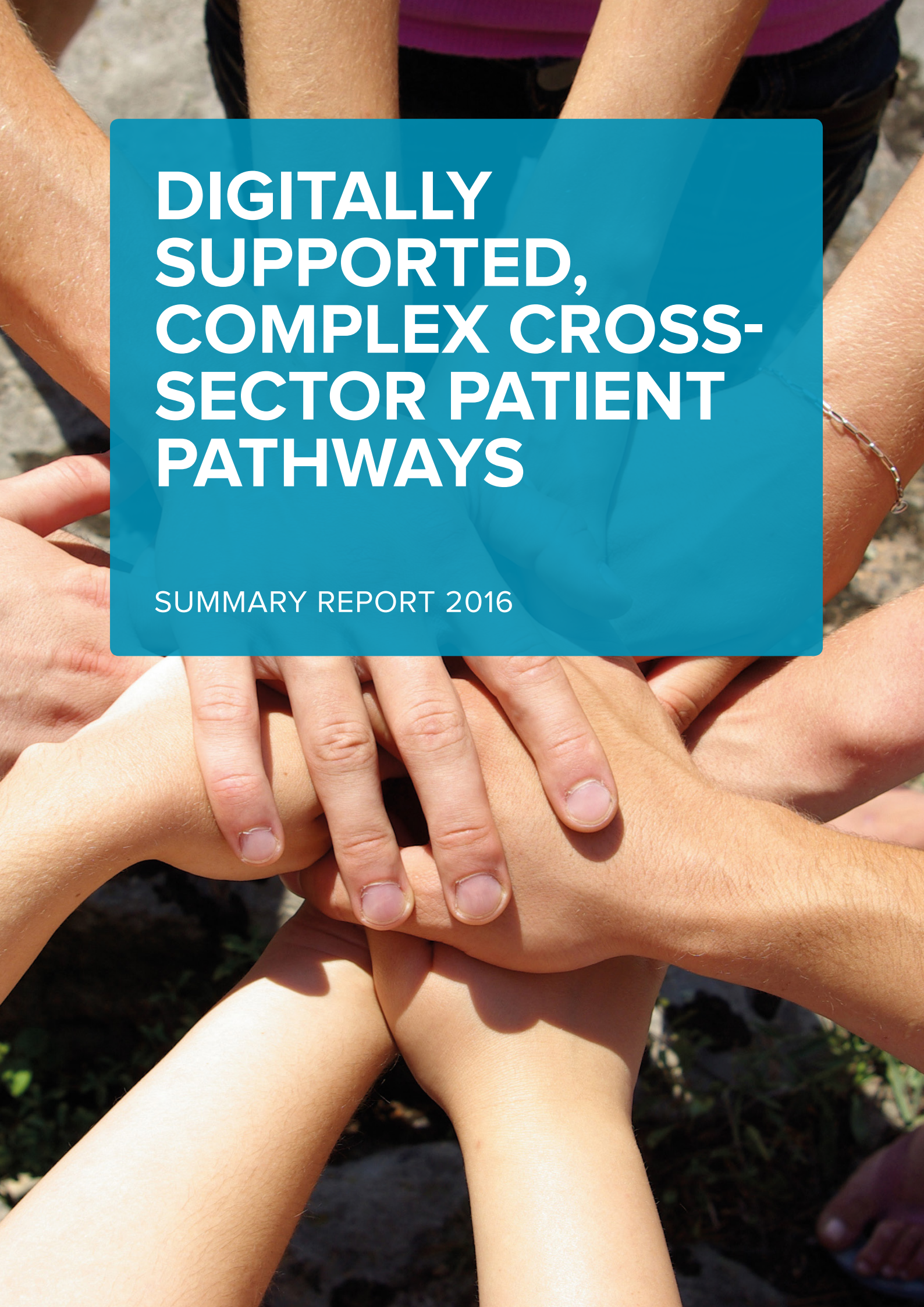


DIGITALLY SUPPORTED, COMPLEX CROSS-SECTOR PATIENT PATHWAYS

SUMMARY REPORT 2016

Contents

Summary and recommendations

The objective of the common public-sector project ”Digitally supported, complex cross-sector patient pathways” project was to identify the challenges currently facing healthcare providers, patients and their relatives in collaborative work on complex cross-sector patient pathways.

To address these challenges, the project set up a framework of objectives for improved digital collaboration on complex cross-sector patient pathways, and has provided recommendations for further work in this area.

Problem and vision

Patients with complex care pathways are often elderly people with chronic disorders and cognitive problems, e.g. diabetes, cardiovascular diseases, chronic respiratory diseases, osteoporosis and arthritis, as well as mental disorders. These patients repeatedly come into contact with many different healthcare providers and need hospital services, services from general practitioners and municipal health services.

A pre-analysis for the project revealed that, in 2012 around 50,000 citizens had a substantial need of coordination between the hospital, the general practitioner and the municipality. Of these citizens, 36,000 were elderly people (65+ years) with chronic diseases, with contact to their municipality in six out of twelve months, and 14,000 were younger people (18-65 years) with chronic diseases, who received one out the following four types of public assistance: sickness benefits, social benefits, rehabilitation benefits and unemployment benefits.

The many points of contact and treatment pathways across all sectors of the health services for this group of citizens require improved cross-sector collaboration and coordination. Furthermore, there is a need for a higher degree of involvement of patients and their relatives. The need to ensure coordination, communication and sharing of information about the individual patient's treatment grows as the health services develop towards shorter hospitalisation periods for patients and a greater focus on outpatient treatment at hospitals. This moreover increases the role of the municipal health services and the requirements for collaboration with general practitioners.

Today, patients often experience fragmented and non-coherent contact with their healthcare providers. An anthropology study (IIAB, 2015), conducted as a part of the project, found the following general statement from selected patients from the target group:

> ***I have no overview of my care pathway and no one else seems to have.***

An analysis performed by Local Government Denmark in the context of the project identified the following six main challenges facing patients and their relatives (Business analysis, 2015):

- **Insufficient sharing of information** – patients find that they have to repeat themselves over and over again.
- **Insufficient overview of points of contact** – *"I have no overview of my care pathway and no one else seems to have".*
- **Uncertainty about responsibilities** – Patients describe being discharged from hospital as "being released" without a clear idea about who will follow-up on their case and when and how this follow-up will be organised.
- **Lack of common goals** – Patients with several disorders may be subject to multiple treatment pathways with different goals, and these are not being coordinated.
- **Lack of involvement of relatives** – *"I didn't like being given a telephone consultation because it meant my wife couldn't participate in the consultation."*
- **Difficult to retrieve relevant information** – Because they lack the necessary overview, healthcare providers sometimes experience chaotic and often unsatisfactory consultations with their patients.

These challenges are particularly difficult for patients with limited personal resources. These patients are especially vulnerable to a lack of coordination and coherence in the transition between health care providers. Unlike patients with good personal resources, such as a substantial network of friends and relatives, patients with limited resources have difficulties acting as carriers of information between different healthcare providers.

To address these challenges, the healthcare sector should aim at integrated cross-sector cooperation in complex patient pathways as described in the business analysis. This requires improved cross-sector ICT (Information and Communications Technology) solutions which facilitate coordination and knowledge sharing. The vision for digitally supported, complex cross-sector patient pathways is therefore as follows:

Patients with complex treatment pathways and their relatives experience a healthcare system characterised by collaboration across sectors and in which everyone involved in the treatment of the patient has digital access to information and to rapid communication about the patient's overall situation.

Solution

Framework of objectives for digitally supported, complex cross-sector patient pathways

A substantial part of cross-sector communication in the health services today is adequately supported by ICT (Deloitte 2014). However, the current ICT support functions primarily by sending structured messages to the next healthcare provider. This is appropriate to provide support for a collaboration model such as *transferred care*, in which the task is passed onward like the baton in a relay race. However, this paradigm is challenged when providing support in *shared care* models. In this model, patients undergo multiple treatments at the same time and these situations require a greater extent of continuous collaboration about, and with, patients and relatives.

Furthermore the current ICT support is designed to provide support for the specific tasks of the individual sector and support is therefore not designed for cross-sector communication, which entails collaboration using common information and involving patients and their relatives. Information sharing that provides support for coordination and collaboration across sectors is needed. This includes sharing treatment goals and treatment plans, a common overview of the patient's appointments with the health services, as well as an overview of the healthcare providers involved in the patient's treatment. It is the assessment that in order for providers to be able to share information in a structured manner to a greater extent, there is a need for an overall architecture vision and for a framework of objectives that can underpin an overall development, which, as far as possible, allows the parties to keep in step with each other and to coordinate investments on an ongoing basis. It is against this backdrop that a digital foundation for continued joint efforts has been prepared.

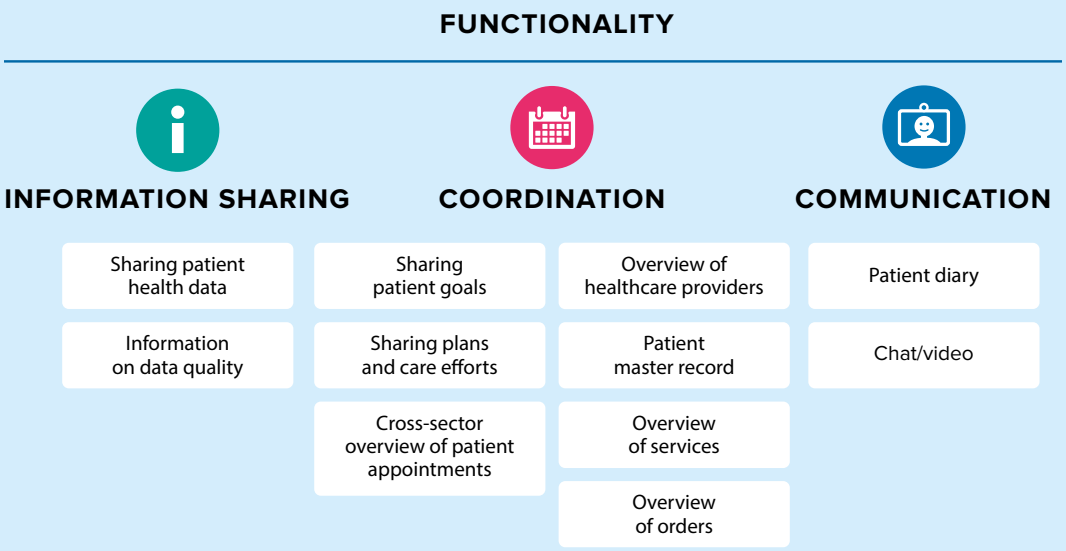
The framework of objectives for cross-sector complex patient pathways contains the IT architecture described below, as well as a number of principles for digital transformation in this area:

"A common digital foundation, in which patients, relatives and health professionals collaborate on the health and treatment of the patient on the basis of a holistic approach. The foundation is composed of a series of solutions from different public-sector and private-sector parties working together in an overall ecosystem."

The digital foundation is composed of a series of solutions from different public-sector and private-sector parties. These solutions work together in an overall ecosystem with a number of elements (standards, tools, services and systems, etc.), which are supplied by a number of different parties. This means that a solution is not necessarily a technical solution; it can also consist of IT architecture or standards, for example.

The framework of objectives is specified as 11 overarching functionality areas that provide support for information sharing, coordination and communication. The framework of objectives was prepared on the basis of 55 solution elements identified by the cross-sector working group. The framework of objectives also contains general functionalities, such as consent, power of attorney and security. The overarching functionality areas are listed in figure 1 below.

FIGURE 1
Functionality areas



The business analysis identifies a need to be able to provide support for new, integrating collaboration models such as *relational coordination,* the central elements of which are common goals, shared knowledge, mutual respect, and communication which is problem-solving, frequent, on-time and correct. The areas assessed as key to ensuring that the above is digitally supported are:

- Sharing patient health data
- Sharing patient goals
- Sharing plans and care efforts
- Cross-sector overview of patient appointments
- Overview of healthcare providers

More analyses and trial projects in the functionality areas are needed to achieve the framework of objectives. Furthermore, business cases must be prepared and clarity provided about the legal framework, just as agreements on roles and responsibilities for the area will have to be established.

Recommendations for further work

The project was headed by a common, public-sector steering group with representatives from the Ministry of Health, Local Government Denmark, Danish Regions, the Agency for Digitisation, the Danish Health Data Authority, the Danish Medical Association, and MedCom (as observer). On the basis of the conclusions in the analysis, discussions and workshops in the project, the steering group has drawn up the following recommendations:

1. Functionality development should be prioritised in five selected areas
The steering group recommends work further on the following five functionalities, which is assessed to provide the most value in the collaboration effort on complex patient pathways:

- Sharing patient health data
- Sharing patient goals
- Sharing plans and care efforts
- Collective overview of patient appointments
- Overview of healthcare providers

2. Common public-sector management of further efforts
Other projects that are launched in efforts to achieve the framework of objectives for complex cross-sector patient pathways should also be coordinated by the steering group for complex pathways.

The launch of specific further projects concerning analyses, standards and trial projects, including initiatives under the new common public-sector digital strategy (Digital Strategy 2016-2020), should be agreed among the parties.

Furthermore, the steering group notes that, as a part of initiative 3.1, coherent welfare pathways, the Digital Strategy 2016-2020 includes an agreement to continue the steering group for complex pathways. In this connection, the steering group recommends that:

3. The architecture vision and principles of the framework of objectives should, in the future, be followed in connection with decisions on new common public-sector eHealth initiatives.
In future, common public-sector eHealth initiatives should follow the architecture vision and principles of the framework of objectives with regard to providing digital support for complex cross-sector patient pathways. Maintenance and any needs for further development of the framework of objectives should be placed with the Danish Health Data Authority's advisory committee on standards and IT architecture, which refers to the National Board of eHealth.

4. The framework of objectives should be used in long-term planning
In general, the parties and the National Board of eHealth should use the framework of objectives when launching initiatives and projects in the area. The framework of objectives enables joint, long-term planning, which is beneficial since development and maturation, especially of the more immature areas that require analyses and IT architecture, take time and therefore should be set in motion well in advance of the actual development projects.

1. Introduction

1.1 Content

This report contains the collated conclusions from the common public-sector project "Digitally supported, complex cross-sector patient pathways" project, which the Government, Local Government Denmark and Danish Regions launched though the budget agreement for 2015 as a part of the digitisation strategy for the healthcare sector, *Making e-Health Work 2013-2017.*

The basis for the report includes:

- A 2014 report on digital solutions in support of relevant workflows across the healthcare sector (Deloitte 2014 for the National eHealth Authority/the Agency for Digitisation).

Project deliverables:

- Atlas of eHealth solutions (National eHealth Authority, spring 2015).
- Compilation of experience from seven, existing Danish projects which involve digital support for new types of cross-sector collaboration (Devoteam, spring 2015).
- An anthropology study of complex cross-sector patient pathways (Nielsen and Jensen, IS IT A BIRD, spring 2015).
- Business analysis: Towards improved digital support for complex cross-sector patient pathways (Local Government Denmark, November 2015).
- System technical framework of objectives for digitally supported, complex cross-sector patient pathways (Danish Health Data Authority, April 2016).
- Pilot project involving more specific identification of needs and content for ICT solutions in support of common goals, and appointment-overview of complex cross-sector patient pathways (CoLab, spring 2016).

The deliverables in the report constitute the framework of objectives for digitally supported, complex cross-sector patient pathways for 2020. The framework of objectives describes the digital initiatives which can address the challenges described in the business analysis and realise the overarching vision described below.

Vision for digitally supported, complex cross-sector patient pathways:

Patients with complex treatment pathways and their relatives experience a healthcare system characterised by collaboration across sectors and in which everyone involved in the treatment of the patient has digital access to information and to rapid communication about the patient's overall situation.

(The vision was adopted by the project steering group in spring 2015 as the basis for joint efforts under the project)

The framework of objectives also includes a description of how to provide digital support, i.e. through a common digital foundation in which solutions (standards, tools, services, systems, etc.) from public-sector and private-sector parties function together on the basis of a number of common principles. However, the framework of objectives is also a description of what is required, i.e. in which areas functionalities will have to be developed, and which areas are most important with regard to achieving the desired benefits. The solution elements required to achieve the desired functionality, i.e. the concepts, standards, infrastructure components, etc. required, are also described as part of the work. Furthermore, the degree of maturity of each of the 55 solution elements was assessed as a part of the project. In order to meet the 2020 framework of objectives for complex cross-sector pathways, a number of activities will have to be performed in each functionality area. In addition to work on the solution elements, there will be a need to prepare business cases and describe legal and governance concerns, e.g. in relation to roles and responsibilities.

1.2 Background

In order to ensure a clearer direction for work to ensure full digital communication in the healthcare sector, the 2013-2017 digitisation strategy for the healthcare sector contained an agreement to conduct a survey and analysis of digital support for relevant workflows across the sector.

Based on this, the budget agreement for 2015 included an agreement to examine the health and financial benefits of improved digital collaboration between municipal care units, general practitioners and hospitals on complex cross-sector pathways.

This work was specified in a joint project, the objective of which was to clarify how collaboration between hospital, municipality and general practitioner on complex patient pathways is best supported digitally, so that healthcare providers across sectors can share the relevant information.

This project is a cross-institutional collaboration project agreed between the common public-sector parties and carried out with participants from the Ministry of Health, the Danish Health Data Authority, the Agency for Digitisation, Danish Regions, Local Government Denmark, the Danish Medical Association and MedCom.

1.3 Business drivers for improving digital support for cross-sector collaboration

A large number of factors are changing the way healthcare providers collaborate in the health services today. The business drivers behind this change include:[1]

- Active involvement of patients in management of their own illness will help alleviate pressure on the healthcare system.
- Provide support for the trending reduction in number of bed days and limit the number of unnecessary outpatient check-ups.
- Improved conditions for handling coordination as hospital stays become ever shorter.
- Prevent deterioration in patients' condition and, thus, prevent an increase in care intensity.
- Develop support for treatment pathways that (to an ever greater extent) will be influenced by geographical distances.
- Provide support for the promotion of, and follow-up on, pathway programmes and quality.
- Prevention and early detection.
- Increased specialisation of care, so that a greater number of healthcare specialists are involved in the individual patient pathway.

1) Deloitte, Board seminar, March 2014

These business drivers mean that there is a need for more active coordination and control of pathways, as well as for far greater involvement of patients and their relatives, e.g. through *shared care*.

Such a change requires digital support across the health services, so that healthcare professionals, patients and relatives can access the information they need, when they need it.

"Almost two out of three Danes (65.8%) call for more patient collaboration between hospitals, general practitioners and local government. The second-most important priority is shorter waiting times (62.5%), followed by more extensive use of technology in treatment and care (37.7%)."

Opinion poll, Mandag Morgen and Trygfonden, June 2015.

1.4
Results of analysis of digital cross-sector communication in the health services

In 2014, as part of the 2013-2017 digitisation strategy for the healthcare sector, an analysis and survey of the digital transformation of cross-sector communication was prepared (Deloitte, 2014).

Among other things, the report identified a need to design communication to match emerging developments in the healthcare sector, including that it should be possible to involve patients/citizens (and their relatives).

The analysis showed that, although much of the communication in the healthcare sector today is digital, it is also characterised by message-based communication designed to provide support for a sequence of care efforts, in which the care effort is transferred from one healthcare provider to another in sequence like the baton in a relay race (transferred care). This type of communication is appropriate for patients with simple treatment pathways that involve only a few numbers of healthcare providers, but it is insufficient when a patient has many points of contact to different healthcare providers and receives multiple treatments. (Deloitte, 2014).

The survey also revealed that the development of digital communication has taken place incrementally, and that no overall plan has been drafted for how to share information and provide ICT support for closer cross-sector collaboration (Deloitte 2014).

This means there is need for a common framework of objectives for more coherent sharing of data and digital collaboration on complex cross-sector pathways able to address the issues identified with regard to the parallel exchange of data between several parties.

Therefore, a sub analysis was conducted that took a closer look at solutions based on a *shared care* model, in which care is provided by a collective network of healthcare providers. Deloitte identified a number of patient groups with complex care pathways. These groups were characterised as having one or several chronic disorders as well as extensive, transversive points of contact with all three sectors. These citizens have extensive consumption of health services and points of contact with many different health care providers, which means there is a substantial need for coordination between the different providers involved (Deloitte 2014).

The sub analysis showed that, in 2012, 345,600 chronically ill patients aged 18-65+ had had points of contact with their general practitioner, the hospital and the municipality. Out of this group, 125,000 chronic patients (36%) received 10 or more services from their general practitioner and/or medical specialists, and had four or more points of contact with the hospital in 2012.

In this group, 36,000 elderly chronic patients (65+ years) had contact with their municipality in at least six months out of 12 months, and 14,000 younger chronic patients (18-65 years) received one out the following four types of public assistance: sickness benefits, social cash benefits, rehabilitation benefits and unemployment benefits.

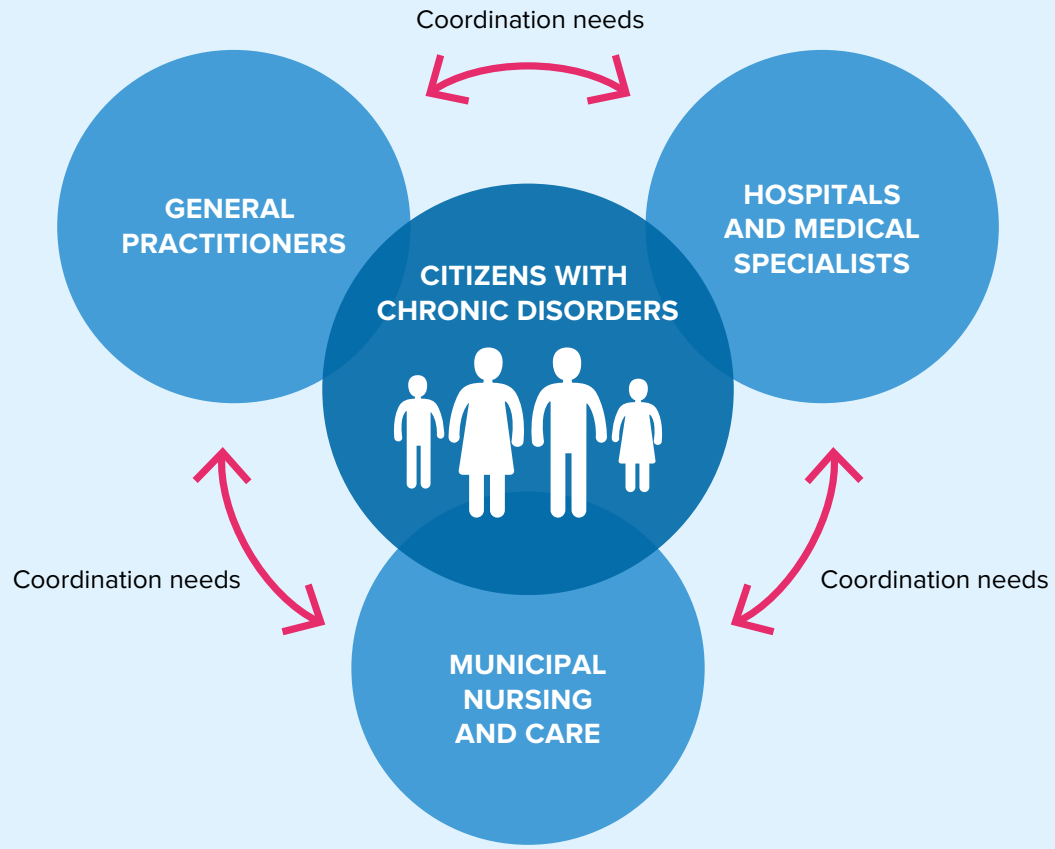
Thus, in 2012, for around 50,000 citizens, there was a substantial need for coordination between the hospital, the general practitioner and the municipality.

With this patient group in mind, four *shared care* solutions in use outside Denmark were examined, including the calculations underlying these models (Deloitte 2014).

The report concluded that stronger digital collaboration across sectors on complex patient pathways could provide benefits for patients in the form of reduced hospital admissions, fewer bed-days, fewer visits to the general practitioner and unnecessary outpatient check-ups.

FIGURE 2

Need for coordination between general practitioners, secondary healthcare providers and municipalities



2. Challenges for healthcare professionals, patients and relatives

2.1
Challenges in complex cross-sector patient pathways

Building on the project vision of meeting the framework of objectives for ICT support for collaboration on complex patient pathways, an anthropological study of the challenges for complex patient pathways was conducted, along with an analysis (the business analysis) describing business-related challenges and problems for patients with complex pathways. The business analysis also identifies the structural changes likely to be needed to accommodate the challenges identified, as well as the demands this places on digital solutions.

The business analysis describes six overall challenges that healthcare professionals, patients and relatives experience with regard to complex cross-sector pathways. The six challenges are:

- **Insufficient sharing of information** – patients find that they have to repeat themselves over and over again.
- **Insufficient overview of points of contact** – *"I have no overview of my care pathway and no one else seems to have".*
- **Uncertainty about responsibilities** – Patients describe being discharged from hospital as "being released" without a clear idea about who will follow-up on their case and when and how this follow-up will be organised.
- **Lack of common goals** – Patients with several disorders may be subject to multiple treatment pathways with different goals, and these are not being coordinated.
- **Lack of involvement of relatives** – *"I did not like being given a telephone consultation because it meant my wife couldn't participate in the consultation".*
- **Difficult to retrieve relevant information** – Because they lack the required overview, healthcare providers sometimes experience chaotic and often unsatisfactory consultations with their patients.

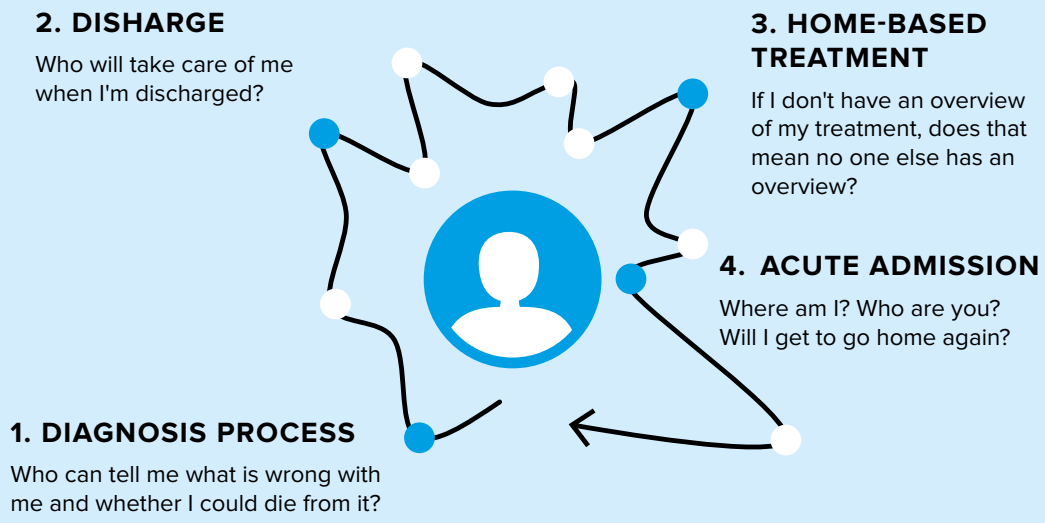
These challenges are not as difficult for patients with sufficient personal resources, who can manage to act as carriers of information between different healthcare providers. They typically have supplementary resources they can draw on in their network of friends and family, etc. For patients who have limited personal resources, these challenges are particularly difficult. These patients are especially vulnerable to a lack of coordination and coherence in transfers between health care providers. (Business analysis, 2015)

The sections below describe four situations with challenges in connection with complex cross-sector patient pathways.

2.2
Four *pain points* in complex patient pathways

Complex patient pathways are not linear, so patients often experience the same problems repeatedly throughout their complex treatment pathway (IIAB, 2015). The anthropology study identified the following four areas as areas in which patients felt there was a particular lack of coherence.

FIGURE 3
***Pain points* in complex cross-sector patient pathways**



Patients experience the **diagnosis process (1)** as chaotic and driven by circumstance. Patients feel they have to repeat themselves over and over again, and that errors occur when "the system" fails to see them as whole persons.

Patients find that they are often the last person to know when they are being **discharged (2)**. They are confused and feel insecure about not knowing who will follow up on their treatment when they have been discharged from hospital.

Patients **receiving home-based treatment (3)** have difficulties keeping track of appointments and admission letters. It is a full-time job to manage appointments, who to meet and where. Patients often feel that they are alone with this responsibility, and that it is a responsibility they cannot adequately cope with. Furthermore, coordinating appointments requires proactive efforts and resources that many of these patients lack. The majority of patients do not have access to digital means of communication, such as computers, tablets and smartphones, or they are reluctant to use these means of communication in their communication with healthcare professionals.

Complex patients often end up feeling alienated during the **acute admission (4)** process in a system which they otherwise thought they knew. Patients meet a number of new people in a very short period of time and have to repeat the same information to each of them. The information which their homecare nurse and others hold about them is easily lost in the transfer to hospital.

The study concludes about all four situations in general that patients with complex cross-sector pathways lack an overview of their care pathway and feel that the health services lack this overview too. Relatives typically end up serving as the connecting link and coordinator for the patient, who rarely has the energy to manage his or her own disease.

These challenges indicate a need for closer collaboration between hospitals, general practitioners and municipalities, and for this collaboration to involve patients and their relatives, if a more coherent process is to be ensured for patients with complex pathways.

2.3
Collaboration across sectors – from relay race to treatment network

Developments in the structure of the health services and increasing specialisation mean that multidisciplinary and cross-sector collaboration and coordination are becoming ever more important. This is especially the case for patients with complex pathways.

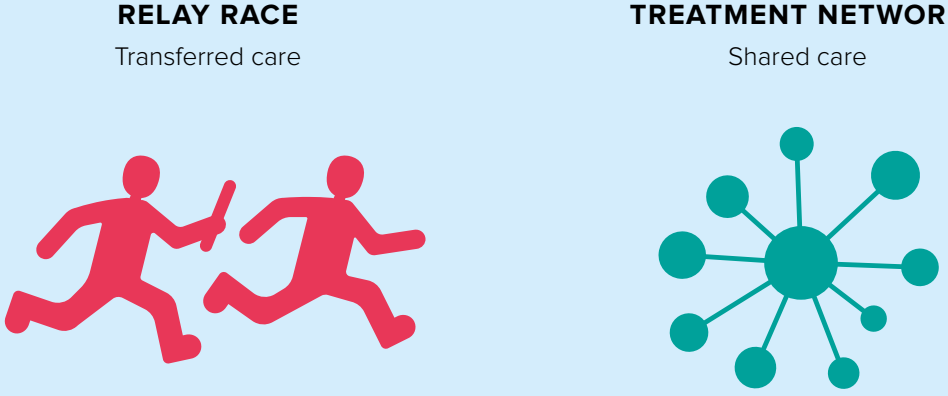
> ***Recent years have seen a growing demand for health-care services that prioritise "coherent patient pathways", comprehensiveness and continuity, evidence-based treatment and high-quality care. This has led to an increased demand for new work methods, work processes and solution models at different levels (Business analysis, 2015).***

Generally speaking, this is a movement away from a *transferred care* approach (a relay-race approach towards) to a *shared care* approach (a more integrated and network-based approach), see figure 4. This movement also characterises the seven collaboration projects from which this project found inspiration. These are:

1. TeleCare North – telemedicine and empowerment
2. The ACCESS project (Acute Combined CarE for Seniors in Soenderjylland)
3. "Horsens på forkant" (a research and development project to improve quality of life for chronic patients in the Municipality of Horsens, including giving them better insight into their illness)
4. Integrated Care
5. The Shared Care Platform
6. Telemedical Ulcer Treatment
7. The Lyngby-Taarbæk Project (project offering a telemedicine solution (Epitalet) to chronic patients with chronic obstructive pulmonary disease).

The compilation of experience revealed that all seven projects involve some form of shared-care collaboration across sectors, but that this collaboration takes place differently depending on the manner in which work is structured locally, and on the type of patients and treatment pathways in question.

FIGURE 4
From relay race to treatment network



Transferred care refers to the situation in which the needs of a patient can no longer be met e.g. by the primary sector and, so, the patient is referred to the secondary sector. Thus, the collaboration form is sequential and treatment, care and responsibility for the patient are transferred from one provider to another like the baton in a relay race.

In the *shared care* model, several providers collaborate on the patient's treatment and care in a coherent network, and communication is therefore not sequential but takes place continuously and is adapted to the patient's overall needs for treatment and care.

In order to provide digital support tailored to the many different modes of collaboration and organisation between hospitals, municipalities and general practitioners locally, as the basis for flexible digital support, the project proposes focussing on *relational coordination* as a method of collaboration. *Relational collaboration* has proven efficient in cross-sector business processes that require close collaboration in several collaboration projects.

2.4
Digital support for closer collaboration

In a health context, *relational coordination* can be seen as an example of a specific method to introduce closer collaboration across organisational borders.

In relational coordination, collaboration relies on the ability of frontline staff (physicians, nurses, municipal employees, etc.) to coordinate and communicate with each other. The common basis for this collaboration is built through the establishment of:

- Common goals
- Shared knowledge
- Mutual respect

Furthermore, relational coordination grows stronger through communication which is problem-solving, frequent, on-time and correct.

The project uses relational coordination as a guide for what digital support for improved collaboration on patients with complex cross-sector pathways should contain.

Based on the methodology behind relational coordination, the project points out that it is especially important to share the following information:

TABLE 1
Sharing of information in relational coordination

Common goals	Shared knowledge	Mutual respect
I. Know goals II. Coordinate goals III. Common goals	Health conditions (e.g. diagnoses, health problems, measurements) Initiatives *(e.g. benefits, interventions, care plan (what))* Activities *(e.g. check-ups, follow-up, care plan (when))* Providers *(e.g. outpatient department, home nursing care, general practitioner)*	Data must be of sufficiently high quality *(e.g. when was the measurement taken, using what equipment and by whom? (A healthcare professional or the patient?))*

The table illustrates how the need for common goals, shared knowledge and mutual respect can be broken down into a series of information. Working with common goals requires that goals are shared, e.g. treatment goals, and, in a possible later version of the solution, it requires improving the possibilities for coordinating goals. Similarly, it will be necessary to ensure that knowledge about the patient's health condition is shared in order to ensure that all healthcare professionals involved in the patient's treatment are kept up-to-date with relevant patient data. Furthermore, knowledge about e.g. appointments and points of contact is necessary if coordination for, and with, patients and their relatives is to be efficient.

Sharing of information between healthcare professionals across sectors does not in itself help establish mutual respect, but the project proposes to ensure there is sufficient knowledge about the information that is shared, and that it is of a sufficient quality, so that healthcare professionals in other sectors have confidence in the information to which they have access. For example, this could be meta data, which explains to the healthcare professional how measurements were taken and with what equipment.

In the next chapter, this need for information is translated into a suggested framework of objectives for digitally supported, complex cross-sector patient pathways, that is: in which general areas do functionalities have to be prepared in order to underpin the need to share this information digitally?

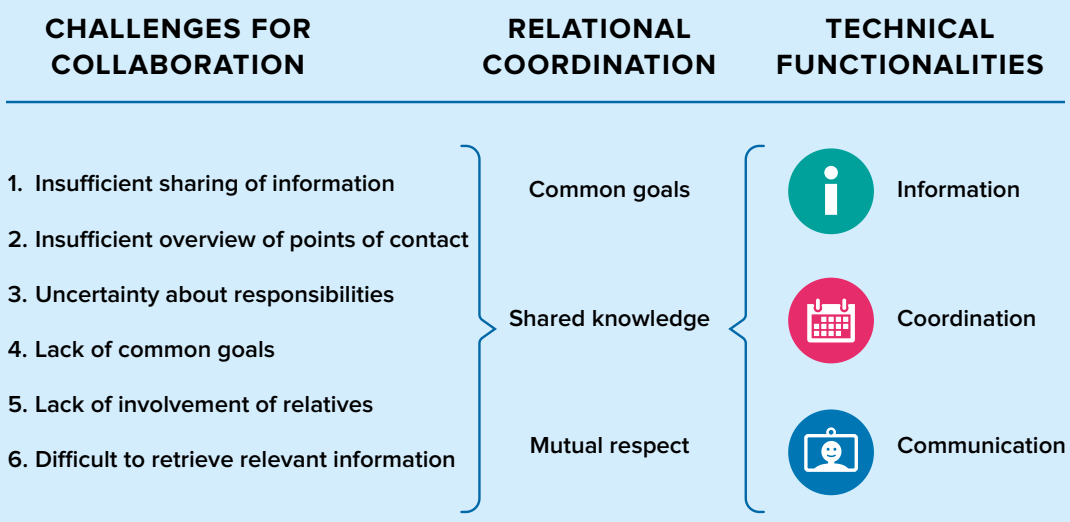
3. Technical framework of objectives for digitally supported, complex cross-sector patient pathways

In order to provide support for closer collaboration between sectors on complex cross-sector patient pathways and address the challenges described in chapter 2, a technical framework of objectives for future digital support was prepared.

On the basis of the methodologies used in relational coordination, see section 2.3, in which work is in accordance with common goals, shared knowledge and mutual respect, the framework of objectives describes what is required in order to digitally underpin future cross-sector collaboration in integrated treatment networks instead of as sequential processes.

The technical framework of objectives for digitally supported collaboration on complex cross-sector patient pathways focusses on increased sharing of information (patient data), better opportunity for coordination and rapid communication, see figure 5.

FIGURE 5
Correlation between challenges, relational coordination and technical functionalities



The following sections elaborate on the content of the technical framework of objectives by describing the technical vision for common ICT support for Information, Coordination and Communication. The sections also give a more detailed description of the technical functionalities in the framework of objectives that should be further developed in order to ensure rapid and smooth information sharing and provide a better overview of complex cross-sector care pathways.

3.1
Architecture vision for digitally supported, complex cross-sector patient pathways

The framework of objectives is based on a common overarching vision for digital transformation in the area; a vision that describes the common principles for ICT developments that will make it possible to share information between the many different ICT systems used by regions, municipalities, general practitioners and the state.

Architecture vision

A common digital foundation, in which patients, relatives and health professionals collaborate on the health and treatment of the patient based on a holistic approach. The foundation is composed of a series of solutions from different public-sector and private-sector parties working together in a common ecosystem.

Note that "digital foundation" does not refer to a system from the individual supplier. Rather, the foundation is composed of a number of elements (standards, tools, services and systems, etc.), which are supplied by a number of different parties.

The vision sets the strategic direction for development of solutions in support of the collaborative efforts on complex cross-sector patient pathways.

Work on the vision has taken account of some of the most important current technology trends (System technical framework of objectives, 2016), which places demands on, or provides new opportunities for, future ICT development. This is necessary in order to ensure that the framework of objectives is appropriately resilient and durable with regard to the development of new digital solutions, which are increasingly impacting the health services and require appropriate changes.

Furthermore, a number of principles have been laid down for digital support of collaborative efforts on, and coordination of, complex cross-sector pathways. These principles describe the overall framework for choosing solutions, including IT architecture, standards and systems.

The establishment of common principles is a prerequisite, because conflicting principles would otherwise work against realisation of the common framework of objectives. For example, the principle to procure monolithic solutions would be in direct conflict with the ambition to develop an ecosystem in which many different solutions from private-sector and public-sector parties function together. A more detailed description is provided in the project deliverable "System technical framework of objectives, 2016".

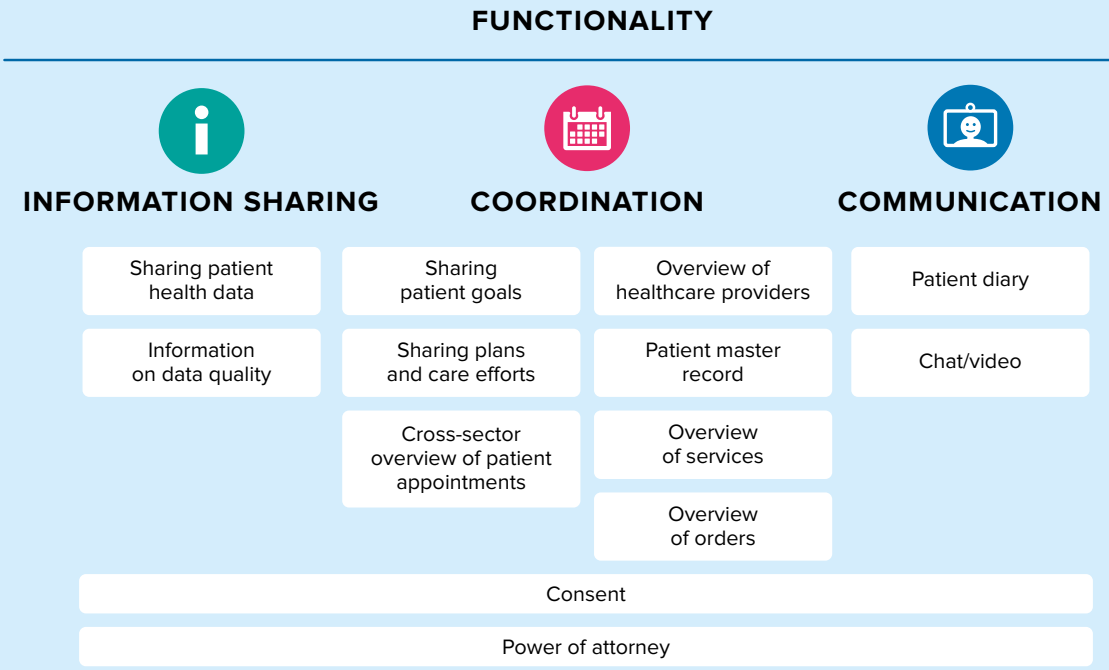
3.2
Detailed description of the architecture vision

The framework of objectives has been specified through a description of the areas for which functionalities must be developed jointly, so as to enable rapid and smooth information sharing and data overview in complex cross-sector pathways – whether for healthcare professionals at hospitals, in the municipalities or in the general practitioner sector.

In this context, functionality refers to a description of what a solution should contain if it is to be used by regions and municipalities and if it is to offer more coherent information sharing, easier cross-sector coordination and rapid communication to healthcare providers, citizens and relatives.

A functionality does not describe how solutions can be realised in technical terms, including whether the need is for infrastructure, direct communication between systems, or something else. The functionalities support: Information sharing, Coordination and Communication, see figure 6.

FIGURE 6
Functionalities in the framework of objectives



The *cross-sector overview of patient appointments* functionality in figure 6 above, for example, entails developing digital solutions that will allow patients and healthcare providers to gain a rapid overview of the patient's appointments with the health services across organisational borders and local systems. The patient will then be relieved from having to keep track of appointments, and when booking new appointments, healthcare providers can take account of other appointments that have already been booked for the patient and see any other ongoing activities in the patient's care plan.

Thus, a functionality in the framework of objectives should identify the areas which need to be in focus in order to ensure more coherencies across sectors.

The maturity of the solution elements underpinning the functionalities in the figure above varies considerably. In some areas there is agreement about which IT standards should be used, while in others there is not. A more in-depth assessment of maturity with regard to existing systems and standards was prepared for a sub report in the project (System technical framework of objectives, 2016).

3.3 Digitally supported collaboration

In order to provide digital support for the many different forms of collaboration, the project examined how to develop common functionalities which can underpin the need for common goals, shared knowledge and mutual respect.

Below is an outline of the functionalities which are needed to provide support for cross-sector collaboration and coordination.

3.3.1

Information sharing

A common challenge highlighted in the anthropological observation study was that patients felt they had to repeat themselves over and over again, and that they experienced having to be responsible for passing on information between different healthcare providers. Healthcare providers pointed out in interviews that the lack of a quick overview and the lack of information about the patient meant that meetings with the patient were unsatisfactory. For example, patients with complex pathways are often examined by many different hospital employees during the first couple of hours of their acute admission, and these employees do not have any basic information about the patient. One patient explained:

> ***The physicians can only refer to what is in my medical record. And they aren't always on top of your situation. For example, a physician once asked me about my stools. What was he on about? I've got an ostomy bag (IIAB, 2015).***

The patients in the study said that the acute admission unit came across as busy and that having to explain the same basic information over and over again made them frustrated and unsure that they were being heard.

The project identifies two focus areas that need further work in order to address the challenges described above:

1. **Sharing patient health data:** The project identifies a need for a common functionality which, based on a large number of patient data, can present overall descriptions and conclusions about the patient's current health in a single summary which the healthcare professional can access quickly and easily. This summary can contain information, e.g. about diagnoses, medication, vital health data, test results, a relevant description of functional ability and factors related to diet, smoking, alcohol and physical activity. Therefore, this functionality serves as an umbrella for a number of underlying data sets.
2. **Data quality:** It should be possible to register and share information about the instructions and guidelines followed and measuring equipment used, so that healthcare professionals gain insight into the quality of the patient's health data.

The solutions above contribute in particular to providing healthcare providers with a good basis for assessing the patient's condition. Furthermore, they contribute to building a healthcare provider's confidence in the assessments, measurements, tests, etc. made by other healthcare providers.

3.3.2

Coordination

The business analysis and the anthropological observation study in the project have revealed that patients are troubled by the lack of coordination and data overview. Amongst other things, the observation study concluded that patients didn't feel they – nor anyone else – had a proper overview of their care process. One patient in the study said:

> ***Not one single person has a full idea of what's going on in my treatment. I'm on my own. I could just as well have stayed at work (IIAB, 2015).***

Patients are often uncertain about who is going to be responsible for their care after they are discharged from hospital. One patient described this as "being released" without a clear idea about who will follow-up on their case and when and how this follow-up will be organised. Furthermore, patients with many parallel treatment pathways experience a lack of alignment of treatment goals between different treatments and this makes them uncertain about the quality of their treatment.

The project identifies the following areas as important with regard to addressing these issues:

3. **Sharing patient goals:** Patients can describe their own overall treatment goal (possibly in collaboration with their general practitioner) and the status with regard to realising this. Other healthcare providers should be able to see this information, and they should be able to receive notice of any changes made to the goal. In a later version of the solution, it should also be possible to relate current treatment goals from different healthcare providers to the patient's own goals.
4. **Sharing plans and care efforts:** It should be possible to share data on complex cross-sector patient treatments and care initiatives between the different healthcare professionals involved in the treatment. This area includes: Health concerns, risks, goals, treatments (interventions, activities), status and, possibly, references to assessments and test results.
5. **Cross-sector overview of patient appointments:** Patients and healthcare providers can gain a quick overview of the patient's appointments with the health services. The patient will then be relieved from having to keep track of appointments, and when booking new appointments healthcare providers can take account of other appointments that have already been booked for the patient and see any other ongoing activities in the patient's care plan.
6. **Overview of healthcare providers:** If they need it in a treatment situation, healthcare providers can access an overview of all providers with whom the patient has points of contact, including access to the contact information of these providers. For example, this overview of contact information will provide a nurse involved in the patient's care, opportunity to coordinate care efforts with other healthcare professionals or with relatives. This could be in connection with the patient's discharge from hospital; a situation referred to as particularly difficult for patients with complex pathways.
7. **Patient master record:** Healthcare providers can gain quick access to the patient's master data in their own system, and, thus, retrieve knowledge about the patient's address, relatives, contact information and any special personal considerations to take into account.
8. **Overview of services:** Healthcare provides can gain an overview of the services provided by other healthcare providers. For example, a general practitioner can see which services the municipality is offering the patient (such as help to stop smoking, rehabilitation, etc.).
9. **Overview of orders:** Healthcare professionals can gain easy access to an overview of requisitions and referrals.

3.3.3 Communication

This area concerns solutions that can contribute to faster and smoother dialogue between healthcare providers across sectors when sharing information and when coordinating between healthcare providers, patients and relatives.

As an example, the observation study in the project mentions the fact that the municipal home care services and hospital staff see potential for a common discharge interview inspired by the process in palliative pathways. Interviews in these care pathways are more holistic in their approach, at physical, mental, social as well as spiritual levels (IIAB, 2015).

Furthermore, healthcare employees at hospitals stress that direct contact to relatives or to a homecare nurse can reduce the number of questions they have to ask the patient (IIAB, 2015).

Often, it will not be possible for every healthcare provider involved to meet the patient in person for such an interview. So, instead, the interview can be supported by video-based technology, chat rooms, common notes, etc. The following functionalities have been identified to underpin this communication:

10. **Patient diary:** It should be easier to have a dialogue with healthcare professionals. A digital diary will be made available as a tool for the patient. Here, the patient (or relatives of the patient) can write down his or her own notes and questions about

the treatment, and these can be viewed by the relevant healthcare professional in connection with conversations with the patient. In an extended version of the solution, it will also be possible to link health data to the notes.

11. **Shared chat and video functions:** Chat room, telephone and/or videoconferencing: The business analysis recommends looking into developing user interfaces that allow e.g. video consultations, chat dialogues, etc. between the patient and healthcare providers.

3.3.4

Important cross-sector functionalities – consent and power of attorney

Furthermore, the project recommends developing a national consent function and a digital power of attorney function, which can be used across sectors. It will also be necessary to ensure the required security with regard to the infrastructure. It will be necessary to look at the legal basis for sharing information for each functionality area.

12. **Consent:** Citizens should be able to prefer *not* to give access to information in general or to specific persons, just as it should be possible to give consent to healthcare professionals or health organisations to access the citizen's data. A consent functionality is a cross-sector functionality that is relevant in many of the situations in which access can be given easily and quickly to data, or in which patients prefer not to have access to certain information.

13. **Digital power of attorney:** Citizens can give a digital power of attorney to view the citizen's information to a relative, patient friend, or an alternative therapist, etc. This is yet another cross-sector functionality which is particularly relevant in connection with patients with complex care pathways, who often need their relatives, or another support person to be able to access their information.

The solutions outlined above form part of a system technical framework of objectives for digitally supported, complex cross-sector patient pathways aimed to provide support for the vision and objectives of the initiative. For a more in-depth description of the framework of objectives, see the *System technical framework of objectives for digitally supported, complex cross-sector patient pathways*.

The areas with functionalities for Sharing patient goals and Cross-sector overview of patient appointments were described in more detail in the pilot to the project and are described in brief in the following chapter

3.4
Primary functionalities for sharing information with regard to relational coordination

Section 2.3 describes how *relational coordination* can be used as a thoroughly tested example of a specific method to introduce closer collaboration across organisational borders. Furthermore, the section describes the information that will be particularly important to share.

Certain functionalities are particularly important with regard to supporting the possibility for relational coordination. These include:

- Sharing patient health data
- Sharing patient goals
- Sharing plans and care efforts
- Cross-sector overview of patient appointments
- Overview of healthcare providers

At a workshop for selected managers and employees from regions and municipalities with experience from cross-sector collaboration, it was confirmed that these functionalities are the most important and also most likely to provide the greatest value with regard to providing support for complex cross-sector patient pathways.

4. Results from pilot project on appointments and goals

A pilot project was conducted within the context of the project. This pilot focussed on two functionalities from the technical framework of objectives in chapter 3. The two areas are *Sharing patient goals* and *Cross-sector overview of patient appointments*.

In collaboration with the consultancy firm, CoLab, four workshops were held at which patients, relatives and healthcare professionals from all sectors discussed the need for these solutions and identified requirements for their content.

On the basis of profiles, user journeys and clarification of concepts, a "view of patient goals" was developed, along with a prototype for an appointments calendar for patients with complex care pathways. The purpose was to illustrate what the desired functionalities could look like (CoLab, 2016).

4.1
Cross-sector overview of patient appointments

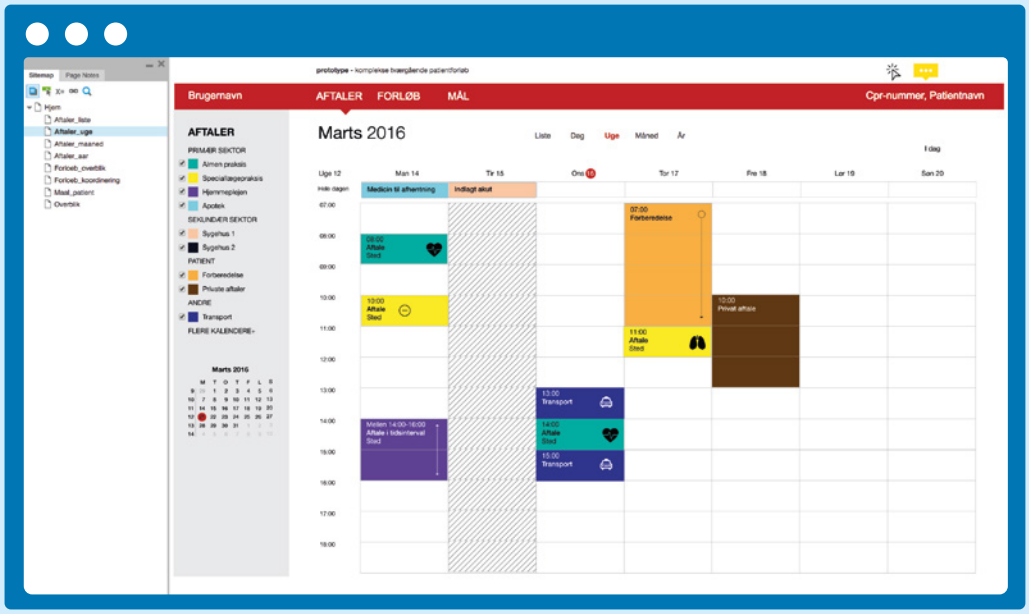
The pilot revealed general agreement among patients, relatives and healthcare professionals that a common appointments overview would be valuable for everyone.

The design of a clickable prototype for displaying patient appointments and the specific functions reflects the qualitative requirements of the workshop participants. That is, the simple design of the prototype and the specific functions that were identified at workshops are the sum of the needs and qualitative requirements of the users for a digital solution for appointments. The functions identified include:

- Filter/search function:
- The individual appointment, including time, place and contact person (healthcare provider)
- Possibility to highlight the fact that a patient is admitted to hospital
- Preparation and reminders
- Appointments within time ranges
- Alternative display modes for appointments
- History
- Transport to treatment

Thus, the prototype developed for patient appointments seeks to address the general need for a quick and simple overview of the patient's appointments.

FIGURE 7
Screenshot of clickable prototype for appointments



Furthermore, a solution architecture was prepared for a common national infrastructure, and standards for the *Cross-sector overview of patient appointments* functionality were identified.

4.2
Sharing patient goals

The work on goals was generally difficult, because most of the workshop participants were unaccustomed to setting goals in their daily work. The concept of goals was more vague when combining the different appointments in the overview. It became evident that the understanding, use and relevance of working with goals differed across sectors and functions making an aggregate overview difficult. Over the course of the series of workshops, however, it became more obvious for the participants that setting goals and sharing goals across sectors can be valuable for their work and can help promote better coordination of the care effort. In this connection, the compilation of experience from the seven collaboration projects also revealed that the work on common goals is key to ensuring coherence between care efforts across organisational borders in complex patient pathways (Devo, 2015).

In the pilot, healthcare professionals stated that if the work on goals is to be of value across sectors, it must be based primarily on the goals and requirements of the *patient*. Patients and relatives had conflicting opinions about the value of providing digital support for an overview of common goals. The positive statements indicate that the overview allows the patient opportunity to create focus, direction and options for action, while the negative statements see no value in the overview.

Once there is common and widespread understanding of the concept of goals, it will be of value that the overview contains the goals of all healthcare providers, including an indication of the significance of the individual goal with regard to ongoing treatments, the ambition behind the goal, and whether the goal is short-term or long-term. Furthermore, the solution could also include an overview of the advice and actions that have already been instigated to address relevant goals. For an elaboration on deliverables and the prototype for goals, see the report from CoLab (CoLab, 2015).

The conclusion drawn from the pilot and the workshops is that the concept of goals needs further work in order to establish a common, cross-sector framework of understanding about this concept before a real prototype can be prepared.

5. Activities in the project

The project was conducted by a joint project group with participants from the Danish Health Data Authority, Local Government Denmark and Danish Regions. The project group was responsible for the following tracks and activities:

- Compilation of experience from seven ongoing *shared care* projects[2] (by Devoteam). The Danish Health Data Authority was responsible this activity.
- Track 0: Atlas of eHealth solutions, prepared on the basis of a workshop attended by IT architects and managers from Local Government Denmark, Danish Regions, municipalities, regions and the state. The Danish Health Data Authority was responsible for this track.
- Track 1: Identification of challenges and laying down a vision and goals based on a workshop with clinicians from regions and municipalities, as well as a workshop about technological goals, attended by IT architects from regions and municipalities. Furthermore, a vision workshop was hosted, involving the steering group, and an anthropology study was prepared by Is It A Bird. Danish Regions was responsibility for this track.
- Track 2: An analysis of current and future work processes for collaboration on complex care pathways and the need for information and data sharing across sectors (Business analysis). As part of the work on the analysis, two workshops were held, which were attended by IT architects from regions, municipalities and the state, as well as sector organisation representatives. Local Government Denmark was responsible for this track.
- Track 3: Establishment of a system technical framework of objectives for digital support for complex care pathways, specifying the more technical and solutions-oriented framework for future ICT support for the business needs identified in the business analysis. The system technical framework of objectives was prepared on the basis of four workshops involving IT architects from municipalities, regions and the state, as well as from MedCom, the *sundhed.dk* eHealth portal and suppliers identified by sector organisations. The Danish Health Data Authority was responsible for this track.
- Track 4: Development of a mock-up for sharing goals, care plans and patient appointments across sectors, and testing this at workshops with clinicians, patients and relatives (by CoLab). Description of a national architecture for sharing patient appointments and development of an infrastructure. Four workshops were held with patients, relatives and clinicians from regions, municipalities and the general practitioner sector in the user-oriented track. Furthermore, one workshop was held in the technical track. The Danish Health Data Authority was responsible for this track.
- Finally, a dialogue meeting was held attended by invitees from all parties as well as a workshop to set priorities primarily attended by participants from municipalities and regions with insight into the managerial and strategic goals for cross-sector collaboration.

2) The seven pilot projects from which experience was gathered are: the ACCESS-projekt (Acute Combined CarE for Seniors in Soenderjylland; the "Horsens på Forkant" project; the Integrated Care project; the Shared Care Platform project; the Lyngby-Taarbæk project (Epitalet), the TeleCare North project; and the Telemedical Ulcer Treatment project.

6. Literature

CoLab, 2016; User clarification and mock-up of goals and prototype of appointments.

Deloitte, 2014; Digital solutions in support of relevant workflows across the healthcare sector, Deloitte 2014 for the National eHealth Authority/the Agency for Digitisation.

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Solution architecture for appointments, Danish Health Data Authority, April 2016.

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