Online Health Information
Accuracy, quality and privacy

Several e-Health initiatives are underway to empower the patient with the right information. The Internet, with its vast amounts of information, is a key player in turning the patient into an 'informed patient'.

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The ever-growing fields of science and technology have advanced the quality of human life in leaps and bounds in all aspects, from Internet banking to eco-friendly cars.

The health domain has also been influenced in this wave of development in various aspects with discoveries in the field of research, new and improved diagnostics and minimally invasive procedures, to name a few. As always, there is room for improvement. The Patients' and Citizens Task Force of the European Health Telematics Association (EHTEL) describes several possible ventures.

One such improvement is through the use of Electronic Health Records (EHR). The patient should be master of the EHR as consent for information sharing on the EHR would be given by him / her. This consent should be taken at the onset, following which reviews would be done upon considering new conditions. If the patient suspects any information abuse, he / she would have the right to intervene and call for action. The patient would also have the right to restrict information sharing (but should be made aware that this may affect care) and would not be discriminated or refused care as a result of this. Electronic communications and a log book facility are essential in such a record to enable proper information sharing in addition to providing a record of all such transactions. Also, cross-border issues should be addressed by the EHR, thus enabling the patient to access it regardless of his / her geographical location.

Authenticating info-systems

Another foreseen venture is the information system within a clinical setting (which encompasses the EHR). Unlike new medications or devices, many information systems are not tested thoroughly before implementation, thereby increasing the risk of errors. Information systems to be implemented in the clinical sector especially require vigorous and independent testing before actual implementation, as well as the proper training of all who use it, to ensure that errors, such as faulty data entry and accidental security breach are minimal. The Internet has brought a wealth of information to the patient and provided a way to research aspects of medication and alternative management strategies. Indeed, the patient can often have more time to spend on this issue than a pressured and time-limited professional. This empowers the patient and provides greater control over his / her health. The concept of the 'informed patient' is one that needs to infiltrate the existing consultation and treatment regime. The views of the patient need to be listened to and respected.

Focus on homecare, safety

Patients requiring homecare can also benefit from the aspects of eHealth. Homecare is usually provided for the elderly and those with severe disabilities or debilitating diseases. Like in all other aspects of healthcare, in homecare as well, patient safety is paramount. To ensure this, patient should be informed about the benefits as well as the risks of homecare. The patient must be in control and privacy should always be respected. Any homecare technological device should be easy to use and developed bearing in mind the elderly or those with limited mental ability. Patients also require appropriate education and training in the use of such technology. The risks or benefits of the technology should be clearly defined and patients should have an option of declining any technology. Respect and sensitivity are vital to the success of homecare and should be constantly observed.

Patient perspectives can bring new and practical solutions to eHealth issues. eHealth has to take into account the needs of all major stakeholders; the patient being one of these should be recognised as a key player.

Personalised Information Platform for Life and Health Services (PIPS)

PIPS is an e-Health integrated project ▶

The PIPS system will enable:

- Professionals to deliver just-in-time personalised healthcare services according to the individual's personal health state, preferences and ambient conditions
- Individuals to make informed decisions about therapies and nutrition at any time / place according to the real-time evaluation of their health state
- Healthcare authorities to improve risk management in the healthcare systems as well as to get access to and generate valuable information assuring the global sustainability of the system.

aimed at the provision of innovative services to support the patient in his / her daily life. Started in January 2004, within the 6th Framework Program of the EU, it will be finalised in June 2008 and involves 17 partnering organisations from five EU member states, supranational organisations and other countries, such as Canada, China, Israel and Switzerland. The aim of PIPS is to create a new Health and Life knowledge and services support environment, improving current modes of healthcare delivery using the latest innovations in Information Technology. Its services are personalised according to the individual profile and are based on preventive / predictive medicine. The system is designed to develop innovative technological solutions ranging from continuity of care to education and impact on lifestyles.

Bringing personal care to the fore

The scope of PIPS is to create a dynamic knowledge environment that gives value added feedback for personalised knowledge and services to improve the public welfare. Services are personalised and based on medicine, ranging from drug compliance to continuity of care.

The technical infrastructure presents these significant core parts:

- Knowledge Management - where the aim is to transform heterogeneous information sources into a trusted homogeneous valuable knowledge base
- Decision Support - where the aim is to use intelligent technology to generate new personalised user-oriented knowledge and support action
- Trust Infrastructure - which aims to integrate security protocols to protect sensitive information
- User Interaction - where the aim is integrating a new generation of multimedia personal assistance devices (e.g. home telecare equipment, Internet-enabled home appliances).

In fact, PIPS is a virtual assistant supporting the individual in every moment and in any environment. It also provides interactive multimedia and multi-platform services tailored to their intellectual capacity and include services for children which create a healthier lifestyle through edutainment (education through entertainment); support in daily life through personalised nutritional advice, shopping lists, technological assistance like the Smart Shopping Cart; personalised motivation for physical activity through the use of various technological systems; drug compliance support with real time detection of drug intake and verification with prescriptions and self-monitoring through the continuously available and pervasive support for risk level controls of chronic disease management.

The PIPS healthcare delivery model addresses societal challenges by facilitating the shift from treatment-oriented medicine to prevention-oriented healthcare for individuals. PIPS will be utilised by three levels of users: professionals, external experts and the end users.

Empowering patients with targeted information

Information prescription, defined as health professional-directed information access, which has been tailored as much as possible to the individual patient with regards to personal content, language, intellectual / emotional capacity and locality, is being evaluated in the US and initiated in the UK.

This is based on the argument that patients should be empowered with information so that they are able to make better decisions about their health and lifestyle and also take a more active role in managing their health. Also, due to the information overload on the Internet, patients should ideally be directed to correct information sources, so that they are not overwhelmed. Parts of the medical advice or information provided by the healthcare professionals are forgotten by the patients (40-80 per cent), while the rest of the information remembered is mostly incorrect. Therefore, it is essential that medical information be delivered at the right time and at the place of the individual. The objectives of Information Prescription are: to support the patient in self-care and disease management, improve health literacy (the ability to make sound health decisions in the context of everyday life) and to empower the patient in decision-making regarding his / her health.

Information for every need

The type of information provided also varies, as it not only caters to individuals with varying needs but also to the same individual with different needs at different times. The different styles include practical information and advice on healthy lifestyles, information on treatment options and outcomes, advice on long-term self-care, local care and self-help and social care through peer support. The key concepts of Information Prescription are: it provides appropriate and targeted information at the right time to meet the needs of the individual in sound decision making; it is issued by professionals at strategic points in care pathways; it usually points to sources of information and ▶

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The PIPS system

Over the past 11 years, HON has accredited close to 6000 websites consisting of over a million Web pages in 32 different languages and has grown to become a household name, not only amongst webmasters, but also the general public. HON grown in terms of implementation of services, it has also increased its liaisons worldwide to include the World Health Organization (WHO) and the United Nations (UN), where it has consultative status to the Economic and Social Council of the United Nations (ECOSOC). In view of its pioneering work and long expertise, the HON Foundation has been chosen by the HAS (Haute Autorité de Santé or the French National Authority for Health) to implement the certification of French health websites according to the French bill passed on the August 13, 2004. This certification is performed by HON through the implementation of the HONcode. Now, more than ever, the HON Foundation and the HONcode play a vital role as new and extended treatment modalities come into play, such as the empowering of patients through provision of information.

knowledge only (where these information sources would be accredited for reliability and trustworthiness); and it does not display or hold any information. Information Prescription would be in the format most convenient for the patient and could include printed information, SMS (reminders, encouragement), email (reminder, follow-up), DTV (targeted programming) and Web references.

Information Prescription systems are currently being initiated in the UK where patients are sign-posted to relevant information at different stages of the care pathway such as the diagnosis and treatment.

In the USA, doctors are provided with customised prescription pads containing the list of websites of the National Library of Medicine. The patient would be given such a prescription with advice on the websites relevant to his / her condition. Off course, one of the obstacles, which have to be overcome, is regarding the authenticity of the information provided. Guiding patients to reliable online information is of paramount importance and thus websites, which have already undergone rigorous testing and have been accredited according to a specification or code of conduct, would be provided as sources of information for patients.

Health On the Net - Current initiatives

The Internet, with its vast quantities of information is now the largest global database and offers an immense amount of information on every topic conceivable. The domain of health is no different from all the rest and is filled with various websites advising the public on how to keep their diabetes in check, detoxify in one week, eat well balanced nutritious meals...the list is endless. This information overflow can be overwhelming to an individual who would not know what information to trust and what to disregard.

The mission of the Health On the Net (HON) foundation is ascertaining which health websites could be trusted, and which cannot. Established in 1996 as a non-governmental organisation, HON implements one of the most well known codes of conduct. The HONcode made up of eight principles to which the website would have to adhere, in order to be accredited and thus be deemed as trustworthy. It is free of charge and though given voluntarily (webmasters request for accreditation of their website), it is in high demand because of the seal of quality and trustworthiness that it confers onto a site.

Making information user-friendly

Due to the vast amounts of information available, it is imperative that quality information be filtered from this information pool for the benefit of the public, which will in turn educate them and thus result in a better-informed and responsible patient. i.e. a resourceful patient. With a usage growth of 250 per cent in seven years (2000 to 2007) and 1.1 billion Internet surfers in the world, the Internet continues to change the relationship between the health professional and the patient by making them co-players in the game, thus replacing the teacher / pupil relationship of old. These few examples present solutions which take into account the current situation i.e. a situation where the patient is able to access information related to their medical condition and can then take their own decisions regarding their medical care.

AUTHOR

Célia Boyer is the Executive Director of the Health On the Net Foundation, has been serving at the HON since it's inception in 1995. She is recognised as an expert in quality assessment of medical information on the Internet and has taken part in several projects and conferences-both European and International and has authored more than 50 scientific articles on the subject. Célia has a degree in Science and Applied Physics from the University of Luminy of Marseilles, France and an engineering degree from the Federal Polytechnic School of Lausanne, Switzerland.

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