



2004 The “Year of the Citizen” for eHealth and Health ...

by **Benedict Stanberry**, Editor-in-Chief and Board Member of EHTEL Association

Almost all of this year’s major conferences will prioritise the benefits of eHealth solutions for patients and citizens as their core themes [...]:

Contents

▶ 2004 – The “Year of the Citizen” for eHealth and Health.....	1
▶ EHTEL Session at eHealth 2004 Conference (Cork)	1
▶ EHTEL Present at Med-e-Tel.....	2
▶ Support for EFMI Smart Card WG	2
▶ TF Update: Medical Challenges for Treatment of Chronically-ill Patients	2
▶ TF Update: Reimbursement, Incentives & Value	2
▶ "Everyone wants to talk for the patient – it’s time they let us do that for ourselves!" - An interview with Angelica Frithiof	3
▶ TF Update: Patient and Citizen High-Level Position Paper on eHealth Information Systems	3
▶ TF eHealth and the Internal Market will hold Kick-Off at ICMCC 2004 (Amsterdam).	4
▶ Join EHTEL	4
▶ Further Patient and Citizen centred events	4
▶ Tip of the Day	4
▶ eHealth Diary 2004.....	4
▶ EHTEL Event Updates.....	4
▶ Imprint	4

[...] Including the Tromsø Telemedicine and eHealth Conference taking place in Norway in June titled “Citizen Participation in eHealth” and the European Health Management Association’s event later that month which takes as its theme “Citizen Empowerment: Opportunities and Threats for Health Management”.

This month, however, all eyes are on Cork, Ireland where the Irish Presidency of the European Union is hosting, with the support of the European Commission, “eHealth 2004” – a high-level conference and exhibition designed to follow-up on the very successful ministerial conference and exhibition hosted by the European Commission under the Greek Presidency of the European Union in Brussels last year.

This year’s event will discuss and showcase advances in eHealth with a specific emphasis on tools and services for the benefit of European citizens. An exhibition will provide the opportunity for real life demonstrations of the most current eHealth tools and the associated 2004 eEurope Awards for eHealth will ensure that the best examples will be exhibited.

EHTEL will be there too and our Patients and Citizens Task Force, led by Board member Angelica Frithiof, will be hosting a special parallel session titled “Empowering the Patient” at which they’ll be publishing their new High Level Position Paper which considers eHealth from the patient’s and citizen’s point of view. The session will also feature presentations from our members about their real-life eHealth services.

We’re proud to be involved in what promises to be another exciting and significant event in European eHealth and look forward to meeting you in Cork and at other EHTEL Association events such as our NICTIZ-supported seminar on ePrescribing – taking place in Amsterdam in early June – and our workshop on Quality & ICTs in Healthcare which we’re hosting jointly with the European Society for Quality in Healthcare in Lahti, Finland later that same month. See you there!

“Everyone wants to talk for the patient – it’s time they let us do that for ourselves!” (see interview – page 3)

EHTEL Session at eHealth 2004 (Cork)

Empowering the Patient

16:00 hrs, Wednesday 5 May 2004

eHealth:

Patients’ and Citizens’ Views

Angelica Frithiof, the Board member leading the EHTEL Patient and Citizens Task Force, together with colleague **David Garwood**, will present patients’ and citizens’ views on eHealth. The Task Force has two audiences for its work: the key stakeholders in the eHealth community such as developers and national institutions and, separately, patient organisations. It is giving a voice to patients and citizens and articulates both their hopes and their fears in relation to the ICT revolution in health and social care.

eHealth in General Practice

Dr Russell Jones (Chorleywood General Practice) and **Dr Malcolm Clarke** of Brunel University have turned the GP practice into a showcase for what ICTs can achieve to make specialist medical expertise available to support the management and treatment of patients in a primary care setting.

eHealth in the Home

Wendy McLellan and **Mary Lou O’Kennedy** work with Tunstall Group, one of Europe’s leading manufacturers and developers of personal and home reassurance solutions and response centre systems. These home telehealth solutions can be applied to many different areas of disease management and enable vulnerable people to live and be cared for in their own homes. Such products and services care for, protect and save the lives of millions of patients every year around the world.

The session will be chaired by EHTEL Board member **Benedict Stanberry** and at our stand in the exhibition area you’ll be able to meet the Association’s Liaison Officer, **Céline Van Doosselaere** as well as other members and friends of the Association.

eHealthNews:

EHTEL Present at Med-e-Tel

By Céline Van Doosselaere, EHTEL Liaison Officer: On April 21-23, EHTEL attended the second edition of Med-e-Tel, the international trade fair of telemedicine & eHealth, in Luxembourg.



One of 30 exhibitors, EHTEL welcomed at its stand interested persons from a wide variety of backgrounds, professions and nationalities. Attendees included industry, governing authorities (local and national), physicians, technical experts, and universities, all in all representing over 50 countries in the discussion of eHealth through concrete examples as well as in more general terms in the educational programme.

Parallel sessions included one on the need for eHealth standardization. The eHealth Standardization Coordination Group, a joint initiative of the ITU and the WHO, also held its first meeting during Med-e-Tel.



The Telemedicine & eHealth Directory 2004, sponsored by the [ITU](#) (International Telecommunications Union), the [ISfT](#) (International Society for Telemedicine) and Med-e-Tel, was published and distributed at the fair. The directory can be obtained online at www.medetel.lu/teldir/teldir.html.

For more information on Med-e-Tel, please consult www.medetel.lu.

eHealthNews:

EHTEL supports EFMI in developing its Smart Card WG

by Marc Lange, EHTEL Manager: The eEurope Smart Card Charter trailblazer Health has completed its mission in spring 2003 by delivering its contribution to the "Open Smart Card Infrastructure for Europe".



Since December 2003, this trailblazer is hosted by [EFMI](#) and strongly supported by EHTEL. A number of priority actions have been decided and will be launched soon:

- ⇒ The creation of a repository of health card systems in operation on a large-scale basis, including a description of the purpose of the system, the content of the card, the infrastructure used as well as its expected evolution. It is intended to be used for further activities on card interoperability issues.
- ⇒ An analysis of what the relevant standards/legalisations are in the field of health cards and the drafting of half a page summary on the relevance and the readability of these standards.

EHTEL Task Force Update:

Medical Challenges for Treatment of Chronically-ill Patients

by Karl-Jürgen Schmitt, Vice President of EHTEL: Networked applications and health care processes allow for improved and increasingly efficient services to citizens and health care providers. Chronic diseases – which constitute 5% of all illnesses – represent 60% of medical care expenditures. Health and social care providers of all kinds need to work together using comprehensive information of the patient's life. The patient has to be included more closely in this process to enable him to cope successfully with his disease and to avoid emergency conditions: disease management is therefore a concrete way of placing the patient at the centre of care, thereby empowering the patient to take action and control of his or her illness to live better. Tailoring care through effective disease management not only increases the quality of care but also lower the costs. At a time when the numbers of chronically ill patients are rapidly increasing and healthcare expenditures threaten to spiral out of control, the positive financial aspects of disease management are certainly not non-negligible.

It is also in the interest of both the individual patient as well as the medical community to understand how to prevent emergencies and episodes of acute illness in the life of a chronic ill patient, enabling the patient to live longer in a good health condition. This involves supporting patients to manage their well-being based on a natural lifestyle. There is a shift in the health care paradigm, moving away from acute care – which means mostly "repair" work – to preventive care, focusing on life-long self-care.

The EHTEL Task Force "ICT-supported Disease Management" is promoting comprehensive medical and technical solutions for a more efficient treatment of chronically-ill patients, a topic that will seriously affect healthcare systems. If you are interested, please mail info@ehtel.org and/or Karl-Juergen.Schmitt@siemens.com.

EHTEL Task Force Update:

Reimbursement, Incentives & Value

by David Lloyd-Williams, EHTEL Board Member One of EHTEL's key aims is to provide support to all stakeholders in implementing and using ICT to deliver health and social care. Studies on obstacles to automating healthcare delivery in both US and Europe have shown a consistent pattern where by far the largest perceived barrier is people and processes.

The goal is large scale deployment of ICT to support the transformation of health and social care. A vital part of this is our understanding of people and processes, their views about how ICT could help them, their willingness to participate and take ownership and their understanding of the day to day benefits to be gained. We need to know more about how ICT is seen on the ground, how it can help and support rather than hinder and distract.

- ⇒ What are the local, organisational and practical constraints that inhibit its developing use?
- ⇒ What sort of perverse incentives exist? What sort of practical encouragement is needed?
- ⇒ What are the realities of value at the point of care?

EHTEL plans to address these questions in three stages:

- ⇒ Information collection to gather a baseline of material from across Europe about perceptions of ICT, specific inhibitors, local constraints / opportunities and about the potential available. This will be done via a questionnaire based survey distributed broadly via EHTEL members and through other connections. Free form input will also be welcome
- ⇒ Summary, distribution and comment to respondents and other relevant groups.
- ⇒ A formal task force to consider the material and look at the implications for all stakeholders and for policy makers. The task force will produce a first stage set of recommendations and become a forum for discussions and dissemination on an ongoing basis.

In the initial stages, the information collection will be co-ordinated by David Lloyd-Williams as the EHTEL Board member responsible for this task force.

If you have comments about the subject area, about the content and format of the questionnaire, or you would like to participate or support the collection phase please contact EHTEL at info@ehtel.org or David at dlw@dlw.demon.co.uk

EHTEL Task Force Update:

"Everyone wants to talk for the patient – it's time they let us do that for ourselves!"

An interview with patients' advocate Angelica Frithiof

Angelica has led the EHTEL Association's Patients and Citizens Task Force since its formation and was elected to the Board of Directors of the Association in October 2003.

In preparation for the eHealth conference in Cork we have asked Angelica a few questions. The full interview is published on EHTEL's website, www.ehtel.org.

How did you first get into patient advocacy?



Because of my own experiences as a patient. I was originally approached by a Professor at Uppsala University in Sweden in 2001 who wanted me

to give a speech on the patient's perspective on telemedicine at a conference that took place that summer. My first reaction was to tell him to ask someone else – anyone else! I'd never given a speech in English before and I was terrified! But in the end I gave a little speech about patients and ethics in telemedicine and it went down very well.

And how did that lead to working with the EHTEL Association?

After Uppsala I was asked to participate in a workshop and met people like Dr Russell Jones and Mats Larson. They told me about the organisation and encouraged me to get involved in running a group focusing on patient's issues, so I did!

What would you say has been the group's best achievement so far?

I would say it is our "Patients' Charter" because it gave us the chance to put patient issues on the eHealth agenda properly and opened lots of doors for the group to communicate our position to a wide audience at lots of international events.

What are the group's aspirations for the coming year?

The Position Paper we're publishing in Cork is very important for us because it creates the basis for building on the Patients' Charter by looking in much more detail at issues like homecare, self-management and e-consultation. We can really go into more depth on things like this.

This year every major conference and event has the patient or the citizen as its focus. What do you think of this?

I think that these conferences don't really have much choice in the matter – it's not a voluntary decision but a politically correct one. I'm not convinced that those in charge really want patients to have a bigger voice or more influence.

Why do you say that?

Because giving patients real power would, I think, destabilise the political status quo. Patients are doing so much for themselves right now – using the Internet to search for information about their treatment options, moving across national borders to find better or cheaper healthcare. We're taking more and more power over our own healthcare and it's like a tidal wave that threatens to drown the establishment. Politicians realise this and as a result I think that they and others are far too ready to speak for us, to try and pretend they know what we want and that they have our best interests at heart. I'm really critical of people who stand up and say "I'm for patients". Everyone wants to talk for the patient – it's time they let us do that for ourselves!

When you're not working with EHTEL, how do you keep busy?

I have a successful private consultancy practice that trains doctors and nurses in communication skills and healthcare ethics.



This interview was conducted by Benedict Stanberry, EHTEL Navigator Editor-in-Chief.

EHTEL Task Force Update:

Patient and Citizen High-Level Position Paper on eHealth Information Systems

By Benedict Stanberry, Editor-in-Chief and Board Member While supporting professionals in the delivery of healthcare, eHealth information systems also have the potential to empower the patient and the citizen. The EHTEL Association's new Position Paper recognises, however, that the expectations of patients (who are already engaged with the healthcare system) and citizens (who generally are not) vary tremendously. The vast majority of people are fit and well and go through life as healthy citizens who occasionally fall ill and, temporarily, become patients. Others may suffer

from chronic diseases or conditions that do place them in the position of being both citizens and patients throughout their lives.

It is important therefore that constant and ongoing patient orientated issues are available to policy makers and others in order to ensure that important decisions encompass the needs and requirements of the patient. For eHealth to succeed, acceptance by patients – both short and long term – is vitally important. Decisions taken around the committee table by healthy citizens are unlikely to reflect the views of the patient unless a conscious effort is made to listen to them. Thus the Task force seeks to interact with the national stakeholders across the European Union either directly or by encouraging the involvement of patient organisations in the decision making process.

Some of the new eHealth applications which concern patients include:

Patient Monitoring in the Home (eHome)

Including issues of privacy, of dependency on technology, of invasiveness of technology, of potentially diminishing personal contact between caretaker and patient.

The Use of Technology for Remote Consultation (eConsultation)

Including issues of privacy and security, of communication between professional staff and patient to ensure an accurate consultation all the while respecting the patient's dignity.

The Development of the Electronic Patient and Health Record (eRecord)

Including issues of confidentiality and privacy, of accuracy of personal records, of patient access and ownership of data.

The Use of Technology to Support Self-Management

Including issues arising from the growing trend of self-medication and furthering research into the consultation and information processes to avoid such practices; including quality criteria for health-related websites.

Smart Cards

Including issues such as the purpose of the card, the information it should and should not contain, ownership and control of the card.

Cross Border Mobility

Including consistency of standards of care (cf. Patients Charter for eHealth Information Systems).

Task Force eHealth and the Internal Market will hold its Kick-Off at ICMCC 2004 (Amsterdam)

The International Congress on Medical and Care Compunetics is scheduled to take place in The Hague from 2-4 June. The use of Medical and Care Compunetics (the combination of computing and networking is becoming increasingly important as patients begin to be considered also as clients, voicing their opinions and expectations as to how, where and when they want to receive their care, be it social or related to health prevention or medical treatment. ICMCC will be organised as a central place for IT specialists, academic, industrial, clinicians, pharmacologists, management care practitioners, patients and policy makers to meet, thereby enabling crosslinks between users, implementers, creators and developers and also between the various fields and disciplines addressed in compunetics.

EHTEL's Task Force on "eHealth and the Internal Market" will kick off its activities at the conference, with a first meeting at 2pm on Thursday 3 June. All interested are invited to send an email to info@ehotel.org.

Join EHTEL: Become a Member

EHTEL is an international, non-profit, non-political association of members representing all categories of stakeholders for eHealth in the health and social care domains.

Joining EHTEL means:

- ⇒ enabling the cultivation of partnerships and networking across the eHealth domain;
- ⇒ being a part of an independent organisation, influencing eHealth policies in Europe;
- ⇒ an opportunity to share experiences and to hear the lessons learned by others.

Members are also entitled to such benefits as reduced registration fees to seminars, workshops and other events, email notifications of important news in the eHealth field, as well as individualized access to EHTEL's website www.ehotel.org.

If you'd like to hear more about EHTEL or about becoming a member, please call us at +32 (0)2 230 96 50 or email us at info@ehotel.org. We look forward to hearing from you!

Further Patient and Citizen centred events in eHealth

Tromsø Telemedicine & eHealth Conference: 21-23 June 2004



The theme of this year's Tromsø Telemedicine & eHealth Conference will be "Citizen Participation in eHealth: Challenges for Research, Technologies and Health Care Organisations" and will focus on three poles:

- (1) policy – organization – strategy (what should we strive for?),
- (2) research (what do we need to know?),
- (3) technologies – applications & practices (what do we have?).

Angelica Frithiof, member of the Board of EHTEL, will be a keynote speaker on the opening day. For more information, please consult www.telemed.no.

EHMA 2004: 23-25 June, Berlin, DE

"Citizen Empowerment: Opportunities and Threats for Health Management"

The annual conference of EHMA (European Health Management Association) will be held in Berlin, Germany on 23-25 June. This year's theme will focus on "Citizen Empowerment: Opportunities and Threats for Health Management", in an attempt to investigate the implications of new citizen attitudes in healthcare in order to comprehend the impact of empowered citizens on health care management, both at macro and at micro level.

Will empowered patients be the driver of future health care systems? Or, alternatively, will citizen empowerment lead to less rationality in policy and decision-making processes? Are health-care systems genuinely responding to patients as pro-active consumers? Or are they simply making cosmetic changes that do not alter the traditional dominance of healthcare providers? These questions, among others, will be explored at the conference. For more information, please consult www.ehma.org/conf2004/program.shtml

Tip of the day: Register your interest in EHTEL task force activities

Most of our new task forces have started their activities and it is now time to express your interest. If you want to participate or contribute or you just need to be kept informed ...

Then the best to do is to register! Do not hesitate to visit our web site, in the front page of the task force section and you will find a form which we invite you to fill in and send to info@ehotel.org

eHealth Diary 2004

17 May, Brussels (BE)
EU Open Forum: "Health in an Enlarged Europe"

1 June, Brussels (BE)

eHealth Interoperability Workshop:

The Government and Expert View. This workshop, an initiative of the German Government is **co-organized by the European**

Commission and the EHTEL Association.

[please check www.ehotel.org for updates].

The workshop will be furthermore supported by the eTEN project Netc@rds and the CEN/ISSS eHealth Standardization Focus Group.

2 June, Amsterdam (NL)

EHTEL ePrescribing Seminar

2 – 4 June, The Hague (NL)

International Congress on Medical and Care Compunetics

18 - 19 June, Lahti (FI)

"Quality & ICT in Healthcare" Workshop jointly organised by ESQH and EHTEL

21 - 23 June, Tromsø (NO)

"Citizen Participation in eHealth"

23 – 25 June, Berlin (DE)

"Patient Empowerment" Annual EHMA Conference

24 – 27 June, Nicosia (CY)

3rd EMISPHER conference "Continuity of Care"

7-9 September, The Hague (NL)

"Shaping the EU Health Community"

EHTEL Event Update:

EHTEL ePrescribing Seminar, 2 June 2004
Dorint Sofitel Amsterdam Airport (Schiphol)

In this one-day seminar EHTEL will offer an update on the current situation on Electronic-Prescribing in Europe. The seminar is intended as a start for further EHTEL activities in the medication management domain. Members are invited to engage in this work and to join the network in preparing future activities. Updated Information is at: www.ehotel.org.

EHTEL Event Update:

Joint ESQH & EHTEL Workshop:
Quality & IT in Healthcare, 18-19 June 2004
Lahti (Finland), Sibelius House

The Workshop "Using Information and Communication Technologies to Promote the Quality Agenda in European Healthcare" in Southern Finland is organised in co-operation with STAKES (Helsinki) and the City of Lahti. Updated Information is at: www.ehotel.org.

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