutions, the *Gesundes Kinzigtal* project has opted to work with three IT-companies in parallel. First, about 80% of the practices changed their practice IT-system to one provider and one service company who produced all the daily services for the practices. Second, another company was made responsible for the software needed for the technical implementation of the transmission of laboratory data, the development of the central electronic patient record and a secure e-mail communication within the network. A third company was commissioned for the implementation of a software solution (program name: integrated care information system - IVIS) in the management office to collect and manage the integrated care data of enrolled members and billing of medical services. The latter one also has provided the "IVIS client" software for integrated care data acquisition in practices.

No problems occurred regarding the hardware installation. However, setting up the gateway and the integration into the local practice network,

there were severe issues in terms of data transfer and running of the central patient record. These were caused by premature and unfinished software products and by deficient interfaces between the three systems. The products were in some small but decisive parts incompatible with each other. Some data did not arrive in the central electronic patient record so that it was incomplete. Each system claimed for itself to run error-free but that errors would occur in the interaction of the components.

Therefore, the management of the *Gesundes Kinzigtal* project decided at the end of 2009 to decouple transmission routes for the laboratory data and the central electronic patient record on one hand and the data on integrated care (such as billing with the statutory sickness funds) on the other hand. The solution was to take the data of the other two software developers kind of "piggyback". A separate pathway for data transmission of the integrated care software was established. This solution turned out to be the right decision for the handling of the integrated care data because from then on the central server in the management office could receive the data from the physician offices virtually without loss.



### ***From Agreement to Realisation***

Still, there were problems, however, to export data to the central electronic patient record. The handling in the practices, a) related to the export, reading and writing the data to the central patient record and b) related to transferring the full details of the local file into the mutual documentation, proved to be a restraint in the application of the central electronic patient record. The procedure did not fit properly into the practice flow and the software developed for this task proved to be not manageable and not comfortable. The initiation of the health passport was too costly because this procedure was conducted only rarely. Either the patients did not carry the health passport with them or did not show it to the staff or the practice staff did not ask for it. Therefore, many electronic patient records were incomplete.

Altogether, in the reality of practice visits this smart card developed more logistical problems than expected. As a consequence, after nearly two years of running less than 800 patient files were accessed by more than one physician. Therefore, in terms of the amount of time and money invested it had to be regarded as a failure. Previous research on the side effects of the implementation of an electronic patient record have pointed out that either very clear convenience gains or on the other side adequate bonus systems are required to make sure that the staff who fulfill the work obtain appropriate rewards (Pratt et al., 2004). It has to be conceded that the project was not able to demonstrate these convenience gains on the spot and that *Gesundes Kinzigtal* neglected as well to build adequate bonus systems as it was thought that to be the obligation of the physicians and office owners. The latter unfortunately very seldom incentivised their physician assistants for this reorganisation of working routines – and on the other hand the (female) physician assistants were not used to ask for extra money or time for this work. The feminist literature stresses the fact that there is an “important, subtle and largely unexplored territory of ‘hidden work’ by groups such as nurses, administrators and data

entry clerks which demands further research and offers potential for systematically exploring and addressing the gap between theory and practice in healthcare” (Greenhalgh et al., 2009:756).

More time-consuming problems arose in troubleshooting and support. The responsibility for these problems was pushed back and forth and efforts to provide the evidence that the modules developed by different companies were working properly were rather limited. Another weakness resulted from the interface with the practice software. Since the practice management systems receive an update every three months these reports always were expected with tension by the management team. On a regular basis, these updates also caused errors that were difficult to correct by the staff of the *Gesundes Kinzigtal* project. Any changes in a single physician’s office database required changes in the software of the central electronic patient record. In retrospect, the proposed solution for the central electronic patient record relating to the health passport was theoretically a good solution, but practically it was not successful.

The situation was different in the progression of the own software of the *Gesundes Kinzigtal* project, which proceeded in close coordination with the software developers. There was a stability and ease of use both in physician offices and in the management office. Just the development of the *Gesundes Kinzigtal* software and the related costs gave reason for concern. Dependence on a single software engineer had the advantage of a close and collegial cooperation but on the other hand the requirements in terms of the software and the support could be provided only within a limited scope. Thus, the project dragged on and costs for the development of integrated care pathways rose.

In 2012, therefore, the idea matured to adjust the strategy and to select a more capacious partner to work out a new solution. Since at that time almost 90 percent of the physicians’ offices manage their practice data with a single product, it was obvious to plan a new networking solution

with this company. However, even in the product presentation the question was raised carefully by the IT coordinator (who is part of the staff of the management office) whether it is wise to hand over a large part of the responsibilities to a “giant”, who would then dictate the conditions in the future. His concerns were shared with the physicians and discussed in detail. Further experience showed that this question was justified because deadlines are not determined by the customer *Gesundes Kinzigtal*, but by the seller. In the previous strategy the responsibilities had been distributed between three different companies. In a large IT company, however, several departments of the same company are responsible for different software modules.

The above mentioned problems remain, regardless of whether they relate to the development, the module update, the error analysis or support. Also, the duration that it takes to implement the software requirements or to handle programming errors is similar to the effort of working with smaller companies. Large IT companies afford many programmers and project managers who act as “translators” of the system requirements. The project showed that large IT companies tend to prefer their already existing software modules and “squeeze” the special requirements of a physician network into these modules. As a consequence, the risk of an incorrect translation of problems into non-fitting solutions for problems in this particular practice exists anytime. Nevertheless, the administration and the partnering physicians of *Kinzigtal* are strongly supporting the idea of working with the larger IT-company and feel confident to be able to solve the still existing problems. Also, it proved to be significantly cheaper than working with several small companies at the same time.

In summer 2013 the administration of *Kinzigtal* introduced the networking solution which also allows the configuration of data to be transmitted from the practice IT-system, if this refers to a product of the main software providing company for the *Kinzigtal* practices. If a physician adds

data which are non-relevant for the *Gesundes Kinzigtal* project to the local patient record s/he has the opportunity to prevent data export to the central patient record from the local file card. Also, there now is the ability to import data from the central patient record generated and uploaded by other attending physicians into a local physician’s office system. These patient data, generated by colleagues, are displayed with special marks in the office’s electronic medical record.

The new networking solution continues to enjoy the patients’ trust and confidence in better care through the application of a mutual documentation. At its first presentation in three of the physicians’ offices one of the elected patient representatives of *Gesundes Kinzigtal* had been present and had given access to his own patient data as a template for the presentation of the system. The data will no longer be accessible from the smart card “health passport”, but the repeated delivery of participation policies and Privacy Policy in the respective physician offices is equally comprehensible for the patient and - above all - for both the patient and the respective physician’s office easier to handle.

In summary, the overarching goal of the *Gesundes Kinzigtal* project is the best possible and efficient treatment of the patients enrolled into the project. Repeated examinations, drug intolerance, and waste of drugs should be avoided by electronic networking. Therefore, *Gesundes Kinzigtal* has established the electronic patient record in a process of trying and learning from 2006 until today. The purpose is to supply physicians’ offices and other provider with IT-systems which save on time and to provide the complete relevant information to the patient. In the end, this may lead to a substantial reduction of costs and more patient and provider satisfaction.



## From Agreement to Realisation

Table 1. Status of achievements of project requirements in March 2014

Requirement	Current Status
Easy administration	95% fulfilled. Some lacking import/export functions are still in progress
Joint integrated care pathways	Fulfilled
Provider access to the data and securing data privacy	Fulfilled. Priority was given to specialists and general practitioners and case management within the administration. Data protection secured. Next health care providers to be connected are: Nursing agencies Hospitals Therapists (such as psycho-, physio-, speech- and occupational therapists)
Information instead of data overflow	Mainly fulfilled – each physician may use special filters to show or hide the data from other practices from his/her main window.
Avoidance of repetition	90% fulfilled. Only for those practice IT systems of companies who are not connected to the main provider some data has to be documented repetitively.
Data exchange between central administration and medical practices	Fulfilled
Information added	Partly fulfilled. Lists of correct reimbursement-relevant diagnoses are part of the mutual IT-system.
Patient access to the data	Only partly fulfilled as patients may ask their providers to have a printout of their data or to have them look into the data and the computer. Currently, problems of comprehensibility and data protection hinder to offer direct access via internet. That will be tackled in a second phase.
Affordability - cost-benefit relationship (2008-2013)	Costs for external supplier and service providers about 670,000€ (2007-2013). The budget for linking physician practices with the mutual network was about 470,000€. Costs for staff (IT-specialist and support) about 300,000€. The benefit has not been calculated yet.

## OUTLOOK AND FUTURE RESEARCH DIRECTIONS

The problem of expanding the system in terms of e.g., the digital collaboration of hospitals with the physician offices of the *Gesundes Kinzigtal* project proved to be a serious issue. Although the nearby hospital is willing to engage in talks and closer cooperation and even has bought the technical software for linking, an actual implementation of the IT- crosslinking solution has not yet been decided from their side. Future studies should explore the incentives required for a hospital to join the electronic network fully (Reponen et al., 2004). As the individual practices before, the hospitals in the area may benefit from giving up their status of distinction and prepare for a structured exchange of patient data to allow a higher level of transparency, safety and cost efficiency. Furthermore, re-admission rates may be

reduced. Instead of many hospitals spearheading the attempt for electronic networking others are emphasising the problems and potential disadvantages of an electronic patient record such as issues of liability, confidentiality and potentially created loopholes for electronic intrusion by non-authorised attackers. On the other side, hospitals may use the electronic patient record as a tool to monitor patients' compliance during clinical trials (Newsham et al, 2011).

*Gesundes Kinzigtal* hopes for a fresh impulse resulting from the new networking solution introduced in summer 2013 and insofar for a speedy connection of the hospital to the mutual documentation of the integrated care project. The integration of additional health professionals such as nursing agencies and homes, psychotherapists and physiotherapists shall be inspired by the cooperation with the seller of the IT-systems as well. Already, there is great interest on the part of other actors in

the health care field to network with the IT-system used. As suggested in the literature, *Gesundes Kinzigtal* aims to first cooperate closely with the nursing profession (Mills et al, 2005; Hellesø et al., 2005). Some ambulant nursing care services and nursing homes are just in the process of deciding to buy a new documentation software. They agreed to check and compare together with the *Gesundes Kinzigtal* IT manager different software systems in terms of the technical requirements for a connection to the central patient record.

Gradually, all partners involved in the *Gesundes Kinzigtal* project will have the opportunity to join the central electronic patient record system. By installing a simple interface software the participating institutions and offices will enjoy a special insight, e.g., related to the medication in the central electronic patient record. Nurses or physiotherapists also can enter data into this software. For the future, this simple interface software should also provide the opportunity to integrate training data, e.g., stemming from the exercise equipment of health centres and of a planned training facility being operated for severe ill patients by the administration of *Kinzigtal* itself. Another very demanding issue will be to connect the patient records with the data deriving out of the self tracking and mobile health solutions from smart phones. Up to now these data are not at all connected to the practice IT-systems and are highly undervalued in their potential use for health improvement in the medical professions (Topol, 2013).

A lot of research questions arise out of the achieved as well as planned electronic integration efforts, just to name a few:

- What are the real case cost-benefit outcomes of integrated eCare in practices?
- What are the real case cost-benefit outcomes of integrated eCare for the entire health care system and the health care costs of a given population?
- What are the process, the liability, the confidentiality issues and the cultural characteristics of each provider and how are these pitfalls to be overcome?
- What will be the role of the patient in future health care settings and if this role will be of more decision latitude, how will this be reflected in the planning of the IT-infrastructure of the health care system?
- How will integrated (medical) eCare connect with the need to integrate itself with the voluntary sector, the friends and relatives of patients and with the communities in times where professional resources decline?
- How will the discussion about data security and data protection in integrated eCare develop in times of the critical discussion of “big data” and national and international capacities to break even highest security and encryption standards?

However, not only benefits but rather unintended side effects were found in previous studies on the implementation of electronic patient records. They may bear risks such as cognitive overload, loss of overview, errors in data entry and retrieval, excessive trust in electronically-held data, and the tendency to conflate data entry with communication within and between care teams (Greenhalgh et al., 2009: 759). Whilst the implementation of the electronic patient record was considered a success by the physicians and management in the *Gesundes Kinzigtal* project we have to admit that in-depth research into potential unintended negative effects of this process or at least upfront surplus work, e.g., among the staff of practices were not documented in detail. In general, more studies are needed to evaluate the benefits, the convenience gains as well as the upfront surplus work and the costs of electronic patient records.

**From Agreement to Realisation**

*Table 2. Levels of progress in terms of the implementation of the central electronic patient record in the Gesundes Kinzigtal.*

Level/Year	2006 / 2007	2008	2009	2010	2011	2012	2013
Decisions by the associates	<ul style="list-style-type: none"> <li>- Decision to link physicians' practices electronically</li> </ul>	<ul style="list-style-type: none"> <li>- Decision to hire an IT-specialist to deal with the prominent IT problems.</li> </ul>		<ul style="list-style-type: none"> <li>- Affirmation of the physician partners to establish and use a central electronic patient record.</li> </ul>	<ul style="list-style-type: none"> <li>- Decision to start the project Aquik</li> <li>- Analysis of the quality indicators of the National Association of Statutory Health Insurance Physicians (2011-2013, publication 2014).</li> </ul>	<ul style="list-style-type: none"> <li>- Physician board member meeting opts for a conversion of the mutual IT-system to the software developed by the company which already provides IT practice software for 90% of the physicians' practices.</li> </ul>	<ul style="list-style-type: none"> <li>- Decision to hire a staff member responsible for addressing the needs of the physician's practices.</li> </ul>
Technical infrastructure	<ul style="list-style-type: none"> <li>- Documentation of practice IT systems</li> <li>- Implementation of a communication server in each physician's practice</li> <li>- Implementation of applications (e.g., lab data)</li> <li>- Development of software for online subscription of members and of first integrated care pathways.</li> </ul>	<ul style="list-style-type: none"> <li>- List of abbreviations used on medical records compiled</li> <li>- Start of the installation of card readers (Generation 1) in the practices to prepare the use of the health passport</li> <li>- Development of software for new integrated care pathways.</li> </ul>	<ul style="list-style-type: none"> <li>- Decoupling of transmission routes and establishing a separate service of replication for the data of Gesundes Kinzigtal.</li> <li>- Starting the first mutual documentation of the central electronic patient record using the health passport.</li> </ul>	<ul style="list-style-type: none"> <li>- Further development of software for integrated care pathways</li> </ul>	<ul style="list-style-type: none"> <li>- Further development of software for integrated care</li> </ul>	<ul style="list-style-type: none"> <li>- Conversion of practice IT-systems to meet the requirements for the mutual networking among physician member practices.</li> <li>- Implementing a central data server in the administrative office of Gesundes Kinzigtal.</li> <li>- Linking practices with this communication server.</li> <li>- Establishing of a new and matured software for billing physicians practice services at the administrative office and for a new administration for the patient members of the Gesundes Kinzigtal.</li> </ul>	

Level/Year	2006 / 2007	2008	2009	2010	2011	2012	2013
Organisational service infrastructure	<ul style="list-style-type: none"> <li>- Opening of the first administrative office in Kinzigtal.</li> <li>- Establishing the administration for the members of the <i>Gesundes Kinzigtal</i>.</li> <li>- Establishing the infrastructure for networking among physicians' practices and for billing their services.</li> <li>- Online subscription of members is feasible</li> <li>- First integrated care pathways ("strong heart" and "Healthy weight") are available.</li> </ul>	<ul style="list-style-type: none"> <li>- Moving into a larger administrative office that includes space for course programs and meetings</li> <li>- IT-specialist becomes part of the staff at the <i>Gesundes Kinzigtal</i>.</li> <li>- Integrated care pathway "Strong muscles, firm bones" becomes available.</li> </ul>	<ul style="list-style-type: none"> <li>Integrated care pathways ("Smokefree Kinzigtal", "Wound management") becomes available.</li> </ul>	<ul style="list-style-type: none"> <li>-About 800 health passports issued.</li> <li>- Issuance of membership cards by the administrative office instead of physician practices.</li> <li>- Integrated care pathway "Depression management" becomes available.</li> </ul>	<ul style="list-style-type: none"> <li>- Integrated care pathway "Healthy back" becomes available.</li> </ul>		<ul style="list-style-type: none"> <li>-A new staff member at the administrative office responsible for addressing the needs of the physician's practices is present.</li> </ul>

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## **KEY TERMS AND DEFINITIONS**

**The Electronic Patient Record (EPR):** Contains information from all healthcare providers. It is a secure, patient-controlled mutual information resource that supports clinicians in evidence-based decision-making by providing access to patient information from all his or her providers. The EPR communicates all clinical and social background information and improves delays in response that result in delays or gaps in care.