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Uses and Risk of the Internet Resources for First Generation of ePatient

Summary: The information revolution of ICT has stimulated the development of new forms of market members' relationships – based on knowledge and knowledge management skills. Emergence of information society results in weakening of domination in information asymmetry, specific to medical services. Nevertheless, the massive growth of health information on the Internet and the absence of real protection from harm for citizens who use the Internet for health purposes are seen to be real problems.

This article presents selected results of research about how first generations of ePatients use the Internet to get medical and health information. It looks at the kind of information they seek and the impact of their searches on their health behaviour.

Keywords: E-patient, Internet, Consumer Behaviour, Health information.

Introduction

The ICT revolution that has taken place over the last decade resulted in the development of a new form of relations connecting market members based on knowledge and knowledge management skills. As a result, the ensuing emergence of the information society weakened the domination of the information asymmetry, which had hitherto been so specific to healthcare services sector. The patient, being so far a passive recipient of services, has become an independent customer looking for the information that is reliable by their own standards and suitable for their own needs and perception capabilities. The fact that the patient belongs to the information society increases their market awareness and contributes to the changes of their behaviour on the market of medical services.

The aim of the article is to analyse the use of the Internet information resources by the first generation of Polish e-patients. The conducive findings of the research conducted by the author on the sample of 109 students of the University of Łódź in January, 2010 and of 115 students in January 2012 have been

selected as exemplification. The survey, the aim of which was to get acquainted with the extent of the students' interest in the Internet information on healthcare issues and their evaluation of its usefulness, was carried out with the use of the standardized questionnaire interview method. The survey also raised the issues of the Internet information resources about health, consulting specialist physicians on the Internet and participation in the Internet forums and discussion groups focused on health in the broad sense of the term.

1. The ePatient – a new consumer of medical services

The notion of the information society and attempts to define it cause a lot of problems. There is no single commonly accepted definition of the term so far. Each of the authors dealing with the problem usually uses their own definition [11]. All the authors, however, commonly emphasise the importance of information and IT for almost all the aspects of the contemporary man's life, which signifies a new quality both in the life of an individual and the society. As R. Łukaszewicz i J. Unold [10] rightly observed the broad understanding of the term „information society” cannot be limited to purely technological aspects but it should combine them with their consequences for the society in its economic and particular social development. Therefore we can assume after J. Penc [14] that: „The information society is the one developing a global information network... that ensures the speed of communication and easy access to information, which creates new human relations in terms of quality as well as quantity both in economy and everyday life”. It is an undeniable fact that the driving force standing behind the growth of the information society is the enormous technological progress that took place over the last two decades of the previous century. The introduction of the WWW world computer network and common, almost unlimited, access to computer facilities these days has a revolutionary impact on the market position of today's consumers and changes the character of relations between the participants of social and business processes. Above all, these technological advances brought about massive changes in people's mentality and their perception of the world and as a result they shaped a new type of consumer whose consumer behaviours are significantly different than they used to be. The dynamics of this process has been primarily influenced by the Internet growth. The global Internet network made it easier and quicker for potential consumers of healthcare services to access the information and content previously intended for the healthcare professionals and inaccessible for the average man.

Not so long ago, the main source of objective healthcare knowledge for the patient was exclusively his or her physician. The patients' information could additionally be derived from informal communication, i.e. chats with friends and advice given to each other. Currently, a new type of the healthcare services con-

sumer – an e-patient has emerged, among others, due to the development of the Internet network that created new, and improved old ways of information acquisition as well as multiplied the extent of the impact of informal communication among patients. In the literature on the subject an ePatient [2] (or e-patient) is considered to be the Internet user seeking for healthcare information for themselves or their beloved ones.

2. Uses of the Internet resources for healthcare information

According to research, the percentage of ePatients in populations all over the world is growing increasingly. The studies of *Pew Internet and American Life Project* from 2012 indicate [5] that over 69% of all adult Americans and 8 out of 10 Internet users [4] seek for healthcare information on the net, which is an 8 percentage point increase on the year 2009. The development of healthcare Internet is one of the priorities of the European Commission adopted by all EU countries within the framework of the e-Europe programme. The research findings included in the „*WHO/European survey on eHealth consumer trends*” report also confirm that a very high percentage of Internet users search the net for healthcare purposes. The percentage of ePatients in the EU countries under survey accounted for 52% of the population under survey, which was equivalent to 83% of all the Internet users [8].

We can observe similar tendencies in the Polish society. Although the distance separating Poland from the countries at the highest level of the information technology development is still considerable, it is decreasing systematically. The number of Poles at the age of over 16 using the Internet has increased by almost 10 percentage points over the two years to reach the level of 61,1% in 2011 [1]. According to the findings of the research reports on the use of the Internet for healthcare purposes in Poland, the number of ePatients increased from 34% in 2009 [12] to 88% of the Internet users in 2011 [13]. Analysing the demographic structure of ePatients, it should be noted that according to the majority of the data available, a typical ePatient belongs to a younger age category and is a studying or well-educated person with an above average income. Although systematic diffusion of this innovation of communications is taking place in all age groups, youth between 16 and 24 years of age still represent the highest number among them [1] which is the reason why the presented survey also focused on this group.

Over 89% of the respondents were searching the net for healthcare-related content last year. They were doing so both for their own purposes and at the request of their beloved ones. The most frequent reason for searching the net was to diagnose one's own illness after its symptoms have been acknowledged (over

a half of respondents), whereas almost half of the respondents were motivated by a request of the beloved person.

The results of the survey on the information search methods indicate that the most frequent way to acquire the information was to click in the key word in the search engine. The second most useful way of this information search appeared to be this time the healthcare-related websites verified by respondents. This is a significant change of 18 percentage points as compared to the year 2010 and it can point out to a broader knowledge concerning the Internet resources but also to the patients' growing reliance on them. In comparison with the previous survey, healthcare related sections on Web portals dedicated to general topics and the Ministry of Health websites turned out to be less useful (compare Chart 1).

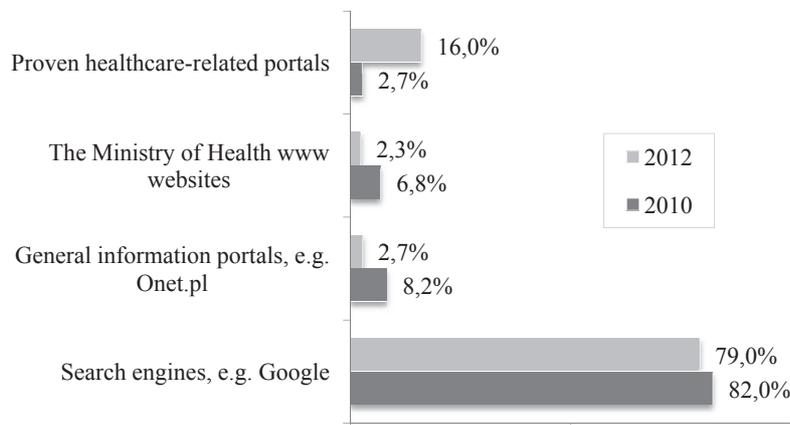


Chart 1. The most frequent methods of the healthcare information search

Source: own research.

When the object of interest is health, the patients have very clearly specified expectations as to the Internet information. They are looking for comprehensive information arranged by particular illnesses including all the treatment available. On the other hand they also expect links to related websites, among others the ones presenting people with similar health problems. The ePatients surveyed were most often searching for the information concerning different kinds of diseases, diets/losing weight and cosmetics. There has been a significant increase in the number of respondents looking for an opinion on a particular clinician (compare Chart 2).

As follows from the analysis of different kinds of information searched for on the Web, ePatients are not interested in tools enabling medical examination over the Internet that, in a sense, replace a direct contact with a clinician. They treat the Internet as a source of information that makes their decisions easier rather than use the eHealth applications available (compare Chart 3). As many as

over 92% of ePatients admit visiting the Internet forums and discussion groups dedicated to healthcare and healthy lifestyle issues. The percentage of the people surveyed that take active part in discussions on these sites is still relatively low for this age group.

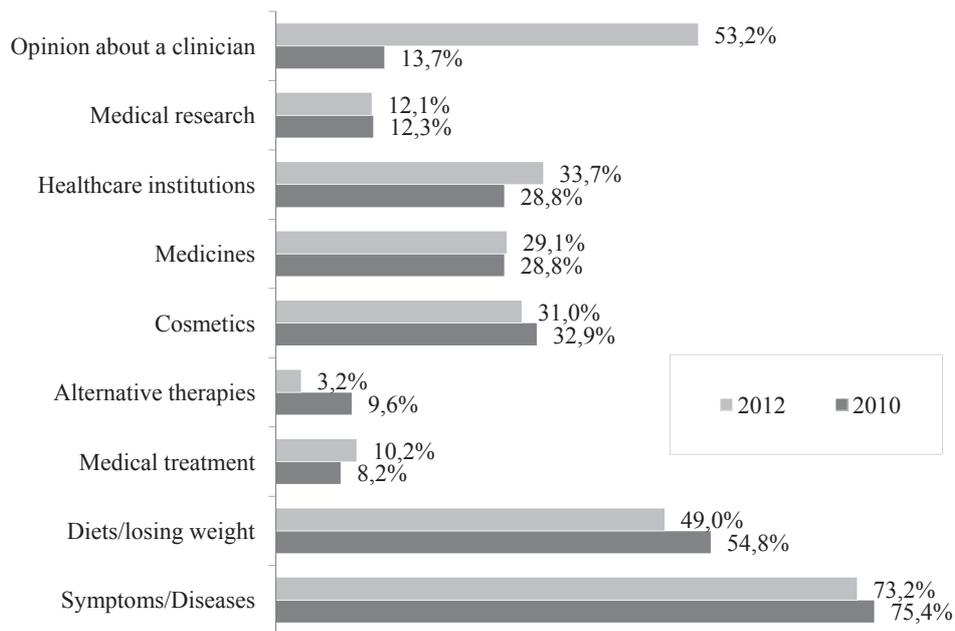


Chart 2. Categories of healthcare information searched for most frequently

Source: own research.

In 2012 already every five respondents admitted to generating their own information on health issues from the Internet forums and discussion groups. The comparison of the types of information that are searched for and shared leads to interesting conclusions. What respondents most expected of these web resources was to get acquainted with other patients' opinions about the effectiveness of a particular diet, the course of the disease, medicine dosage and the therapy side effects and to confront this information with the clinician's counsel in the real world. It should be emphasized that in comparison with the year 2010 the students got considerably more interested in ePatients' opinions on clinicians and healthcare institutions (compare Chart 4).

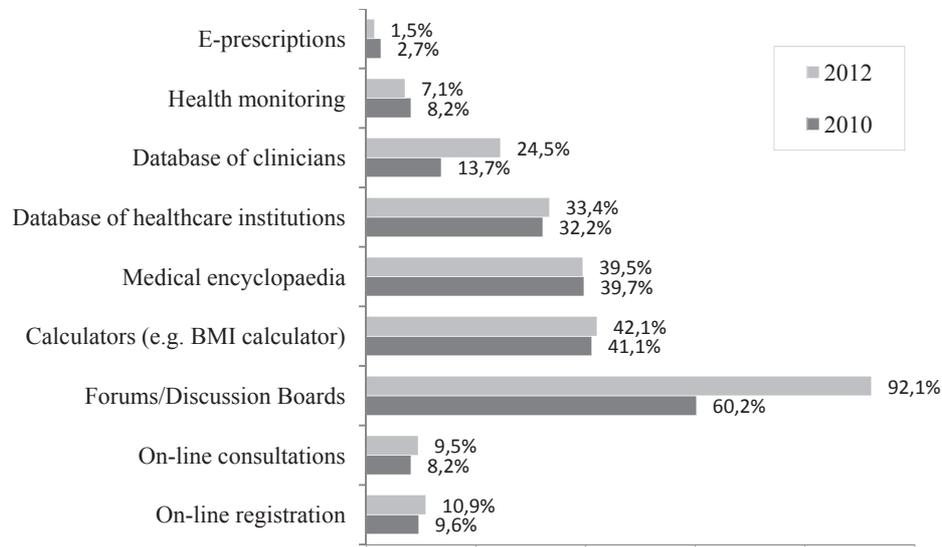


Chart 3. Use of functional tools available on healthcare-related portals and services

Source: own research.

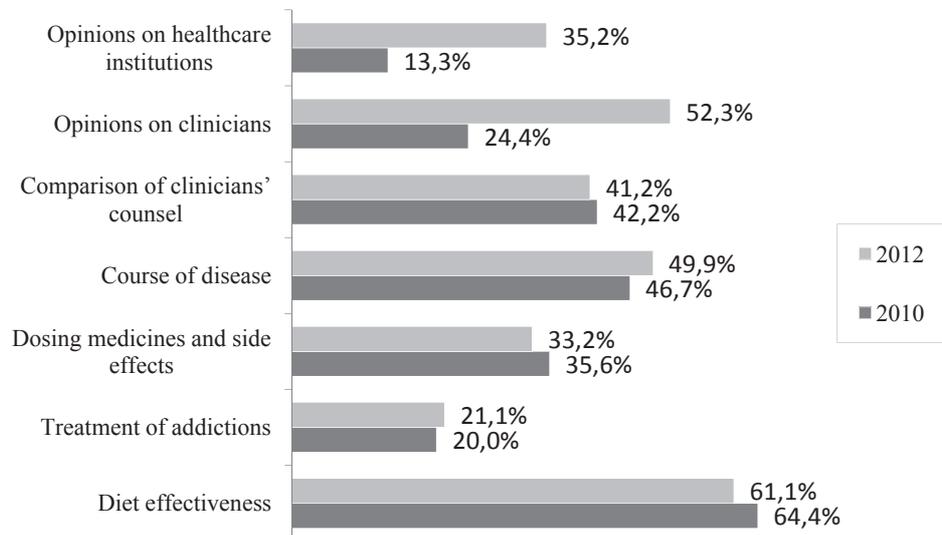


Chart 4. Information searched for on the Internet forums and in the discussion groups

Source: own research.

Tendencies concerning the process of sharing healthcare information are similar. The information that respondents still share most frequently, however to a lesser extent than in 2010, are their disease-related experiences and knowledge

(compare Chart 5). On the other hand, the tendency among the students surveyed to pass on their opinions about clinicians and healthcare institutions has considerably increased. The analysis of ePatients' opinions on one of the Internet forums (www.beutywpolsce.pl/opinie) indicates their bigger openness and readiness to share intimate medical experiences or even photos, not only by email.

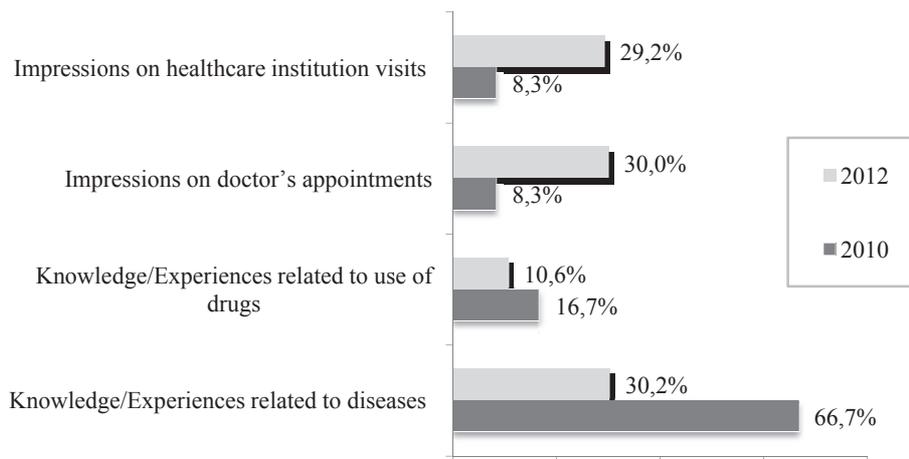


Chart. 5. The most frequently commented health-related issues on the Internet forums and in discussion groups

Source: own research.

The respondents were also asked to evaluate the usefulness of the health-related information obtained on the Internet. The proportions related to this issue have significantly changed over the period of two years. In 2010 43,8% of the respondents considered this information as less useful than the information given by the doctor whereas 15% of the respondents thought it to be more useful. In 2012 only 32,3% of the respondents treated the Web information with reserve whereas 40 % of the respondents gave priority to the Internet information over the clinician's counsel. These findings are not only surprising but also alarming. The kind of health information that the students are looking for on the net, the sources of this information as well as the trust they place in it require paying special attention to the ensuing situation.

3. The risk involved in unreliable medical information on the Internet

The patient's capacities to evaluate the knowledge acquired this way are largely limited. Apart from professional medical Internet services run by clini-

cians or doctors' associations, there are independent websites dedicated to health issues that do not always provide reliable information based on scientific data. There are cases when the patient's expectations shaped by this sort of information are unrealistic, which leads to the patient's frustration if they have not been satisfied. Sometimes the information acquired on the Internet is contradictory to the clinician's opinion or counsel. This can diminish the patient's trust for the professional and as a result have a negative effect on the patient's perception of the medical service and on the medical treatment itself and the patient's compliance with the regimen of the therapy, which, from the social point of view, is significantly more important. Unfortunately the more often patients look for medical information on the Internet, the more likely they are to try to diagnose their health on their own, to suggest or even demand particular treatment from the clinician and to insist that the doctor prescribe them some specific medicine, the name of which they know [9]; they are also more likely to take medicines in a different way than the doctor prescribed or to abandon the treatment [4]; paradoxically their requirements for detailed explanations during the course of medical treatment tend to be considerably bigger. This may, to a large extent, result from the flood of Internet data being difficult to interpret. The incorrect information on the net may bring about serious consequences [6]

1. The patient will start to believe that he or she can get cured over the Internet. The use of medical web services, even the ones enabling the patient to ask questions to professional clinicians cannot replace a direct contact with the doctor. Although in some situations the Internet can facilitate an early diagnosis, the website should clearly specify that in case the patient develops symptoms of the disease they should visit a trusted doctor.
2. The patient may overdose drugs or use diagnostic procedures excessively. Statistical surveys conducted in Great Britain [17] proved that the persons using the web to obtain information on medical treatment tend to overuse drugs. It is associated with aggressive advertising activities of pharmaceutical companies.
3. The patient may use drugs in a different way than the doctor prescribed. These discrepancies may result from the patient's misinterpretation of the drug dosage recommended by a pharmaceutical company that may differ from the dosage of the drug prescribed by the doctor following the doctor's professional experience.
4. The patient may try to apply inappropriate unproven methods of "treatment". An example can be the use of different kinds of diets without appropriate medical consultations and examinations, which usually causes more health problems for the patient.

Medical circles try to defend themselves against such situations. Special measures are initiated to verify and control the medical information on Internet [15]. In order to promote reliable information in terms of content, one of these

initiatives, Health on Net Foundation [16] based in Geneva defined principles that set up specific conditions to declare WWW services reliable and to grant them the “HONCode” certificate (“Health On the Net Foundation Code of Conduct for medical web sites”):

- The authors of the web service medical information should be specialist healthcare professionals. If it is not the case, it should be clearly notified.
- The website service can be just an educational element or explanation and it cannot replace direct contacts of the patient with a physician.
- Principles of privacy and confidentiality of the patient’s personal data should be strictly observed.
- The website information should contain all data concerning sources and literature and in case of clinical data, also clear and legible information concerning their last modification.
- Any data referring to the benefits of particular procedures or treatment as well as commercial information about particular pharmaceuticals should be based on reliable sources.
- The authors of the website service are obliged to provide clear and explicit information about how they can be contacted including their personal data and email address placed on their WWW site.
- It is also required that the data about the institution or person presenting the service be provided. It should be stated whether the service provider is a non-profit institution, a commercial institution or an individual.
- If the material is a commercial or when it is sponsored it has to provide this information in an easily noticeable way stating in a brief note who the sponsor is or what connection there is between the company and the advertised material. This HONcode clause imposes on web service providers an obligation to clearly separate the original material of a given institution from a commercial or a material sponsored by another company or institution.

Up till now HONcode has been granted to over 5,000 medical services in 72 countries worldwide.

Conclusions

We need to be aware of the fact that the research findings presented in the article are not representative. However, it appears that they may be a starting point for more in-depth research and analyses. The findings indicate that up till recently the young generation, although susceptible to different technological innovations, behaved in a quite conservative way in the area of healthcare services. Taking into consideration the results of the conducted research, however, we can observe quite an interesting characteristic trend. In fact, each succeeding year, representatives of the first generation ePatients are increasingly giving priority to the medical information provided on the Internet forums over the infor-

mation provided in a traditional way, that is in a direct contact with a physician. It is a very dangerous trend that points out to the fact that the public confidence in medical professionals is decreasing and it may have a negative impact on many aspects of the provision of medical services.

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Internetowe źródła informacji medycznych – wykorzystanie i zagrożenia dla e-pacjentów

Synopsis: Rewolucja informacyjno-komunikacyjna, jaka dokonała się w ciągu ostatniego dziesięciolecia, spowodowała rozwój nowej formy stosunków łączących podmioty rynku, formy opartej na wiedzy i umiejętności posługiwania się nią. W wyniku powstania społeczeństwa informacyjnego następuje zachwianie dominacji asymetrii informacyjnej, tak charakterystycznej do tej pory dla usług medycznych. Pacjent z biernego przedmiotu świadczenia staje się suwerennym klientem, poszukującym w sieci wiarygodnej, w jego odczuciu, odpowiadającej jego potrzebom i możliwościom percepcyjnym, informacji. Ta sytuacja z kolei stwarza poważne zagrożenia wynikające z braku realnej kontroli nad pojawiającą się w sieci informacją medyczną. Artykuł prezentuje wybrane wyniki badań dotyczących wykorzystania internetowych źródeł informacji medycznych przez pierwszą generację e-pacjentów.

Słowa kluczowe: e-pacjent, Internet, zachowania konsumentów, informacje medyczne.