PERSONALISATION AND DYNAMISATION OF CARE PATHWAYS – FOUNDATIONS AND CONCEPTUAL CONSIDERATIONS

Kai Gand  
*Dresden University of Technology, kai.gand@tu-dresden.de*

Hannes Schlieter  
*Dresden University of Technology, Hannes.Schlieter@tu-dresden.de*

Follow this and additional works at: [http://aisel.aisnet.org/ecis2016_rip](http://aisel.aisnet.org/ecis2016_rip)

Recommended Citation  
[http://aisel.aisnet.org/ecis2016_rip/68](http://aisel.aisnet.org/ecis2016_rip/68)

This material is brought to you by the ECIS 2016 Proceedings at AIS Electronic Library (AISeL). It has been accepted for inclusion in Research-in-Progress Papers by an authorized administrator of AIS Electronic Library (AISeL). For more information, please contact elibrary@aisnet.org.
PERSONALISATION AND DYNAMISATION OF CARE PATHWAYS – FOUNDATIONS AND CONCEPTUAL CONSIDERATIONS

Research in Progress

Gand, Kai, TU Dresden, Dresden, Germany, kai.gand@tu-dresden.de
Schlieter, Hannes, TU Dresden, Dresden, Germany, hannes.schlieter@tu-dresden.de

Abstract

The transition of western health care systems can be facilitated by Integrated Care (IC) approaches helping to diminish demographic challenges. The concept of clinical pathways is an approach for a more structured, overarching and broader care as it allows higher system efficiency, i.e. a better coordination of treatment especially for patients with complex diseases (co-morbidities). They can be sustained by Information and Communication Technology (ICT) that enables a better coordination and integration of patients within their care and social network. However, there is no broad use of such pathways as it lacks of a concept for the utilisation of a holistic pathway usage for the care of people with co-morbidities. The paper contributes by developing a framework for the design, handling and work of or with personalised dynamic pathways (PDPs). By suggesting the PDP-Framework, we aim at providing a concept that has the potential to improve the care. It also fosters the application of ICT-based care in terms of a concept for shaping ICT services. Our contribution builds the fundament for a multi-actor involvement along the care processes and facilitates the monitoring of the patients’ statuses, their activities and compliance with care measures.

Keywords: Care pathways, Clinical pathways, Personalisation, Integrated Care, Framework.

1 Introduction

1.1 Motivation: challenges in healthcare

The western healthcare systems are in transition due to several challenges like the demographic change and the increase of chronic diseases. A shortage of skilled workers and an increasing number of co-morbid patients can be observed (Harper, 2010). Co-morbidity means the presence of at least two chronic diseases (e.g., the Charlson Co-morbidity Index (Charlson et al., 1987) can serve as a basis for the identification of relevant diseases). Such patients are in the main focus here as they need the most support. Co-morbidity is associated with worse health outcomes and increased health care costs. Hence, coordination within a care network (inter-institutional treatments) and possible interdependencies of the sub-symptoms are the great challenges. Information and communication technology (ICT) can be the enabler for a more personalised and Integrated Care (IC) (Dixon, 2007; Stroetmann et al., 2010). ICT in healthcare includes the introduction of (software) information systems that add new care modes, improve existing care processes or allow a higher degree of participation of the diverse stakeholders (patients, (in-)formal care providers, healthy people) in this field (Bashshur et al., 2011).

Multiple factors influence the course of diseases and quality of life. Patient empowerment is a key element to decrease the risk of escalation esp. of co-morbidities (Chaudhry et al., 2006). Empowerment in this regard shall be used as an umbrella term addressing measures for a more personalised and self-determined care or status of the citizens within the healthcare system. The people shall be allowed to take care of their own healthcare needs. They shall be able to overview the medical facilities and possibilities. Patients then deem the healthcare system as working on their behalf, rather than for other reasons (e.g. profits; Walker et al., 2013). Thus, all relevant stakeholders have to be included and coordinated to allow an appropriate treatment. Complex disease statuses require support from a multidis-
ciplinary team of professional and informal carers across a range of organisations and organisation types (i.e., statutory, private, voluntary) along all phases of the care process (Billings 2005; Kodner and Spreeuwenberg 2002). IC deals with the lack of common governance models and discontinuities in the healthcare (Lerum and Frich, 2012).

Reflecting the current situation, there is a high demand for IC models with inter-sectorial teams with common goals as well as the consideration of the relations within the social network (of care). These also entail the need for an efficient technical support accompanied by a suitable business concept. Such support the delivery of continuous care programmes, foster the coordination of all carers across professional boundaries and patients, and allow adequate education of all stakeholders (Curry and Ham, 2010; Suter et al., 2009; Wessel and Gersch, 2015).

A major concept for providing personalised care is the utilisation of care plans (called care pathways or short: pathways (De Bleser et al., 2006; Kinsman et al., 2010; Panella and Vanhaeckt, 2010; Rotter et al., 2010)). Additionally, clinical pathways (CPs) foster the decision making of physicians and help to adjust the treatment corresponding to the patient needs. There is a variety of communication and data standards in the health care field trying to enhance the inter-clinical communication (Dixon, 2007; Stroetmann et al., 2010). However, with regard on the care standards given by CPs, a consolidation framework is missing that describes the application of those standards within a process-oriented health ICT infrastructure. Such a framework has to be smoothly integrated in an existing IT landscape. Such advanced ICT for IC models would have the potential to improve the care situation by managing the care on the basis of agreed pathways, which are the fundament for a multi-actor involvement along the care processes to facilitate monitoring of the patient status, their activities and the compliance with care measures. Thus, the paper contributes by suggesting a framework for personalised dynamic pathways (PDPs) that facilitates the mentioned challenges. It fosters the application of ICT-based care.

1.2 Method and structure of the research

As a Research in Progress Paper, its major objective is to propose a framework for the design, handling and work of resp. with PDPs as the current situation lacks such personalised as well as systematic research. Therefore, this research is assigned to the design science (DS) branch of information systems research. The engineering-based DS approach focuses on creating and evaluating solutions for practical and theoretical problems by designing innovative artefacts with rigorous methods (Hevner et al., 2004). The main steps of a DS procedure can be summarised as problem-centred initiation, definition of objective of a solution, design and development of the artefact as well as the demonstration and evaluation (Peffers et al., 2007). The paper covers the first stages of a DS project and makes a first proposal of the artefact by providing the PDP-Framework. Accordingly, the paper is structured as follows: Section 2 provides insight in the conceptual foundations such as current use of pathways in healthcare and the requirements of IC. These show the need for an advanced pathway framework as presented in section 3. The paper closes with the discussion on open issues in section 4.

2 Conceptual foundations

2.1 The use of pathways in healthcare

The idea of integrated care pathways as sector-spanning process standards originates from CPs, which are specific, standardised descriptions of clinical processes for defined combinations of symptoms adapted to clinical conditions (De Bleser et al., 2006). They are a multidisciplinary tool to improve quality of care for a specific patient type and to achieve a higher degree of efficiency and a higher grounding in the evidence base. Accordingly, pathways function as communication tools between professionals carers (excluding the informal ones) to manage and standardise care, but not personalising it (Vanhaecht et al., 2006). Pathways support the translation of the rather prosaic described, generic recommendations of clinical practice guidelines (CPG) into a more applicable representation adapted to local structures and conditions of a clinic. They focus on quality and efficiency of the care
process (Kinsman et al., 2010; Panella and Vanhaecht, 2010; Rotter et al., 2010). CPs do not only include medical treatments, but also care processes, administrative and other supporting processes (Schlieter and Esswein, 2010). The goal is the improvement of care and the optimisation of resource allocation (Juhrisch et al., 2012). Adaptability (while runtime) as a feature of a dynamic pathway system requires consensus among the stakeholders to allow the choice of the adequate procedures (Burwitz et al., 2012). Pathways empower carers by providing means for equilibrating the clinical and non-clinical aspects of care. The building of pathways and reorganisation of the care processes has to be accompanied by all parties of the multidisciplinary team to be successful (Vanhaecht, 2007). However, pathways are currently limited by the implementing institution, and usually do not consider other health service providers, social care, informal care or self-care (Lehrmann et al., 2015).

Continuous treatments with multiple carers instead of isolated episodes with silo-like data pools are the goal (Lenz and Reichert, 2007). Usually, pathways do not provide much operational support as these are primarily used for descriptive and documentation purposes. The inclusion of evidence information and the transparent depiction of the genesis of pathways from practice guidelines are required, but not broadly implemented. So, the pathway usage is mostly restricted to organisational issues. The integration into IT systems does not take place due to separation of process design and process implementation. Often, pathways are only used in quite restricted scenarios (special hospitals or departments) or with a minority of patients. But especially in hospitals, it is highly relevant to identify and adapt changes in medical knowledge in daily practice and therefore change the hospitals’ processes (preferably IT-supported) (Burwitz et al., 2012; Vanhaecht et al., 2006). An adequate level of process and information integration and semantic interoperability of the healthcare systems are crucial here. The use of pathways is only possible with broad knowledge sharing in the development, implementation and evaluation (Vanhaecht et al., 2006). This is hampered by the variability in, the inconsistent use of knowledge along the pathways resp. care processes (Vanhaecht, 2007). However, formal pathway models are predisposed to be the starting point for a hospital information system (consisting of human task managers and technical application systems; Burwitz et al., 2012; Hideko et al., 2001).

Desirable systems should allow ongoing adaptations according to specific needs of the carers and changing needs for decision support. Such advanced health IT has to provide support for patient treatments as well as the management of the healthcare network’s information reducing cognitive overload and advancing the decision rationale (Lenz and Reichert, 2007). E.g., Burwitz et al., (2013) derive requirements for pathway modelling languages to allow a systematic depiction (in terms of conceptual models) of the course of the treatment. Subsequently, they design a distinct modelling language (its meta-model) that is suitable for the needs of the healthcare sector, and give a brief example how a pathway engine might be designed (Burwitz et al., 2013). Another approach is presented by Winge et al., (2015) who derived an information model for a coordination hub. It allows the frictionless treatment of patients within complex care arrangements given the social interdependencies of modern care and societies (Winge et al., 2015). Such approaches are valuable, but out of the scope of the present paper as the authors aim at proposing an overarching pathway system that in turn may utilise a specific modelling language or a coordination system.

Studies meanwhile show the reasonableness of (inner-institutional) pathways in terms of decreasing lengths of hospital stays or a better coordination of the whole care procedure (Rotter et al., 2010; Rotter, 2013). Nonetheless, the use of pathways varies much regarding length, extent and level of details. Overall, there seems to be uncertainty about the concrete benefit of pathways in practice. This also relates to the differences in methods used to develop, implement, and evaluate a pathway and the integration of the latest evidence data (Vanhaecht, 2007; Vanhaecht et al., 2006). In sum, it is debatable why pathways are not broadly used in the clinical routines. The PDP-Framework (described below) addresses the sketched shortcomings and seeks to be an enabler for forthcoming pathway solutions and the increase of pathway usage and to further promote and diffuse IC supported by integrative health IT systems.
2.2 Requirements of Integrated care

As mentioned, IC is an advantageous approach to facilitate the needs of comorbid patients. So, it is reasonable to ascertain the overall requirements of IC to allow an effective and successful IC treatment process. For the following analysis, we take the requirements for IC from Richter et al. (2016), who address the contribution of overarching electronic health records to the IC- aspiration. However, the identified requirements are surveyed (by means of a systematic literature review) for advanced information systems in healthcare in general and are therefore used here as well. The IC requirements and derived PDP requirements are presented in Table 1.

<table>
<thead>
<tr>
<th>IC and derived PDP requirements (Req. 1-10; adapted from Richter et al. (2016))</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stakeholders</strong></td>
</tr>
<tr>
<td>It is necessary to have a clear understanding of every stakeholder’s role and the distribution of the work and responsibilities in the IC network. Therefore, educational content has to be provided along the process. This has to be integrated and imparted according to the needs, the situation or the cognitive abilities of the patients (Req. 1). Institutional constraints have to be waived – a rather long-term convincing endeavour by showing the approaches’ advantageousness. The degree of patients’ independence shall be increased and a higher amount of decisions shall be made by the patients (i.e. patient empowerment). The concepts of IC and patient empowerment have to be internalised by all stakeholders. Their roles in the complex care scenario in relation to the other members of the care network have to be clearly pointed out (Req. 2). The patients’ safety and wishes shall be central. The specific needs of every (empowered) patient have to be considered. The access to the relevant information has to be ensured to allow an eligible assessment of the health condition. This in turn allows active participation and decision-making. The access of all partners has to be clearly determined. Not all partners shall be allowed to look at every entry (patients’ opt-out; Req. 3)</td>
</tr>
<tr>
<td><strong>Process organisation</strong></td>
</tr>
<tr>
<td>Many per se interdependent and partly overlapping processes and work have to be clearly synchronised and allocated. This in turn leads to a higher degree of complexity, but also improves the process results. The synchronising entity together with a synchronisation mechanism for process synchronisation points have to be set (Req. 4). Sector- and institution-spanning communication and treatments have to be supported and the high amount of complex long-term collected information needs to be represented in a clear manner. A joint documentation base has to be set up. ICT-supported care leads to the introduction of joint (electronic) health records and joint pathways allowing a multidisciplinary and overarching care. Adequate process models that support/use suitable languages are a necessity. Processes and corresponding tasks etc. have to be adequately documented and stored in a machine-parsable manner (Req. 5). Overarching openness is a prerequisite: Building vertical and horizontal, formal and informal networks within and between organisations is helpful for joint working relationships. Virtually, the IC process shall not be separated by outpatient, inpatient and rehabilitation. An overarching information-sharing and an appropriate communication strategy are needed. Centrally managed/established communication and collaboration modes are needed to allow a seamless care across institutions or modes of care to ensure the permeability of the needed data (Req. 6)</td>
</tr>
<tr>
<td><strong>Communication</strong></td>
</tr>
<tr>
<td>Clear and open communication, a common language and permanent feedback are prerequisites for interdisciplinary and inter-institutional care. This leads to a common understanding of and a common knowledge about the patient needs, what is currently happening and what is planned among all stakeholders. This allows properly preparing for further steps, informed decision-making and permanent learning and process improvements. One measure for this is to set up a central communication tool. The relevant information has to be accessible for all authorised stakeholders. The professional language has to be broken down into easier concepts with fewer ambiguities. Process models are a reasonable measure here (Req. 7). To achieve a reasonable documentation, coordination and governance of care, thoroughly documented care plans are needed. Standard operating procedures (SOPs), CPGs and CPs are useful instruments to thoroughly structure/design care. These are of high worth to ensure the homogeneity and transparency of the IC processes across different institutions. IC requires a network-like approach and operational flexibility and openness in care. There have to be adequate access mechanisms and a powerful process description (language; Req. 8)</td>
</tr>
<tr>
<td><strong>Learning</strong></td>
</tr>
<tr>
<td>The IC goals have to be operationalized and regularly measured based on a system-wide performance measurement to manage the complex IC networks and its results. All stakeholders have to experience an added value through the implementation of IC like incentives or the prospect of a better and more self-determined care. Operational flexibility (e.g. unscheduled incidents) and the openness to adopt new techniques are further needs. Continuous improvements on the organisational level have to go along with a change manage-</td>
</tr>
</tbody>
</table>
ment system and process/execution agility on the technical level (Req. 9).

<table>
<thead>
<tr>
<th>Data + IT</th>
</tr>
</thead>
<tbody>
<tr>
<td>IC requires centrally and formally coordinated processes and proper planning. Therefore, centralised informational repositories and centrally coordinating instances are necessary. Data exchange across distinct institutions and sectors is required for IC. The individual’s history and current health status (on a technical level: database entries) have to be accessible for all involved caregivers. Integrated information systems are necessary to allow IC. The information flow within institutions and to other IC stakeholders (esp. for the patients’ informed decision-making) has to be ensured. Respective repositories store and administrate the care plans, current and former pathway types and instances. The access rules are recorded here. Information flows in both directions and improvements/changes of the existing data pools (i.e. treatment data/specifications) have to be possible to allow the learning on the technical level (Req. 10).</td>
</tr>
</tbody>
</table>

Table 1. Characteristics of IC and derived system requirements

3 Introduction into the PDP-Framework

The objective of PDPs is to set up an ICT- and pathway-based care network. This should improve the abilities to effectively treat people with co-morbidities as introduced above. The PDP-Framework is therefore the interlinking element of an IC scenario. In terms of a conceptual brace, it describes structures for documentations, responsibilities, the stakeholders’ needs and the procedures themselves as well as the relations between these items combing it with the general advantages of using ICT in healthcare in terms of higher efficiency and central control and data pools (Stroetmann et al., 2010).

Figure 1. Concept of Personalised Dynamic Care Pathways (extending Lehrmann et al., 2015)

The idea of PDPs differs from the traditional inner-clinical pathway approach (see section 2.1), since it involves all stakeholders along an individual’s care process in a sector-spanning manner and coordinates their interactions. Additionally, it considers the need for individualised care, the changing health and social circumstances of the patients. Thus, integration means following a pluri-pathological instead of a single-disease approach. On the one hand such pathways are based on a common care standard that is traceable across different professionals and allows the comparison of similar cases. On the other hand, these release space in integrated interventions since they are adaptable in case of (ad hoc) changes of the care process. Personalisation refers to the possibility to adapt to the individual circumstances and requirements not only on the provider but also on the consumer side (van der Klauw et al., 2014; Leutz, 1999; Singer et al., 2011; Suter et al., 2009; Vlegel-Brouwer, 2013; Walker et al., 2013).
PDPs allow transparency and auditability in medical and social care in terms of exchanging and providing relevant health-related information of individuals among the authorised IC stakeholders. However, if the record owner denies access to information, the transparency could be reduced for some of the stakeholders (Req. 3). Still, common standards are needed to allow fluent data exchange. The integration with a workflow management system, that navigates IC stakeholders through the intended steps of the care process, needs further research. PDPs function as a control instrument for IC reaching beyond a solely institution-centred view by involving all health care providers along the care process of a patient as well as his/her home and daily life environment (Billings, 2005; Eason and Waterson, 2013; van der Klauw et al., 2014; Singer et al., 2011). Moreover, an integration across single pathways and overarching data exchange is necessary to allow IC approaches (Amelung et al., 2012; Leutz, 1999; Stroetmann et al., 2010). In the following, the components of the PDP-Framework will be described in detail (see Figure 1). These conceptual thoughts are compared to the ascertained requirements of a system following the IC approach (see Table 1). The PDP-Framework’s core is the integration box (middle of Fig. 1), which represents the need for a health IT system (of the care network) having the capability to design and execute the pathways. This information allows continuous improvements (right box of Fig. 1), flexible configurations and uncomplicated adaptability to achieve the desired dynamism of the solution (Req. 9). To get a wider view on health status of the patients (left box of Fig. 1), additional data analyses from multiple sources (personal health data, clinically recorded health data, data from social software) are needed for the personalisation of the pathways (Req. 3).

3.1 Data collection

The process of deriving PDPs (in the end patient-specific instantiations) starts with data collection. This data is the base and source for the personalised pathways. Formerly existing pathways (classically derived ones) are the overall starting point of the personalisation and improvement of those (Req. 2, 9). While run-time, this would mean to combine social data and health data of an individual with evidence-based data about special treatments, care pathways and CPGs supplemented by patient context data (Tillmann et al., 2015). The generation of the patients’ profiles (based on clinical and social aspects, habits and lifestyles and the context of living) allows the desired individualisation (Req. 3). Aggregating information from heterogeneous databases (electronic health records, hospital, laboratory or radiology information systems, registry offices, etc.) is a necessity here. Aligned combinations and special data formats or conversions are needed here (Curry and Ham, 2010; Kodner and Spreeuwenberg, 2002; Leutz, 1999; Rayner, 2009; Suter et al., 2009). The collected information initialises the “Integrated Care Pathway Template Repository” (ICPTR; see box Integration in Figure 1). Existing pathways and newly built integrated ones are additional sources for this repository. The ICPTR represents a knowledge base with adequate treatments and procedures for different diseases and their associated co-morbidities (partly Req. 7). It contains generic pathways with connections to administrative services forming interrelated and configurable path modules (Req. 2, 4, 5). New pathways need to be hosted in the platform so that practitioners, hospitals, specialists and social workers can access and contribute to. Informal caregivers and patients should also be able to provide input to the platform (Req. 2-6). So, it has to be ensured that diverse external data sources are connected with the pathway system (Req. 10). Common data standards/formats and distinct interfaces have to be envisaged and designed (Häyrinen et al., 2008; Tsiknakis et al., 2004).

3.2 Integration

The main phase (middle box of Fig. 1) is the derivation of the personalised care pathways that are supported by an ICT system fostering the continuous integration of the different data sources and thereby makes the pathways more and more dynamic (Req. 3, 5, 10). Therefore, the pathways have to be described in semi-formal diagrammatic models to allow human as well as ICT-based (automatically) understanding and implementation of those (Req. 2, 5, 7, 8) (Burwitz et al., 2013). Furthermore, it is necessary to have modularised paths and mechanisms for the configuration, rules and sense-making
checks for the combination of those. This ensures or allows the interchange and the easy orchestration of distinct paths (Req. 6-8). A common data exchange standard between the path modules and for the exchange of those together with the adherence to commonly shared building rules of such (avoiding processual pluralism) are necessary (Req. 4, 5) (Amelung et al., 2012; Leutz, 1999; Rayner, 2009; Suter et al., 2009). The system has to be agile/flexible in terms of allowing ad-hoc changes of pathways when it comes to unexpected changes of health data or care procedure (Req. 8, 9, 10) (Burwitz et al., 2012). The customisation of individual pathways (Req. 3) is conducted by means of combining the data of an individual with generic paths from the ICPTR. This pathway – adapted to specific needs and the specific health condition – is implemented in practice as Individual Integrated Care Pathway (IICP). The social status, the familial background, the skills and the specific information needs of the citizen are major influencing factors here (Req. 1-3). This leads to the provision of individual information on in- and out-patient level as well as at other stages or forms of care (Req. 3). Ad-hoc changes of the path as a consequence of the approach’s dynamism are possible at every stage of the process (Req. 8, 9; see middle of box Integration in Figure 1). An individual’s data can be exchanged across institutional borders and between different caregivers, based on an open standard to allow highly integrated care (Req. 6-8, 10). The single pathway executions of IICPs are stored in an IICP Repository.

3.3 Interpretation

The interpretation phase covers improvements of the current pathways (Req. 9, 10). Multidimensional overarching analyses are needed to allow significant statements whether distinct care plans or decisions should be retained, further developed or discarded. Semi-formal models may also play an important mediating role here. The IICP Repository allows organisational learning and improvements of the related pathway template stored in the ICPTR (Req. 9; see box Interpretation in Fig. 1). Especially reference models can be used here (Lehrmann et al., 2015). Real intervention-based care data can be analysed and interpreted with regard to practical problem adequacy (Req. 9). The process within the care pathway and the pathway template can be adapted if necessary. The new insights are utilised for the initialisation of progress in healthcare management (Req. 6, 7, 9).

3.4 Further ICT-related research

As a final assessment, the requirements all can be covered by the PDP-Framework. Admittedly, concrete implementations are not present yet. Especially, the organisational and stakeholder aspects have to be reconsidered. Overarching cultural and stakeholder will related aspects are in fact part of the framework as an approach for designing information systems (Kummer et al., 2012). But the willingness and openness to follow the IC approach and patient empowerment require accompanying educational and informative measures coming to a cultural change. Up to now, the PDP-Framework is primarily located on a conceptual level. In the outlook of further steps, a basic ICT infrastructure is needed for the initial data collection or path initialisation and for the health information exchange between the diverse healthcare providers across several care institutions and sectors. Furthermore, there is a need for open and universal standards, common data models etc. to allow the data exchange. There also has to be a consent regarding the used terminology and general content of the recorded data to allow the data exchange on the semantic level coming to nearly uniform representations. Furthermore, the choice of an adequate process description language for/of the pathways is a basic prerequisite. Such a language should support adequate concepts for intersectorial and institution-spanning processes. The transferability (of data and processes, resp. their descriptions/presentations) and integrability into the mostly still existing application system in the clinics, surgeries etc. have to be ensured. Trust in the new system has to be ensured by standards for authentication, data security and long-term retention of the data by means of adequate data formats etc. Here, the potentials/functions of distinct IHE profiles/standards should be taken into consideration achieving a suitable solution. As the PDP-Framework lays the groundwork for an advanced health ICT solution allowing IC facilitated by the overarching pathways, the overall system relies on the integration of several single health IT solutions.
The framework aims at aligning and combining them. The data collection requires primarily existing systems. More or less official records of the formal care providers (in terms of any form of electronic health record) as well as privately gathered data (from personal health records or health apps; on voluntary basis) can serve as a source. The further processing steps (the derivation of the personalised pathways) then needs special applications or the adaption of existing ones. Respective integration/adaption concepts are a further necessity.

4 Conclusion and Outlook

The presented PDP-Framework contributes by addressing the need for a broader care with the integration of multidisciplinary teams across institutional borders. It allows the generation, use and ad-hoc changes as well as long-term learning and process improvement for care plans in terms of CPs. A tool for organising IC, structuring the main concepts and features for a prospective solution, helping to identify further research demand and bringing together the stakeholders of the care network is proposed. The framework’s high-level requirements are an ambitious vision that has to be transferred into concrete measures or system design. The authors assume a substantial improvement in care by (partially) implementing the framework’s ideas and following the respectively spanned research agenda.

Notwithstanding, the presented concept hinges on the question regarding its system-wide implementation. This in turn raises the question of data safety and security. Privacy aspects and informational self-determination are of high importance due to the intimacy of the collected health data. The systems should be compliant with the data protection laws without hampering the necessary and legitimate data exchange. Nevertheless, focussing on the rights and needs of the citizens is highly important. However, a blanket statement is not possible here as every country primarily governs the respective regulations. At least, the recently introduced reformed EU Regulation on Data Protection is an important step towards harmonisation here. The overall objective should be that every citizen is in charge of the own health data and is able to decide very granularly who is allowed to access information. Furthermore, the data could contribute to more evidence-based health care systems, given the possibility to analyse the data for public health purposes. However, the pros and cons with regard to privacy issues have to be weighed. Here, the governmental precepts are major drivers of prospective developments.

The development of a concrete evaluation strategy for the framework is a further necessity as it would finally show the framework’s reasonableness and initially completes the DS procedure (Hevner et al., 2004). A possibility for the evaluation are use cases with exemplary chosen diseases and demonstrate the procedure within a system following the PDP-Framework. Another idea is to test major ideas of the framework in smaller groups within a regional care network and a telehealth platform the authors have access to. These ideas will be reconsidered when conducting the in-depth evaluation strategy.

For the conceptual refinement of the framework, it is necessary to achieve a module-based concept. The idea is to define sector-specific building blocks, to identify the information that has to be forward-ed between the sectors and to conceive the transfer points for this. To allow a high acceptance rate among the prospective PDP-users, it is advisable to conduct a distinct need assessment for every stakeholder group. This will in turn increase the users’ system literacy. Also educative elements esp. to support the informal carers or the less experience ones in general (newly recruited; uncommon diseases/courses) should be included. Patients have to be trained to allow higher involvement and empowerment. Professional and non-professional caregivers have to be sensitised for the characteristics of IC processes and the advanced role of the patients and their living environment. Here, special educational plans have to be conducted. The integration of assistance functions to support and further qualify the users is also advisable (Howarth et al., 2006). Learning in terms of process or data analyses (Big data approach) should also be considered. This in turn poses the question, which data sources can be merged in what manner.

Finally, the PDP-Framework is a first result conceptualising IC. As Research in Progress, the paper provides the first steps within a DS process. Its completion paves the way to achieve a real implementation of the PDP concept.
References


