Abstract

Integrated care (IC) helps to diminish demographic challenges. Electronic health records (EHRs) are recognized to support IC with regard to continuity, efficiency and quality of care. Lifetime EHRs (LEHRs) allow an even higher level of integration by including all care-related stakeholders along the whole lifetime of an individual. The article aims at qualitatively assessing to what extent LEHRs are a sufficient enabler for IC. A literature review was conducted regarding IC implementation requirements. Therefore, LEHRs were characterized and discussed with respect to ten IC requirements, classified into four perspectives (stakeholders, data & IT, processes and economics). The analysis revealed that LEHRs especially support data exchange, teamwork and communication, inter-professional collaboration, focus on the individual and add value in terms of efficiency and continuity. LEHRs enable IC, but need to be complemented by workflow and communication supporting systems to achieve a holistic IC implementation with regard to the proposed requirements.

1. Introduction

Demographic change and the increase of chronic diseases are main reasons for transition processes within health care. Health care systems face skilled worker shortage and an increasing number of multimorbid patients [17]. Integrated care (IC) can ensure the quality of care given these challenging circumstances [30,36]. Current obstacles for implementing IC include tension and communication problems between care providers with differing professional cultures. This leads to difficulties and imbalance when it comes to inter-professional teamwork across hierarchy levels [3]. Thus, IC demands a coherent set of methods and models allowing connectivity, alignment and collaboration within and between the participants [28]. Information and communication technology (ICT) solutions are a key instrument to achieve the vision of IC, to allow effective overarching communication, integration and networking, and to reduce the bottleneck of human resources and budgets [12,21,34,44]. Electronic health records (EHRs) support IC with regard to continuity, efficiency and quality of care [19,23,44] as these allow a linkage between consumers, as well as payers and providers across the continuum of care by providing relevant information to the stakeholders [46]. Lifetime EHRs (LEHRs) allow an even higher level of integration by involving all relevant stakeholders in the care process (i.e. formal healthcare providers such as practitioners, specialists or nurses as well as informal caregivers from family or community) and storing retrospective, concurrent and prospective information regarding an individual's health status [23] and thus covering the whole lifetime of an individual (individual is the preferred term and used throughout this paper in context of LEHRs, since the understanding of patient is rather disease-related and does not cover non-treatment related activities, such as prevention or wellness activities [47]). As IC is of most value in complex care arrangements, an overarching database (across processes, care providers and time) is of special value [31,34,36].

The article aims at qualitatively assessing whether and to what extent LEHRs are an enabler for IC. The paper is structured as follows: A methodical insight is given in section 2. LEHRs are defined and distinguished from other record types in section 3. The characteristics of IC and requirements for its implementation are presented in section 4. The identified requirements are described and compared to LEHRs in section 5, assessing the suitability of LEHRs to enable IC. The paper closes with a discussion of open issues and need for further research in section 6.

2. Method

The conducted research follows an argumentative-deductive approach in terms of a literature analysis [38]. The data to derive the definition and requirements of IC was collected by searching Academic Search Complete, Business Source Complete, CINAHL and Google Scholar for the following terms within abstract or title: (“integrated care” AND (requirement OR
defin* OR concept* OR implement* OR enable* OR review)). This resulted in 242 overall articles. Two independent reviewers checked the titles and abstracts of the papers found, to assess whether they fit the sketched topics. Repeating articles were not considered further. Articles focusing on specific diseases or interventions were excluded, as a more holistic view is of interest. Backward and forward searches completed the process. Altogether, 47 peer-reviewed articles were selected and analyzed regarding IC definition and requirements. The requirements were compared to the concept of LEHRs to discuss its suitability. The comparison relies on the results of a literature analysis on LEHR characteristics conducted by Gand et al. [16].

3. Lifetime electronic health records

There are various terms representing different record types for electronically stored and shared health-related information. They differ with respect to seven dimensions as derived by Gand et al. [16] (see Table 1). With respect to the classification dimensions, LEHRs are defined as the “lifelong electronic collection, storage and provision of all health related information about its owner, an individual, allowing IC and functioning as a data basis to improve the quality of health care on the individual and societal level” [16]. There are various synonyms representing the LEHR approach, such as EHR for integrated care [23], lifelong personal health record (PHR) [2], integrated EHR [50] and lifelong virtual EHR [32]. These synonyms reveal that the terms EHR, PHR and LEHR are not used consistently in the literature. Especially the term EHR is used ambiguously: on the one hand, EHRs represent a concrete record type that already partly represents the vision of LEHRs, but differs significantly being provider-based in regard to usage, ownership, and responsibility for record maintenance. Furthermore, EHRs are not typically lifetime oriented and do not include alternative treatments or lifestyle (non-professional) information [6,26,53]. On the other hand, the term EHR is used as a generic label for different types of electronic health records [19,23]. Other record types such as electronic medical records (EMRs) and PHRs are defined more distinctly. Distinguishing characteristics of EMRs, PHRs and LEHRs are summarized in Table 1.

Table 1 shows noticeable overlaps of PHRs and LEHRs. However, one main difference is, that PHRs are manually compiled and maintained by the owning individual [11] and rather used on private interest. The record owner is responsible for providing PHR information during health service encounters, because they are not provided automatically. This might be a reason for the perceived low usefulness of available PHR solutions such as Microsoft HealthVault and Google Health [43]. The latter was even discontinued in 2011 due to its low impact [54]. An LEHR on the other hand, shall be auto-populated [11]. The record is still owned by the related individual, but the responsibility for information management and provision can be delegated. LEHRs allow the compilation, integration and usage of health-related information even when individuals are not capable (e.g. due to physical or mental limitations) or do not want to hold the responsibility of this task (e.g. due to low health literacy [2,13] or in phases of life when people are healthy and do not directly perceive benefits.

<table>
<thead>
<tr>
<th>Dimension</th>
<th>EMR</th>
<th>PHR</th>
<th>LEHR</th>
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<tr>
<td><strong>Width of application</strong></td>
<td>Patient-centered</td>
<td>Phase, possibly</td>
<td>Individual’s lifetime</td>
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<td><strong>Institutional linkage</strong></td>
<td>Intra-institutional</td>
<td>Inter-institutional</td>
<td>(e.g. across hospitals)</td>
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<td><strong>Sectoral coverage</strong></td>
<td>Intra-sectoral</td>
<td>Inter-sectoral</td>
<td>(e.g. across hospitals, doctors)</td>
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<tr>
<td><strong>Data range</strong></td>
<td>Patient and case data, medical documents</td>
<td>Patient and case data, medical documents, alternative treatments, lifestyle data (fitness, wellness etc.)</td>
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<tr>
<td><strong>Record owner</strong></td>
<td>Health service provider</td>
<td>Individual</td>
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<td><strong>User group</strong></td>
<td>Health service provider (HSP)</td>
<td>Individual</td>
<td>HSPs, individual, research &amp; health reporting inst.</td>
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<td><strong>Responsibility of maintenance</strong></td>
<td>HSP</td>
<td>Individual</td>
<td>Individual or independent agent</td>
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<td><strong>Purpose of use/ functionality examples</strong></td>
<td>Scheduling, order entry, registration, prescribing, documentation, results retrieval, billing</td>
<td>Manual documentation (e.g. personal/family history, allergies, immunization) for primary care purposes</td>
<td>PHR functionalities, access to relevant info at point of care, research &amp; education, health reporting, auto-population</td>
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Table 1. Classification of EMR, PHR and LEHR [2,6,11,16,19,21,23,25,26,42,53].
from their efforts [43]). This raises the question on sustainable organizational approaches for LEHR delivery. The establishment of Independent Health Record Banks has been proposed as a feasible solution, because neither the owning individual nor the care providers seem to be capable of providing the compilation and a safe, sustainable storage [41,42].

Although there is no implementation on the national scale yet, LEHRs have already been implemented by regional initiatives, e.g. in Crete, Greece [25] and Lombardy, Italy [2]. The LEHR solution of the Lombardy region, for example, in this scenario named lifetime PHR, is embedded in the structure of the regional Healthcare and Social Service Information System. Almost all general practitioners, pediatricians, hospitals, pharmacies, local healthcare units and 80% of private healthcare organizations joined this regional IT infrastructure. The LEHR contains demographic information (accessed from a central patient registry), administrative information, e-prescriptions, clinical documents (e.g. clinical examination reports, pathology summaries, therapy plans, vaccination information), patient summaries (health history, current status, emergency data), consent information (e.g. consent for organ donation) as well as an optional “patient notebook” containing uncertified data (e.g. allergies, lifestyle, diet information), exclusively managed by the patient. The content was defined in national guidelines. The automatic document update whenever a healthcare provider generates content is emphasized as being the most important feature of the Lombardy LEHR. In 2012, there were more than 6 Million active LEHRs. However, the individually managed patient notebook was not used widely [2].

4. Integrated care

There are various definitions and characterizations for IC. It is commonly understood as a care concept that aims at increasing continuity, quality and efficiency of care in cases of multidimensional, long-term and costly health needs [27,28,35]. This shall be achieved by planning, managing and delivering personalized services by care professionals working together with informal caregivers across a range of organizations and organization types (statutory, private and voluntary) along all phases of the care process (from health promotion to rehabilitation) [3,28,35,39]. Thus, IC also involves an individual’s informal care network (e.g. family, friends, community) as well as providers of health-related social and supportive services (e.g. transportation, food delivery). Accordingly, IC affects stationary, ambulant and home care professionals and non-professionals (summarized as IC participants in the following). Furthermore, IC addresses the empowerment and autonomy of an individual [3,35], understanding patients not only as consumers of integrated health and care services but also as providers in terms of self-care and preventive actions.

Although there seems to be a clear and common understanding of IC, it appears in various forms such as shared care, coordinated care, transmural care, comprehensive care and managed care [28,39]. Prominent techniques to achieve the goal of integration in healthcare are disease management and case management, which may thus not be confused with being IC [27]. The real impacts of IC are not as clear from literature, as rigorously or statistically reliable data on a broader level is quite hard to ascertain. But there are some findings that underpin the assumptions of the advantageousness of IC. For example, IC seems to be at an advantage in terms of healthcare costs [36]. There is some evidence of improved partnerships and organizational integration, of improved capacity and improved focus on governance and adherence to guidelines [37]. Beyond, there is empirical evidence on the effectiveness of IC at the regional or single-institution level (e.g. [22,24,48]).

As the conducted literature analysis revealed, a successful and sustainable implementation of IC has ten key requirements. The identified requirements were classified to four perspectives as shown in Table 2. They are described in detail in the following assessment in section 5. The perspectives go along with other proposed levels of integration like functional, organizational, professional and clinical integration [36].

<table>
<thead>
<tr>
<th>Perspective</th>
<th>Requirement</th>
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<tr>
<td>Stakeholders</td>
<td>Teamwork and communication</td>
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<td>Development of human resources</td>
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<td>Inter-professional collaboration</td>
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<td>Focus on the individual</td>
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<td>Data and IT</td>
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<td>Processes</td>
<td>Centrally managed work processes</td>
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<td>Structured work processes</td>
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<td>Economics</td>
<td>Added value</td>
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<td>Accordance with funding</td>
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According to Leutz [31] the highest level of integration is achieved when there are interprofessional teams managing the whole care process, including finances. Particularly, those patients with the highest needs (due to multimorbidity and chronic
diseases) need the highest degree of integration. This relates to diseases such as diabetes, hypertension, depression, Aids or cancer. For example, IC for a patient with diabetes and hypertension could include an aligned, evidence-based and coordinating care pathway across the relevant IC participants fostering frequent contacts. Furthermore, it could provide risk stratification, individual target agreements and the assessment of target achievements, integration and provision of relevant information to the IC participants, self-monitoring, motivational messages, alerting of the patient and his or her responsible doctor in case of major derivations from the individual standard value (e.g. of blood pressure), decision support services for the patient and his or her informal caregivers, contact to a responsible service-center, intervention reminders, regular evaluation and feedback regarding the quality of processes, or patient education for self-management and self-care [7,15]. This demands common patient records that support the treatment in terms of joint health data repositories [11,31,36]. Thus, the contribution of LEHRs is apparent and further examined.

5. Discussion

The previous results already show a positive relation between the definitions of IC and LEHRs. The identified requirements for successful implementation of IC along with potential contributions of LEHRs are described below. These perspectives are accompanied with results of research on barriers for (L)EHR implementation such as need for appropriate education and skills, inappropriate incentives, limited added value, loss of autonomy and workflow disruption through record adoption, low physicians’ acceptance and satisfaction with the system [4].

5.1. Stakeholder

5.1.1. Teamwork and communication. Working in highly performing teams with the shared willingness for and commitment to IC is a necessary prerequisite to cope with the complex integrative task. The involved organizations and the IC network itself should be supportive in terms of cultural willingness towards IC. A common language, mutually accepted respectful communication and behavior standards are needed to achieve this goal. Routinely held meetings are a reasonable measure for this [3,20,31,33,40,45]. LEHRs contribute to this requirement by providing the relevant information to every IC participant and thus, supports communication and teamwork [19]. However, an LEHR should be embedded into an overarching system [29], which provides various communication channels like chats, videoconferences or wikis. Information exchange can be supported by an underlying ontology [53]. LEHRs support this by providing a commonly used and uniformly structured data repository [2].

5.1.2. Development of human resources. Qualification regarding the adoption of new medical techniques and insights is essential. A commonly accepted understanding of IC is important. Besides the medical knowledge, managerial skills, ways for teamwork and empathetic modes of behavior towards colleagues and clients and the acceptance of other professional roles are necessary for smooth cooperation [18,20,33,40].

An LEHR is only partly an enabler regarding this demand. For example, implemented assistance and reminder functions (communicating the desired culture for the participants in a IC arrangement) could support and further qualify the users. The users’ education is a success factor for LEHR implementation as well [2]. According to Tang et al. [47] this requires early education and training of all users and could start in elementary school by teaching the importance of managing health using different tools. The promotion and explanation of EHRs (used as general term for all kinds of electronic health record types here) should be included in the curricula of medical/ nursing schools and of post-doctoral training programs to teach HSPs record usage and patient-education [47].

5.1.3. Inter-professional collaboration. Inter-professional collaboration across different disciplines is crucial for successful IC. Professionals with overlapping roles communicate and mutually coordinate care for their clients and share problem solving and decision making, which makes communication so essential. Tasks might be rearranged between the staff [3,5,18,33,45].

The cross-institutional and cross-sectorial data access and the exchange of health-related information provided by an LEHR strongly supports the collaboration between different professions and institutions [19,21,29].

5.1.4. Focus on the individual. Individual patients’ needs are of main priority for IC solutions. An assessment of needs according to health status, former diseases, lifestyle, familiar background and current crises/ emergencies is desirable. Service-packages from participants along the care process should be individually combined, building joint care plans [3,10,28,29,31,33]. Individuals shall be involved in
their own health/disease management (patient empowerment) and take part in prevention [52].

LEHRs allow the auto-compilation of all health-related information collected during different encounters with HSPs. This enables individuals to monitor their own health status and illness development due to transparent representation. Furthermore, additional non-medical information can be managed and provided to IC participants if necessary and permitted by the owning individual. This empowers individuals by giving them the possibility and responsibility for own health information management, enabling informed decision making and an active involvement in the care [19,29,51]. But even if individuals are not able or willing to participate as actively, they are put in the center of care, since LEHRs provide all the necessary health information to IC participants when needed.

5.2. Data and IT

5.2.1. Support systems. IC requires new supporting ICT solutions enabling its overarching approach [10,18,46]. Sector- and institution-overarching communication and treatments have to be supported [1] and the high amount of complex long-term collected information needs to be represented in a clear manner.

An LEHR actually represents a support system, providing a common database and rigorous basis for decision-making [2,25,29]. Accordingly, the aims of an IC approach corresponds well with those of LEHRs [11].

5.2.2. Data exchange. Data exchange across distinct institutions and sectors is required for IC [1,31]. The individual’s history and current health status (on a technical level: database entries) have to be accessible for all involved caregivers [40]. Integrated information systems are necessary to allow IC [10,28,46].

The major aim of LEHRs is the exchange and provision of relevant care information among all participants throughout the care process. Hence, this requirement is completely fulfilled by LEHRs. However, common standards are needed to allow data exchange [19,50]. Furthermore, the inclusion of information added by non-professionals can create unstructured, subjective and noisy data. This raises the question of information trustworthiness, which is a clear barrier to the adoption of PHRs, and thus LEHRs, and calls for behavioral change of all users [47]. Trustworthiness could also be improved by the separation of editable and read-only information for different user types. However, the health-related information collected by individuals in combination with structured, objective medical information collected by professional HSPs hold great potentials as new sources for medical research [49].

5.3. Processes

5.3.1. Centrally managed work processes. IC requires centrally and formally coordinated processes and proper planning [1,3,10,34,46]. General practitioners as patients’ first point of contact might undertake the task of coordinating multiple health providers and services. Strategic alliances or networks of different caregivers, the specialization and distribution of single task fields, are other possibilities. Therefore, centralized informational repositories are a necessity. Governmental regulations and administrative structures should support the overarching approach by adequate resources allocation or the provision of reasonable precepts [28,34].

An LEHR functions as an information repository that is necessary for overarching and centrally managed processes. It does not directly support workflows, but builds the basis for effective and efficient process execution [2,29].

5.3.2. Structured work processes. Following established practice guidelines and standards allows handling the multitude of IC participants and continuity [3,10,28,34,52]. Therefore, thoroughly documented care plans are highly relevant [3]. Building vertical and horizontal, formal and informal networks within and between organizations is helpful for joint working relationships [28,40]. Horizontal work processes and therefore inter-professional care are corresponding measures. Operational flexibility (e.g. regarding unscheduled incidents) and the openness to adopt new techniques are further needs [18,28].

LEHRs primarily document health-related information, but do not represent care processes. However, the stored data has relevant supportive functions for reasonable, medically sensible care and therefore for the wellbeing of the record owning individual. For instance, integrated prescription systems allow the consideration of possible side effects, interaction with other drugs and impact on the treatment in general [2,9]. LEHR systems could provide predefined need assessment sheets, directing care towards relevant quality goals or treatment steps. The relation of IC with care pathways may also improve the decision making process based on individual needs as these can be derived from the uniform data provision by means of an LEHR [14,46].
5.4. Economics

5.4.1. Added value. There has to be a recognizable additional value and further incentives for all IC participants. Without perceivable advantages IC policies will not be accepted [1,10,46]. High rates of integration might be a competitive advantage for the participants as this is an indicator for high quality [1,40]. Costs and quality of IC programs have to be adequate to satisfy the individuals [28]. However, IC implementation is expected to pay off in long term [1,36]. IC-related goals have to be operationalized and regularly measured based on a system-wide performance measurement [40].

LEHRs are not (broadly) implemented yet and thus, long-term quality or efficiency improvements are not measurable. However, LEHRs are expected to reduce information asymmetries by empowering the individual, increasing continuity, improving effectiveness and efficiency throughout the care process and thus reducing costs as well as redundant work while increasing the quality of health care and patient safety [8,25,47]. As previously mentioned, LEHR-related education and training of all users is of high importance to reinforce their willingness for participation and to establish trust in the system.

5.4.2. Accordance with funding. Implementing IC needs to be done in accordance with health care insurance funding, which is often a highly political field and therefore quite crucial. Restriction of resources might be rather strict. Therefore, it might be challenging to implement a complex concept like IC. An overarching funding pool is a potential financing option, transferring the idea of integration to the financial level [10,28,40,46]. Initial evidence from literature shows a general financial value of IC approaches [36]. Thus, it would be reasonable to support this approach by means of advanced eHealth measures like LEHRs.

However, there are no direct contributions evident yet, since LEHRs are not broadly realized over longer time periods and concrete implementation designs need to be discussed. But as LEHRs are expected to increase continuity, quality, patient safety, effectiveness and efficiency along the care process and thus reduce redundant work as well as costs, the advantageousness can be assumed [8,25,47]. First regional pilot projects substantiate this assumption [9].

6. Conclusion

The not yet widely implemented but technically feasible concept of LEHRs is argued to be an enabler for IC. LEHRs particularly provide solutions regarding those IC requirements focusing on stakeholders and data and IT. However, LEHRs do not contribute to all proposed IC requirements. The analysis revealed the necessity for combining a rather static and structure supporting LEHR system with more process-focused communication and workflow supporting systems, considering dynamic aspects (e.g. integration in clinical and care pathways, integrated prescription systems). Still, LEHRs considerably enable IC in comparison to EMRs and PHRs, which are not as overarching tools in terms of the number of different IC participants involved and in terms of patient-centricity. In the sense of LEHRs, patient-centricity not only means giving individuals the opportunity and tools to be involved in their own wellbeing by holding the responsibility for their health information. It also means granting the right to not being actively involved but still making relevant information available at any point of care to IC participants. This view broadens the trend of patient empowerment. LEHRs set individuals and their needs in the center of care and support equality regardless of their health care literacy level or their willingness and ability to use such system. Looking at present PHR solutions it is conceivable to enhance this approach towards LEHR characteristics. In this context, the development of an LEHR maturity model would be valuable to provide step-by-step guidance for implementation.

A broad implementation of IC with the help of LEHRs is still a long way off. Therefore, some assumptions regarding LEHR features might be rather hypothetic. The advantageousness of LEHRs is assumed in literature and a further argument to intensify research on this topic, e.g. by conducting case studies on existing pilot projects to generate evidence of efficiency and effectiveness of the LEHR concept. The typical reserved attitude when it comes to participating in new forms of care can only be reduced by transparently showing the advantages of IC [1]. This is a further prerequisite for a successful implementation of such approaches. In this context, ethical, trust and security issues as well as the concrete needs of IC participants (resp. the users of LEHRs) and how to address them in the development of LEHR solutions need to be further analyzed.

Critically reflecting on the methodical approach of the present paper, the literature review could be broadened to increase rigor and to further verify the proposed requirements for IC. In addition, more potentially supportive tools, e.g. clinical and integrated pathways, should be analyzed with respect to the proposed requirements. This will identify further components for a holistic realization of IC. Thus, future research regarding the potentials and possibilities of consolidating clinical pathways and
workflow management systems with LEHRs is desirable. Quality measures for IC services (including LEHRs) as well as sustainable concepts for adequate reimbursement need to be discussed.

7. References


with systems science models. Journal of Medical Internet Research 17, 3 (2015), pp. e64.


