Introduction

There is a need for clinicians, private and public healthcare providers, health managers and funding organisations to define the classes of concepts and their descriptive terms regarding all processes of care, especially considering patient-centred continuity of care, shared care and seamless care.

Continuity of care depends on the effective transfer and linkage of data and information about the clinical situation and the care provided to a subject of care, between different parties involved in the process, within the framework of ethical, professional and legal rules. The description and formalisation of continuity of care in information systems implies that related concepts and descriptive terms are defined, thus establishing a common conceptual framework across national, cultural and professional barriers.
Scope

The actual implementation of continuity of care relies on the good management of health information in two different perspectives:

- the complete integration of the information about the subject of care in the records held locally by the various healthcare providers, so permitting an optimal assessment of the health status of the subject of care by each of them
- a smooth information interchange between the different healthcare agents involved, provided that the existence of sharable and actually shared data supports a genuine, more or less formal, organisational pattern, commonly called ‘network’; such a pattern facilitates professional teamwork.

In turn, a network pattern, as well as teamwork, imposes heavy constraints over data organisation and data flow.

This European pre-standard seeks to identify and define those processes that relate to continuity of care. It specifically addresses aspects of sharing patient-related information needed in the process of care. It identifies and defines relevant data and information flows, together with their relationships to ‘time slots’.

In order to support the delivery of high-quality care to each patient, and to facilitate continuity of care, a full understanding is needed of the temporal aspects of the delivery of health care, the role of each party in the healthcare process, and their interaction in each patient’s environment. The concepts describing the characteristics of the ongoing process of care should not differ in nature from those that are used to structure and organise the data locally in the Electronic Health Record (EHR).

This European pre-standard addresses such topics as:

- organisational principles of longitudinal care (continuity of care, shared care, seamless care, integrated care)
- actors’ roles (subject of care, healthcare parties, healthcare providing organisations, healthcare professionals, third parties, healthcare devices and software)
- events: health issues and their management
- concepts related to time and ‘situations’ (contacts and encounters, record access, episodes of care and periods of service)
- concepts related to decision support, use of clinical knowledge, and activity (healthcare services, guidelines, protocols, programmes of care, care plans)
- concepts related to responsibility (mandates and their notification)
- concepts related to health data management (sharable data and specific requests, data generated by automated processes or by the activity of the natural human environment of the subject of care).

In order to establish a common conceptual framework for continuity of care across national, cultural and professional barriers, all these concepts are defined in this document, and their inter-relationships identified.

The system of concepts and the terms defined in this European pre-standard are designed to support the management of healthcare-related information over time and the delivery of care by different healthcare agents who are working together. This includes primary care professionals and teams, healthcare funding organisations, managers, patients, secondary and tertiary healthcare providers, and community care teams.

This harmonised system of concepts will be used to facilitate clinical and administrative decision making, healthcare logistics, such as provision of coherent services – and to enhance relationships between healthcare professionals and their patients.

Within this European pre-standard, ‘subject of care’ – a concept definitely restricted here to human beings – refers to an individual. It is assumed that in those cases where a healthcare service addresses a group of more than one individual (such as a family, a community, and so on), and where a single healthcare record is used to capture the healthcare services provided to the group, each individual within the group will be referenced explicitly within that healthcare record.

This European pre-standard does not intend to define how the processes should be performed in a particular healthcare framework. It does not intend to have any regulatory impact on the actual delivery of care. For example, it defines what ‘a hospital stay’ is, but it does not specify in any way the events that may occur during a hospital stay.

The specific management of prescriptions for drug therapy and of laboratory tests and their results are not part of this European pre-standard; nor does the pre-standard define any other aspects of the healthcare process, such as security, act-specific management, the life cycle of acts, terminology and classification, or the financing mechanism of healthcare delivery.

While this European pre-standard can help manage the logistics of healthcare delivery, it does not intend to refer specifically to the issue of resources needed in the provision of healthcare services.

Domain description: organisational principles of longitudinal care

Various terms have been commonly used to designate and qualify the continuing process of delivery
of health care to a subject of care. Without clear definition, there is potential for confusion, and this European pre-standard addresses the need to clearly define such terms.

**Continuity of care**: an organisational principle, where one or more healthcare providers deliver several healthcare services to a subject of care. This organisational principle focuses on the time-related links between those different healthcare services.

**Shared care**: an organisational principle where two or more healthcare providers jointly co-operate to provide healthcare services to a subject of care for a continuing health issue. This organisational principle focuses on joint objectives and responsibilities.

**Seamless care**: a quality principle, focusing on the timely and appropriate transfer of activity and information, when responsibility for the delivery of healthcare services is wholly or partly transferred from one healthcare provider to another.\(^6\)

**Integrated care**: an organisational principle, encompassing at the same time each of continuity of care, shared care and seamless care.

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**Overview of the concepts embedded in ENV 13940**

The concepts are reviewed in the same order as they appear in the official standard which, for a better understanding, includes a UML representation.

**Actors in continuity of care**

**Healthcare agents**

Devices as well as individuals perform activities and provide information for, about, or useful to a subject of care. Data produced by software can be computed and provide relevant information which, once duly validated by a healthcare professional, can be used for the benefit of the subject of care.

**Healthcare parties**

**SUBJECT OF CARE**

In this European pre-standard the option has been taken to consider an individual patient or client as the subject of care, despite argument that a subject of care may also be, in other contexts, a population or a group of individuals. It is possible that healthcare services are provided to a group of persons: group therapy or family therapy are well-known examples of such procedures. Healthcare services are particularly likely to be delivered to populations of individuals if they have a preventive purpose. Nevertheless, in the context of the EHR, and continuity of care across EHRs in different parts of a health service, it has been felt that the subject of care is only appropriately understood as a single individual. In many cases, a subject of care both receives healthcare services delivered by a healthcare professional and is actively involved in the provision or planning of these healthcare services. This involvement may actually be a feature of high-quality healthcare provision.

**HEALTHCARE PROVIDERS**

*Healthcare providers* will have different roles depending on whether they are individuals or organisations, particularly with regard to their professional skills and legal responsibilities.

**HEALTHCARE ORGANISATIONS**

A *healthcare organisation* is any kind of formal or informal grouping or partnership between healthcare professionals intervening jointly or in continuity to provide consistent healthcare services to a subject of care, with regard to one or more health issues. Thus the concept of healthcare organisation encompasses hospitals and all types of healthcare teams. Kinds of healthcare organisations are:

- individual care provider (with loose relationships with other actors)
- set of interchangeable care providers in the same organisation
- team with various competencies and tasks
- set of teams operating ‘independently’
- set of teams allocating tasks between them, in a non-predefined way
- set of teams operating in cascade
- set of teams operating according to an integrated programme.

Organisations involved in the indirect provision of healthcare services are considered in this European pre-standard to be healthcare third parties.

**HEALTHCARE PROFESSIONALS**

They can be seen as individual healthcare providers among others, sharing several attributes with healthcare organisations, but also having specific personal responsibilities. For this reason they need to be
individually identified in the continuity of care process.

Healthcare third parties
This concept covers all parties that indirectly contribute to the delivery of healthcare services. Two categories of healthcare third parties have been specified in this European pre-standard: other carers and healthcare funding parties. Other carers encompasses all providers of services related to health care: for instance, social workers, logistical services workers (such as ‘Meals on Wheels’), parents and other family members, benevolent neighbours, and so on. Healthcare funding parties are quoted here only as an illustration, since the kind of relationships that may exist between the delivery of health services and the healthcare funding parties lie outside the scope of this European pre-standard. Other categories of healthcare third parties can also be identified, such as health authorities, pharmaceutical companies, governmental agencies, etc.

Health issue and health issue threads

Health issue
The concept of health issue – probably first put forward in Canada – broadens the common concept of ‘health problem’ to encompass issues that should not actually be labelled as ‘problems’. There are many reasons why ‘health care’ is sought, other than making a diagnosis or treating ill health in a patient. For instance, items of preventive care to a person or to a group of persons (for example, a family, a population) may be considered to be health issues. A health issue bears a label, given by the healthcare professional currently in charge within a period of service, according to her or his professional culture. However, all is relative: the observation depends on the observer; furthermore, with the same observer, the observations may vary over time: while a given clinical condition or event is fundamentally unique, the way any healthcare party perceives it may vary over a period. In addition, the terms used to label a health issue also vary from one healthcare professional to another.

All healthcare services delivered in relation to a health issue form the content of an episode of care.

Health issue thread
The health issue thread concept unifies or reconciles the whole range of labels and health issues related to the variety of scopes of each of the healthcare parties. It is a link that may need to be established between health issue labels specific to various professions in order to reconcile them. Its use may be, for example, to trace all healthcare services (or services bundle) provided to a subject of care with regard to a given condition, in the common perspective of a group of healthcare parties, or of only one healthcare party. Examples of healthcare parties interested in the use of a health issue thread are: the subject of care, a healthcare team, a healthcare funding party, a continuity of care facilitator.

Each healthcare party has his/her own perception of the clinical condition presented by a subject of care (including the subject of him- or herself), according to his/her education, know-how, experience, skills, role, the clinical information available to him or her, and the diagnostic and therapeutic activities performed under his/her jurisdiction. In his/her own perspective, each observer may view this clinical condition as a definite health issue.

Furthermore, the interpretation of a health issue may evolve over time, with both its changing context and its intrinsic evolution. Different labels may thus successively be assigned to it, even locally in each observer’s record.

Having a given task to perform, a healthcare party may also need to build his or her own health issue thread from the various health issues resulting from the series of local specific scopes that are present in the shared care environment.

In the same way as a given health issue (labelled by a healthcare professional) delineates an episode of care, a health issue thread delineates a cumulative episode of care. Health issue threads can either be defined a priori, according to shared rules, or be identified a posteriori to produce a consistent view of a past situation.

‘Situations’ in continuity of care
The term ‘situation’ shall be understood here according to the definition provided in ENV 12381: 1996 ‘Time-related concepts’: a phenomenon occurring (or having the potential to occur) at a particular time or over a period of time in a given world context'.

A period of service encompasses all healthcare services delivered to a subject of care in the framework of a care mandate and over the time span of that mandate. During a period of service (under the responsibility of a healthcare provider that can be either a single healthcare professional, or a healthcare organisation), the subject of care is involved in one or more contacts with one or more healthcare professionals. Indeed, whenever the healthcare provider mentioned above corresponds to a single healthcare professional, all contacts in that period of service are managed by this very healthcare professional. It may occur – if the period of service is, for example, a hospital stay – that it is the occasion for addressing more than one health issue. Over the course of a period of service, a new care mandate may be issued for another healthcare provider.
or be restricted to a specific healthcare provider (such as a healthcare team, a medical specialist, a specialised unit within a hospital, and such like). In such a case it can be said that a period of service is nested within another period of service, just as a healthcare provider can be considered as being a member or a part of another healthcare provider.

In the same way as periods of service may address more than one health issue, a contact may be the occasion for addressing more than one health issue. This is often the case for example in a consultation with a general practitioner.

Within the framework of ENV 13940, the relationships of continuity of care to health information systems and health data management are an important focus. If a health information system is to support continuity of care, it must be structured according to this necessary function. In this context, a contact includes an interaction of a healthcare provider with the health information system (for example, opening and acting on information within an EHR), whether the patient is present or not. Two kinds of contacts can therefore be identified:

1. Record access in the direct or indirect presence of the subject of care (face-to-face, by phone, and so on), that is, an encounter.
2. Record access not in the presence of the subject of care (even indirectly).

An encounter is a category of contact that takes place between a healthcare professional and a subject of care in the presence of the latter, either in actual face-to-face physical encounter, via a telephone conversation, or any situation during which an interaction takes place between both parties. The important thing is this interaction. A situation where the interaction and the interchange between the subject of care and the healthcare professional takes place at some time point (for instance, a home visit), while the record access about that interaction takes place somehow later (for example, when the healthcare professional is back at her or his surgery) also belongs to this category of contact: in such a case, the changes introduced to the healthcare record reflect the interaction. It is not clear whether, following their nature, interventions of telemedicine actually belong to that category.

A record access and update is a situation where the changes made to the healthcare record are not based on any immediate interaction with the subject of care, but instead derive from some new information input, or from some kind of computation of pre-existing data in the healthcare record. For instance a team meeting not in the presence of a subject of care may give way to some kind of statement that is included in a healthcare record. However, a record access which simply consists in reading the content of the healthcare record without making any change to it should not be counted as a contact, although it will be necessary that the system traces such accesses for other reasons, including security, privacy, and the system audit trail, which have no real influence over the process of care.

The notion of contact element refers to the statement that in the course of a contact, more than one health issue may be addressed. In order to organise and structure the data, particularly at the level of the healthcare record, or for better management of healthcare services delivered to a subject of care, or for quality management, and so on, it is important to be able to sort out those healthcare services that are related to each specific health issue. That fraction of a contact that relates specifically to one health issue is defined as a contact element.

An episode of care is formed of the series of all contact elements managed by one healthcare professional with regard to one health issue. It is to be stressed that the episode of care concept is primarily an operational one. An episode of care does not coincide with an episode of disease or of illness, since it is based on the healthcare services that are delivered to a subject of care with regard to a health issue. The upsurge of the first often vague symptoms of a disease, the time when a patient may feel ill or simply tired, though he/she has not yet decided whether or not he/she contacts a healthcare provider, are not part of any corresponding episode of care. It is only when a demand for care is expressed and when a health issue is stated and labelled by a healthcare professional that an episode of care starts. On the other hand, an episode of care terminates when the last healthcare service for that health issue is completed, even if some signs and symptoms persist, or if some other healthcare services are delivered to the same subject of care by another healthcare provider for the same condition.

A cumulative episode of care is formed of several episodes of care, linked together in relation to a consistent health issue thread. A cumulative episode of care corresponds to a view of a set of healthcare services provided by several healthcare providers. Depending on the healthcare party who defines the health issue thread, the span of a cumulative episode of care may vary.

Concepts related to responsibility in continuity of care: mandates

During the course of a process of shared care, whenever the co-operation among healthcare professionals is addressed, the responsibility for playing a specific role may be offered to one healthcare professional, accepted or rejected by this healthcare professional, and possibly transferred later to another healthcare professional. Mutual roles and limits of autonomy for each healthcare professional must be defined.
Conceptually, the responsibility for playing such a role relates to a mandate that expresses the scope and limits of responsibility given, and each healthcare professional operates according to this mandate.

In the real world a mandate can actually exist either explicitly or implicitly, depending on local legislation or regulations, or simply circumstances. Such a mandate may be given either by the subject of care, a natural carer, a health authority, a citizen endorsed by law, or by a transfer from one actor to another (partial or total, temporary or permanent); for example, a hospital stay may imply a temporary total responsibility.

A mandate can be open and generic (that is, regarding all possible health issues presented by a subject of care, as for instance in general practice), or limited to one or more predefined problems (for example, with specialists).

The mandate may involve various kinds of healthcare services, for example, a visit, a diagnostic test, a diagnostic judgement on existing data, a therapeutic decision, the performance of a therapy according to a protocol, and so on.

From the point of view of an information system or workflow, a mandate can be either explicit, or implicit or pre-assigned (every healthcare professional in a hospital receives a mandate automatically after the assignment of the subject of care to a ward or a unit of care; the mandate may be passed at change of shift).

If necessary, software within the EHR could ensure that proper negotiation of a mandate is performed (for example, proposal, acceptance/rejection, notification). This negotiation may be facilitated by a telematic application, or by a human ‘facilitator’, who guarantees that the relevant mandates are assigned and accepted, without loss of continuity, in some health systems, as appropriate.

This aspect of the ‘facilitator’ function is not related to any direct clinical role, but to continuity management only. Therefore, it can theoretically be performed by any healthcare professional, not necessarily a physician.

A mandate can be assigned to a healthcare organisation or to a named person, or to a named role within an organisation (such as the physician in charge of the emergency department). In this case, the mandate is transferred to a named person as soon as he or she is identified. The same principle holds for transfer of mandates according to working shifts.

From the point of view of the information system, a mandate also corresponds to an obligation to record and to attest information. In this sense, a mandate has a relationship to a local healthcare record.

Four types of mandates are identified, plus ‘Mandate notifications’.

Demand mandate (mandate to express a demand for care)

A demand mandate is an explicit or implicit mandate to express a demand for care on behalf of a subject of care; in most situations, when the subject of care is a conscious patient, the demand mandate is implicitly held by the subject of care him- or herself.

Care mandate (mandate to deliver healthcare services)

Once a demand for care is expressed to a healthcare provider (that is, a healthcare professional or a healthcare organisation), an implicit mandate is given to the healthcare provider, the responsibility for which he or she may accept or refuse. However, the scope of the mandate may be restricted by the law or by regulations, according to the competence of the healthcare provider. Subsequently the subject of care may be referred, the responsibility then being transferred in all or in part.

Mandate to export personal data

By such a mandate, a subject of care, or other person mandated by the demand mandate, authorises a healthcare party to send out a defined piece of personal data to a designated receiver. Consequently, no piece of personal data should be sent without the consent of the subject of care or of a mandated person. The opposite situation may also occur, where a general mandate to export personal data is implicit. The denial of the right to send out a specific piece of data may also be explicitly requested.

Continuity facilitator mandate (mandate to facilitate continuity of care)

This can be delivered by either the subject of care, one or several healthcare providers, or a health authority. There can be no actual continuity of care without the timely intervention of a continuity facilitator, who is a healthcare agent to whom a mandate is given, in order to act at least to make concurrent healthcare providers aware of the care mandates accepted by each other.

Mandate notifications

Mandate notifications contain information about the changes that have occurred in the status of an explicit mandate granted to a healthcare party – as a consequence of the evolution of the process of care, or for other reasons – that is made available to other healthcare parties. It is not the purpose of a mandate notification to deal with detailed information about
the subject of care’s clinical status. In practice, all changes with regard to mandates regarding healthcare services provided or to be provided must be notified. A mandate notification is a piece of sharable information (sharable data) and, as such, is sent to the sharable data repository, where it can be accessed according to distribution rules.

Concepts related to use of clinical knowledge, decision making and activity

These concepts address the process according to which generic clinical guidelines are eventually implemented in programmes of care and care plans for the sake of a specific subject of care. A distinction is to be made between broad statements and their operational implementation in the framework of the activity of a healthcare professional.

The European pre-standard identifies four levels, ranging from the most generic set of principles and recommendations to the most specific with regard to the subject of care and the healthcare professional on duty:

- clinical guidelines
- protocols
- programme of care
- care plan.

A distinction should be made between clinical guidelines and more tightly tailored protocols that have been adapted to the particular contextual characteristics of an individual subject of care, and which lead to the design of a programme of care to be carried out by a healthcare provider (or healthcare organisation), for example, a healthcare team.

A comprehensive programme of care, endorsed by a healthcare provider or healthcare organisation may be further split down into many separate care plans, effected by healthcare professionals, whose activities collectively contribute to a programme of care.

The common healthcare objectives of a healthcare organisation applying a programme of care are specified in the operational healthcare goals that drive the action of each particular healthcare professional.

Each programme of care aims at fulfilling stated healthcare objectives. The achievement of these healthcare objectives will correspond with healthcare goals of each involved healthcare professional.

Healthcare services consist of any kind of activity provided by a healthcare professional or by a healthcare organisation for the benefit of a subject of care, in relation to one or more health issues over one or more contacts. Surgical procedures, nursing procedures, counselling and referral are all examples of healthcare services.

The notion of services bundle refers to the expected consistency (shared healthcare objectives or shared healthcare goals) of a set of healthcare services provided within the framework of a period of service with regard to one health issue.

The concept of healthcare compliant activity covers all kinds of activity provided by carers other than healthcare professionals (other carers), given that they are complementary to these professionals’ activity, and can be considered as supporting the implementation of a programme of care.

Healthcare automated activities are activities performed by an automated device or software.

All kinds of healthcare activities – healthcare services, healthcare compliant activities and healthcare automated activities – generate data that are potentially useful in the further steps of the process of health care. Those data that do not directly result from the activity of a healthcare professional need to be acknowledged and validated before being subsequently used in the management of a process of care.

Health data management

Continuity of care implies the management of health information from two different perspectives:

- local management of information about the subject of care, at the site of care provision
- information interchange between healthcare providers.

Telematic tools facilitate reciprocal awareness among the various healthcare professionals (within different organisations) participating in healthcare services delivery to subjects of care. Awareness involves:

- the perceived status of the subject of care
- the healthcare services delivered, performed or planned, with the corresponding healthcare goals
- the mutual responsibilities of actors
- the presence of local healthcare records and of sharable data repository(ies) (possibly in electronic format) and the nature of available clinical information, or rather the existence of information identified as potentially valuable for the ongoing process of care.

Continuity of care involves appropriate flows of information within and between healthcare records, in order to permit both the synchronisation of activities and information in records, and, from the perspective of seamless care, correct sequencing of activities; it also provides a comprehensive view of the status of the subject of care.

All healthcare agents may produce data. Healthcare devices and healthcare software may also create data. No healthcare provider can take responsibility for the content of these automated data until they have been
validated by a clinician (with regard to appropriateness and applicability). Accepting the use of such data in the management of the health care process without their explicit validation might expose the healthcare provider in charge to legal redress.

Apart from acknowledged healthcare professionals, other carers and the subject of care, take their part in health care, by performing activities that are called here healthcare compliant activities. Such activities may also generate data. Again, it is the responsibility of a healthcare professional to validate such data. Importing them into the local health care record, or stating their content to justify the delivery of healthcare services, makes an implicit validation.

Until validated, all data should be regarded as non-validated clinical data. Once they have been validated, they become clinical data for import. Even clinical information (tailored clinical information) resulting from a specific clinical information request must be validated prior to being imported into a local health care record.

Identifiable data that are part of the health care record can only be sent out from the health care record for use in the interest of the subject of care with respect to privacy protection and professional ethics (professional secrecy). For continuity of care, this defines two situations:

- **Sharable data** that are put at the disposal of other healthcare professionals
- **Tailored clinical information**, following, or not, a specific clinical information request, sent to identified healthcare parties.

In both cases, distribution rules have to be taken into account.

**Conclusion**

Since its formal approval by CEN in 2000, many health information systems experts and health authorities in a wide variety of European countries have expressed their interest in this European pre-standard. This interest most probably stems from the fact that it helps them to reach a better practical understanding of how health care is delivered to the citizens in the perspective of continuity.

Most major concerns and features that belong to the professional culture of all parties involved in this process, and that are part of their everyday practice, are – or should be – embedded in this document. This is particularly true with regard to general practitioners and all workers acting in the community.

While such a technical document targets informatics experts and developers rather than primary healthcare physicians, it might prove worthwhile for the latter to try and match the way continuity of care is modelled hereby against their own personal views and practical experience, not the least because this might trigger interesting comments that would help standards experts to correct possible misfits for the revised version to be produced within the two coming years.

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**REFERENCE**

The texts of both ENV 13940 (2000), Health Informatics – systems of concepts to support continuity of care, and ENV 12381 (1996), Healthcare Informatics – time standards for healthcare specific problems, are available on the CEN technical committee 251 website (www.cenitc251.org/Tcmeet/doclist/Tc00/N00-053.pdf). They can also be obtained from the CEN/TC 251 secretariat: Secretariat CEN/TC 251 Health Informatics, SIS, Swedish Standards Institute, Sankt Paulsgatan 6, S-118 20 Stockholm, Sweden. Tel: +46 8 555 520 00; fax: +46 8 555 520 01; email: karin.kajbjer@hss.se

ENV 13940 provides us with numerous diagrams following UML conventions.

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