Medical information asymmetry in cyberworld of Manuel Castells

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Till 1997 Internet was strong associated with universities and education including medical research. Those time was small number of virtual community members but all had equal access to whole information placed in net. In this time each networking participant was active not only to retrieve but create and distribute medical information as well. We can say, it was presented symmetry between passive and active form Internet using. Since time big medical (and generally) commercialization of Internet the still increasing asymmetry has been observed. There is seen division into providers serving and distributing of medical information on net and consumers, who get such prepared by providers "products". This is new challenge and situation for academic and practicing e-health physicians. First - while all great initiatives to certify medical portals had been failed they must be educated to chose valuable, good quality medical information self. Secondly - this imbalance favors abusive behavior forced by commerce as spams, spreading viruses and advertising without content-related information. Stimulating to restore previous idea of Internet for non-profit activity seems to be best way to avoid continuation of Internet "degeneration". Manuel Castells has defined future industrial and postindustrial progress of humanity as activity in global virtual communities interchanging ideas, knowledge, information. The role of medical professionals in this world seems to be educating patients and their families how to search good quality medical information, stimulate other medical professionals, researchers as well as patients supportive groups to be active themselves. Reducing of medical information asymmetry will be positive trend to progress e-health in future. The Open Source software may help costs reducing by creation such resources.

Reality and vision

The number of noise in virtual world can be measured with number of spams – unusual post, which is delivered touch our mailbox every day. To search interesting information unfortunately we are absorbing to read advertising information including promoting drugs as viagra or anabolic hormones. Through network are resenting still more number high sophisticated viruses, which must be scanned by antiviral software, which of course slows down a operating systems of our servers and work stations and need to improve quality of antiviral technology.

```
make[2]: Entering directory `/export/home/pekasz/src/clamav-0.67/libclamav'
source='mbox.c' object='mbox.lo' libtool=yes \
depfile='.deps/mbox.Plo' tmpdepfile='.deps/mbox.TPlo' \
depmode=gcc3 /bin/bash ../depcomp \
/bin/bash  ../libtool  --mode=compile  gcc  -DHAVE_CONFIG_H  -I.  -I.  -I..  -I..  -
I./zziplib    -g -O2 -c -o mbox.lo `test -f 'mbox.c' || echo './'`mbox.c
rm -f .libs/mbox.lo
gcc -DHAVE_CONFIG_H -I. -I. -I.. -I.. -I./zziplib -g -O2 -c mbox.c -MT mbox.lo -MD
-MP -MF .deps/mbox.TPlo  -fPIC -DPIC -o .libs/mbox.lo
gcc -DHAVE_CONFIG_H -I. -I. -I.. -I.. -I./zziplib -g -O2 -c mbox.c -MT mbox.lo -MD
-MP -MF .deps/mbox.TPlo -o mbox.o >/dev/null 2>&1
mv -f .libs/mbox.lo mbox.lo
source='message.c' object='message.lo' libtool=yes \
depfile='.deps/message.Plo' tmpdepfile='.deps/message.TPlo' \
depmode=gcc3 /bin/bash ../depcomp \
/bin/bash  ../libtool  --mode=compile  gcc  -DHAVE_CONFIG_H  -I.  -I.  -I..  -I..  -
I./zziplib    -g -O2 -c -o message.lo `test -f 'message.c' || echo './'`message.c
rm -f .libs/message.lo
gcc -DHAVE_CONFIG_H -I. -I. -I.. -I.. -I./zziplib -g -O2 -
```

above fragment of compilation process of known free (GPL license) known antiviral software clamav-antivirus 0.67 on Unix using gcc 3.2 compiler

This additional horrible part of this story are numerous info about systems cracking and violations with illegal handling of secret computer data. A important question is were should we placed in such virtual world and what shall we do, to give e-health again appropriate

substantial and ethical character? Last observed trends show, Internet including e-health take a form other mass media – this same it has created significant division in to information creators (now first of all big commercial portals) and clients – here medical professionals searching helpful information for education and medical practicing. This resulted with characteristically for traditional media asymmetry, although as known, Internet and like it forms of communications give all participant equal privileges to be "consumers" as well as "creators". Manuel Castells in his trilogy about problems of human in cyber-world has described. "He space of flows has introduced a culture of real virtuality which is characterized by timeless time and placeless space. Timeless time...the dominant temporality in our society, occurs when the characteristics of a given context, namely, the informational paradigm and the network society, induce systemic perturbation in the sequential order of phenomena performed in that context"[1] Replacing traditional media by new – e-media changes also this traditional division. Moreover, when such division exits, this is enhanced more in our brain (consciousness) rather, than in codes of new technology. The Vision resulting from M. Castells papers advises to increase power of good, independent and "non profit" initiatives in telemedicine made for networking societies of doctors, patients and supportive groups. Large education is core of success. Better educated patient is less suitable on different form internet frauds, advertising or violations.

```
received: from cr80.neoplus.adsl.tpnet.pl (HELO am.torun.pl) (80.54.214.80)
  by dorota.am.torun.pl with SMTP; 28 Feb 2004 10:58:54 -0000
From: your@domain.com
To: "xxxx"@am.torun.pl
Subject: information
Date: Sat, 28 Feb 2004 11:58:47 +0100
MIME-Version: 1.0
Content-Type: multipart/mixed; boundary="33812802"
X-Qmail-Scanner-Message-ID: <107796594252627244@dorota>

--33812802
Content-Type: text/plain; charset=us-ascii
Content-Transfer-Encoding: 7bit

do you?

--33812802
Content-Type: application/x-zip-compressed; name="msg.zip"
Content-Transfer-Encoding: base64
Content-Disposition: attachment; filename="msg.zip"
```

UEsDBAoAAAAAAFdXXDBdbrAiAFYAAABWAAALAAAAbXNnLmRvYy5zY3JNWpAAAAwAAAAQAAAD/
/wAAuAAAAAAAAABAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAACAAAAADh+6
DgC0Cc0huAFMzSFUaGlzIHByb2dyYW0gY2Fubm90IGJlIHJ1biBpbiBET1MgbW9kZS4NDQok
AAAAAAAAAFBFAABMAQMAfQwQAAAAAAAAA4AAPAgsBAjgAUAAAABAAAABAAQDQkAEEAAFAB
AACgAQAAAEAAABAAAACAAAEAAAAAAAAAQAAAAAAAAALABAAAQAAAAAAAgAAAAAEAAA
EAAAAAAQAAAQAAAAAAAEAAAAAAAAAAAAZK0BAIABAAAAoAEAZA0AAAAAAAAAAAAAAA

Fragment of computer virus attached to mail with MIME stopped by mail-scanner system on dorota.am.torun.pl mailserver

Safer Internet is a part of principles of European Union[2] realized in medicine by MedCIRCLE project, which are idea of G. Eysenbach[3] developed under auspice of EU. In Poland the important discussion about medical Internet quality certification system has been performed during 5th. Polish Medical Internet Conference in Poznan[4], where I was representing a group of enthusiasts propagating such certification system. About 64% members of Internet community on medical mailing list for patients and their families in two independent studies

have said for certification "yes" but during 1st E-health conference held here in Krakow one year ago I have confronted skeptical opinion about possible success of such method[5]. Even Eysenbach[6] initiative left still "under creation" stadium. If project to create voluminous rating systems , assessing information about millions web-sites, fails to operate all Internet users are not sure how to rank as a good or bad quality service. The reason of failing such ideas seems to be trivial. All world each day accumulates more medical information than this can be in real time and ,at glance, evaluated by a teams of authorities. This fact changed my opinion in relation to this topic. I am currently inclined to promote user education rather than force creating such certifying institutions, working with tortoise speed. In era of the progress , commercial Internet, seems to be visible as real as well potential risk to interest conflicts between aspiration (to achieve maximal financial benefit) and to present good quality medical information.

```
Date: Sat, 28 Feb 2004 21:32:19 -0800
From: Overheats S. Nymphomaniacs <astronomer@three-iron.com>
To: Lek <lek-med@achilles.wam.lodz.pl>
Subject: Explore top-rated Super ViagrDa! =] A skeeters rehabilitator weighshaft.


    [ Part 2.2: "Attached Text" ]

How do you do?
It is not possible for a man to be elegant without a touch of femininity.
CialiWs (Regalims), at cheap prices.
Most zones charge $20, we charge $4.95. Quite a differennce.

Ciali8s is knnown as a Super ViagTra or Weekend Viagwra because its efcfets start
soeonr and last much loegnr.

Shipped worldwide.

Here you will find it: http://www.***



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If you do not wish to be hendecoic 8-]
The really great novel tends to be the exact negative of its author's life.
```

Spam advertising Viagra sent to mailing list lek-med@achilles.wam.lodz.pl **(about 500 subscribers) and stopped by list moderator to reach list.**

Informationalism in medicine – a new stage on information paradigm[7]

A way of network society as contemporary power[8] of world progressing and opening new chapter global society has been started from analyzing traditional structure (including relation physicians/patients) formed through centuries by social evolution. Now it is emphasized replacing paternalistic relation model in relations between doctors and patients by partnership to achieve desired target – health restoring. This cooperative model may change role of medical professionals in modern urban society but in my opinion has not defined yet the place of medical professionals and patients in society of information age. Otherwise, it can be said, replacing paternalistic model to based on partnership is not sufficient to "set free" all possibilities offered by e-health practicing. To understand this process it can be presented four model of relation. First **traditional** independently if *paternalistic* or *based on partnership* patient/doctor relation is based upon formalized structures care model as insurance model, public or private health system with first contact physician, referencing system (to hospital

care) and regionalism. Patient is inside of model and under him has been made the action using traditional health care system institutions supervised by government or local authorities. Second, which can be named *anarchic* represents transient form from traditional to more "mature" models of information age. Patients known about existed on net information about his disorders, which can give him additional knowledge and benefit but he posses no ability how search it and during and builds his knowledge on casual/accidental information, which self can pick up from net. Anarchic model is characterized as "without target", casual, not confirmed information, not organized method of data collection, minimal help of medical professionals, many mistakes,. This is simple to recognize, that this model is unsafe and many worse quality information or advertising information alone can create opinion of patient. The next are two parallel coexisting models of mature stage - *dispersed/altruistic/non-profit* model and *targeted/business/commercial* model. Crucial for further idea of harmonious progress of e-health is in my opinion stable balance between both, what I will confirm in further part of my presentation. First (dispersed/altruistic/non-profit) is based upon represented hacker (in positive meaning) culture dispersed on net medical professionals with altruistic intention to help patients, their families and supportive groups and supporting them first of all with good quality information.. Medical information created by such groups including web pages, electronic journals, forums, cooperation on medical mailing list and usenet groups. There are not government's or local authorities supervising on this model, but like university and scientific society natural form of control has been developing, which (as I will write in next chapter of this presentation) not certification but education (how to use medical knowledge from net) seams to be most important. Medical scientific societies may involved into this model and this can be very favorable to improve substantial value non-profit initiatives. In Poland good example is Polish Cardiac Society power to create free for all medical web-pages provided for physicians as well as for patients, KARDIO-L (common with Polish Society of Arterial Hypertension) mailing list and provided "internet cafe", where was discussion with known professors of cardiology. Second (targeted/business/commercial) is result of activity e-business oriented peoples. This model characterize first of all with using advanced technology and to be targeted of concrete group of peoples – consumers with concrete forms of interactions – service. Investors look to achieve financial benefit and activity of medical portals (portal is most often meet form of e-technology) is legitimized usually neither by authorities control nor scientific supervising but by market rules – a number of using any portal peoples and number potential interested advertisers. This is discussible if medical (quality) value were only "additional, adverse value" seen as tool for money only or one important part of mission (such portal). Maybe, this can be different – some portals can also join altruistic mission (good quality medical information) with market rules of activity, what increases confidence of consumers (including professionals) to information served by such portals. My good such examples are Canadian Docguide (http://www.docguide.com) and MedWeb (http://www.medweb.com).

Asymmetry

Unfortunately – this good examples of ability to join mission of good professionally and "money making" seams to be rare. This same imbalance between "non profit" and "business" mode is not favorable for development of e-health based upon evidence based medicine and substantial knowledge.

Because commercial institutions has sources as well as precise and stable form of it organization – this same we are observing process of squeezing out "non profit" e-health initiatives by commercial. Paradoxically, it should be remembered – Internet gives all members equal right and is incentive to use enhanced resources as well as create resources self by all. But the social process described above, which consist in imitating (by previously

not divided peoples on resource creators and consumers) Internet to traditional media, where (in traditional) such division are essential due to specialize its users into two groups. This process and its effect in medical e-health is called by me **medical information asymmetry in cyber-world**. It has been generally from social viewpoint clarified in different papers by M. Castells[9], what it has been found in suggest on title of my presentation. Ideal situation were to keep balance between "producing" and "consuming" medical information in cyberworld. The asymmetry, I suppose, is caused first of all by amplification of commercial model and squeezing out "non profit"/altruistic activity on Net. The lobby of patients (families, supportive groups and doctors) – including countries or European Union can be to promote "non profit" initiatives in medical internet in recently accessed countries to change this unfavorable situation (imbalance). The result of imbalance is social uncontrolled flow of unusual information including spams, advertising mails, frauds, oriented only for business portals. The question is, does not market sufficient regulator of it. As seen till today not. Maybe, Internet is still young (immature) community with still presented anarchic trends of progress. Market is also now insufficient to regulate it quality in such branches as medicine (for instance but other too).

Education of health-oriented e-communities

Internet has changed pattern of interpersonal contacts and this after-industrial revolution . Internet is characterized also with very anarchic construction and lack of possibility regulation of information. Additionally described by Castells *timeless time* and *space of flow* produces a culture of "real virtuosity". If as suspected, it were not possible to certify medical resources (as all resources presented on web) other method to pay attention of consumers (patients, families and supportive groups) seams to be large education action. In my opinion there is not sufficient to create information pages informing how-to choose good substantial medical information and refuse bad. More effective should be training programs directed to all interested with e-health persons or to chosen group suffering from concrete diseases or interesting more about any substantial problems. From my observation and practice there is not sufficient to create "passive" documents, which learn to use properly e-health but the presence of doctors and other medical professional on different mailings lists, groups, where met patients, families and supportive groups is desirable.

> **It seams to be urgent necessity to create educational programs for patients, their families and supportive groups how to seek good quality information on net. The presence devoted this topic information on net only is in my opinion not sufficient. The presence in e-health oriented communities doctors and other medical professional not joined with any medical business and being independent from e-commerce, playing role "guru" and "tour guide", is important point to do e-health more useful and safe for all. The European countries as well as European Union should support such initiatives.**

Reducing asymmetry

Manuel Castells in „The Internet Galaxy" has characterized a culture of information age by describing different groups of peoples, who play here great roles to widespread this innovation. This division has other meaning, than cited in my previously papers Roger's "diffusion of innovation" but here first of all is to promote "non profit" initiatives particularly associated with university or medical societies activities. European Union as well as countries should finance telemedical projects, which outcomes can be suitable to use in public health sector. Public health sector can be in future supported by many e-health activities, what improve standard of care. The first step is creating large education programs for patients,

families and supportive groups as well as medical professional. In future will be necessary to solves many problems associating with medical practicing in information age (including for instance last discussed on "SIM" mailing list about purchasing drugs on net[10])

[1] Felix Stalder The Network Paradigm: Social Formations in the Age of Information *http://felix.openflows.org/html/netparadigm.html*

[2] *http://www.europa.eu.int/information_society/programmes/iap/text_en.htm*

[3] Collaboration for Internet Rating, Certification,Labeling and Evaluation of Health Information *http://www.medcircle.org/about.php*

[4] P. Kasztelowicz Certifikaty moje zdanie „za" (Certify my opinion „yes")

[5] P.Kasztelowicz Doctors - the role of creating and promoting high quality medical information on the Internet Presentation on E-health in Common Europe 2003 Krakow - *http://www.am.torun.pl/~pekasz/Kasztelowicz-ehe.pdf*

[6] Gunther Eysenbach, Gabriel Yihune, Kristian Lampe, Phil Cross, Dan Brickley „Quality Management, Certification and Rating of Health Information on the Net with MedCERTAIN: Using a medPICS/RDF/XML metadata structure for implementing eHealth ethics and creating trust globally" J Med Internet Res 2000;2(suppl 2):e1 *http://jmir.org/2000/3/suppl2/e1/*

[7] Subtitile taken from Bo. Groenlund „The Urba Question and The Rise of the Network Society Manuel Castells confronted" – *http://hjem.get2net.dk/gronlund/Castells.html*

[8] M. Castells „The Internet Galaxy" 2001

[9] Bo Groenlund „'The Urban Question' and 'The Rise of the Network Society' – Manuel Castells confronted - *http://hjem.get2net.dk/gronlund/Castells.html*

[10] look to archives of this disscusion *http://hilist.au.dk/pipermail/sim/2004-February/thread.html*