



SLOVENSKI STANDARD
oSIST prEN 17398:2019
01-julij-2019

Vključevanje bolnikov v zdravstveno varstvo - Minimalne zahteve za oskrbo, osredotočeno na posameznika

Patient involvement in health care - Minimum requirements for person-centred care

Patientenbeteiligung bei der Gesundheitsversorgung - Mindestanforderungen an die personenzentrierte Versorgung

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[SIST EN 17398:2020](https://standards.iteh.ai/catalog/standards/sist/530e0-f43e-446b-a503-5011a151b82c/sist-en-17398-2020)

Ta slovenski standard je istoveten z: prEN 17398

ICS:

11.020.10	Zdravstvene storitve na splošno	Health care services in general
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oSIST prEN 17398:2019

en,fr,de

EUROPEAN STANDARD
NORME EUROPÉENNE
EUROPÄISCHE NORM

DRAFT
prEN 17398

May 2019

ICS 11.020.10

English Version

Patient involvement in health care - Minimum requirements for person-centred care

Patientenbeteiligung bei der Gesundheitsversorgung -
Mindestanforderungen an die personenzentrierte
Versorgung

This draft European Standard is submitted to CEN members for enquiry. It has been drawn up by the Technical Committee CEN/TC 450.

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EUROPEAN COMMITTEE FOR STANDARDIZATION
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European foreword

This document (prEN 17398:2019) 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 currently submitted to the CEN Enquiry.

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SIST EN 17398:2020

<https://standards.iteh.ai/catalog/standards/sist/22c730e0-f43e-446b-a503-30f1a151b82c/sist-en-17398-2020>

prEN 17398:2019 (E)**Introduction**

This document aims to facilitate patient involvement and the development of a partnership between the patient and the care personnel. Patient involvement and partnership originates from the patient's resources, capacities, wishes and needs, primarily focusing on the patient's narrative/story, shared decision-making, information sharing as well as documentation on the individual, operational and strategic level (see annex B.1).

Guiding principle

This document provides minimum requirements for patient involvement in health care. It aims to facilitate the partnership between patients and care personnel in the design, implementation and evaluation of services. The document can be used to help in the planning, management, implementation and systematic evaluation of daily activities, enabling the patient to manage his/her daily life and be empowered in his/her own care process. In addition, it can be used to support patient involvement on a systemic level; ensuring that the patients' perspective is included in the development, implementation and evaluation of health care services, research and policy.

This document is focused on patient involvement in health care. However, in many situations social care is closely related to, or occurs alongside, health care services. Thus, this document could be used as a guide for social care alongside health care services.

This document applies to all health care services, e.g. general practice, primary care centres, dental practices, home care, rehabilitation, preventive and long-term care. Further, when the needs of the patients are being considered, these also should include the family and support networks around the patient e.g. patient proxy and representatives where appropriate (see Annex B).

This document can be used before, during and after a procurement process. It provides all parties with a common understanding of the minimum level of patient involvement and enables related processes and structures to be put in place for all aspects of the contact between the patient, care personnel and health care service providers. This also includes transitions between different levels of care.

The document can be used for education, training and continuous professional development of health care providers (see Annex B). The document can support quality aspects related to patient involvement, e.g. in EN 15224.

Patient involvement

Effective inter-professional communication, that involves the patient in sharing knowledge and creates a common understanding of goals and self-care strategies, is a key aspect of optimising care. The health care provider should create favourable conditions for establishing a partnership with the patient.

A partnership involving patients respects confidentiality, privacy and necessary consents when applicable, and builds on the notion of:

- at least two parties, including the patient;
- the sharing of information and knowledge and taking into account the patient's perspective;
- striving together towards a consensus about the goalsetting and outcomes;
- a context in which there is access to documentation and possibility for the patient to provide input regarding the plan of care and any follow-up.

Person-centred care

Person-centred care (PCC) is a model with a more structured approach in which the patient takes part in his or her care, decision-making process and self-care. A person has capacities, feelings, wishes and needs – and should therefore be a partner (in some cases may also involving relatives) in his/her care and

treatment. This reflects an understanding that patients are experts on their own condition by virtue of their health knowledge and lived experience. Patients are persons and should not be reduced to their health status alone, but rather be integrated within a given environment, with their rights and future plans recognised. Hence, during most of time, the patient is in a context that is not health care. Therefore, there is a strong reason to acknowledge and endorse every patient's resources, interests, needs and responsibilities in situations which concern him or her. Particularly 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 person's resources for self-care capacities. PCC is facilitated when care personnel 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 care goals that incorporate what health and quality of life means for the individual person,
2. the professional judgment and guideline driven care that incorporates evidence-based care and national/local routines (see Annex A for examples).

Patients and care personnel identify and discuss problems and strategies related to the patient's condition(s), giving due consideration to the patient's experiences and preferences, clinical analyses, tests and treatments and the practical, social, and emotional effects of their condition(s) and care on their daily lives.

In a Cochrane review of central components of PCC (n=19.000 patients), significant improvements were observed in medical outcomes, increased self-efficacy and self-care and management when PCC was applied. Controlled clinical trials have shown positive outcomes regarding shorter length of hospital stay, cost reduction, improved activity of daily living and discharge process, increased self-efficacy, disease knowledge, improved health status and improved quality of life in end of life care.

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 operationalise patient involvement, something that should be seen as the basic level of providing high quality health care.

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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.

It is intended to be used before, during and after the actual care provided by care personnel and to be available for use by the patient who is the recipient of the care.

This document is also intended to be used on a strategic level for quality assurance and improvement, during procurement, education and supervision 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

There are no normative references in this document.

3 Terms and definitions

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

ISO and IEC maintain terminological databases for use in standardization at the following addresses:

- IEC Electropedia: available at <http://www.electropedia.org/>
- ISO Online browsing platform: available at <http://www.iso.org/obp>

3.1

care

health care services, social care services or an integration of both, including informal carers

Note 1 to entry: An informal carer includes any person such as a family member, friend or a neighbour, who is giving regular ongoing assistance to another person without payment for care given.

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 that episode of care is ended

3.3

care personnel

individuals working in the provision of health or social care services, whether as individual practitioners or employees of health institutions and programs

3.4

care plan

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

Note 1 to entry: In some European countries, an individual care plan is provided by national legislation to patients with long term health needs.

3.5**contact**

any interaction or communication between patient and care personnel

Note 1 to entry: any interaction includes physical and non-physical communication as facilitated by assistive technology.

3.6**continuum of care**

provision and consistency of care over a period of time spanning all levels and intensity of care

3.7**documentation**

data repository regarding the health and health care of a patient, based on the patient's narrative

3.8**health care**

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

3.9**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 life

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 specialised knowledge, skills, and methods, who are committed to a common purpose, performance goals and approach for which they are held mutually accountable

Note 1 to entry: Terms such as interdisciplinary, inter-professional, multi-professional, and multidisciplinary are often used interchangeably.

3.12**narrative**

patient's own account about what matters to them in relation to the current situation, past experience and future expectations

3.13**partnership**

collaboration and mutual respect between patient and care personnel

prEN 17398:2019 (E)**3.14****patient**

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

Note 1 to entry: In situations where patients for any reason are incapable of defending their interest, a patient proxy should assist or stand in for the patients.

Note 2 to entry: in some care facilities patients are not labelled as “patients” but rather as residents, clients, etc.

Note 3 to entry: a person can be with or without a diagnosis.

3.15**patient involvement**

patient’s participation in their care on organisational or individual level

3.16**patient proxy**

representative who acts with or on behalf of the patient in the narrative, decision-making and patient care

Note 1 to entry: A patient proxy can be a legal guardian who acts with or on behalf of a person in need of care if persons are incapable of making decisions. A legal guardian can be appointed to act on behalf of the person

Note 2 to entry: A patient proxy and representative includes legal guardian, legal representative, relative, patient representative, patient advocate, legal interest and coordinator

Note 3 to entry: The term patient proxy can have different meaning and legal context depending on national legislation

3.17**process**

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

[SOURCE: ISO 9000:2015, 3.4.1]

3.18**public involvement**

participation, or attempt thereto, of public or lay people and/or organisations in decision- and policy making

3.19**quality in health care**

degree to which health care fulfils requirements related to defined quality aspects

[SOURCE: EN 15224:2016, 3.11]

3.20**quality of life**

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

3.21**self-care and management**

person's behaviour and actions regarding their own health and care, and ability to engage in health promoting activities, and if needed facilitated by collaborative partnership between the patient and care personnel or other parties

3.22**service**

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

Note 1 to entry: In health care and social care, the service can be provided by an individual.

[SOURCE: ISO 9000:2015, 3.7.7, modified - Note 1 to entry has been added]

3.23**shared decision-making**

decision-making in partnership between patient (3.14) and care personnel

3.24**social care**

care provided that focuses on help and support in coping with activities of everyday life

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

4 The patient's narrative and experience of illness**4.1 General**

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The patient's narrative is essential to identify the person's 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, disease knowledge and perception, and motivations/goals. The question "what matters to you" can be a starting point for the patient to present her/himself as a person in the form of a narrative. (see annex A.1) The narrative should then build on a collaborative, equalitarian partnership between care personnel and patient that encourages and empowers patients to take part in the provision of care.

Through narratives care personnel 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, care personnel should listen carefully to each patient's narrative. The care personnel's responsibility is to understand the patient's goals and 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 (see annex A.3). The essence is to understand what an illness means in daily life for the person. This needs to 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. Through a process of interpretation, from words or observations, the care personnel gather the needed insights (see annex A.7 for an example).

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In order to facilitate patient involvement in health care services, the following focus areas regarding narrative and experience of illness need to be considered to guide the process:

- inter-professional person-centred approach,
- respect for values, preferences, and expressed needs,
- physical comfort,
- emotional support.

Functional communication between care personnel and patients is a prerequisite for patient involvement. It needs to be recognised that e.g. sensory or cognitive impairments, educational differences, differences in language, or culture can hamper communication between patient and care personnel (see annex A.7).

In paediatric settings, the patient may be represented by their parent or legal guardian who can help form their narrative and experience of illness. However, it is also essential to involve children and young people as much as possible in an appropriate way, in discussions about their care, even if they are not able to make decisions on their own. A young patient's ability to communicate and contribute to their narrative, and make decisions depends more on their ability to understand and consider options, than on their age. It is important that assessment of maturity and understanding is made on an individual basis. Even a very young child will be able to contribute to some degree (see annex A.8 for an example).

4.2 Requirements**4.2.1 Organisational level**

The organisation shall ensure that:

- a) 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 narrative which are required throughout the care period.
- b) the environment facilitates the possibility for the patient to be prepared prior to the contact, if the situation is deemed possible (see annex B.3 for tools and resources).
- c) allocated care personnel time allows discussion and exploration of the patient's narrative.
- d) care personnel are sufficiently trained to obtain the narrative.

4.2.2 Point-of-care level

The care personnel shall ensure that:

- a) the environment facilitates capturing and sharing of the patient's narrative, while recognising the need for privacy (see annex B.3 for tools and resources).
- b) patients have the opportunity at each contact and on a timely basis thereafter to provide their narrative.
- c) the patient's narrative can include the following:
 - Why the patient seeks help or advice and how their everyday life is impacted;
 - The patient's feeling of wellbeing;