# Why (and how) an electronic tool for prevention and early finding.

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Why should a dedicated tool be necessary for prevention and early findings? If yes, what should such tool look like?

It would not be wise to answer both questions by exhibiting the "perfect software" without a previous and accurate definition of these concepts and of their biotope.
To make a proper analysis often demands for some hindsight; we will do it resolutely by first exploring the new paradigms and concepts that are nowadays visibly modeling the health universe; then we will define what prevention stands for in such context in order and ask if a decision support system is needed and what it could look like.

Once needs are be clearly stated, we will examine why a system that allows for telling the health journey of a person is also the proper tool for having a team manage the personal health project of this person. Finally we will understand how such system can give family doctors their natural position in health: as her patient's main risk manager and as the pivotal actor for continuity of care.

## Contents

## *A brand new medicine is appearing*

## Historical view

Writing an History of Medicine is far from being goal that this document can pretend to reach. However, one can hardly assert that a new medicine without at least a limited historical view.

A rough drawing is enough to claim that, from World War 2, a true technological big bang has been considerably expanding the medical knowledge area. Positive outcomes are obvious in term of life expectancy and long term functional status. However there is also strong evidence that this centrifugal force has deeply restructured the medical domain: the constant need to take up this growing space has led to an hyper-specialization of many actors, and the fame attached to those who surfed the wave of technology has overvalued the technical support center and deprecated the classical clinical examination.

Dr Roger Dachez, who just published his book, « Histoire de la médecine de l'Antiquité au XX$^{e}$ siècle » (History of Medicine from ancient times to the 20$^{th}$ century), made a really enlightening answer to a reporter asking him: "In your book, from ethical, methodological and sociological thoughts to multiple anecdotes, we go from centuries to centuries. Why does it stop at the beginning of the 20$^{th}$ century?":

> "Because between 1930 and 1950, the very nature of medicine has been metamorphosed. Save anatomy, some physiological knowledges and several elementary clinical acts, everything else – that's to say the vision we have of the disease, its understanding and its treatment – was restructured. Nowadays medicine is a fascinating discipline, but it is glaring at a point that it blinds its practitioners. Fresh graduated doctors now regret to only see their patients through imaging media and biological measurements. But what somatizes sometimes comes from the deepest part of human being – a part that is not simply organic – and doesn't appear in imaging or tests. Where is medicine going? While exploring the genome, it is not far from getting the power of acting on people and their descendants. It is a radical innovation, and it is also a new history.
>
> To tell the truth, the historian that I am would probably have loved to be a medical doctor in the days of Hippocrate, Vésale, Ambroise Paré or even Bichat and Laennec, who, besides, all have had exceptional destinies that I made my best to tell. But above all, in these times, every skilful and hard working practitioner could master all the knowledge of the moment. Medicine was then homogeneous, it was a whole, an humanism. Nowadays, medicine is burst, atomized, put into orbit as innumerable sub-specialities. As a consequence, if you allow me an hyperbole, we are in risk of having a twofold medicine, with a row of those who know quite everything about quite nothing, and a row of those who know quite nothing about quite everything. Do we wish to restrain our practice to only be a dispatcher for major pathologies? It may be the task devoted to General Practitioners, healing low severity cases and delegating the rest to the specialists. Specialists, in turn, just address a limited set of diseases. This shift in medicine's unity was probably inevitable and allowed for tremendous progress, but it also comes with risks.
>
> I don't want you to believe that intend to deliver a past praising message. I just issue some warning, and I would like, through this book, keep a living memory of an immemorial practice. Modernity is to be accepted, to be properly used, but we also have

to make sure that medical art never part from the humanist tradition it comes from."

There is little indulgence in the picture that Dr Dachez depicts; however the state he describes is very accurate and bears the seeds of a needed evolution, of a regain of unity in medicine where a human being is envisioned as far more than the sum of her organs and diseases. Such progress would have remained in the real of nostalgia weren't two deep unrelated trends to appear and reinforce it to the point it can now be stated as necessary:

- The deceleration of technological expansion that now reach an asymptote as well for fine chemistry (where the blockbusters era is nearly over and will be replaced by a period of niche market innovation) than for medical devices (electronic and computer revolutions are now behind us). The next step, involving genomic treatments and nanotechnologies is still in labs tubes and is not expected to reach the market soon.
- Population ageing, along with an excess in wellness, are step by step reversing the acute versus chronic treatments ratio. Such modifications in the time scale and location of care are moving the gravity center from the reference technical center to much personalized care.

## New paradigms and new models of care

Nowadays, it is already possible to talk about new paradigms and new models of care, and even to describe them according to J. Cohen (21st Century Challenges for Medical Education; 9th International Medical Workforce Conference; Melbourne, Australia; November 2005) :

*New paradigms of care:*

| | | |
|---|---|---|
| The individual | → | The community |
| Acute diseases dominates | → | More chronic illness/disability |
| Episodic care | → | Continuous care |
| Cure of disease | → | Preservation of health |
| Reactive | → | Prospective |
| Physician provider | → | Teams of providers |
| Paternalism | → | Partnership with patients |
| Provider centred | → | Patient/family centred |
| Parochial health threats | → | Global health threats |

*New models of care:*

| | | |
|---|---|---|
| Cost indifference | → | Extreme cost consciousness |
| Anecdotal care | → | Evidence Based Medicine (EBM) |
| In-patient focused | → | Ambulatory/home centered |
| Solo/small groups | → | Integrated systems |
| Quality assumed | → | Performance is measured |
| Trust assumed | → | Trust must be earned |

Prevention and early findings processes will be legitimated by such concepts and their practice shaped by this set of constraints.

## *Prevention and early finding*

We just have seen, among the new paradigms defined by Cohen, that preservation of health must overweight cure of disease, and that a prospective team work, in partnership with the patient will eventually become the usual practice. This is a good initial definition for prevention.

## Prevention modalities

To go any further, and more accurately define the various facets of prevention, we can listen to Marc Jamoulle and Michel Roland[1]:

> Four categories of clinical prevention can be distinguished, as actions taken over time according to the four fields of activity of a medical doctor during her encounter with a patient. Consultation is the encounter of two human beings inhabited by distinct doubts. One of them doubts of his being while the other has doubts about her knowledge. We can state that a consultation is the meeting point of a science and a consciousness.
>
> From the combination of a medical practice trying to detect diseases and of the natural evolution of the patient, who some days feels that he is changing from a state of well being to a state of illness, it is possible to distinguish four categories of preventive activity.
>
> The first field comes from the encounter of a well being patient in which the practitioner can not detect any health problem. It is the primary prevention area, inoculation or health education.
>
> The second field comes from a practitioner eager to discover some health problem in a patient that considers himself as well being. We can tell it case research in individual practice or early finding for populations.
>
> In the third field of activity, both the practitioner and the patient agree on the reality of a health problem. Of course, it is the curative field. From prevention point of view, it is about reducing or avoiding complications, it is also the place for rehabilitation. As shown in the table hereunder, the definitions of primary, secondary and tertiary preventions perfectly fit the corresponding cells.

| Patient's feeling | Practitioner's knowledge, disease natural evolution<br>Absent ----------> Present | |
|---|---|---|
| well being feeling | I | II |
| sick feeling | IV | III |

> From this observation, one of us made the hypothesis of the existence of a quaternary prevention[2], corresponding to the medical practice field where a practitioner tries in vain to find a problem in a sick feeling patient. This conflicting zone in the relationships between a patient and his practitioner has been widely documented along centuries and many publications are referring to the «Non disease disease»[3],[4] or the «Abnormal illness behaviour»[5], [6]. It is the refuge cell, the place for the Chronic Fatigue Syndrome or the fibromyalgia. It is also the square for a scanner prescription for headache, in short the place where Dr Knock meets the Imaginary Invalid, where patient's anguish

exponentializes practitioner's anguish[7]. This field of activity is a decisive part of health economy[8]. Its existence conditions the development of Evidence-Based Medicine or quality assurance. It is also a major factor for some aspects of ethic in doctor-patient relationship ethical.

From the sentence structure model of the three existing definitions for prevention, quaternary prevention has been quoted as:
**Action taken to identify a patient or a population at risk of overmedicalisation, to protect them from invasive medical interventions, and provide them with scientifically and medically acceptable procedures.**

Emphasised points are patient's protection and the necessary control on the scientific and ethic validity of medical activity, validating the ancient rule *Primunnonnocere*

To sum up, it is possible to define the prevention field according to the table hereunder, whose definitions are now part of the WONCA International dictionary of general/family practice[9]:

| | |
|---|---|
| **I**<br>**Primary Prevention**<br><br>Action taken to avoid or remove the cause of a health problem in an individual or a population before it arises. Includes health promotion and specific protection<br>(e.g. immunization) | **II**<br>**Secondary Prevention**<br><br>Action taken to detect a health problem at an early stage in an individual or a population, thereby facilitating cure, or reducing or preventing its spreading or its long term effects.<br>(e.g. Methods, screening, case finding and early diagnosis) |
| **IV**<br>**Quaternary Prevention**<br><br>Action taken to identify a patient at risk of overmedicalisation, to protect him from new medical invasion, and to suggest to him interventions which are ethically acceptable. | **III**<br>**Tertiary Prevention**<br><br>Action taken to reduce the chronic effects of a health problem in an individual or a population by minimizing the functional impairment consequent to the acute or chronic health problem.<br>(e.g. prevent complications of diabetes)<br>Includes rehabilitation. |

## Risk management

It is not anecdotal to see such concepts as health economy and Evidence Based Medicine appear as integral part of the prevention process, especially in quaternary prevention.

It is also very noticeable that, in the same way that several atoms were discovered while trying to fill the discrepancies in the periodic table of elements (Mendeleiev table), quaternary prevention is born from an empty cell when crossing in the same table both a practitioner's and his patient's consciousnesses about the morbid or not state in the later.
By this change of perspective, that gives up a view limited to the practitioner and deals with the perception of the two partners in the encounter, it becomes possible to envision the whole prevention process in a brand new way – along with Cohen's new paradigms of care: **the family doctor becomes the risk manager of his patient**, and he is in charge of managing the risk of having a disease appear or worsen as well as the risk induced by inadequate care procedures. We will see this concept appear in prostate cancer early detection, that is unchecked by default, as well

as in cardio-vascular risk management where prescription (say of a statine) is only done on purpose.

The prevention process must accordingly address the wide spectrum of risk management for a patient, comprising a recursive process that takes care for such process not to reach the 4th overmedicalisation square. The family doctor becomes a long term manager of the "risk level function" and a pivotal team work actor, scheduling specialized procedures and adapting the ongoing process according to its outcomes.

It undoubtedly is a major evolution in the way care giving is envisioned, and it leads to wonder if it is possible to keep on using usual medical practice softwares or if it is now mandatory to provide practitioners with tools that are adapted to their new conditions. This question has already been answered by Dr Lloyd Michener (Chair, Department of Community and Family Medicine, Duke University Medical Center) when comparing the usual duration of a family practice visit and what it would be, were the practitioner to apply minimal time clinical guidelines:

| Type of visit | **Current** (hours per day) | **Minimal time clinical guidelines** (hours per day) |
|---|---|---|
| Acute | 4,3 | 4,3 |
| Chronic | 2,8 | 10,6 |
| Preventive | 1,2 | 7,4 |
| Total | **8,3** | **22,3** |

What is self evident, according to this study, is that the family doctor workload will not be sustainable if he is not assisted by a decision support and continuity of care management system, in support of his new position as the operational leader in a global process endorsed by the patient.

It is thus mandatory to keep up the concept of record management software (medical practice software, patient record software, etc) and replace it with a true health information system; an electronic environment that is able to collect all scattered snapshots in a continuous and action oriented vision in benefit of team work. Episodus is born from this specifications.

## *Episodus*

Episodus is born from the expressed need to provide a tool for continuity of care, to tell in a structured way the health journey of an individual. Inheriting from episodes of care management, its main graphical user interface, the Ligne de vie, was elaborated from very limited specifications: how to put on a screen the **mental view of a patient history** that a practitioner elaborates once he has (after spending lots of time) studied the pile of document that constitutes his health record.

The drawing hereunder, from 2001, depicts the kind of "mental representation" that acted as a foundation for building the software.

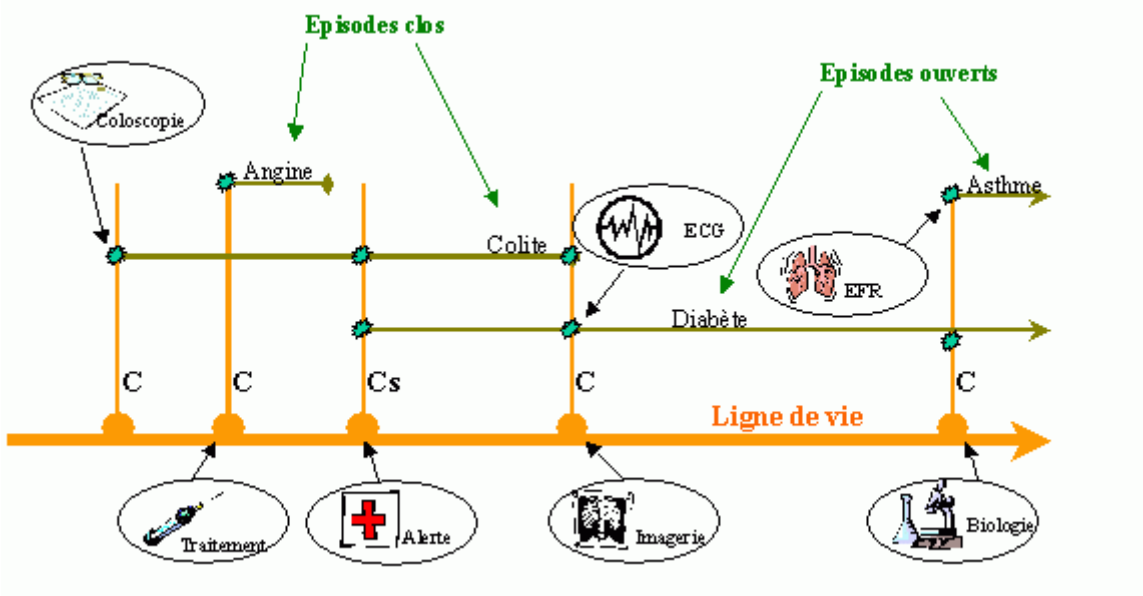



*Illustration 1 : mental representation of continuity of care*

Providing a health professional with such a diachronic view of his patient is already a kind of decision support and also a way for a team to share a common vision. However, our initial ambition was to go further and to benefit from the information accuracy this model permits in order to have smart agents support users of Episodus.

We had the opportunity to develop the first agents in the field of personalized cancer early detection (for mouth, cervix uteri, colon, epithelioma, melanoma, breast), and it was a chance since since it lead to the extension of Ligne de vie into two new dimensions: health goals management and explicit risk management.

Ligne de vie was initially designed to manage episodes of care and to host pointers toward significant documents, thus answering two key questions: "what problems are to be addressed?" and "what actions have already been undertaken?"; now complete with health goals ("what are the goals?"), it is now in charge of all basic functions of a project management system and becomes a tool in support of the Personal Health Project (PHP) of the patient.

These concepts will be more accurately described, along with their derivatives like the Health Team and the Access Rights Roses. Some insight in the technologies that make all this working will also be given in order to refer to the versatility of their application field. Finally, some new dimensions will be explored, such as quality assurance and the way the social dimension can be addressed.

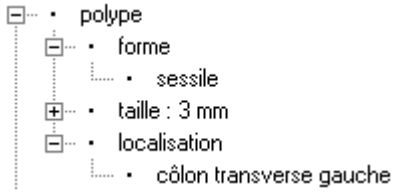
## To tell a story

Every medical software designer should be aware that she has to tell the health story of individuals, or at least is contributing to telling this journey. For the patient himself, it is self evident that each piece of information gleaned here and there is a part of a puzzle, constituting as a whole his health journey.
This is, however, usually incomprehensible for application developers, whose concern is to store a local record as a set of database information and electronic documents. It is actually not a problem that this local puzzle part doesn't fit the global continuity of care schema of an individual since, in the dominant model, this information is stored for internal use inside an organization only.

Of course, when continuity of care becomes the main target, it is mandatory to tell this long time story and, when possible, to use it as a backbone where scattered and mismatching information that are stored here and there can be connected together. This vision has shaped Episodus' architecture, with its medical information description language and the Pilot, a smart data broker. It's time to describe this.

### *Grammar*

In order to express a discourse in natural language (e.g. English), words of this language (the vocabulary) are inserted inside a sentences frame (the grammar). In the same way, inside Episodus, the Lexique, a tank containing more than 50,000 words of the medical universe (the vocabulary) can be used to build trees (the grammar).

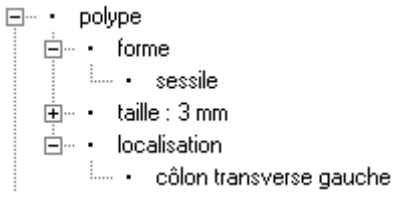



Is is easy to see that a tree like this one can describe a "3 mm sessil polyp located in the left transverse colon".

Each concept comes from the Lexique, who contains pathologies names, like "polyp" as well as anatomy elements like "left transverse colon" or qualifiers like "shape" and "position", but also biometric data like "size", adjectives like "sessil" or units like "mm".

Such tree shaped grammar is called a *Dependency Grammar*. The basic rule in a dependency grammar is that a word depends on another one. In a sentence, words are not simply put side by side, they are inter-related; in the same way, inside a dependency tree, the father node is called the *governor* (or head) while its son nodes are called *dependents*.

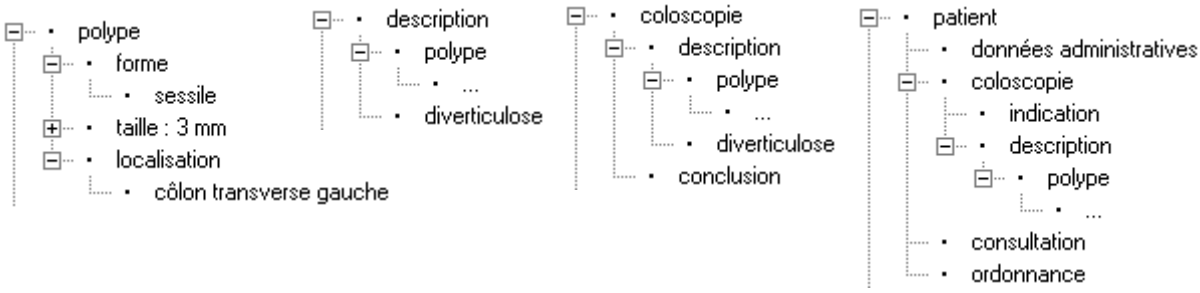
A dependency grammar is well adapted to Knowledge Management, since it exhibits information in a way that is immediately processable by smart agents. To demonstrate this, such tree can be envisioned as a formal intermediate representation in an automatic translation system:

| | | |
|---|---|---|
| polype sessile de 3 mm situé dans le côlon transverse gauche |  | 3 mm sessil polyp located in the left transverse colon |



It is self evident that the center form is far more easily processable for a computer, all the more than natural language labels have been used here for readability purposes while the tree is actually only made of Lexique concepts' codes, a very precious thing when it comes to get rid of terms ambiguity since the Lexique stores synonyms in different way.

Another noticeable property of trees is their "fractal" shape: if a basic description element is a tree, it is also possible to describe the whole patient record as a tree that fosters this sub-tree.
This property is illustrated hereunder, with the polyp description tree being a sub-part of a description tree, this later being a chapter inside a colonoscopy report, and this report may itself be integrated is part of a patient record tree.




Such fully scale independent representation is a major advantage in use for several reasons:

- Patient record can be processed in the same way whatever the precision level, for example when it comes to copy and paste or use knowledge management algorithms. The polyp description tree could be copied from the colonoscopy report and pasted in a colorectal cancer risk management form; accordingly, an algorithm that looks for a high glycemia level will be able to fetch this information and process it in the same way if it is stored in a lab result tree, a visit note or a diabetes follow-up form. Information processing is made easier and more powerful because the whole record is available.
- The whole system is based on a single information storage element, the tree node, and such genericity greatly eases back office operations like data historization (evolution tracing), access rights management, record synchronization, etc.

In short, Episodus' dependency grammar can express any medical discourse with the same accuracy as natural language, but in a non ambiguous and computer processable way. It is used to describe the Ligne de vie, the diachronic backbone, as well as any information (visit notes, reports, lab results, prescription, etc). Due to the genericity of processes permitted by this data representation, it has been possible to create smart agents in support of care givers daily practice.

With the benefit of a more than 20 years hindsight in using a dependency grammar to express medical discourses, it is possible to state that the most positive aspect in using such technology lays in the constant necessity to express information in a way that makes sense. It is not always easy because some meta-concepts can be complex to parse – for example, "comes back for the second time and still coughs" (really encountered in an hospital pneumology record); but time spent to give sense to such concept in order to express it as a tree that can take place as a Ligne de vie element is greatly rewarded by the scope of processing possibilities it later permits: this "well formed" and semantically processable sentence becomes a plain element of the patient's "health biography". Then this information becomes processable, exchangeable and usable by human actors as well as smart automatic processes all along the patient's health journey.

On the contrary, creating a dedicated code for the concept "comes back for the second time and still coughs" as it had been done in this hospital, and is usually done in records that are dedicated to a medical specialty leads to an information that is only understandable within the walls of this care place, and, even in this restricted context will hardly be able to evolve over time toward some more (or less) accurate information. The need for a semantic, induced by a dependency grammar, can bear an initial cost, mainly because of the expertise capture process that is needed in order to arrange this information in a way that is both accurate and consistent with it's author thoughts, but it

is plainly justified by the processing scope extension it provides. This aspect will be also dealt with in the chapter about the federation of heterogeneous information.

A grammar is nothing if there is no vocabulary to "fill its slots". The Lexique will now be more accurately described, with the ambition that ontologies no longer remain a mystery.

### *Vocabulary*

The Lexique has already been dealt with when giving the example of the polyp description tree. No need to say that the Lexique contains a much larger range of concepts, since it permits a full description of an individual health journey, including demographic information (such as "name" or "social ID"), management information (like "hospital stay", "stay ID", "document") and, of course, the core information of the Ligne de vie: "health concern", "risk follow-up", "health goal" and "treatment". Not to forget drugs, labs data, imaging, etc.

The Lexique can be defined as being the set of all the words from the bio-psycho-social universe, plus all the words involved in this universe's management (documents management, administrative information and identities management, and of course, information system concepts).

Actually, the Lexique is not only a set of words, it is also a set of concepts and even, due to additional components, an ontology.

The table hereunder exhibits some entries from the Lexique (out of the 52,451 that it contains today). The left column holds the label (in English here), the middle columns contains the code (the only information that is actually stored in a person's record) and the right column contains a grammatical qualifier for this word (in the English Lexique, NS stands for a singular noun with no gender, INV stands for invariable).

| | | |
|---|---|---|
| size \|s\| {dimension} | VDIME2 | NS |
| size \|s\| {of the patient} | VTAIL1 | NS |
| dimension \|s\| {in space X, Y or Z} | VDIME1 | NS |
| mm {millimeters} | 2MM001 | INV |
| colon \|s\| | ACOLO1 | NS |
| colitis | PCOT11 | NS |
| inflammatory pathology\|y/ies\| | PINFL6 | NS |

It has already been stated that homonyms have different codes (anyway homonyms in a given language are usually not homonyms in another one). Besides, true synonyms like "size (dimension)" and "dimension" share the same code, except for the last character. Actually, the 5 first chars are the code that define the concept, while a 6 chars code is a reference to one of the way this concept can be expressed.

Besides, another component, the Semantic network, establishes some relationships between concepts. Such relator establishes a labelled link between a concept and another one (it is called called a Typed Trait); by far the most frequent label, "is a", expresses categorization.
For example :

colitis ─ is a → inflammatory pathology

Two other relationships are frequently used: "is at" (also understandable as "part of" depending on the semantic of linked concepts) and "measure unit" that links a numerical information and its

unit(s).
For example:

colitis ─ is at → colon
size ─ measure unit → mm

These examples demonstrate that such very simple system permits to define that a colitis is an inflammatory pathology. In this case, it is a pretty good basic definition. It is easy to understand that, due to this "general culture", the system will be able to apply to a colitis every processes that have been developed for an inflammatory pathology, for example in case of drug contra-indication.

Completed with such set of links, the Lexique permits the expression of a semantically defined discourse; it is a possible definition for an ontology in knowledge management.

To be more accurate, along with its semantic network, the Lexique is a basic ontology, where predicates of valence 2 only can be expressed; for example it could be possible to write something like isA(colitis,inflammatory pathology). More complex predicates, whether predicates of valence 2 with numeric information like normalValue(glycemia level, < 1.27 g/l) or predicates of higher valence like isA(uncle,brother,father) can't be expressed in the Lexique (at least without spoiling it with artificial compound concepts). In order to address such complex information, the dependency grammar comes to the rescue, and a tree can be attached to any Lexique concept in the same way a dictionary text accurately describes an entry. This way, the ontology can become as rich as needed.

The Lexique "only contains" around 50,000 words; it could seem small considering that some ontologies claim several hundred thousand concepts. It comes from the very construction of the Lexique, that contains only princeps terms since complex ones are expressed by trees. Usual ontologies, since they are built to fill mono-dimensional "attribute-value" slots, contains compound concepts such as "left ankle fracture". In Episodus, such concept is described with a tree in the form:

fracture
    localization
        left ankle

It is very hard to manage "compound terms ontologies", one reason being that they are born to have a no limit growth.

### *Data model*

The representation model that uses the Lexique and a dependency grammar in order to describe any medical discourse in a uniform way is called Modèle unifié étendu (MUE) standing for Extended Unified Model (EUM).

In the past, the predecessors of Episodus only stored medical descriptions as trees (it was called the Unified Model), but relied on standard databases for the representation of demographic and document management information. Episodus is a major evolution, where every information is uniformly stored as trees; the next chapter will demonstrate that it is a crucial advantage for heterogeneous data federation. Hence the new name of Extended Unified Model.

The hereunder schema is a rough description of what a patient record looks like with the extended unified model.

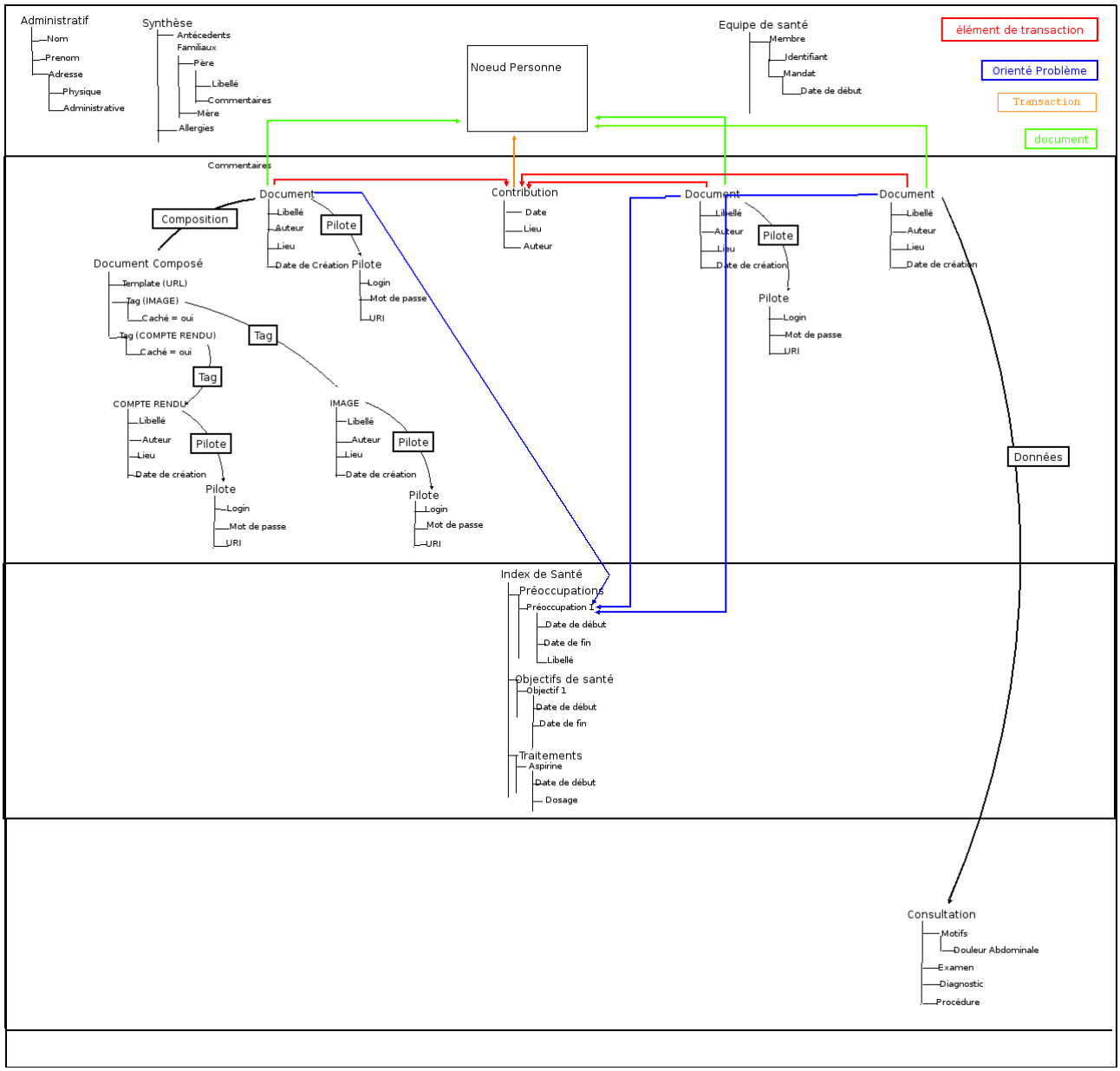



*Illustration 2 : data model, the graph of trees*

Trees belong to four categories:

- Single instance trees, such as demographic information (first name, second name, birth date, address...) or the health team.
- Management trees, like document labels or contribution descriptions.
- The health index, containing the Ligne de vie information.
- Description trees (reports, notes, etc).

Trees are connected together by links: some typed traits which label is a concept from the Lexique. This way, it is possible, from the "root tree" - the graph entering point, to find all documents label trees by following the links whose label is the "document" concept from the Lexique.

Each document has a label tree, describing its title, type, date, author, etc. This label is used to represent a document as an icon on the Ligne de vie.

The extended unified model is a very generic one, and it allows for any tree node to be connected to another one (or to a tree) through a link; for example, it suffices that a document label tree be connected to a node representing a health concern (in the health index tree) through a "health concern" link to have its icon get displayed on this health concern.

Inside Episodus, a person's record is, as we just described, handled as a graph of trees, i.e. A set of tree nodes and a set of links between these nodes.

### *Federating heterogeneous information*

Nowadays, most information is stored in standard systems that were designed to only fulfill the local vision of their owners, and not at all to express this information as a "puzzle part" that is consistent with the global vision of a person's health journey. Here again, the powerful versatility of the dependency grammar is a major advantage when it comes to federate such heterogeneous data repositories.

Usual systems have a data model based on a rigid database schema. The discourse they can express is accordingly static (such schema is hard to modify) and rather limited; usually based on lists of (attribute, value) pairs. Such pairs can be of the kind:

(weight (kg), 75)
(reason for encounter, dyspneua)
(lab test prescription, glycemia level)

The "value" is stored in a table, while the "attribute" is the name of the column in this table or, to be more accurate, the pathway that leads to this column in the relational database schema.
Since the attribute is fixed at system's design, the only way a proper information accuracy can be reached is to put rich information in the value; this is the reason why multi-axial coding systems and compound ontologies are being developed.

Two reasons explain why it is usually so complex to share information between such systems: first the rigidity of the attribute (intangible inside a system while not the same between two systems), then the full flexibility of the value, which can contain free text, a code from a classification or a coding system (sometimes locally created), a compound ontology concept, etc.

The extended unified model can't make miracles, and interpreting information from a usual system needs a mapping work, however it has been precisely made generic in order to make it possible. The first task is to build a tree representation that mimics the database schema (the data model); in short the issue is to express attributes as tree branches, i.e. to "semantise" them. The second step is to make the same operation with the values. Once done, the "heterogeneous" tree can be represented

as a set of trees federated by the Ligne de vie.

During such process, a "semantic of position" (the local semantic is implicitly given by the position inside the database schema) is transformed into an explicit semantic, since each node has a semantic of its own as an ontology element, and a context given by its position in the tree (for example the node "breast cancer" doesn't mean the same thing if it belongs to the "risk management" branch or to the "health concern" branch).

As a summary, systems which data model is rigidly represented by a database schema can hardly be made compatible with one another. On the contrary, the plasticity of the dependency grammar, very close from natural language, allows for mimicking any structure and, above all, to make it semantically available for continuity of care.

Inside Episodus, a component greatly eases this process: the Pilot. Pilot was developed in the scope of the Synex European project in order to interconnect big hospital databases. It executes complex data fetching workflow scripts, stored as XML files, in order to broke information from various systems and translate it into the target system format.

Inside Episodus, Pilot is in charge of storing and fetching persons' graphs. It allows for Episodus to switch from a storage technology to another one just by changing an XML file ; moreover, Pilot has the ability to provide Episodus with a graph which is partly made of a real graph and partly made of information coming from heterogeneous systems and dynamically expressed as trees.

## At work

With a data representation technology based on a graph of trees, it could be natural to imagine a graphical interface full of trees – and admittedly it is a tentation that must constantly be fought against!

In computer design, the "physical" representation that a user envisions from the information he manipulates with a software is called the "Mental Model"; the way the software interface allows him to interact with what is displayed on the screen is called the "Represented Model" and the way this software precesses this information is called "Implementation Model". Usually, a software is considered as being user friendly if its represented model is close from the mental model (it is operated on the screen in a way that is consistent with what the user "feels" he is manipulating). On the contrary, when the user has to comply with the implementation model, it is usually an evidence of weak design.

To build a represented model that is as close as possible from the concepts actually operated is a constant concern, and since very few users are at ease with graphs manipulation, the data model is seldom perceivable on the screen. This is the reason why it is so accurately described in this document.

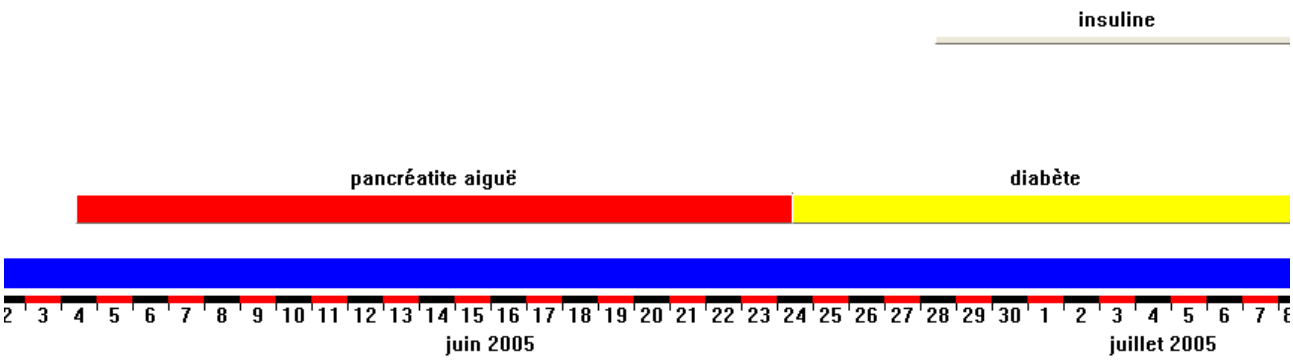
Interfaces will now be described, starting with the core component: Ligne de vie.

### *Ligne de vie*

Ligne de vie has been designed to tell a health story and to allow for the diverse health team members to bring their contribution in an efficient and enlightened way.

When a patient is newly created, Ligne de vie is blank, with only the blue base line. A right click opens a popup menu from which a new health concern or treatment can be created.
Health concern lines are thick (they can host documents icons) and their background color can be gray, blue, green, yellow or red depending on their severity level. Treatment lines are much thinner with a grey background.

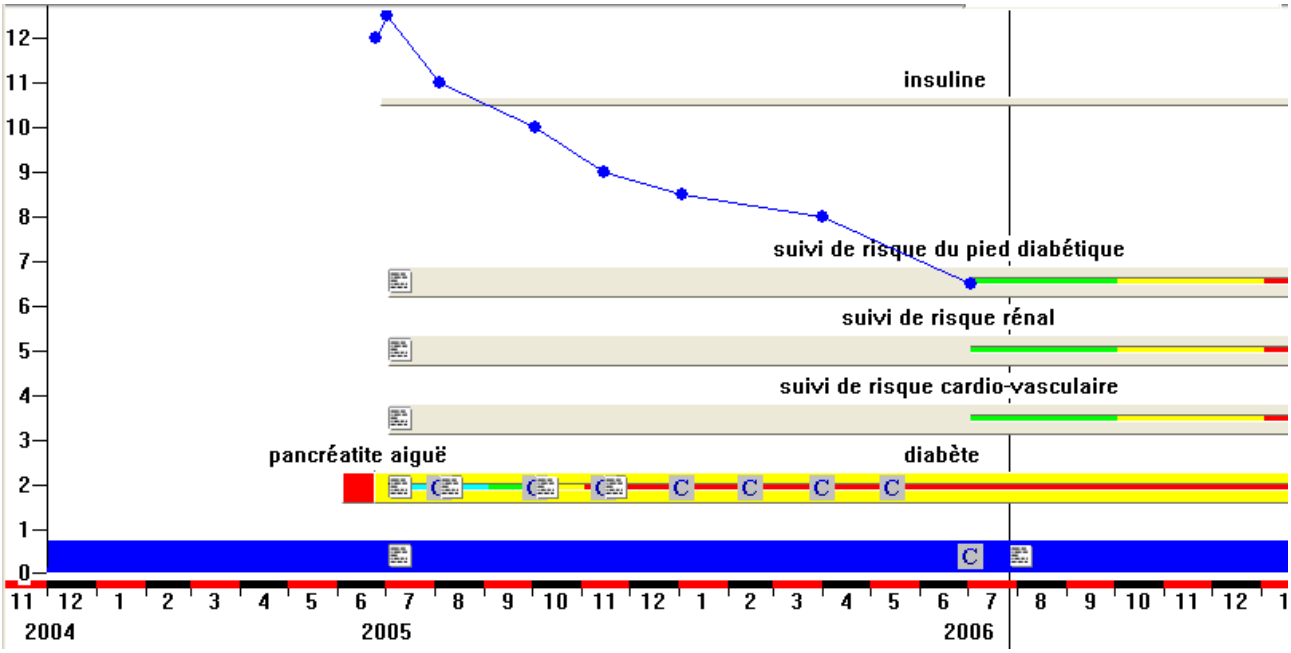
The hereunder Ligne de vie tells the story of a person whose diabetes has been diagnosed as a consequence of an acute pancreatitis; he receives an insulin treatment.




It is possible to zoom step by step up to a very sharp vision, where the whole screen width barely displays half an hour, and on the other hand, to take hindsight up to embracing the person's whole life.

The hereunder screen copy shows that Ligne de vie can become enriched with many elements:

- Risk follow-up lines (which remain grey since they have a void severity level).
- Biometric curves, like the blue Hba1c curve. Thanks to the unified model, the data which are used to draw such curve are available whatever the documents hosting them. Moreover since units are part of the Lexique, they carry a semantic meaning that allows for automatic unit conversion.
- Documents icons, scattered on the lines they are related to. By default they are located on the base blue line, but a simple drag & drop on a health concern line allows for attaching them to this health concern. Each type of document can be represented by a dedicated icon, making it possible to evaluate the follow-up quality at a glance. A document can be displayed by simply double-clicking on an icon.
- Health index fulfilment level, displayed as coloured areas located in the middle of health concerns' lines.




What is at stake here is to embrace at a glance a person's current situation: what issues to address, what has already been done, and what are the goals. This is the three core concepts of a person's Personal Health Project.
It is obvious from this screen copy that the glycosilated hemoglobin has been normalized (blue curve), and also that the health goals fulfilment level for diabetes is "red", indicating that crucial goals have not been reached. It is now time to describe what a health goal is.

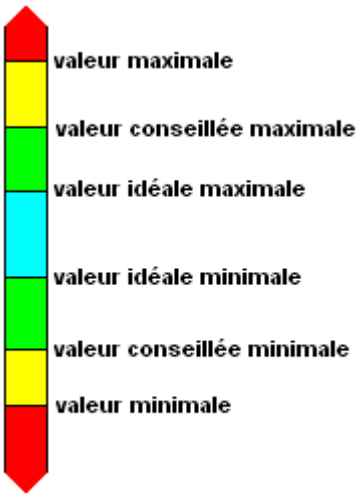
### *Health goals*

A health goal can relate to:

- A biometric data that must be brought to, or maintained in, a given interval.
- An event, such as a diagnostic or therapeutic act, which must occur cyclically or at a given moment.
- An information that must be, or not be, on Ligne de vie, for example a drug.

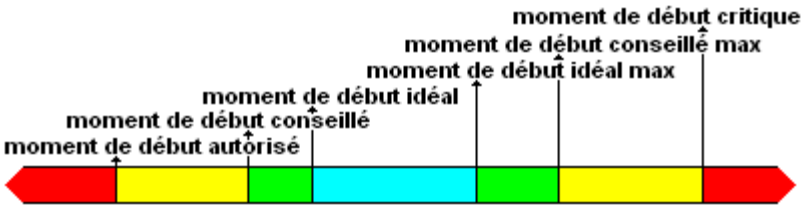
It is possible, inside the same health goal, to mix to two first points, in order to express that a biometric information must be measured at a given date (or at regular time intervals) and that its

value must be in a given interval.




Each health goal is a target on time scale and/or values scale, as displayed on both drawings.
Targets have a blue center that stands for ideal conditions, surrounded by green areas for fine conditions. Outside, a yellow area stands for conditions out of guidelines, that may be surrounded by a red "alert" area.

None of these areas are mandatory. For example in case when there is no "ideal" condition, the center area is green.




The fulfilment level displayed in the middle of health concern lines indicates the global fulfilment level as, at any time, the worst level for each goals attached to this health concern. If a single health goal is red at a given time, then the line will be red at this moment.

A list of health goals can be displayed in order to get their current fulfilment status and to check what events are scheduled and their agenda.

When an information is added to a person's Ligne de vie, all corresponding health goals are automatically closed if they are only scheduled once, and scheduled again if it is cyclic.

Health goals usually come from prevention guidelines and are automatically selected by smart agents according to the state of the person.

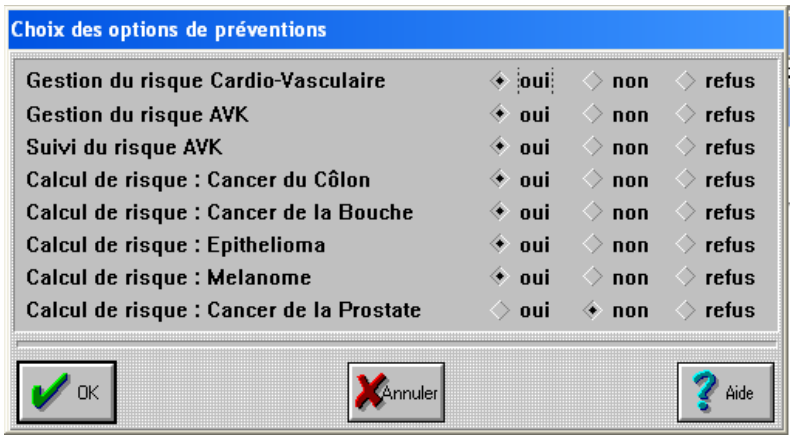
This process will now be described.

| Objectif de santé | C | Rythme | Autorisé | Conseillé | Idéal |
|---|---|---|---|---|---|
| hémoglobine glyquée | V | cyclique | | | |
| cholestérol-LDL | b | cyclique | | | 03/07/2005 |
| cholestérol-HDL | b | cyclique | | | 03/07/2005 |
| triglycéridémie | b | cyclique | | | 03/07/2005 |
| cholestérol total | b | cyclique | | | 03/07/2005 |
| électrocardiogramme | b | cyclique | | | 03/07/2005 |
| créatininémie | b | cyclique | | | 03/07/2005 |
| fond d'oeil | b | cyclique | | | 03/07/2005 |
| pression artérielle diast... | b | cyclique | | | 03/07/2005 |
| pression artérielle systol... | b | cyclique | | | 03/07/2005 |
| pression artérielle systol... | b | ponctuel | | | 03/07/2005 |
| indice de masse corporelle | b | cyclique | | | 03/07/2005 |
| éducation diététique | v | ponctuel | | 03/07/2006 | |
| Calcul de risque cardio-... | v | ponctuel | | 03/07/2006 | |
| fond d'oeil | v | ponctuel | | 03/07/2005 | |
| dentiste | v | ponctuel | | 03/07/2006 | |
| Calcul de risque rénal | v | ponctuel | | 03/07/2006 | |
| triglycéridémie | v | ponctuel | | 03/07/2005 | |
| Calcul de risque pédieux | v | ponctuel | | 03/07/2006 | |
| cholestérol-LDL | v | ponctuel | | 03/07/2005 | |
| cholestérol-HDL | v | ponctuel | | 03/07/2005 | |
| cholestérol total | v | ponctuel | | 03/07/2005 | |
| électrocardiogramme | v | ponctuel | | 03/07/2005 | |
| créatininémie | v | ponctuel | | 03/07/2005 | |
| hémoglobine glyquée | v | ponctuel | | 03/07/2005 | |
| pression artérielle diast... | v | ponctuel | | 03/07/2005 | |
| indice de masse corporelle | v | ponctuel | | 03/07/2005 | |
| Calcul de risque de com... | v | ponctuel | | 03/10/2005 | |

### *Guidelines and Knowledge Sources*

A Knowledge Source (KS) is a smart agent controlled by a Blackboard. Since the core component for knowledge management in Episodus is a Blackboard, its agents are KSs. Among all KSs hosted by Episodus at a given moment, those which deal with prevention wake up when the PreDi button is pressed (PreDi stands for Prevention and Dépistage Individualisés – Personalized Prevention and Early Detection).

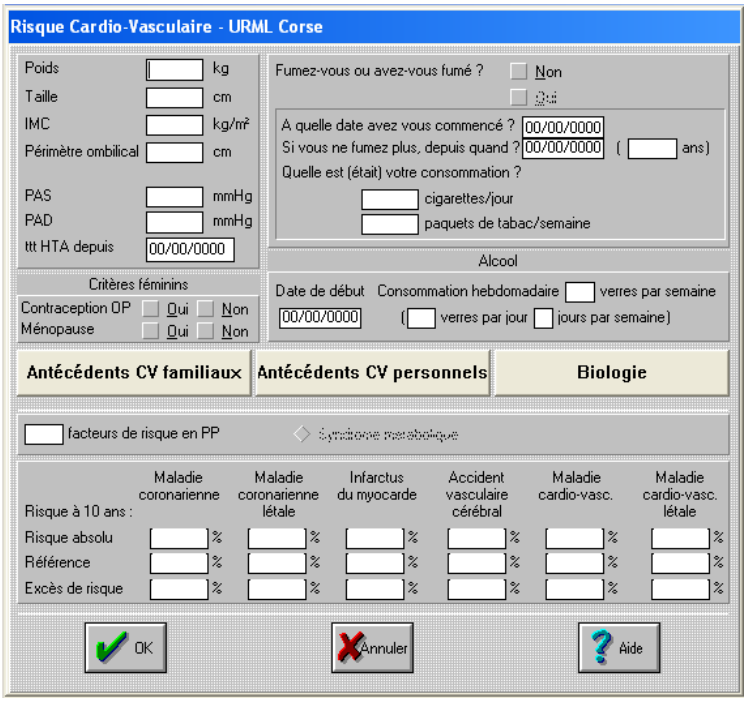

When these agents "wake up" they first check if they are ok for this patient (an agent dealing with cervix cancer will not volunteer if the patient his a male); if they are, they are displayed in the selection dialog box.

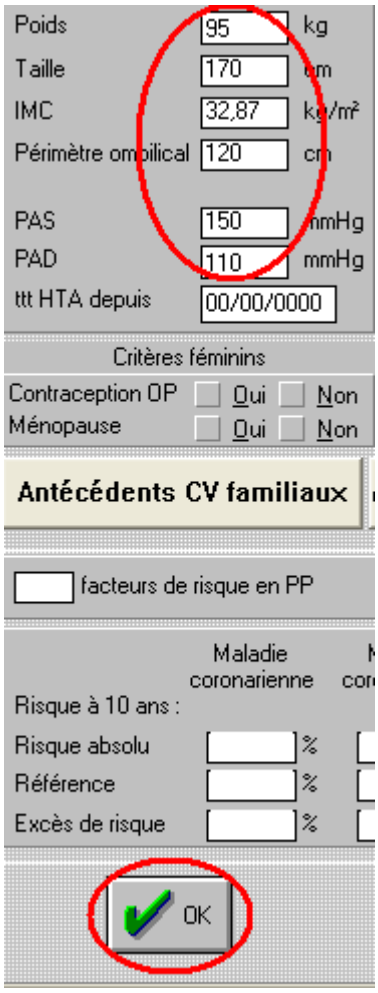



The user can decide what agents he wants to start. He can also decide than he no longer wants a specific agent to be proposed for this patient.

Each selected agent can then fetch information in the patient's graph and open a form to ask the user to fill any missing information.

The form for cardio-vascular risk is displayed hereunder.

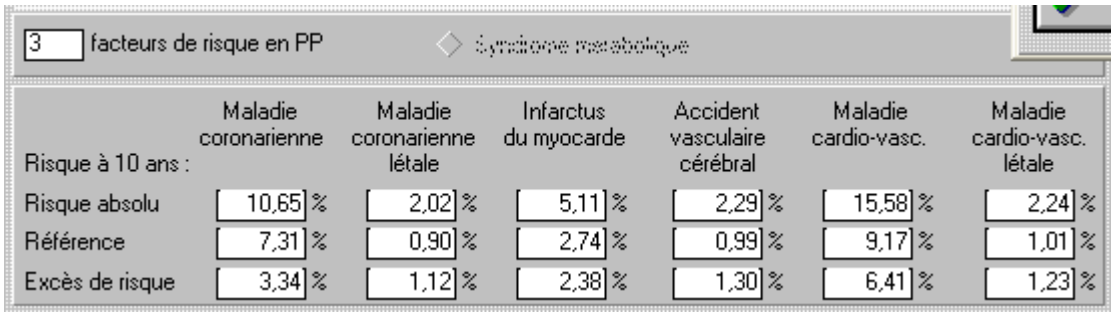



Some information are automatically filled at windows opening if they have been found in the graph.

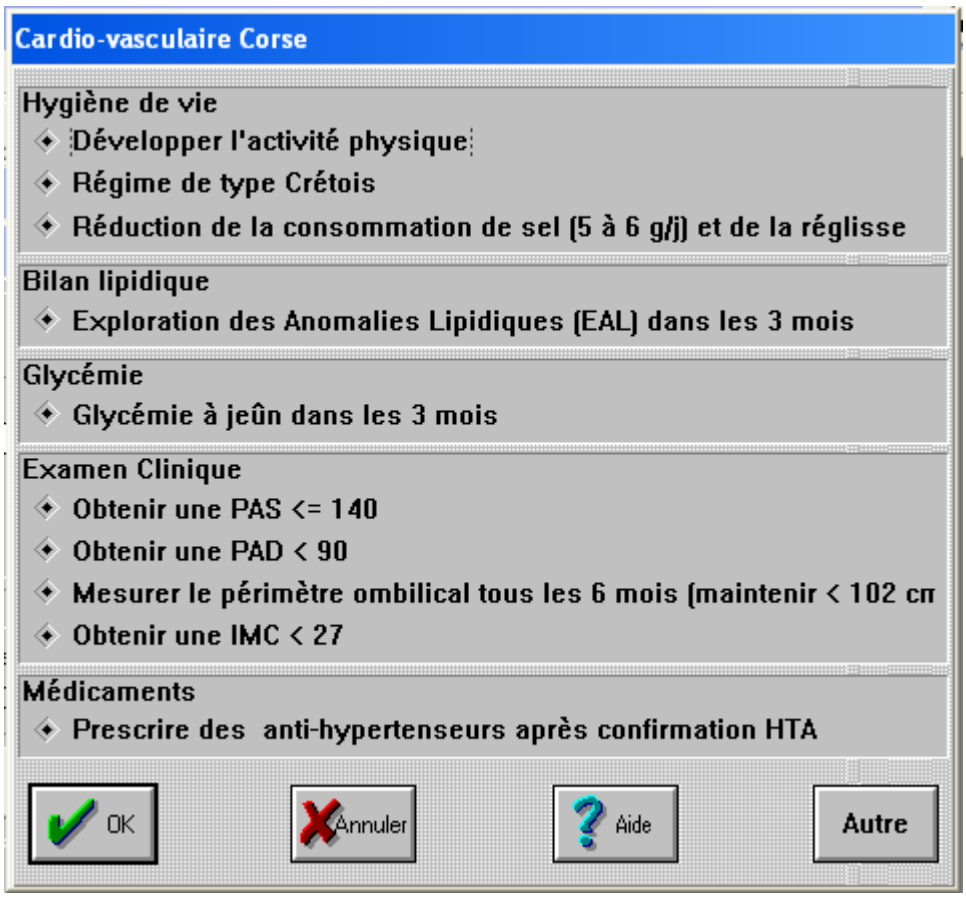
Once the form is completed, the user can press the Ok button and free the smart agent to let it process all entries.

The cardio-vascular risk agent will evaluate if it is relevant to alert for a diabetes (from glycemia level history) or a metabolic syndrome, or even to add an arterial hypertension concern on the Ligne de Vie.




Then he calculates the number of risk factors for primary prevention (PP) and evaluates the 10 years risk level using Framingham equations.

Once every useful information is collected (from user, then from the KS), Episodus can suggest the list of all health goals that are relevant for this person. Each prevention process is attached to a set of all possible health goals, and each goal includes a validation algorithme that determines if it is relevant or not for a given person (processing this algorithme is done by asking questions to the Blackboard – and many KS may be involved to answer it). Hereunder window displays the list of all health goals that were elected as relevant for this patient.




This list contains health goals that are directly targeted against risk factors (in this case a high arterial pressure and a weight excess) and health goals dedicated to refine the set of clinical information, such as lab tests for lipidic anomalies and glycemia level.

It is the initial step that starts a recursive process. The risk level will be evenly evaluated and health goals refined depending on both this person's status and the set of information made available for the practitioner.

By activating the "Autre" (Other) button the user can gain access to the full list of health goals, and can manually select some goals that were not selected as consistant. On the contrary they can also unselect a goal (in this case it is possible to ask him to justify this behavior).

## *Conclusion*

This document is by far not a full description of Episodus' technologies and functions.

Natural language synthesis from the dependency grammar has just been mentioned (in order to build ready to sign reports).
Artificial Intelligence components where also not described; they host and control smart agents, such as the prevention agents, and enable agents to cooperate with each other in order to optimize the way user entries and person's graph information are processed in order to provide relevant and useful decision support.

This document was dedicated to explaining why any health information system should now be able to tell persons' health stories, to introduce core technologies that enable for such story telling and finally to illustrate daily practice prevention processes with Ligne de vie.

This technology is continuously evolving over time and always more components are based on XML files in order for the practitioners community to be able to manage it.
Feel free to consider Ligne de vie as a backbone and to imagine what new processes can get plugged on it in order to gain a better vision of who a person is and to efficiently manage continuity of care.

# Index

1 JAMOULLE M., ROLAND, M. -Champs d'action, gestion de l'information et formes de prévention clinique en médecine générale et de famille. LOUVAIN MED. 122: 358-365, 2003. http://www.md.ucl.ac.be/loumed/CD/DATA/122/358-365.PDF
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