§144

Svar på patientdelaktighet i personcentrerad vård - SIS-remiss 18552 (Beslut enligt delegation)

RS190836

Beslut

Regionstyrelsens hälso- och sjukvårdsutskott beslutar att

- anta förslag till yttrande

Ärendet

Region Halland har getts möjlighet att yttra sig över remissen Patientdelaktighet i personcentrerad vård (SIS-remiss 18552), ett förslag till europeisk standard för personcentrerad vård.

Region Halland arbetar för och står bakom utvecklingen mot en mer personcentrerad vård och det har länge påverkat hur patienter involveras, bemöts och hur team inom vården arbetar kring patienten. En standardisering riskerar dock att konservera och stagnera utvecklingen av arbetet, och i förslaget saknas också en tydlighet i hur uppföljning ska ske. Region Halland anser därmed att förslaget ska avstyrkas.

Förslag till beslut

Regionstyrelsens hälso- och sjukvårdsutskott beslutar att

- anta förslag till yttrande

Beslutsunderlag

- Tjänsteskrivelse Patientdelaktighet i personcentrerad vård - SIS-remiss 18552
- Svarsblankett remiss18552, Region Halland
- Kommentarer remiss18552, Region Halland
- Presentation HSU 13 augusti
- SIS-remiss 18552 avseende prEN 17398. Patientdelaktighet i personcentrerad vård. Swedish Standards Institute.

Expedieras till

SIS Swedish Standards Institute
Driftnämnden Ambulans, Diagnostik och Hälsa
Driftnämnden Hallands sjukhus

Driftnämnden Närsjukvård
Driftnämnden Psykiatri
Driftnämnden Regionservice
Privata vårdcentraler

Vid protokollet

Maria Fransson

Justerat 2019-08-20

Mikaela Waltersson		Lise-Lotte Bensköld Olsson

Protokollet har tillkännagivits på Region Hallands anslagstavla 2019-08-21

Utdragsbestyrkande

Ylva Johansson

Ylva Johansson

Region Halland

TJÄNSTESKRIVELSE

Datum
2019-08-06

Diarienummer
RS190836

Förvaltning
Verksamhetsområde
Susanne Johansson
Hälso o sjukvårdsstrateg

Regionstyrelsen

Patientdelaktighet i personcentrerad vård - SIS-remiss 18552

Förslag till beslut

Regionstyrelsens hälso- och sjukvårdsutskott beslutar att
- anta förslag till yttrande

Sammanfattning

Region Halland har getts möjlighet att yttra sig över remissen *Patientdelaktighet i personcentrerad vård* (SIS-remiss 18552), ett förslag till europeisk standard för personcentrerad vård[1].

Region Halland arbetar för och står bakom utvecklingen mot en mer personcentrerad vård och det har länge påverkat hur patienter involveras, bemöts och hur team inom vården arbetar kring patienten. En standardisering riskerar dock att konservera och stagnera utvecklingen av arbetet, och i förslaget saknas också en tydlighet i hur uppföljning ska ske. Region Halland anser därmed att förslaget ska avstyrkas.

Bakgrund

Den europeiska kommittén CEN/TC 450 har utarbetat ett förslag till europeisk standard för personcentrerad vård. Standardiseringsarbetet syftar till att reda ut begreppen, ta fram tydliga riktlinjer för patientdelaktighet i personcentrerad vård och, om möjligt, skapa förutsättningar för att mäta och jämföra patientdelaktighet. Sverige deltar aktivt i kommittén, och arbetet är ett svenskt initiativ från GPCC, Centrum för personcentrerad vård vid Göteborgs universitet. Även patienter har varit involverade i framtagandet.

Standarden ska vara till stöd i det operativa arbetet, och underlätta partnerskapet mellan patient och personal. Det ska också kunna användas på strategisk nivå i projekt, kvalitetsutvecklingsarbete och som ett verktyg vid design av forskningsstudier, samt vid upphandlingsprocesser.

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[1] Personcentrerad vård innebär ett partnerskap mellan patienter/närstående och professionella inom vård, omsorg och rehabilitering. Baserat på noggrant lyssnande på patientens berättelse och övriga undersökningar skrivs en gemensam hälsoplan, som innehåller mål och strategier för genomförande samt kort- och långsiktig uppföljning (GPCC, Centrum för personcentrerad vård, Göteborgs Universitet).

En eventuell fastställd europeisk standard kommer även att bli svensk standard, men till skillnad från en tvingande lag är en standard frivillig och innebär därmed inte vidare krav på implementering.

Den europeiska kommitténs förslag

I förslaget anges de minimikrav som bör följas för att möjliggöra patientdelaktighet och skapa goda strukturella förutsättningar för en personcentrerad vård. Förslaget omfattar också patientfall där delaktighet beskrivs på olika nivåer och i olika faser i vårdprocessen. Partnerskap, patientens berättelse, patientdelaktighet, dokumentation och organisation står i fokus. För att leva upp till standarden krävs att:

- det finns rutiner för hur patienters och närståendes erfarenheter, kunskaper och resurser ska tas tillvara på alla nivåer, även på strategisk ledningsnivå
- det ges tid för patienten att dela sin berättelse med personalen, vilket är avgörande för att identifiera patientens behov, motivation och mål med sin vård och behandling
- det finns ett partnerskap mellan patient och personal i hela vårdprocessen – innan, under, och efter ett vårdmöte, något som förutsätter god kommunikation
- vårdpersonal och patienter tar gemensamma beslut om vård och behandling
- vården ger stöd till patientens egenvård
- det skapas struktur och tydlighet kring det som ska dokumenteras
- det erbjuds regelbunden kompetensutveckling i personcentrerad vård
- arbetet följs upp på ett strukturerat sätt med stöd av ex. PROM[2] och PREM[3].

Regionala synpunkter

De synpunkter som har kommit fram rör i första hand formen av en standardisering av området samt intern påverkan inom hälso- och sjukvården i Region Halland.

- En standardisering av området riskerar att konservera och stagnera utveckling
- En ökad administrativ börda för enskilda verksamheter bör undvikas
- Förslaget om strukturerad uppföljning bör hanteras regionalt via nationella patientenkäten och i ordinarie uppföljningsprocess, exempelvis i den årliga kvalitativa revisionen i närsjukvården
- Avsaknaden av effektmått är påtaglig. I förslaget berörs detta endast diffust (uttryckt så som PROM, PREM, tillräcklig tid, tillräckliga resurser).

Så här besvaras remissen

Remissen kommer att besvaras via särskilda blanketter (se bilaga 1 och 2) genom att Region Halland tillstyrker förslaget med eller utan kommentarer, avstyrker förslaget alternativt avstår helt från att svara. Kommentarer ska anges på engelska. Region

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[2] Patient Reported Outcome Measures (patientrapporterade mått)

[3] Patient Reported Experience Measures (mäter patientens vårdupplevelser och nöjdhet med vården)

Halland ska också uppge eventuell erfarenhet inom den föreslagna standardens tillämpningsområde.

Ekonomiska konsekvenser av beslutet
Några ekonomiska konsekvenser av beslutet kan inte ses då förslaget till standardisering avstyrks.

Regionkonkontoret

Jörgen Preuss	Martin Engström
Regiondirektör	Hälso- och sjukvårdsdirektör

Bilaga:
Bilaga 1: Svarsblankett remiss18552, Region Halland
Bilaga 2: Kommentarer remiss 18552, Region Halland

Styrelsens/nämndens beslut delges
SIS Swedish Standards Institute
Driftnämnden Ambulans, Diagnostik och Hälsa
Driftnämnden Hallands sjukhus
Driftnämnden Närsjukvård
Driftnämnden Psykiatri
Driftnämnden Regionservice
Privata vårdcentraler

e-post: mattis.rundgren@sis.se

SIS Swedish Standards Institute
Remissvar
Joakim Falk
Box 45443
104 31 STOCKHOLM

SIS/TK 602, Patientdelaktighet i personcentrerad vård
Svar på SIS-remiss 18552
avseende prEN 17398

Senaste svarsdatum **2019-08-13**

Uppgifter om svarslämnaren

☒Företag/Organisation/Myndighet ☐ Enskild person

Företag/Organisation/Myndighet Region Halland

Handläggare (namn, telefon) Susanne Johansson, 070-205 07 79

Datum 2019-08-06

Remissvar

- ☐ Avstår
- ☐ Tillstyrker utan kommentarer
- ☐ Tillstyrker med kommentarer
- ☒ Avstyrker med motivering
- ☒ Har erfarenhet inom det område förslaget täcker
- ☐ Har tillämpat förslaget
- ☐ Ej berörd
- ☐ Kommentarer till föreslagen svensk titel

Template for comments and secretariat observations

Date: 2019-08-06	prEN 17398	SIS-remiss 18552

MB/ NC[1]	Line number (e.g. 17)	Clause/ Subclause (e.g. 3.1)	Paragraph/ Figure/ Table/ (e.g. Table 1)	Type of comment[2]	Comments	Proposed change	Observations of the secretariat
RH				ge	Region Halland is definitely positive to the development towards more person-centered care and it has long influenced how patients are involved, approached and how teams in healthcare in the region work around the patient. However, standardization risks preserving and stagnating the development of the work and Region Halland is thereby not in favor of the suggestion. Region Halland does not see that standardization in this matter would improve quality of care.		

Svar från: Region Halland

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1 **MB** = Member body / **NC** = National Committee (enter the ISO 3166 two-letter country code, e.g. CN for China; comments from the ISO/CS editing unit are identified by **)

2 **Type of comment:** **ge** = general **te** = technical **ed** = editorial

BÄSTA LIVSPLATSEN

Region Halland

Patientdelaktighet i personcentrerad vård

SIS-remiss 18552

Susanne Johansson, Avd. för kvalitet

HSU 2019-08-13

Europeisk standard för personcentrerad vård

- arbetet med patientdelaktighet och personcentrerad vård behöver utvecklas
- ett svenskt initiativ, men utarbetad av en europeisk kommitté tillsammans med patienter
- stöd på operativ och strategisk nivå
- standarder är frivilliga

Den europeiska kommitténs förslag

- det finns rutiner för hur patienters och närståendes erfarenheter, kunskaper och resurser ska tas tillvara på alla nivåer
- det ges tid för patienten att dela sin berättelse med personalen
- det finns ett partnerskap mellan patient och personal i hela vårdprocessen
- vårdpersonal och patienter tar gemensamma beslut om vård och behandling
- vården ger stöd till patientens egenvård
- det skapas struktur och tydlighet kring det som ska dokumenteras
- det erbjuds regelbunden kompetensutveckling
- arbetet följs upp på ett strukturerat sätt

Regionala synpunkter

- en ökad administrativ börda för enskilda verksamheter bör undvikas
- förslaget om strukturerad uppföljning bör hanteras regionalt
- avsaknaden av effektmått är påtaglig. I förslaget berörs detta endast diffust (PROM, PREM, tillräcklig tid, tillräckliga resurser)
- breddinförande av personcentrerad vård i Region Halland kommer att innebära stora behov av resurstillskott, alternativt uttalade undanträngningseffekter.

Remissvar

- Region Halland arbetar för och står bakom utvecklingen mot en mer personcentrerad vård
- Region Halland anser att förslaget kan tillstyrkas, men betonar betydelsen av att förtydliga hur arbetet ska följas upp samt att en översättning är nödvändig.

Patientdelaktighet i personcentrerad vård

SIS-remiss 18552

Remisstiden utgår: **2019-08-13**

Remissen omfattar:

prEN 17398	Patient involvement in health care - Minimum requirements for person-centred care *Patientdelaktighet i hälso- och sjukvård - Minimikrav för personcentrerad vård*

Patientdelaktighet i personcentrerad vård

2019-06-05

Ditt svar är viktigt

Det är viktigt att svenska företag, myndigheter och andra organisationer får möjlighet att påverka hur standarderna är utformade. Dina synpunkter på standardförslaget bidrar till att testa riktigheten i den kommande standarden och genom ditt svar ökar också möjligheten att standarden kommer att bli använd och accepterad. SIS eftersträvar att miljöhänsyn tas i standardiseringsarbetet. Vi tar därför gärna emot dina synpunkter även när det gäller dessa frågor. Om du vill påverka innehållet i den kommande standarden ska du använda svarsblanketten som är bifogad.

Orientering

Den europeiska kommittén CEN/TC 450, i vilken Sverige aktivt deltar har utarbetat det förslag till Europastandard som presenteras i denna remiss.

Fastställd Europastandard kommer även att fastställas som svensk standard. Om Europastandarden i något avseende strider mot svensk lag, förordning eller myndighetsföreskrift ska myndigheten begära en A-avvikelse från standarden. De slutgiltiga standarderna kan i vissa delar komma att avvika från förslaget beroende på resultatet av den europeiska remissbehandlingen. Motstridande svenska standarder upphävs när Europastandarderna fastställs som svensk standard.

Det är mycket viktigt att berörda svenska myndigheter besvarar denna remiss och klarlägger om förslaget strider mot lag, förordning eller myndighetsföreskrift.

Förslaget finns tillgängligt i engelsk, fransk och tysk språkversion. Här presenteras den engelska versionen.

Svaren på denna remiss kommer att utgöra underlag för det svenska yttrandet. Kommentarerna ska vara på engelska.

Något om förslaget

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.

Översättning

Den engelska texten föreslås ges ut som svensk standard utan översättning. Om ni anser att texten bör översättas ber vi er ange detta i ert svar. Samtidigt ber vi er då meddela om ni är beredda att bidra till de extra arbetsinsatser som en översättning skulle kräva. Synpunkter på föreslagen svensk titel tas tacksamt emot.

Svensk kommitté

Svaren på denna remiss kommer att behandlas av Patientdelaktighet i personcentrerad vård, SIS/TK 602, som är svensk referensgrupp för CEN/TC 450. Gruppen har följande sammansättning:

Karl Swedberg, Göteborgs Universitet, GPCC, Ordförande
Ashraf Anwar, ODM
Charlotta Borelius, Region Dalarna
Frederik Buijs, Region Dalarna
Hans Göransson, Sveriges Tandläkarförbund
Håkan Hedman, Njurförbundet
Maria Johansson, Region Jönköpings län
Gerd Klang, Sveriges Konsumenter
Sara Maripuu, Region Kronoberg
Jesper Nordlinder, Essity Hygiene and Health AB
Rasmus Nord-Schönbeck, Region Skåne
Sara Norman, Njurförbundet
Charlotte Svensson, Sveriges Kommuner och Landsting
Kristina Söderlund, Funktionsrätt Sverige
Helle Sörensen, Östersunds kommun Vård- och omsorgsförvaltningen
Susanne Tedsjö, Västra Götalandsregionen Regionens Hus
Helle Wijk, Göteborgs Universitet, GPCC
Axel Wolf, Göteborgs Universitet, GPCC
Annika Wåhlin, Vårdförbundet
Robin Åberg, Vårdförbundet
Joakim Falk, SIS, projektledare

Frågor

Frågor kring remissen besvaras av Joakim Falk, SIS,
telefon: 08-55552259, epost: joakim.falk@sis.se

Vilka får remissen?

Remissen har sänts ut till följande:
RG 602, SIS/TK 602

Svar på remissen

Besvara remissen genom att returnera bifogade svarsblankett, till mattis.rundgren@sis.se. Se anvisningar.

Anvisningar för remissvar

Ett remissvar består av två delar:
Svarsblankett (där du röstar ja eller nej till förslaget, eller avstår);
Kommentarer.

Om remissen innehåller flera standardförslag ska ett svar avges för varje ingående standardförslag. I svarsblanketten finns förberedda svarsalternativ för samtliga standardförslag.

Så här fyller du i svarsblanketten

"Avstår" om du inte är insatt i förslaget och dess konsekvenser eller om du inte har tid eller möjlighet att sätta dig in i förslaget.

"Tillstyrker utan kommentarer" om du anser att förslaget kan godtas som standard utan förändringar.

"Tillstyrker med kommentarer" om du anser att förslaget kan godtas som standard, fast med de förändringar du angivit i dina kommentarer.

"Avstyrker med motivering" om du anser att förslaget innehåller felaktigheter eller är olämpligt att godta som standard. Du ska ange en motivering till avstyrkandet och skälen ska vara av allvarligare karaktär.

Ange om du/ni har erfarenhet inom den föreslagna standardens tillämpningsområde och om du/ni haft möjlighet att pröva förslagets tillämpning i er verksamhet.

Kom gärna med synpunkter på den föreslagna svenska titeln

Om du vill lämna kommentarer

Fyll i medföljande blankett för kommentarer enligt anvisningarna nedan,

Om standardförslaget är på engelska ska kommentarerna vara på engelska. Detta för att säkerställa en korrekt användning av fackuttryck.

Så här fyller du i blanketten för kommentarer

För att skapa en ny tabellrad ställer du markören i sista tabellcellen och trycker *tab.*

MB/NC1
Lämna blankt eller ange en kortform av er identitet som svarslämnare (t.ex. initialer, eller förkortning av företags-/organisationsnamn)

Clause No./Subclause No./Annex (e.g. 3.1)
För varje kommentar ges en referens till relevant avsnitt i standardförslaget.

Paragraph/Figure/Table/Note (e.g. Table 1)
Om möjligt preciseras relevant stycke, figurnr, tabellnr, not, eller dylikt i standardförslaget.

Type of comment
Varje kommentar kategoriseras med någon av förkortningarna
te, ed, ge med följande innebörd:

te: teknisk kommentar
ed: redaktionell kommentar (editorial)
ge: generell kommentar

Comments (justification for change)

Föreslagna ändringar motiveras/förklaras kortfattat.

Proposed change
För te- och ed-kommentarer ges entydiga förslag till ersättningstext, tillägg eller strykning, gärna enligt följande exempel:
Change ”shall” to ”should”.
Add the text ”see enclosure”.
Remove the text ”see enclosure”.

Line number (e.g. 17)
Ange radnummer om det finns angivet i standardförslaget.

e-post: mattis.rundgren@sis.se

SIS Swedish Standards Institute
Remissvar
Joakim Falk
Box 45443
104 31 STOCKHOLM

SIS/TK 602, Patientdelaktighet i personcentrerad vård

Svar på SIS-remiss 18552

avseende prEN 17398

Senaste svarsdatum **2019-08-13**

Uppgifter om svarslämnaren

☐ Företag/Organisation/Myndighet ☐ Enskild person

Företag/Organisation/Myndighet ……………………

Handläggare (namn, telefon) ……………………

Datum ____________________

Remissvar

☐ Avstår

☐ Tillstyrker utan kommentarer

☐ Tillstyrker med kommentarer

☐ Avstyrker med motivering

☐ Har erfarenhet inom det område förslaget täcker

☐ Har tillämpat förslaget

☐ Ej berörd

☐ Kommentarer till föreslagen svensk titel

Template for comments and secretariat observations

Date:	prEN 17398	SIS-remiss 18552

MB/ NC[1]	Line number (e.g. 17)	Clause/ Subclause (e.g. 3.1)	Paragraph/ Figure/ Table/ (e.g. Table 1)	Type of comment[2]	Comments	Proposed change	Observations of the secretariat

Svar från:

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1 **MB** = Member body / **NC** = National Committee (enter the ISO 3166 two-letter country code, e.g. CN for China; comments from the ISO/CS editing unit are identified by ******)

2 **Type of comment:** **ge** = general **te** = technical **ed** = editorial

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.

If this draft becomes a European Standard, CEN members are bound to comply with the CEN/CENELEC Internal Regulations which stipulate the conditions for giving this European Standard the status of a national standard without any alteration.

This draft European Standard was established by CEN in three official versions (English, French, German). A version in any other language made by translation under the responsibility of a CEN member into its own language and notified to the CEN-CENELEC Management Centre has the same status as the official versions.

CEN members are the national standards bodies of Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, Former Yugoslav Republic of Macedonia, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Norway, Poland, Portugal, Romania, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Turkey and United Kingdom.

Recipients of this draft are invited to submit, with their comments, notification of any relevant patent rights of which they are aware and to provide supporting documentation.

Warning : This document is not a European Standard. It is distributed for review and comments. It is subject to change without notice and shall not be referred to as a European Standard.

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

CEN-CENELEC Management Centre: Rue de la Science 23, B-1040 Brussels

Ref. No. prEN 17398:2019 E

Contents

Page

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.

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.

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

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

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).

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;

  - The patient's goals, motivations and values regarding the process and outcome of care.

d) when a narrative is not possible to obtain, an alternative approach is used to capture the information needed (see Annex A.7 and A.8).

5 Partnership

5.1 General

Applying an inter-professional person-centred approach throughout the continuum of care, including transitions between levels of care, where the patient is a partner of the team is a key aspect in care. All involved experts including the patient should be taking part in the decisions concerning the care. In order to facilitate patient involvement in health care services, the following focus areas need to be considered to guide the partnership process:

- inter-professional person-centred approach
- coordination and integration of care
- information
- communication
- continuous education.

5.2 Requirements

5.2.1 Organisational level

The organisation shall ensure that:

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

b) through a systemic structure, dedicated care personnel time is set aside to enable patient-care personnel in establishing partnership.

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

5.2.2 5Point-of-care level

The care personnel shall ensure that:

a) the patient´s understanding and preferences regarding how shared decision-making is undertaken is established.

b) the patient´s motivations, values, and goals are explicitly discussed and strategies for supporting the patient’s resources, goals, wishes and needs are incorporated into the care plan (see annex A.2 and A.3).

c) the patient and the health care professional have a common and mutual understanding regarding care, impact on symptoms and possible side effects including the foreseeable consequences of lack of care (see annex A.1).

d) the patient´s concerns and fears are explicitly discussed and strategies for reducing the patient concerns and fears are incorporated into the care plan (see annex A.6).

e) shared decision-making processes are continued throughout the care period, and if required also throughout the transition of care/continuum of care including self-care and self-care management.

f) a common agreement is set regarding the responsibilities of the patient and care personnel regarding the agreed care plan, within the current care episode, and if needed also throughout the transition of care/continuum of care (see annex B.2).

g) 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 and care personnel. If no common understanding/agreement is reached regarding a central aspect of the caring process, the divergent opinions shall be documented.

h) all resources, including training and information for the patient to facilitate self-care and self-care management are provided.

6 6. Documentation, care plan and information sharing

6.1 General

This section describes the documentation necessary for information and knowledge sharing. This can be in the form of a care plan, which can be either by digital or traditional media with the aim of providing information on 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 the continuum of care. The care plan is discussed and, if necessary, revised throughout the continuum of care 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 (see annex A.2). It is also important to highlight that the key issue is co-creation and information sharing, not only the documentation.

In order to facilitate patient involvement in health care services, the following focus areas need to be considered to guide the documentation process:

- access to relevant and understandable information
- communication,
- continuous education
- transition of care
- continuity of documentation.

6.2 Requirements

6.2.1 Organisational level

The organisation shall ensure:

a) that there are procedures in place and sufficient staff time for a systematic revision of the care plan and a continuous access for the patient to the revised care plan.

b) systemic structure that sets aside dedicated care personnel time to document the narrative summary and create and review the care plan.

6.2.2 Point-of-care level

The care personnel shall ensure that:

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

b) the patient takes part in the evaluation of the care plan and discharge planning.

c) the patient’s symptoms, resources and needs are followed and evaluated in a systematic way and with validated instruments when available.

d) there is sufficient time provided to create the care plan.

7 Patient and Public Involvement in Management, Organisation 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 contact but may also include the structure and organisation of care within the continuum of the patient's care trajectory. 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. (see annex A.4) Patient involvement is an important element in the constant improvement processes throughout the continuum of care including but not limited to health and technology assessments, legislation, pricing and reimbursement policies.

In order to facilitate patient and public involvement in health care services, the following focus areas need to be considered to guide the process:

- inter-professional approach,
- involvement of patient,
- transition
- accessibility,
- continuity.

This section provides an overview of the structure, responsibility and resources, which are required to ensure continuous improvement and learning at the point of care by focusing on outcomes important for the patient and relatives. For small and medium size organisations (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, organisations and policy-makers shall ensure the following:

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

b) a continuous quality assessment of processes and policies regarding patient involvement.

c) a structured evaluation and follow up of 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 annex B.3).

d) the encouragement and provision of necessary resources for the presence, involvement and, if needed, the creation of patient-organisations.

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

f) creation of structures for continuous and systematic quality improvement regarding patient involvement (see annex A.4).

g) 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, an improvement plan shall be developed, operationalised and evaluated within the following year.

Annex A
(informative)

Cases

A.1 General

This annex presents explanations on how patients can be involved in different ways by giving examples and practical ideas through the description of cases. The cases can be used as examples in the application of this document in all levels of health care services.

A.2 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 collapsed. Resuscitation was immediately 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 a month afterwards.

Mr. G. 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. None of the records made any reference to Mr. G's concerns about surgery or his preferences for treatment. Instead they had simply informed him that he was to be operated on and he assumed that he had no other option.

What can we do to improve patient involvement in health care?

With respect to the patient's narrative:

Through narrative the care personnel identify what Mr. G.'s goals, needs, preferences, values and resources are. This can be obtained by asking "what matters to you?". This way Mr. G. can indicate that, to maintain a good quality of life, it is important to him to remain physically active and play golf. After collecting medical data, different treatment options and information from the patient (needs, preferences etc.) the care workers and Mr. G. can proceed to the choice of treatment: shared decision making.

These actions are in compliance with requirement 4.2.1.c: The organisation ensures sufficient protected care personnel time to allow discussion of the patient's narrative including means to adapt to each patient's resources and needs.

With respect to partnership between the patient and care personnel:

Based on the narrative we know that Mr. G. prefers a treatment that has as little influence as possible on his physical mobility and would prefer not to be operated if possible. From the narrative it was also clear that Mr. G. had no symptoms such as dyspnoea or chest pain. 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. After the views of both the caregivers and Mr. G. were heard and necessary information was collected and discussed, Mr. G. decided not to have the surgery and instead continue with his medication.

These actions are in compliance with requirement 5.2.2.c: The care personnel ensure that the patient and the care personnel have a common understanding regarding medical treatment, impact on symptoms and possible side effects including the foreseeable consequences of lack of treatment.

With respect to the care plan of the patient:

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.

These actions are in compliance with requirement 6.2.2.c: The care personnel ensure that the patient's symptoms, resources and needs are followed and evaluated in a systematic way and if possible with validated instruments.

A.3 Dentistry

For some years Mr B. didn't visit a dentist, until he got worried because there was a gap between his front teeth in the upper jaw. He visits dentist K. and the examination done shows a developed periodontitis for which he needs treatment with scaling and root planning. There are also several teeth that are decayed and needs filling treatment. Mr B. asks to be treated without anaesthesia. Without asking why, dentist K. agrees.

During the years that follow, Mr B., regularly goes to visit the dentist for treatment with scaling. The treatment always follows the pattern of the first appointment: no anaesthesia is used. There is no improvement in the periodontal disease. Several recently done fillings also fail.

What can we do to improve patient involvement in health care?

With respect to the patient's narrative:

One day, Mr B. decides to instead consult Dentist R. since there is no positive result of the treatment from dentist K. The gum is bleeding, he has a bad breath and there are two teeth with recently done fillings that are broken. Mr B. explains that he wants to be treated as he is used to at dentist K.'s practice, which is without anaesthesia. Dentist R. tries to talk with Mr B. in order to find out why the patient has been willingly suffering pain for so many years. By taking the time to talk with the patient, dentist R. finds out that Mr B. is actually anxious about injections and is afraid of needles. Mr B. explains the underlying reasons for why he hadn't agreed on anaesthesia and has therefore been suffering whenever he had to go to the dentist practice.

These actions are in compliance with requirement 4.2.2.c: The care personnel ensure that the patient can prepare the narrative including the following:

— *Why the patient seeks help or advice and how their everyday life is impacted*

— *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*

With respect to partnership between the patient and care personnel:

Dentist R. explains to Mr B. that a good treatment can only be delivered by using anaesthesia. The pain from the scaling in the tooth pocket is so strong that the muscles in Mr B´s face will be so tense that it is impossible to do an adequate scaling in the bottom of the pockets.

He supports his explanation with x-rays of the patient's teeth and tooth bone, showing the bone-loss caused by the periodontal disease. He also explains step by step how anaesthesia is injected and that by locally numbing the area, Mr B. won't feel a thing. Dentist R. also comforts Mr B. by saying he can express his fear and let him know if it hurts or something worries him. After both the dentist and the dental assistant reassured the patient, Mr B. agrees on treatment with anaesthesia. The treatment goes fluently and ends well.

These actions are in compliance with requirement 5.2.2.d: The care personnel ensure that the patient´s concerns and fears are explicitly discussed and strategies for reducing the patient concerns and fears are incorporated into the care plan.

With respect to the care plan of the patient:

Dentist R. explains, using the patient’s x-rays, that Mr B. also suffers from decayed teeth and that treatment using anaesthesia of these teeth should be considered as otherwise they will give problems in the near future. The patient agrees and after 4 more appointments five teeth are treated, with anaesthesia. The patient has overcome his fear of needles and is very happy for that.

During the next 6 years the patient only goes to dentist R. for his annual check-up, completed with scaling on a regular basis from Dentist R. In the same period the periodontal status has improved, and no more fillings are lost. Mr B. understands that his fear of needles in the past, has indirectly led to inferior treatment which forced him to visit the dentist monthly back then. no more teeth have broken, or fillings lost. Mr B. understands that his fear of needles in the past, has indirectly led to inferior treatment in the past.

These actions are in compliance with requirement 6.2.2.a: The care personnel ensure that the care plan is commonly formulated, documented and accessible to the patient.

A.4 Breastfeeding

Mrs. B. is 26 weeks pregnant with her first child. Both mother and child are in good health and until now the pregnancy went well. When she was 20 years old, Mrs. B. had a breast reduction performed due to neck and back complaints.

After giving birth Mrs. B. wants to breastfeed. She has studied the benefits of breastfeeding and is fully convinced. Mrs. B. realises that the choices she made in the past and the choices she will make in the future, also have an influence on her (unborn) child. During the prenatal check she asks the gynaecologist whether breastfeeding is possible despite of her breast reduction. The gynaecologist thinks that there is only a small chance of success of breastfeeding. He proposes an alternative, namely artificial nutrition.

What can we do to improve patient involvement in health care?

With respect to the patient's narrative:

Through narrative the professional can check what Mrs. B.’s goals, needs, preferences, values and resources are. The story of Mrs. B. clearly shows that breastfeeding is of a big importance to her. It also becomes clear that she feels guilty about her breast reduction and the possible negative influence on her milk production. The professional does not take premature conclusions and finds out on the basis of a clinical breast examination how much glandular tissue is still present. After hearing both perspectives, Mrs. B. can make an informed choice.

These actions are in compliance with requirement 4.2.2.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*
- *The patient's goals, motivations and values regarding the process and outcome of care*

With respect to partnership between the patient and professionals:

The clinical examination shows that there is sufficient glandular tissue present. The doctor communicates this to Mrs. B. The doctor notices that Mrs. B. is enthusiastic. She is convinced that breastfeeding now will succeed at any cost. The doctor indicates that, despite the clinical examination is promising, it doesn’t guarantee a successful breastfeeding. As with every woman, several factors have an influence. He indicates that this has nothing to do with being a good mother and formula feeding is a good alternative. He assesses whether they have a common understanding and if she is comfortable.

These actions are in compliance with requirement 5.2.2.c: The care personnel 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.

With respect to the care plan of the patient:

The doctor refers Mrs. B. to a lactation consultant. Mrs. B. agrees to be followed up by the lactation consultant, also during the pregnancy. The consultant encourages her that she can start breastfeeding and suggests starting to pump manually and electrically soon after delivery. Mrs. B. has the feeling that she is well-informed, and the different options were offered. She is still motivated to breastfeed and knows that she will receive extra support and knows the possible alternatives for breastfeeding.

These actions are in compliance with requirement 6.2.2.d: There is sufficient time provided to create the care plan.

A.5 Patient and public involvement

Mr. C. has an appointment for an MRI scan of his right knee on Tuesday at 15h00. He lives far away from the institution and has everything planned and sorted out in order to be on time for his scan. At 14h30 Mr. C. finds himself lost nearby the hospital because of road works and the alternative routes brings him to another entrance of the hospital. Stressed and worn out, Mr. C. tries to find the corresponding route to the radiology department, but no information board is available. He ends up asking a passing nurse, who gives him the right directions.

Arriving at the radiology department, he notices that the professionals are calling out loud the names of the patients for them to stand up and have their scan made. It's 15h18 when he hears "Mr. C.", he stands up but also is another man. After checking, the other Mr. C has an appointment at 15h15 for a left knee MRI scan and has to wait a little more because of a little delay in the appointments. Our Mr. C. goes into the room to get his MRI scan and goes home afterwards.

A week later his general practitioner calls Mr. C. and tells him the results of the MRI scan are those of his left knee and not of his right knee. Dissatisfied, Mr. C. has to go back to the hospital to make another MRI scan.

What can we do to improve patient involvement in health care?

With respect to the patient's narrative:

As engaged as Mr. C. is he agrees to talk to the mediation service of the hospital to talk about his experience. His feedback on hospital directions being not well indicated (outside and inside), the wrong patient almost been called upon and the wrong scan made can be used by the quality and safety committee to put in place improvement strategies such as new direction boards towards the hospital, new information panels in the main hallways to ensure accessibility to the different departments and development of identity-vigilance campaigns for the professionals throughout the hospital.

These actions are in compliance with requirement 7.2.c: Management, organisations and policy-makers shall ensure that 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.

With respect to partnership between the patient and professionals:

The quality and safety committee has approached Mr. C. and asked him to take part in the development and implementation of the improvement strategies. Mr. C. agrees and feels he can be a big value for the institution to put in place improvements and this in order to help future patients and avoid adverse events. He'll be the voice of the patients and guide the professionals through how patients see things and how things could be improved to enhance their experience of care.

These actions are in compliance with requirement 7.2.a: Management, organisations and policy-makers shall ensure that a multi-professional approach to process evaluation and quality improvement of operational and strategic development levels, including the involvement of patient´s representatives.

With respect to the care plan of the patient:

One of the improvement strategies is education and training for identity-vigilance. Mr. C., as a patient, has agreed to participate in several training sessions to narrate his experience and help professionals ask the right question to identify patients. By having a patient story told, awareness is raised among the professionals that patients can be partners in their care and identify potential near adverse events.

These actions are in compliance with requirement 7.2.e: Management, organisations and policy-makers shall ensure that education and continued training in patient involvement/person-centred care as part of training for staff and care personnel.

A.6 Patient with psychosis

Mr. H. is a 35-year-old man married with two small kids and employed. He has been doing fine until a couple of months ago when he suddenly stopped working. After an initiative from his wife, he is seeking help at the department of psychiatry even if he considers himself not ill. The care personnel prescribe him a medicine and discharge him. A few weeks later, Mr. H. doesn't feel any better and hasn't taken his medication correctly.

What can we do to improve patient involvement in health care?

With respect to the patient's narrative:

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, that are invisible to 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. During the subsequent communication with the patient, his wife and the care team, 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. When the care personnel (a psychiatrist and a nurse) have listened to both the patient and his wife, the patient is informed that there is an alternative explanation to his problems and that he could have developed a psychosis.

These actions are in compliance with the following requirements: Allocated care personnel time allows discussion and exploration of the patient's narrative (4.2.1.c) and Care personnel are sufficiently trained to obtain the narrative, the environment facilitates sharing and capturing of the patient's narrative, while recognising the need for privacy. (4.2.1.d)

With respect to partnership between the patient and professionals:

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

These actions are in compliance with the following requirements: Systematic access and routines are in place enabling the patient to be continuously involved in the decision process, follow up and revision (if necessary) of the care process during the care period. (5.2.1.a) and the patient and the health care *professional have a common understanding regarding care, impact on symptoms and possible side effects including the foreseeable consequences of lack of care. (5.2.2.c)*

With respect to the care plan of the patient:

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. 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.

These actions are in compliance with the following requirements: The organisation shall ensure that there are procedures in place and sufficient staff time for a systematic revision of the care plan and a continuous access for the patient to the revised care plan. (6.2.1.a) and the care personnel shall ensure that the patient takes part in the evaluation of the care plan and discharge planning. (6.2.2.b)

A.7 Long-term care

Mr. D. has had a life-long habit of rising early to work on his farm; therefore, he awakens at 5 am every morning and needs 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.

When he moves to the nursing home, he still uses diapers because he can’t get up by himself at night to walk to the bathroom. He’s really annoyed by the situation but doesn't know who to contact in order to know if a solution can be found.

What can we do to improve patient involvement in health care?

With respect to the patient's narrative:

Within 24 hours upon his arrival at the nursing home a nurse listens to Mr. D.’s narrative in order to capture his experiences. During this exchange Mr. D. expresses the feeling that he is really annoyed about having to use a diaper and would very much like to have help with this. The nurse learned about his life-long early morning waking, and the problem this habit now has caused him. The patient narrative was summarized in an assessment protocol supporting the inter-professional team with a comprehensive understanding of Mr. D.’s continent problems and the impact on his well-being.

These actions are in compliance with requirement 4.2.2.b: The care personnel shall ensure that each patient can provide his/her narrative at start of each contact with health care.

With respect to partnership between the patient and professionals:

Based on the narrative, a tentative PCC plan was established by the nurse together with Mr. D. and the interprofessional team. His fears and concerns were discussed and based upon the available resources in the institution a solution was found. It was decided to support Mr. D. 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.

These actions are in compliance with requirement 5.2.2.d: The care personnel shall ensure that the patient's concerns and fears are explicitly discussed and strategies for reducing the patient concerns and fears are incorporated into the care plan.

With respect to the care plan of the patient:

In addition, the PCC plan included information on Mr. D’s personal capacities in terms of a strong motivation of getting rid of the diaper and manage as before. Mr. D. 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 well-being improved.

These actions are in compliance with requirement 6.2.1.a: The organisation shall ensure that there are procedures in place and sufficient staff time for a systematic revision of the care plan and a continuous access for the patient to the revised care plan.

A.8 Woman with aphasia after stroke

Susanne is a 72-year-old woman who was admitted to the hospital during the night due to decreased mobility and speech difficulties after a stroke. Several people come to see her but can't figure out how to talk to the patient and improve her situation. Her family also is in stress.

What can we do to improve patient involvement in health care?

With respect to the patient's narrative:

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 makes 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 she 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.

These actions are in compliance with the following requirements: The care personnel shall ensure that when a narrative is not possible to obtain, an alternative approach is used to capture information needed. (4.2.2.d) and the organisation shall ensure that care personnel are sufficiently trained to obtain the narrative. (4.2.1.d) and that allocated care personnel time allows discussion and exploration of the patient's narrative. (4.2.1.c).

With respect to partnership between the patient and professionals:

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.

These actions are in compliance with requirement 5.2.2.c: The patient and the health care professional have a common understanding regarding care, impact on symptoms and possible side effects including the foreseeable consequences of lack of care.

With respect to the care plan of the patient:

As Susanne has been severely impaired by the stroke she has to move into long-term residential care. To facilitate person-centred 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.

These actions are in compliance with the following requirements: The organisation shall ensure that there are procedures in place and sufficient staff time for a systematic revision of the care plan and a continuous access for the patient to the revised care plan. (6.2.1.a) and the care personnel shall ensure that the care plan is commonly formulated, documented and accessible to the patient. (6.2.2.a)

A.9 Paediatrics

A two-year-old child who has been admitted before and who has had a lot of needle procedures done to her. The child needs an iv-line to be able to go through with an x-ray examination. The girl is really scared and doesn't like the hospital staff. She cries whenever anyone in hospital clothes enters the room.

What can we do to improve patient involvement in health care?

With respect to the patient's narrative:

The nurse informs the parents and the child that the child needs an iv-line because of the examination. The child is really scared and cries a lot. The nurse tries to talk to the child and asks her about her stuffed animal, and asks the child if the stuffed animal also needs a bandage for the magic Band-Aid (EMLA). The child doesn't want her teddy to have a bandage. The nurse shows the little girl the strap, which has some fun animals on it. The child forgets to be scared because it's funny-looking. One strap for the child and one for the nurse. The nurse shows the child her own arm and the child can look and try to feel for the blood vessels. Then, it's the child's turn and she starts to cry and doesn't want to have the strap on, but the nurse is quick and finds some good blood vessels on her hand. The parents help out and try to get the little girl's attention elsewhere. The child gets the magic Band-Aid (EMLA) and then a bandage on top so it stays on for at least one hour. The parents also get a bandage. The child has her bandage with the strap and her stuffed animal until it's time to put the iv-line in.

These actions are in compliance with requirement 4.2.1.c: The organisation shall ensure that allocated care personnel time allows discussion and exploration of the patient's narrative.

With respect to partnership between the patient and professionals:

The nurse takes the child to the examination room, but the child grows really scared and starts crying, and doesn't want to go into the room because she knows what will happen. The parents carry the child into the room, but she doesn't want to sit still in her parents' lap and the situation is hard for both the child and the parents. The nurse asks the parents to go back to their room, and asks both the parents and the child if it would be better to have some medicine (Midazolam) before the procedure so that she can be less afraid. The parents look relieved and agree to the medicine. The nurse gets the medicine for the child, but the child starts to cry as soon as the nurse comes into the room. She asks the parents and the child if it will be better if she goes out of the room and the parents can give the medicine instead. After they agree, the nurse tells the parents how to administer it and then leaves. The girl becomes calmer as soon as the nurse leaves.

These actions are in compliance with requirement 5.2.2.c: The patient and the health care professional have a common understanding regarding care, impact on symptoms and possible side effects including the foreseeable consequences of lack of care.

With respect to the care plan of the patient:

After 15 minutes, the child is a lot calmer and she doesn't cry when the nurse come into the room. The parents show the child a book so she can focus on something else rather than the iv-line. The procedure goes fast and quick as the child is too preoccupied with the book that she doesn't notice that the nurse has put in the iv-line. After it's done, the child is surprised to have a new bandage on her hand. The child arrives in time for the X-ray examination.

These actions are in compliance with requirement 6.2.1.a: The organisation shall ensure that there are procedures in place and sufficient staff time for a systematic revision of the care plan and a continuous access for the patient to the revised care plan.

Annex B
(informative)

Patient involvement in different levels and phases of health care

B.1 General

This annex presents patient involvement at different levels and in different phases of health care, as well as providing resources and tools.

B.2 Patient involvement and person-centred care

Involvement can be on various levels and different ways of involvement also exist depending on the defined objective (See Figure B.1).

Figure B.1 — Levels of involvement

The tool or strategy to use to co-create and involve patients depends on the level of involvement. At the bedside, at the individual contact between care personnel and patients, involvement will be different than involvement of patients at the organisation level for developing a new policy.

Different levels exist (see Figure B.1):

1) Individual level: involvement of patient in his/her own care

2) Operational level: involvement in the design, redesign, implementation and evaluation of a process or pathway at department or unit level

3a) Strategic level - At level of the organisation: Involvement in the organisation of services and in the development of new policies and projects

3b) Strategic level - At higher level: the context in which the health care system works, involvement of patients in development of national programs etc.

B.3 Partnership in person-centred care and responsibilities

This part of Appendix B is intended to demonstrate the responsibilities of the patient and the care personnel during the course of treatment with regard to patient involvement.

Evaluation phase

The evaluation phase describes the initial contact between patient and care personnel and what questions and clarifications should be made.

- The patient's narrative must be clear, including the patient being able to tell it freely and independently
- From the patient's point of view, the need for health care must be clarified
- The care personnel must indicate what possible treatment is available (framework for health care is based on law, ethics and profession)
- Involvement of a representative
- The patient's expectations

There is a shared responsibility between the patient and the care personnel to bring out the necessary facts and clarifications in this phase.

Allocation phase

The allocation phase describes what should be done when an evaluation has been conducted and the patient and care personnel must decide which treatment is to be implemented

The patient is entitled to services that are necessary, justifiable and dignified. The care personnel are responsible for finding out what is the justifiable service in each individual case. The patient is responsible for explaining what he/she considers to be necessary and dignified services. Based on this information, the patient and care personnel will jointly discuss the best solution.

In some cases, there are several treatments possible, e.g. that a treatment may be short and painful or long and painless. It is the patient's responsibility to make this choice or to abstain from treatment. However, the care personnel are responsible for making sure that the patient has received sufficient information regarding the consequences of the patient`s choice.

In some situations where the patient and care personnel are disagreeing regarding the choice of treatment, patient involvement does not mean that the patient can chose their own treatment options. Care personnel are responsible for presenting which treatment options are adequate and available for the patient.

Implementation phase

The implementation phase describes what happens after the health care has been implemented.

During this phase, four conditions will be clarified and possibly lead to a change in the service:

- Are the patient's needs covered?
- Is the service useful (does it work)?
- Do the resources used relate to utility (input/output)?
- Is the patient`s quality of life improved/maintained?

The care personnel are responsible for discussing these conditions. The patient is responsible for providing information that helps clarify the conditions mentioned above.

B.4 Resources and tools

There are various tools available to help involve patients in person-centred care. Examples are listed in Table B.1.

Table B.1 — Resources and tools

Institution	Link
The Health Foundation	General http://personcentredcare.health.org.uk Shared decision making http://personcentredcare.health.org.uk/shared-decision-making Electronic Health record documentation http://personcentredcare.health.org.uk/resources/enabling-patients-access-electronic-health-records-guidance-health-professionals A practical guide to self-management https://www.health.org.uk/sites/health/files/APracticalGuideToSelfManagementSupport.pdf
Informed Medical Decisions Foundation	Six Steps of Shared Decision Making https://www.slideshare.net/fimdm/six-steps-of-shared-decision-making
Institute for Healthcare Improvement	General http://www.ihi.org/Topics/PFCC/Pages/default.aspx Case studies of patient involvement, narrative and shared decision making http://www.ihi.org/education/IHIOpenSchool/resources/Pages/CaseStudies/default.aspx
University of Gothenburg Centre for Person-Centred Care (GPCC)	General https://gpcc.gu.se/english/resources Patient and Public Involvement https://gpcc.gu.se/english/resources/ppi
Canadian Patient Safety Institute	Engaging Patients in Patient Safety – a Canadian Guide http://www.patientsafetyinstitute.ca/en/toolsResources/Patient-Engagement-in-Patient-Safety-Guide/Pages/default.aspx
Imperial College London Patient Experience Research Centre	Participatory approaches to improving health care and biomedical research https://www.imperial.ac.uk/patient-experience-research-centre/

Institution	Link
National Institute for Health Research	Resources for patients and the public https:/www.nihr.ac.uk/about-us/how-we-are-managed/managing-centres/nihr-central-commissioning-facility/ccf-ppi/
Agency for Healthcare and Research and Quality	https://www.ahrq.gov/professionals/quality-patient-safety/patient-family-engagement/index.html
International Alliance of Patients' Organizations (IAPO)	http://iapo.org.uk/sites/default/files/files/IAPO%20Guidelines%20for%20Patient%20Involvement.pdf
World health Organisation	"What is people-centred care": https://www.youtube.com/watch?v=pj-AvTOdk2Q
International Consortium for Health Outcomes Measurement (ICHOM)	Information about PROM: https://www.ichom.org/standard-sets/
Article	Information about PROMs and PREMs: https://academic.oup.com/bjaed/article/17/4/137/2999278 https://kce.fgov.be/sites/default/files/atoms/files/KCE_303C_Patient_reported_outcomes_Short_Report_0.pdf
Patient public involvement overview	Information in French, English and Dutch: https://kce.fgov.be/sites/default/files/atoms/files/KCE_195B_implication_citoyens_et_patients_0.pdf

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Från: Mattis Rundgren (SIS)
Ärende: SIS-Remiss 18552 Patientdelaktighet i personcentrerad vård
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Genom att ge synpunkter på bifogad remiss bidrar du till att göra den kommande standarden mer accepterad och därigenom mer användbar. Dina synpunkter kommer att vägas samman med synpunkter från övriga remissbesvarare och tillsammans utgöra det svenska svaret till CEN.

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Den föreslagna svenska titeln är:
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Om du vill påverka innehållet i den kommande standarden vill vi ha dina förslag på förändringar senast **2019-08-13.**

Svaret på remissen och dina eventuella kommentarer ska du skicka till mailto:mattis.rundgren@sis.se

Skriv dina kommentarer på bifogad svarsblankett. Kommentarerna ska skrivas på engelska för att säkerställa en korrekt användning av fackuttryck.

Ansvarig för remiss 18552 är den Tekniska kommittén Patientdelaktighet i personcentrerad vård, SIS/TK 602.

Vi kommer även ha ett seminarium, tisdag 11 juni 2019 kl. 10.00, för att presentera förslaget. Vänligen anmäl er på nedan länk:
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