



# SLOVENSKI STANDARD

## SIST EN 17398:2020

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**Vključevanje bolnikov v zdravstveno oskrbo - 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

Implication du patient dans les soins de santé - Exigences minimales relatives aux soins axés sur la personne

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**ICS:**

11.020.10	Zdravstvene storitve na splošno	Health care services in general
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EUROPEAN STANDARD

EN 17398

NORME EUROPÉENNE

EUROPÄISCHE NORM

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English Version

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

Implication du patient dans les soins de santé -  
Exigences minimales relatives aux soins centrés sur la  
personne

Patientenbeteiligung bei der Gesundheitsversorgung -  
Mindestanforderungen an die personenzentrierte  
Versorgung

This European Standard was approved by CEN on 10 May 2020.

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EUROPEAN COMMITTEE FOR STANDARDIZATION  
COMITÉ EUROPÉEN DE NORMALISATION  
EUROPÄISCHES KOMITEE FÜR NORMUNG

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## European foreword

This document (EN 17398:2020) 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 European Standard shall be given the status of a national standard, either by publication of an identical text or by endorsement, at the latest by December 2020, and conflicting national standards shall be withdrawn at the latest by December 2020.

Attention is drawn to the possibility that some of the elements of this document may be the subject of patent rights. CEN shall not be held responsible for identifying any or all such patent rights.

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**EN 17398:2020 (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 are based on the patient's resources and capacities as well as wishes and needs, primarily focusing on the patient's narrative, shared decision-making, information sharing as well as documentation on the individual, operational and strategic level (see Annex B).

**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 health care services. The document can be used as an aid in the planning, management, implementation and systematic evaluation of daily activities, enabling the patients to manage their daily life and empowering them in the care process. Furthermore, it can be used to support patient involvement on a systemic level; ensuring that the patient perspective is included in the development, implementation and evaluation of health care services, research and policies.

This document focuses on patient involvement in health care. However, in many situations social care is closely related to, or is provided along with, 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. in general practices, primary care centres, dental practices, home care, rehabilitation, preventive and long-term care. Further, when the needs of the patients are being considered, the family and the support networks around the patient such as patient proxies should be included 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 the establishment of related processes and structures for all aspects of the contact between the patient, the care personnel and the health care service providers. This also includes transitions between different levels of care.

The document can be used for education, training and continuous development (see Annex B). The document can also serve as support when it comes to quality aspects related to patient involvement, e.g. in EN 15224.

**Patient involvement**

Effective inter-professional communication, which involves the patient in the sharing of knowledge and creating a common understanding of objectives and self-care strategies, is a key aspect of care optimization. The health care providers should create favourable conditions for establishing a partnership with the patient.

A partnership involving patients should be based on confidentiality, privacy and necessary consents, when applicable, and encompass:

- at least two parties, including the patient;
- the sharing of information and knowledge, taking into account the patient's perspective;
- a common strive towards a consensus for the setting of objectives and outcomes;
- a context where the patient has access to documentation and can provide input on the care plan and any follow-up thereof.

## Person-centred care

Person-centred care (PCC) is an approach in which patients take part in their care, self-care and in the decision-making process. A person has capacities, feelings, wishes and needs – and should therefore become a partner (in some cases also involving patient proxies) in their care and treatment. This reflects an understanding that patients are, by virtue of their health knowledge and experience, experts on their own health status. 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 being recognized. Hence, for most of time, the patient is not in a health care context. Therefore, there is strong reason to acknowledge and endorse every patient's resources, interests, needs and responsibilities in situations which concern them. Especially in cases of life-long illness, persons manage their life for the vast majority of time without care providers. This makes it important to focus on the person's self-care capacities. PCC is facilitated when care personnel work together with users of health care services, tailoring the services to the resources, needs and goals of the individual.

PCC is a shared understanding and agreement about:

1. what really matters to the patient, in order to set care objectives that incorporate what health and quality of life means for the individual person,
2. the professional assessment 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 to the practical, social, and emotional effects of the condition(s) and care on their daily life.

In a Cochrane review of central PCC components (including almost 11,000 patients), significant improvements were observed in medical outcomes, self-efficacy and self-care when PCC was applied. Controlled clinical trials have shown positive outcomes in terms of shorter hospitalization periods, cost reduction, improved everyday life activities and discharge process, increased self-efficacy, disease knowledge, improved health status and improved life quality in end of life care.

While the above mentioned approaches are often seen as a basis for modern health care, testimonies point to the lack of structure, knowledge and policies to operationalise patient involvement.

## EN 17398:2020 (E)

### 1 Scope

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

It is applicable for use before, during and after the actual care that is provided by the care personnel.

This document is also applicable for use on a strategic level for quality assurance and quality improvement, for procurement, educational and supervisory purposes and as a guiding document for research and development projects in the field of 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 <https://www.iso.org/obp>

#### 3.1 care

activities within health care services, social care services or an integration of both, including care provided by informal carers

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Note 1 to entry: An informal carer includes any person such as a family member, friend or a neighbour, who provides regular ongoing assistance to another person.

#### 3.2 care period

time during which a person receives *care* (3.1), running from the first request or contact between the care seeker and care provider to the end of the episode of care

#### 3.3 care personnel

persons working in the provision of *health care* (3.8) or *social care* (3.24) services, whether as individual practitioners or employees of health institutions and programmes

#### 3.4 care plan

plan of needs, expectations, goals, resources and treatment, developed by the care provider in *partnership* (3.13) with the *patient* (3.14)

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



**3.5****contact**

any interaction or communication between the *patient* (3.14) and the *care personnel* (3.3)

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

**3.6****continuum of care**

provision and consistency of *care* (3.1) over a period of time spanning all levels and intensities of care, and including self-care

**3.7****documentation**

record of the *health status* (3.10), *health care* (3.8) and *social care* (3.24) of a patient, based on the patient's *narrative* (3.12)

**3.8****health care**

care activities, services, management or supplies related to the health of an individual

Note 1 to entry: activities undertaken by care personnel are intended to maintain and improve health, prevent harm and illness, slow down the deterioration of health and alleviate pain and suffering

[SOURCE: EN ISO 13940:2016, 3.1.1, modified - Note 1 to entry has been replaced]

**3.9****health care services**

services covering the whole spectrum of *care* (3.1), from promotion and prevention to diagnostic, rehabilitation and palliative care, as well as all levels of care including self-care, home care, community care, primary care, long-term care and hospital care for the purpose of providing integrated health services throughout life

**3.10****health status**

level of health of a person as assessed in relation to physical and mental functions, body structure, personal factors, activities, participation and environmental aspects

**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, approach and performance goals 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**

patients' own account of what matters to them in the present situation, past experiences and future expectations

**EN 17398:2020 (E)****3.13****partnership**

relationship of collaboration and mutual respect between a *patient* (3.14) and *care personnel* (3.3)

**3.14****patient**

person seeking or needing care or receiving *health care* (3.8) or *social care* (3.24) services

Note 1 to entry: In situations where a patient, for whatever reason, are incapable of defending their interest, a patient proxy assists or represents the patient.

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

Note 3 to entry: A patient may or may not have a diagnosis.

**3.15****patient involvement**

patients' participation in their care on the organisational and/or individual level

**3.16****patient proxy**

representative who assists or acts on behalf of the *patient* (3.14) in the *narrative* (3.12), decision-making and patient care *process* (3.17)

Note 1 to entry: The term patient proxy can be subject to different meanings and legal contexts in 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**

persons' perception of life in terms of physical and mental state, personal beliefs, social relations and relationship to their personal environment

**3.21****self-care**

persons' behaviour and actions regarding their own health and *care* (3.1), and ability to engage in health promoting activities, if needed facilitated by *partnership* (3.13) 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 made in in *partnership* (3.13) between *patient* (3.14) and *care personnel* (3.3)

**3.24****social care**

*care* (3.1) provided with a focus to assist and support a patient in coping with activities of everyday life

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Note 1 to entry: There are variations in social care content in different European countries and the care can be regulated in national legislation. [standards.iteh.ai](https://standards.iteh.ai)

## 4 The patient's narrative and experience of illness

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**4.1 General**

The patient's narrative is essential when it comes to identifying patients' views of their objectives, needs, preferences, values and resources, as well as perception of their own role in their care. The narrative includes information regarding the patient's everyday life, condition, symptoms, disease knowledge and perception, and motivation/objectives. The question "what matters to you" can be a starting point that helps the patients present themselves as persons through a narrative (see Clause A.1). The narrative should in turn build on partnership between the care personnel and patient which encourages and empowers the patient to take part in the care process.

The patient's narrative enables care personnel to listen and try to understand the request (for health care services) of each specific individual. It can be a request for preventive care or relate to the patient's experience of illness. Diseases and conditions can be described according to different criteria, but to understand what illness means in everyday life, the care personnel should listen carefully to each patient's narrative. It is the care personnel's responsibility to understand the patient's objectives, knowledge, self-management skills and confidence, to strengthen these aspects where necessary and to ensure that relevant interventions and support services are available (see Clause A.3). The essence is to understand what an illness means in the everyday life of the person. This should be the point of departure for all subsequent interventions in the care of that person. This can be obtained through a narrative, but also through other means of communication when the patient is not able to provide a narrative. Necessary insights (see Clause A.7 for example) are obtained through a process of interpretation of words or observations carried out by the care personnel.

**EN 17398:2020 (E)**

In order to facilitate patient involvement in health care services, the following focus areas regarding the patient's narrative and experience of illness, should be taken into account in order to guide the care process:

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

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

In paediatric settings, the patients may be represented by their parent or legal guardian who can help form their narrative of the illness or the experience of illness. However, it is also essential to involve children and young people, as much as possible and in an appropriate way, in discussions about their care, even if they are not able to make decisions of their own. Young patients' abilities to communicate and contribute to narratives and make decisions, depends more on their ability to understand and consider options, than on their age. It is important that a the patient's maturity and understanding is assessed on an individual basis. Even a very young child will be able to contribute to some degree (see Clause A.9 for example).

**4.2 Requirements****(standards.iteh.ai)****4.2.1 Organisational level**

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

- a) the patient's narrative can be shared within patient confidentiality among parties in the inter-professional team as soon as possible, including, if needed, all subsequent revisions of the narrative which are required during the care period;
- b) the environment facilitates the capturing and sharing of the patient's narrative, while recognizing the need for privacy;
- c) time for the care personnel is set aside for discussion and exploration of the patient's narrative;
- d) the care personnel is trained to obtain the narrative.

**4.2.2 Point-of-care level**

The care personnel shall ensure that:

- a) patients are prepared, and given the opportunity, to provide their narrative at each care contact;
- b) the following aspects can be included in the patient narrative:
  - the reason why the patient is seeking help or advice, and how the everyday life is affected;
  - the patient's feeling of wellbeing;
  - the patient's objectives, motivations and values regarding the care process and care outcomes;