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Patient involvement in person-centred care

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European foreword

This document (TC 450 WI) has been prepared by the Technical Committee CEN/TC 450 “Patient involvement in person-centred care”, the secretariat of which is held by SIS.

This document is a working document.

Introduction

This document specifies the minimum requirements enabling patient involvement in health care services with the aim to create favourable structural conditions for person-centred care.

Guiding principle
This document aims to optimize the chances for improvement of health care outcome resulting from the meeting between the patient and the health care personnel/professionals, because it provides all involved stakeholders with a set of generic guidance points in order to provide minimum requirements of patient involvement in health care.

Strengthening the persons' involvement and capacities to self-manage health and prevent illness is pivotal to policymakers' attempts to achieve cost-containment with maintained or even improved quality of health care (2). To reach this goal, a systematic and structured system need to be in place to facilitates involvement in all steps of the persons' health care journey.

This document applies not only to hospital care but to all health care services, e.g. general practice, primary care centres, dental practices, home care, rehabilitation and long-term care. Further, the concept of a person also includes the network around the patient e.g. patient representative such as family and next of kin, as well as acknowledging the health care professional as a person.

This document is focused on patient involvement in health care. However, in many situations social care and social welfare are closely related to health care and this document can be used as a guiding principle in such situations.

When a person has actively contacted health care the crucial aspect of secondary and tertiary preventive aspect of the circumstances shall be considered. While some aspects of primary preventions such as immunization are within the scope of this document, other important preventive aspects such as safety and environmental factors in health prevention need to be addressed before disease and illness occur and are not covered in this document.

It aims to facilitate the partnership between patient and health care personnel/professionals in terms of immediate care processes and outcomes (e.g. self-management support or shared decision making) as well as patient involvement in the design of services, or in strategic policy making. It can be used in the planning, management, implementation and systematic evaluation of daily activities in the clinical encounter, enabling the patient to manage his/her daily life related to the condition, as well as being used for patient involvement on a systemic level; ensuring that the patients' perspective is included in the development of health care services, research and policy.

The document can be used as a basis for education and training and continuous professional development of health care providers as well as in public and patient involvement, and provides stakeholders with an opportunity to meet regulators in joint dialogue, to provide and use the information for relevant quality and public national databases.

This document can be used before, during and after a procurement process, providing all parties with a common understanding of the minimum level of patient involvement, enabling structures needed for person-centred care in all aspects of the encounter between the patient, health care personnel/professionals and health care service providers throughout all aspects of health care including the transitions between different levels of care. This document is generic in the sense that it can be used in every care setting regardless of levels of care.

The document can be used as a basis for certification services. Certification is carried out by an accredited certification body that is accredited according to EN ISO 17065 application for certification scheme that is built in accordance with EN ISO / IEC 17067.

Patient involvement

Structured patient involvement in health care started to be explored during the 1960´s in a context of involvement in decisions on care and treatment (5). There are also other meanings of involvement and in recent years there are studies on how patients define their involvement (5). Within this perspective, the concept of involvement has been extended to include a practical knowledge on symptoms, illness and treatment, to share experience of illness and treatment and enable decisions making processes that are of importance for the patient.

In health care, patient involvement has often been limited to patient participation in care and treatment without a more distinct definition. However, patient involvement has different definitions. The WHO International Classification of Functioning, Disability and Health defines involvement as a patient´s engagement in his/her life situation(6). Other describe patient involvement as a relationship between a patient and the health care professional wherein the health care professional must give away some of their power to obtain patient involvement(7, 8).

Regardless of definition, patient involvement is regarded as a central feature in high quality health care on all levels from point-of-care to executive management levels. (9, 10){, 2014 #26}. Thus, the health care provider should create the favourable condition for a process together with the patient which may result in a partnership. Patient involvement can lead to a partnership which builds on the notion of:

- at least two participants—a health-professional and a patient being involved in a discussion;
- all involved parties sharing information/knowledge including the patient and according to the patient´s opinion, and a systematic ongoing access, ability and follow-up for the patient to provide insights/questions/remarks regarding the care plan;
- striving together towards a consensus about the preferred treatment
- an agreement being reached on the treatment to implement (11)
- the legal context of patient confidentiality, privacy and with a need for consent where applicable.

Person-centred care

Person-centred care (PCC) means a shift away from a model in which the patient is a passive target of medical and or care intervention to another model with a more structured approach in which the patient takes an active part in his or her care, decision-making process and self-care. A person is a human being with capacities, feelings, and needs – and should therefore be an active partner (often also involving relatives) in his/her care and treatment. This can be understood from an ethical perspective as the health care provider’s obligation to “aim(ing) at the good life with and for one another in just institutions” (1). Patients are persons and should not be reduced to their disease alone, but rather be integrated within a given environment, with their capacities, their future plans and their rights. Hence, during the majority of time, the patient is together with family, friends, co-workers etc. in a context that is not health care. Therefore, there is a strong reason to acknowledge and endorse every person´s resources, interests, needs and responsibilities in situations which concern him or her (4, 9-11). Not at least in a lifelong disease state, a person manages his/her life for the vast majority of time without his/her care provider, putting importance on the persons resources for self-care capacities (8). PCC is delivered when health care personnel/professionals work together with people who use health care services, tailoring them to the resources and needs of the individual towards what matters to them. PCC is a shared understanding and agreement about 1) what really matters to the patient in order to set treatment goals that incorporate what health and quality of life means for the individual person, and 2) the professional judgment and guideline driven care that incorporates evidence based care and national/local routines. Patients and health care personnel/professionals identify and discuss problems and strategies related to the patient's condition(s), giving due consideration to the patients' experiences and preferences, clinical analyses, tests and treatments and the practical, social, and emotional effects of their condition(s) and treatment(s) on their daily lives.

While the above mentioned approaches are often seen as a basis for modern health care, it has been described that there is a lack of structure, knowledge and policies to operationalize (24) patient involvement, something that should be seen as the basic level of providing high quality health care.

In a recent Cochrane review of central components of PCC (n=19.000 patients), significant improvements were observed in medical outcomes, increased self-efficacy and self-management (5). Controlled clinical trials have shown positive outcomes regarding shorter length of hospital stay (12, 13) , cost reduction (14, 15) , improved activity of daily living and discharge process (16, 17) , increased self-efficacy (18, 19), disease knowledge (20), improved health status (21, 22) and improved quality of life in end of life care (23).

Requirements of patient involvement in health care

Sections 4 to 7 start with an orientation, followed by several requirements. The orientation is not prescriptive but aims to provide a brief, introductory background to the requirements. The different sections together provide instructions for health care personnel/professionals and health care providing organizations to take a person-centred approach to support patients at any age, to plan and perform actions that belong to daily life with the aim of preventing ill-health and disease as well as improving, restoring and maintaining health.

1. Scope

This document specifies the minimum requirements enabling patient involvement in health care services with the aim to create favourable structural conditions for person-centred care.

This document aims to facilitate and assist in the attainment of good and safe health care by initiating patient empowerment and developing a partnership between the patient/patient representative and the health care personnel/professionals that originates from the patient’s resources, capacities and needs, primarily focusing on the patient´s narrative/story, shared decision making and information sharing and documentation. It is intended to be operational, to be used before, during and after the actual care provided by health care personnel/professionals and also to be available for use by the patient who is the subject of the care.

This document is also intended to be used on a strategic level for quality assurance and improvement, during procurement, education, supervision and certification as well as to be used as a guiding document for research and development projects within intervention and implementation of person-centred care.

2. Normative references

The following documents, in whole or in part, are normatively referenced in this document and are indispensable for its application. For dated references, only the edition cited applies. For undated references, the latest edition of the referenced document (including any amendments) applies.

3. Terms and definitions

For the purposes of this document, the following terms and definitions apply.

3.1
care
health care services, social care services or a combination of both

Note to entry: Integrated care services are regarded as the sum of the respective services even if they are provisioned by different providers and informal carers.

[SOURCE: CEN/TC 449, modified – reordering of words]

3.2
care period
time lapse during which a person receives care, starting at the first request or contact between care seeker and care provider until all care is ended

Note to entry: Care seeker can be anyone, including the patient, patient representative or health care personnel.

3.3
care plan
plan with regards to needs, expectations, goals and resources, developed by the provider in cooperation with the patient

Note to entry: In some European countries, an individual care plan is provided by national legislation to patients with long term health needs.

3.4
continuum of care
change in ongoing care

3.5
health care
activities undertaken by healthcare personnel/professionals that are intended to maintain and improve health, prevent harm and illness, slow down deterioration of health and palliate pain and suffering

[SOURCE: 2006/123/EC and Art. 3, 2011/24/EU, modified]

3.6
health care personnel
individuals working in the provision of health services, whether as individual practitioners or employees of health institutions and programs, whether or not professionally trained and whether or not subject to public regulation

[SOURCE: Discursive Dictionary of Health Care, 1976]

3.7

health care professionals

person associated with either a specialty or a discipline and who is qualified and allowed by a regulatory body to provide preventive, curative, promotional or rehabilitative health care services in a systematic way to people, families or communities

3.8

health care service

service that considers the whole spectrum of care from promotion and prevention to diagnostic, rehabilitation and palliative care, as well all levels of care including self-care, home care, community care, primary care, long-term care and hospital care in order to provide integrated health services throughout the life course

3.9

health record

data repository regarding the health and health care of a subject of care

3.10

health state

physical and mental functions, body structure, personal factors, activity, participation and environmental aspects as the composite health of a subject of care

3.11

inter-professional team

team composed of members from the same or different professions and occupations with varied and specialized knowledge, skills, and methods, who are committed to a common purpose, performance goals and approach for which they are held mutually accountable

Note to entry: Terms such as interdisciplinary, inter-professional, multi-professional, and multidisciplinary are often used interchangeably.

3.12

narrative

patient's own story about what matters to their relation to the current situation, past experience and future expectations

3.13

partnership

cooperation with regard to goals, accountability, expertise and resources.

3.14

patient

person seeking or needing health care or being provided health care services

Note to entry: In situations where patients for any reason are incapable of defending their interest, patient representative(s) may assist or stand in for the patients.

[Source: Norwegian Health & Rights Act § 1-3. A - modified]

3.15

patient involvement

patient’s active participation in their care on organizational or individual level

3.16
patient representative
closest relative or family member, proxy, guardian, advocate and/or coordinator which assists the patient throughout the course of treatment

Note 1 to entry: A patient representative can be a legal guardian who acts with or on behalf of a person in need of health care. If persons are incapable of making decisions regarding their own health, a legal guardian can be appointed to act on behalf of the person.

Note 2 to entry: A patient representative can be patient advocate, i.e. a professional legal representative acting both in cooperation and on behalf of the patient.

Note 3 to entry: Figure B.1 presents the concept of a patient representative.

3.17
person-centred care
individual, professional, and organizational relationships emphasizing the engagement of the patient as an active participant in the care process

3.18
process
set of interrelated or interacting activities that use inputs to deliver an intended result

[SOURCE: ISO 9000:2015, 3.4.1]

3.19
public involvement
participation, or attempt thereto, of individuals and/or organizations in societal and political decision-making

3.20
quality
degree to which a set of inherent characteristics fulfils requirements

[SOURCE: ISO 9241-420:2011, 3.26]

Alternatively: degree to which healthcare fulfils requirements related to defined aspects

[SOURCE: EN 15224, modified – "quality" in "quality aspects" has been removed]

3.21
quality of life
individual’s perception of their life regarding physical health, psychological state, personal beliefs, social relationships and their relationship to their environment

3.22
routine
a predefined approach of an activity execution, and the division of responsibility and accountability within the organisation for the routine

3.23
self-care
persons actions regarding their own health, taking into account their abilities and preconditions

3.24

self-management

person’s behaviour and ability to make decisions regarding their own health and care, and engage in health promoting activities facilitated by collaborative partnership between the patient and health care personnel/professional or other parties

3.25

service

output of an organization with at least one activity necessarily performed between the organization and the customer

3.26

shared decision-making

decision-making in consensus as equal partners

3.27

social care

care provided by professionals that focus on help and support in coping with activities of everyday life

EXAMPLE: Maintaining the home and getting around inside the home, social wellbeing, independence and social interaction enabling the older person to play a full part in society and support in vulnerable situations such as dressing, eating, getting in or out of bed or chairs, personal hygiene e. g bathing or showering and using the toilet.

Note 1 to entry: The content of social care varies between the European countries and is regulated in national legislation.

[SOURCE: CEN/TC 449]

4. The patient´s narrative and experience of illness

4.1. General

The purpose of the patient´s narrative is to identify the patients' own views of their goals, needs, preferences, values and resources, as well as their perception of their own role in their care. The narrative includes information regarding everyday life, their condition, symptoms and motivations/goals. Giving the patient the opportunity to present her/himself as a person in the form of a narrative is the starting point e.g. with a question: what matters to you? The narrative should then build a collaborative, equalitarian provider (care and treatment expert)-patient (person expert) partnership that encourages and empowers patients to actively take part in finding solutions to their problems.

Trough narratives health care professionals listen and try to understand the request (for health services) for each specific individual. This can be a request for preventive care or the patient's experience of an illness. Diseases and conditions can be described according to different criteria, but to understand what illness means in daily life, professionals must listen carefully to each patient´s narrative. The health care professional´s responsibility is to understand the extent of the patient's knowledge, skills and confidence to self-manage his or her health, to strengthen this where necessary and to ensure that relevant interventions and support services are available (25). The essence is to understand what an illness means in daily life for the patient and letting that be the point of departure for all subsequent interventions in the care of that patient. This can be very well captured through a narrative, but also through other means of communication that are needed when the patient is not able to provide a useful narrative. It is through a process of interpretation, from words or observations, that the health care professional gathers the needed insights. An example of such a process is presented in Annex A (A.3) .

In order to facilitate patient involvement in health care service, the following need to be considered:

- Key focus: Multi-professional approach, respect for values, preferences, and expressed needs, physical comfort, emotional support, involvement of family and friends

Functional communication between health care providers and patients is a prerequisite for patient involvement. However, some patients' neurological injury or disease, for example, after stroke, in Parkinson's disease, and in different types of dementia, can lead to communication disorders. Some people with communication disorders only have difficulties to speak (dysarthria), others also find it difficult to find words and to understand speech and writing (aphasia). Health care personnel/professional have to be able to adapt the communication to each patient's resources and needs to facilitate patient involvement for people with communication/cognitive disorders. In such situations, the involvement of adult family members or friends is important to enable patient involvement. This also applies to the involvement of children in their care acknowledging both the child and/or a close relative.

In paediatric settings, the patient may be represented by their parent or legal guardian who can help form their narrative and experience of illness. It is also however essential to involve children and young people as much as possible in an age appropriate way, in discussions about their care, even if they are not able to make decisions on their own. A young person's ability to communicate and contribute to their narrative, and make decisions depends more on their ability to understand and weigh up options, than on their age. It is important that you assess maturity and understanding on an individual basis. Even a very young child will be able to contribute to some degree.
Throughout this document the term 'patient' includes the parent or legal guardian in partnership with the child.

4.2. Requirements

4.2.1

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Organisational level

The organization shall ensure that:

- the interpretation of the patient's narrative can be shared within legal context of patient confidentiality among related parties in the inter-professional team as soon as possible, and if needed also share all subsequent revision(s) of the interpretation of the narrative is acquired throughout the care period.

- the environment facilitates the possibility for the patient/patient representative to be prepared prior to the visit regarding the above-mentioned requirements, if the situation is deemed possible. If the patient is acutely ill/unstable in his/her vital parameters, the patient (patient representative) shall be able to provide his/her narrative as soon as possible on behalf of the patient until such time that the patient is able to provide such information himself/herself.

- sufficient protected health care personnel/professional time to allow discussion of the patient's narrative including means to adapt to each patient's resources and needs.

4.2.2 Point-of-care level

The health care personnel/professional shall ensure that:

- each patient can provide his/her narrative at start of each contact with health care.

- an environment within which the patient has an opportunity to prepare for the meeting as well as the health personnel/professional ability to capture the patient´s experience, goals in a daily context.

- the patient can prepare the narrative including the following:
  - Why the patient seeks help and what she/he believes to be the problem,
  - How the condition impacts their everyday life
  - The patient's feeling of wellbeing and psychosocial state
  - The patient's goals, motivations and values regarding the process and outcome of care

- when a narrative is not the most suitable approach, an alternative communication approach such as observation is used to capture information needed.

5. Partnership

5.1. General

The European Patients' Forum states: “Patients and professionals need to build a relationship based on mutual respect, share information and engage as equal partners in dialogue about treatment preferences, priorities and values. (26) Based on the patient´s request a family member, carer/caregiver or friend may also be included in the discussion (5). Since the beginning of the 1970s the concept of shared decision making has evolved in clinical literature but still lacks a common definition. Patients, not at least with chronic conditions self-manage themselves most of the time. Hence, all involved experts including the patient should be taking an active part in the decisions concerning the care. Effective inter-professional communication that shares knowledge and creates common understanding and responsibility of the goals and self-care strategies are key aspects in optimizing the care process throughout the continuum of care. Based on the patient´s request a family member, carer/caregiver or friend may also be included in the discussion. The European Patients' Forum further defines patient decision making as a crucial part of shared decision making: "All health-related decisions, whether long-term care planning for complex needs or one-off treatment/prevention decisions, should be the result of a shared decision-making process between the patient and the health care team" (26).

Applying an inter-professional person-centred approach throughout the continuum of care, including transitions between levels of care, where the patient is an integrated part of the team is a key aspect in health care. All involved experts including the patient/patient representative should be taking an active part in the decisions concerning the care.

- Key focus: Person-centred, multi-professional approach, Coordination and integration of care, Information, communication and education, involvement of family and friends

5.2. Requirements

5.2.1

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Organisational level

The organization shall ensure that:

- systematic access and routines are in place enabling the patient (relatives) to be continuously involved in the decision process, follow up and revision (if necessary) of the care process during the care period.

- systemic structure that sets aside dedicated health personnel time to enable patient / professional partnership is established.

- in situations where a partnership is not possible due to cognitive/physical status, language barriers or other aspects of communication, the decision of the health care personnel/professional shall be explicitly documented and re-evaluated as soon as possible with patient or family/legal guardian.

5.2.2 Point-of-care level

The health care personnel/professional shall ensure that:

- the patient and the health care professional have a common understanding regarding medical treatment, impact on symptoms and possible side effects including the foreseeable consequences of lack of treatment.
- the patient´s concerns and fears are explicitly discussed and strategies for reducing the patient concerns and fears are incorporated into the care plan.
- shared decision-making process throughout the care period, and if required also throughout the transition of care/continuum of care including self-care and self-management.
- the patient´s preferences regarding how shared decision making is undertaken is established within the current care episode.
- the patient´s motivations, values and goals are explicitly discussed and strategies for supporting the patient's resources, goals and wishes are incorporated into the care plan.
- a common agreement is set regarding the patient´s and involved health care personnel/ professionals' responsibilities regarding the agreed care plan, within the current care episode, and if needed also throughout the transition of care/continuum of care.
- the demarcation of resources/outcomes deemed possible and realistic within the medical/nursing and social caring context are discussed and a common understanding is reached regarding this between the patient/patient representative and health care professionals. If no common understanding/agreement is reached regarding a central aspect of the caring process, the divergent opinions shall be documented as a deviant event.
- all means, including training and information for self-management needs are provided.

6. Care plan

6.1. General

This section describes the creation of a care plan designed for information and knowledge sharing between all involved parties. This can be either digital or by traditional media with the aim of providing on-going revision of patient´s goals, preferences and values within the legal context of patient confidentiality.

A structured care plan has shown positive outcomes in a range of different hospital settings and throughout to continuum of care (5, 17). The care plan includes all planned investigations, treatments, treatment goals, estimated length of hospital stay (if hospital stay) and also the transition of care (if needed). The care plan is discussed and, if necessary, revised throughout the continuum of care (if needed) with the patient. Creation and documentation of the shared decisions safeguards the patient involvement by documenting the narrative in the form of patient preferences, beliefs and values, as well as involvement in care and treatment decision (5, 27). It is also important to highlight that the key issue is co-creation and information sharing, not only the documentation.

- Key focus: Access to relevant, understandable information, communication and education, transition and continuity.

6.2. Requirements

6.2.1 Organizational level

The organization shall ensure:

- a systematic revision of the care plan and a continuous access for the patient to the revised care plan

- systemic structure that sets aside dedicated health personnel time to documenting the narrative summary and creating and reviewing the care plan.

6.2.2 Point-of-care level

The health care personnel/professional shall ensure that:

- the care plan is commonly formulated, documented and accessible to the patient.

- the patient takes part in the evaluation of the care plan and discharge-debriefing (if developed during hospital stay).

- that the patient's symptoms, resources and needs are followed and evaluated in a systematic way and if possible with validated instruments.

- ensure sufficient protected health care personnel/professional time to allow creation of the care plan.

7. Patient and Public Involvement in Management, Organization and Policy

7.1. General

Patient involvement in health care services also implies that the patient´s perspective is considered in all strategic levels of the management of care as well as research, development, education and policy. This context is not limited to the individual meeting but may also include the structure and organization of care within the continuum of care trajectory of the patient. Hence, patient and public involvement should be ensured in all strategic management levels in order to safeguard the patient´s perspective in health care service. Patient involvement is an important element in the constant improvement processes throughout the continuum of care including health and technology assessments, legislation, pricing and reimbursement policies

    - Key focus: Person-centred, multi-professional approach, involvement of patient/patient representative, Transition and continuity

This section provides an overview of the structure, responsibility and resources, which are required to ensure creating structures for continuous improvement and learning from the point of care by focusing on outcomes important for the patient and relatives. For small and medium size organizations (SMO), the application of some of these requirements could be seen in the context of an overriding association or network where applicable. The requirements are still applicable to the SMO.

7.2. Requirements

Management, organizations and policy-makers shall ensure the following:

- a multi professional approach to process evaluation and quality improvement of operational and strategic development levels, including the involvement of patient´s representatives.

- a continuous quality assessment of processes and policies regarding patient involvement with focus on the above-mentioned areas.

- a structured evaluation and follow up of important patient reported outcome measurements (PROM) such as symptoms, functional capacity, quality of life, health status etc. and patient reported experience measurements (PREM) during and after the care periods (see (28, 29).

- education and continued training in patient involvement/person-centred care as part of training for staff and health care personnel/professionals.

- routines for continuous and systematic quality improvement regarding patient involvement with focus on the above-mentioned areas.

- monitoring shall be carried out annually of documented care plans that include patient goals and shared decision making. If the set goals are not met the improvement plan shall be developed, operationalized and evaluated the following year.

ANNEX A
(informative)

Cases

This annex presents cases that can be used as examples in the application of this document in all levels of health care services.

A.1. Case 1: Follow-up in primary care

Mr. G is a 72-year-old retired businessman and avid golfer who has had a small myocardial infarction 15 years ago. After recovery from the infarction he returned to playing golf and was in good health until one day he suddenly collapsed. Resuscitation was immediately initiated. An ambulance arrived shortly afterwards and he was defibrillated. A non-ST segment elevation myocardial infarction was later diagnosed at a local hospital and a percutaneous coronary intervention was performed. A significant coronary stenosis was left. He recovered well. Left ventricular dysfunction was diagnosed and treatment with an ACE-inhibitor and a beta-blocker was initiated. He was referred to a tertiary hospital for an Implantable Cardiac Defibrillator (ICD); however, a new angiography of his coronary lesion indicated a potential need for a coronary by-pass operation. The operation was scheduled to be performed a few months later.

1) The patient´s narrative/story – why do you seek help, how does your condition impact on your everyday life and what are your goals/motivations with your health care/contacts
    - Key focus: Person-centred, multi-professional approach, Respect for values, preferences, and expressed needs.

Sometime after being informed about the operation, Mr. G met with his district nurse and Dr. S for a yearly check-up. Mr. G explained that he did not feel well and was very worried about the upcoming surgery. He was so concerned about his condition that he did not dare to walk any distances and had given up golf. But from the illness narrative it was clear that Mr. G had no symptoms such as dyspnea or chest pain. When Mr. G was asked what he wanted to do, he became surprised, saying that none of his doctors had once asked him that question. Instead they had simply informed him that he was to be operated on and he assumed that he had no other option. However, he said that he would prefer not to go through with the operation if possible.

2) Initiating partnership - all involved experts including the patient/patient representatives taking an active part in the decisions concerning the care.
    - Key focus: Person-centred, multi-professional approach, Coordination and integration of care, Information, communication and education, involvement of family and friends

Mr. G was asked if he would mind if Dr. S and the care team took a closer look at his case. After reviewing Mr. G's records, Dr. S concluded that his condition did not clearly indicate by-pass surgery and that pharmacologic treatment was a viable option. None of the records made any reference to Mr. G's concerns about surgery or his preferences for treatment. Dr. S asked if he still preferred not to have surgery and instead continue with his medication as this was what guideline recommended, Mr. G answered that he did and that his wife supported him in this decision.

3) CARE Documentation – to be shared by everyone involved in the care, including a personal health- and/or care plan to the patient.

    - Key focus: Transition and continuity, access to care, information, communication and education

Mr. G expressed some concern about what his physicians at the tertiary hospital would say if he now declined the operation. Dr S assured him that he would inform the physicians about their discussion and that Mr. G's decision about and preference for treatment would be documented in his patient record and that future options, e.g. an operation, would still be valid. After this talk, Mr. G became markedly relieved. During the three years since that time Mr. G has continued with pharmacologic treatment and has felt well and enjoyed an active life without any cardiac-related symptoms.

4) Management and organisation- creating structures for continuous improvement and learning from the point of care by focusing on outcomes important for the patient and relatives.

    - Key focus: Person-centred, multi-professional approach, involvement of patient/patient representative, and health care personnel/professionals, Information, communication and education

A.2. Case 2: Hospital care

Mrs., an 82-year-old woman, widow since two years. The last couple of days, she has felt a severe lack of energy, and experiences increasing dizziness and imbalance. Finally, her daughter persuades her to go to the Emergency Room (ER). Mrs Jonsson is admitted to the ward from the ER complaining of gradually increasing breathlessness and fatigue – without chest pain. Mrs. J was diagnosed with chronic heart failure a year ago and classified as NYHA stage III with known non-ischemic cardiomyopathy. At the physical examination of the ER physical, there is severe dyspnoea, pulmonary crackles, gallop rhythm (3rd heart sound), leg oedema (grade 3+) and hypotension (systolic blood pressure 95/65 mmHg). Her heart rate is 83 bpm with normal sinus rhythm and O2 sat 89% room air at admission to the ER, she has received supplemental oxygen. The registered nurse initiates admission-talk by listening to Mrs. J's narrative, asking open questions such as: why do you seek help, how does your condition impact on your everyday life and what are your goals/motivations with your health care/contacts. At home, Mrs. J experiences a good autonomy and independence, in her activity of daily living, being able to do mostly what she wants, and one great pleasure is the visit to her nearby senior centre at least once every week, and talking with her daughter and grandchildren at least twice a week. The last couple of weeks, she however has experienced increasing fatigue, heavy legs and breathlessness, which has prevented her from visiting the senior centre. She also experiences increasing oedema in her lower extremities since the past 8 weeks, but was not sure what to do about it, yet doesn't find it very functional nor very pretty when going out.

Within 24 hours:
The patient´s narrative/story as the starting point of the partnership

- Key focus: Person-centred, inter-professional approach, Respect for values, preferences, and expressed needs.

Initiating partnership - all involved experts including the patient/patient representative taking an active part in the decisions concerning the care.

Initiating the partnership: at admission, a comprehensive narrative was obtained from Mrs. J, including information regarding everyday life prior to and during the worsening of her condition, symptoms, and her motivation/goals. The patient narrative was summarized in an assessment protocol to provide easily accessible and comprehensive understanding of how the patient's situation and symptoms impact on daily life. One important goal was to be able to be independent and to go to the senior citizens centre at least once every week.

- Key focus: Person-centred, inter-professional approach, Coordination and integration of care, Information, communication and education, involvement of family and friends

Based on the narrative and other clinical information, a tentative CARE plan was then drawn up by the care provider, which included planned investigations, treatment goals of being independent in everyday living (ADL level A) and to be able to visit the senior citizens centre. The length of care was estimated to 5 days. In addition to the patient´s medical status, the care plan included information on personal capacities (e.g. motivation), description of the goals agreed upon and measures needed to accomplish them (such as daily ADL scores, a "six-minute walk test" and physiotherapy), categories of health care professionals required (OT and PT), projected day of discharge (5 days from index admission), schedule and objectives for outpatient and primary care follow-up visits. The care plan was discussed with Mrs. J and her daughter and finalized, when an agreement was reached, preferably within 24 h or up to 48 h.

Working the partnership: Mrs. J was encouraged to be as active as possible, e.g. getting out of bed and staying up, and urine catheters were avoided. She rated her symptoms of dyspnoea, fatigue and ADL levels on a daily basis. These ratings were used as a process indicator for the medical treatment.

Documentation – to be shared by everyone involved in the care, including a personal health- and/or care plan to the patient.

- Key focus: Transition and continuity, access to care, information, communication and education

Safeguarding the partnership (documentation): the care plan stipulated that decisions and assessments be documented throughout the care process in the assessment record form. The care plan included an evaluation of the patients' social situation, need for additional support after discharge, ADL level and self-rated symptom severity, as well as the continuous evaluation of her symptoms, feelings and goals. This structured evaluation aimed at maintaining and reinforcing a partnership with the patient and at promoting joint decision-making with health care professionals. The care plan also served to support decision-making and procedures at discharge to ensure continuity of the patient's care. To assure transparency, medical and nursing discharge notes were shared with the patient.

Additional or new information that could affect the care plan was checked after 72 h from admission and every 48 h thereafter in order to evaluate and adjust the care plan.

All three steps were considered equally crucial in implementing the main goal of care, namely an improved partnership between the patient and health care professionals.

Discharge call and continues improvement

3 days after discharge, the ward nurse called Mrs. J to ask how it is going and if Mrs. J had any questions that she did not think of during her stay. Mrs. J felt quite good, however was still a little dizzy and felt a little insecure when going out. The nurse gave Mrs. J some advice and asked if Mrs. J wanted some contact with the social care coordinator to get some help. However, Mrs. J didn't want to have any contact, and felt quite ok with her situation even if a little dizzy. The nurse provided Mrs. J with a phone number to the ward if she wanted to contact them further during the next couple of days.

The nurse also asked Mrs. J if she would be able to fill out a PREM questionnaire if posted to her and also if applicable answer some questions over the phone about her care experience during the coming week. Mrs. J was very happy to do so and gave her consent for further contact.

A.3. Case 3: Person-centred care for persons with communication disorders in hospital and long term residential care

Functional communication between health care providers and patients is a prerequisite for person-centred care. However, the presence of neurological injury or disease, for example, after stroke, in Parkinson's disease, and in different types of dementia, can lead to communication disorders. Some people with communication disorders only have difficulties to speak (dysarthria), others also find it difficult to find words and to understand speech and writing (aphasia). Healthcare providers have to be able to adapt the communication to each person's resources and needs to facilitate person-centered care with people with communication disorders.

Case with a woman with aphasia after stroke

Susanne is a 72-year-old woman admitted to hospital during the night due to decreased mobility and speech difficulties after stroke. The next day she gets to see Jacob, a medical department physician.

Since Jacob read in the record from the intensive care unit that Susanne has speech difficulties, he assigns extra time for the meeting. He reserves a quiet room and make sure there are writing blocks and pencils on the table for the meeting. Jacob also brings a letterboard and a picture resource with pictures showing various items and activities that often occur in connection with care at the department. Jacob explains to Susanne that he has read in the health record that Susanne has speech difficulties due to the stroke, but that he will do everything he can to help her express her thoughts and feelings about her condition and regarding the planning of the care.

Jacob first offers her a writing block and a pencil and asks Susanne if she has tried to write. If only the speech ability has been impaired, you can usually express yourself in writing instead. When Susanne fails to write, Jacob asks if she can point out the letters in her name on the letterboard. When Susanne again fails, Jacob suspects that Susanne suffers from aphasia and that her comprehension is also affected.

In the conversation with Susanne, Jacob now adjusts his communication by speaking in short sentences and by frequently repeating the information he provides to make it easier for her to understand. Jacob also writes down key words on the writing block with large and clear letters when he asks Susanne questions. Although reading ability is reduced, a person with aphasia can sometimes recognize and understand single words or short phrases.

Jacob finds that Susanne sometimes is able to produce single words or short phrases if she is allowed a long enough time to do so. When Susanne fails to convey what she wants to say Jacob helps her by means of using yes and no questions and by suggesting alternatives. He constantly focuses his attention to Susanne in order to read what she expresses in her facial expressions, body posture and voice quality. Jacob also often sums up how he has perceived what Susanne tries to express in order to give her the opportunity to correct any misunderstandings.

As they go through the planning of care, Jacob uses the picture resource and points to relevant pictures and words while asking and telling. He offers Susanne to use the resource to express her meaning as well. Jacob also asks if he is allowed to talk to Susan's daughter about Susanne. When the conversation is over, Jacob reports what Susanne has managed to convey to him, and what he perceived about her communicative resources and the need for communication support in the health record. He also writes a referral to a speech-language therapist for further investigation of how to best support Susanne's communication skills.

As Susanne has been severely impaired by the stroke she has to move into long-term residential care. To facilitate person-centered care at the residential care facility, the facility has contact with a speech-language therapist who can monitor the communication skills of the residents and provide guidance for the staff. It is also a routine to supplement the care plan for each resident with information in the form of a communication plan. The communication plan provides information on how to best communicate with the individual resident, what may be hindering and what can be done to facilitate communication for the residents and enable them to express their thoughts and feelings.

Advice to facilitate communication with people with communication disorders

- ***Find out how the person best communicates*** - Involve, if necessary, a speech-language therapist who can investigate the individual person's communicative resources and needs.
- Make sure there is ***extra time*** for the planned activity.
- When speaking with a person with impaired comprehension, ***reduce the amount of information*** you provide in each sentence, and ***clarify what you want to say*** by repeating, using gestures and writing key words.
- Make sure there are appropriate ***picture and text materials customized to the particular health care context*** - you may both need to point out pictures and written words that clarify what you want to say! Involve relatives who can support the communication as needed.
- When listening to a person with communication disorder, ***pay attention to nuance in facial expressions, body posture and voice variation***.
- ***Provide paper and pen or other writing aids***.
- ***Adjust how you ask your questions***, the person you are talking to may need you to provide suggestions, or to ask yes and no questions, to be able to express themselves.
- ***Report information on communicative resources and needs*** in the health record or in the care plan.

A.4. Case 4:

35-year-old man, married with two small kids. Employed and at work he has been doing fine until a couple of months ago when he stopped working. After an initiative from his wife, he is seeking help in emergency room at the department of psychiatry even he considers himself not ill.

From his wife, it is understood that he has become more introvert during the last six months. He explains that he is surrounded by a group of individuals could not be seen or heard by others but they have had a major importance for him.

His wife has become desperate and she tells that he has become more and more uninterested of his surroundings which has made him not able to work and he has also become uninterested of his family.

When the health professionals (a psychiatrist and a nurse) have listened to both the patient and his wife and been acknowledged they had understood, it became clear that the patient had developed a psychosis. The patient was informed that the physician thought that there was an alternative explanation to his problems and that he could have developed a psychosis. He was also told they understood that he had a difficult situation and his experience was felt real and that he therefore might have difficulties accepting the alternative explanation.

The Narratives from both the patient and his wife were documented together with the psychiatrist´s interpretation of the situation.

During the subsequent communication, there was a focus on the consequences of the patient´s condition. It was clarified the he did not feel well, he could not work and that the children did not do well as their father was not interested in them and that his wife was desperate and dismal.

Despite that the patient was very affected by his condition, it turned out that he was still receptive about his families' situation and he could reflect what he is losing. He agrees to stay in the hospital and evaluate the effects of medication.

The Agreement about goals and treatment is documented and shared

After another two weeks of treatment, the patient´s experience of the individuals around him has disappeared. He is much more willing to interpret his situation as an illness even if he is uncertain whether his experience is real and the individuals might return.

At discharge, his wife also participates. There is a focus on describing what a psychosis is. It is a serious condition which untreated can affect all areas of life. There is effective treatments which can keep the manifestations of the illness away and he can live a normal life. However, he has a responsibility to take care of his illness

After a meeting with the Outpatient team, the patient is discharged from the hospital for continued treatment. His goals include a return to his regular life and that he therefore has to take his medications and cooperate with the Outpatient team.

Agreement, Care-plan, Partnership and Shared responsibility.

A.5. Case 5: Municipality care

Mr. Davidsson have a life-long habit of rising early to work on his farm; therefore, he awakens at 5 am every morning and need to go to the toilet. Since he has no one to help him to the toilet at home, he has solved the problem by using a diaper. Nevertheless, he is in fact not incontinent, but the current situation without anyone to help him at home, has now developed a continent problem. When he moves to the nursing home, the nurse listen to his narrative in order to capture his experiences. She then learned about his life-long early morning waking, and the problem this habit now has caused him. Mr. Davidsson express that he is really annoyed about having to use a diaper and would very much like to have help with this.

Within 24 hours:
The patient´s narrative/story – why do you seek help, how does your condition impact on your everyday life and what are your goals/motivation´s with your health care/ contacts

o Key focus: Person-centred, Respect for values, preferences, and expressed needs.

Initiating the partnership: when Mr. Davidsson moves into the nursing home, a comprehensive narrative was obtained, including information regarding everyday habits and problems to persue them in the current situation. The patient narrative was summarized in an assessment protocol supporting the inter-professional team with a comprehensive understanding of Mr. Davidssons continent problems and the impact on his well-being

Initiating partnership - all involved experts including the patient/patient representative taking an active part in the decisions concerning the care.

. Key focus: Person-centred, multi-professional approach, Coordination and integration of care, Information, communication and education, involvement of family and friends

Based on the narrative, a tentative PCC plan was established by the nurse together with the interprofessional team. It was decided to support Mr. Davidsson when he awakens at 5 am to help him to the toilet and then back to bed, in order to support continuity in his life-long early morning waking while simultaneously supporting him being continent. In addition, the PCC plan included information on Mr. Davidssons personal capacities in terms of a strong motivation of getting rid of the diaper and manage as before. The whole team including Mr Davidssons family was involved in this strategy and finalized and agreed upon.

Working the partnership: Mr. Davidsson was encouraged to be as active as possible, e.g. getting out of bed and staying up, and the diapers were avoided. His incontinent problems disappeared and his wellbeing improved.

PCC Documentation – to be shared by everyone involved in the care, including a personal health- and/or care plan to the patient.
b. Key focus: Transition and continuity, access to care, information, communication and education

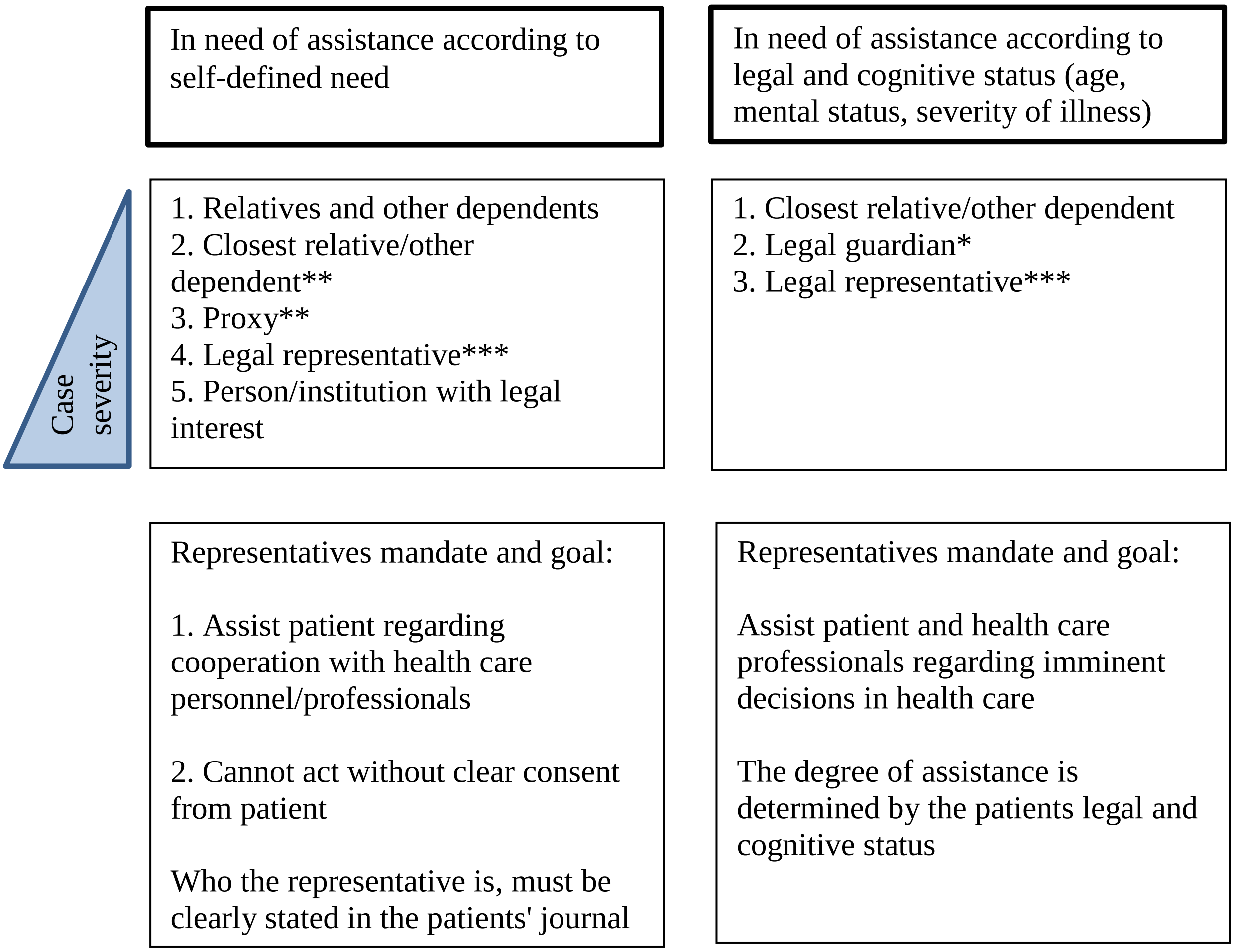
Safeguarding the partnership (documentation): the PCC plan stipulated that decisions and assessments be documented throughout the care process in the assessment record form. '

ANNEX B

(informative)

Patient representative

This annex presents the concept of a patient representative.



In need of assistance according to self-defined need	In need of assistance according to legal and cognitive status (age, mental status, severity of illness)
1. Relatives and other dependents 2. Closest relative/other dependent** 3. Proxy** 4. Legal representative*** 5. Person/institution with legal interest	1. Closest relative/other dependent 2. Legal guardian* 3. Legal representative***
Representatives mandate and goal: 1. Assist patient regarding cooperation with health care personnel/professionals 2. Cannot act without clear consent from patient Who the representative is, must be clearly stated in the patients' journal	Representatives mandate and goal: Assist patient and health care professionals regarding imminent decisions in health care The degree of assistance is determined by the patients legal and cognitive status

***Legal guardian**
acts with or on behalf of the person in need of health care, with regards to decisions

****Patient representative**
closest relative or family member, proxy, guardian and/or coordinator which assists the patient
throughout the course of treatment

*****Patient advocate**
Professional legal representative acting both in cooperation and on behalf of the patient

Figure B.1 Patient representative

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