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TOWARDS FUTURE HEALTH SOCIAL NETWORKING: PATIENT GENERATED CONTENT AND THE ROLE OF COMMUNITY PHARMACISTS

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Abstract

In this paper we aim to develop a patient centered perspective that puts at the centre of our focus patient practices and their appropriation of medical information, prescribed use of drugs and of health-care technology. Within this frame, we will initially discuss evidence from a qualitative case study on the role of community pharmacists in patients dealing with their problems. In line with the 2.0 revolution, we then suggest a technological architecture based on patient generated content and their health social networking – as many Health 2.0 platforms already do – that focuses on local relation and take into account the empirically assessed role of pharmacists and investing them with an interesting local task. Future challenges and initial reflections of the proposed approach will be discussed at the end.

Keywords: *Patient-Centered View, Community Pharmacist, Social Networking, Patient Generated Content*

1   INTRODUCTION

This paper reports on work from an interdisciplinary project exploring the design of future telecommunications services, networks and applications in several ICT related domains. In this work, we will focus on the domain of Health Care (HC). In particular, we aim to develop a patient centered perspective which places at the centre of our focus patient practices, understanding and their daily dealing with medical information, the prescribed use of drugs and of health-care technology. Rather than presuppose patients as necessarily passive actors within the HC system as traditionally understood, we assume that many patients might pro-actively build local knowledge in order to deal with the practicalities and intricacies of their health problems. They might activate local interactions with more or less institutionalised actors, often walking around official channels and may also develop non-compliant strategies and adjust their treatment to prevent their diseases taking undue control over their lives.

In line with the recent rise of more participatory models that extend some of the Web 2.0 characters to different domains (e.g. Health 2.0), we believe that many of the mentioned patients' activities should be supported and their outcomes publicly shared so that different patients can learn from each other. At the same time, much attention is needed to prevent the circulation of health mis-information and the establishment of unsafe practices.

In order to probe our assumptions and to envision our approach, we have built a qualitative pilot study aimed to assess the role of local community pharmacists in patients' practices and their appropriation of medical information, procedures and technology. Drawing on different bodies of literature, we relied on the assumption that, among the many HC professionals, pharmacists might often play a role that exceeds the simple dispensing of drugs (see for instance, Wathen et al. 2007; Cocksey et al. 2002; Keely, 2002; Sleath, 1996; Adamcik et al. 1986). They might have the chance to develop friendly interactions with some patients and develop a certain familiarity with their problems. They can be the first contact for people experiencing practical troubles and an obligatory passage point for those who have been prescribed with a drug. In this sense, community pharmacists become not only precious informants regarding patients' real problems, but also actors that might actually play a relevant role for patients dealing with their health. In this work, we investigate the interaction between community pharmacists

and patients. We acknowledge the need to support a more bottom up knowledge production in the medical domain. By focusing on community pharmacists and their customers, we aim to envision a future participatory Health Care model that supports a patient centered perspective.

This paper is organised as follows: The following section will discuss our research approach which is aimed at putting patients' practices and understanding at the center of our scenarios for future ICT services. In this sense, we will initially provide another look at the traditional model that prescribes a passive role to the patient. We rethink the notion of compliance by showing how a patient centered perspective might extend traditional understanding and make room for the production and circulation of new and relevant patient generated knowledge. We next discuss the role of community pharmacists in the light of evidence from our qualitative field observations and some of the literature from social medicine. A series of specific practices involving an interaction between patients and pharmacists is then discussed as instances of moments where relevant practical knowledge and safe practices are produced. This series of instances aims to inform a participatory platform that we introduce and describe in the second part of this paper. Framed within the 2.0 revolution, we start to envision a technological proposition based on patient generated content and networking – as many Health 2.0 platforms already do – but that takes into account the assessed role of pharmacists and invest them with an interesting local task. The architecture of such participatory platform will be described and accompanied by a design scenario, envisioning how the solution would work. Future challenges and initial reflections of our approach will be then discussed.

2   A PATIENT CENTERED FUTURE OF HEALTH CARE ICT SERVICES

In a traditional perspective patients are understood as passive actors who should comply with academic biomedicine knowledge in order to deal with their health problems. In this case, the role of technology would be that of supporting patients to comply when this is too difficult for them. However, this perspective might only tell one part of the story. Although traditional literature extensively focused on patient adherence to medication, a small number of sociological and anthropological works privileged patients' point of view, sense-making and active practices (Jones, 1979; Helman, 1981; Morgan and Watkins, 1988; Donovan, 1992; Verbeek-Heida, 1993). According to Conrad (1985), for instance, autonomous patients will develop their own medication practice, even though it may not coincide with the institutionalised health professionals' recommendations. Much of this behavior could be seen as non-compliance, but, from the patient's perspective it is not. People adjust their regimens to suit their life situation. They may be solving a problem that a particular drug or procedure creates. They may choose to avoid the stigma of the condition that their medication represents. They may be lowering the dosages to see if their condition has improved. In effect, patients may alter their drug regimens in an effort to retain their own control. In his study of people with epilepsy, using a fairly standard definition of compliance, 42 percent of respondents would be seen as non-compliant.

Yet from the patient's perspective the issue is not about complying or not complying. Embedded in the context of their own experience, their use of medications can better be seen as a form of "self-regulation." […] Most people with chronic illnesses spend only a tiny fraction of their lives in the "patient role." Compliance assumes that the doctor-patient relationship is pivotal for subsequent action, which may not be the case.

For instance, people with diabetes may have the same goal as their doctor, but their method of achieving these goals may include altering their regimes to create – for instance – a balance of caloric exercise and insulin. A five minute talk with an experienced patient with diabetes type 1 would confirm this quite immediately (see for instance Mol, 2008). Take, for instance, the following extract from an interview with a Diabetes Type 1 patient:

I completely manage my therapy myself.... I do not have any interaction with the GP on this aspect.... I do it myself also because you come to realise that the GP cannot follow all your specific problems ... so what happens is that you make some sort of mental plans […] Every time, I make a plan depending on

where I am, what I am supposed to do and it changes according to the fact that I am at home, in the office or not, whether I can prepare my food or just get something from a menu.... For instance, when I know we are going to be walking for a long time because we are sightseeing somewhere or we are in the countryside, I tend to keep my level of glucose a little higher, so instead of 10 units of insulin before lunch, I take only 9 or 8.... If I know I will have a football match to play I will do even fewer units... Of course, at the beginning, you give it a try and you see what happens, but without self-measurement and the meter you cannot even think of doing these things ... and, more importantly, nobody teaches you this ... Marco, Diabetes type 1 patient

While a traditional understanding would depict patients as passive actors in need to comply with biomedical knowledge, a patient centered perspective would rather suggest that some patients actually actively produce a different kind of local and practical knowledge that might need support too[30]. Compliance is fundamental for many people and it should be supported. However, non-compliance should not always be considered a form deviation in need of control and corrections, but rather a precious moment where new practical knowledge is produced in real context. Such practical knowledge that some patients might produce is different from the one institutionalised actors, such as the GP, can provide and could be of great help for those whom experience the same problems and are in need to develop their own personal and safe medication practices. According to Marco, you learn this by experimenting, self-measuring and looking at other patients who do not simply stick with an academic value (which he defines as a *fetish* or *what the GP asks you to do*). Assuming the patients can learn from one another (not only to comply), the question then becomes: how to sustain the development of a patient centered approach that supports appropriation and the production of practical knowledge in Health Care without fostering the circulation of mis-information and unsafe practices?

3 RESEARCH APPROACH AND FOCUS ON COMMUNITY PHARMACISTS

As we mentioned, we intend to develop a patient-centered understanding of Health Care in order to envision future ICT services that privileges patients' understanding and their proactive role in dealing with heath problems. How do people appropriate medical information, construct their own knowledge and understanding and reshape – in practice - prescriptive use of drugs and technology? How and when is it a dangerous thing to be avoided? How and when is this aspect to be supported, produced and reproduced? In order to answer these basic questions, we developed an ethno-methodological approach[31] based on participant observations of pharmacists/patients interactions and a series of in-depth interviews with Irish and Italian chronic disease patients and community pharmacists distributed in the area of Limerick and Galway (Ireland) and in that of Arezzo (Italy). Observations and interviews have been carried out between September 2008 and March 2009[32]. Feedback from pharmacies' customers were also gathered when possible.

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[30] Macintyre and Oldman wrote: 'Those who suffer from chronic illnesses, particularly ones that doctors can do little about, develop a special kind of knowledge of their condition. This knowledge is of a rather different order from that hold by doctors, and from the point of view of the patient, it is subtly superior (1977: 55)'

[31] The father figure of this approach, Garfinkel defined ethnomethodology as: "Ethnomethodological studies analyse everyday activities as members' methods for making those same activities visibly-rational-and-reportable-for all- practical-purposes, i.e., "accountable," as organisations of commonplace everyday activities" (Garfinkel, 1967, p. vii). In this sense, our perspective aimed to privilege and to focus on patients' categories, rationalities, accounts and sense-making without falling into an automatic reproduction of the biomedical standard understanding of disease.

[32] Three Italian pharmacists have been interviewed for 60, 65 and 100 minutes respectively. Three Irish pharmacists have been interview for 75, 80 and 90 minutes respectively. One Irish pharmacist has preferred not to be recorded. Four chronic disease patients (hypertension and diabetes) were interviewed for 150, 100, 65 and 60 minutes. Some feedbacks from pharmacies' customers were gathered during participant observations in community pharmacies. Reported names are purely fictional. Interviews were informal, open and unstructured although a series of general topics were constantly discussed. Interviews with pharmacists generally started with a series of questions concerning professional and legal obligations, then compared with a series of activities and daily practices that seem to surpass and exceed pharmacist's formal role. A series of questions regarding their relation with GPs and what they found problematic in this relationship also followed along with a series of questions

The idea of investigating pharmacists came from the fact that it is very difficult to investigate patients' private practices. How they deal with their health conditions on their own is typically inaccessible for the researcher unless s/he would enter their houses for extensive periods of time. Community pharmacists might instead have privileged access to some patient practices as they probably are one of the most intimate HC professionals people might rely on. Specialised literature already has show that some people might prefer to consult with the local pharmacist before – or even instead of – going to the GP. For example, in discussing the appropriation of medical information of people coming from rural areas, Wathen and Harris (2007) reported:

'"Doctors are so overworked they don't have time to have friendly discussions with people." Another said, "Doctors don't have a lot of time so you have to be very prepared. You have to go in with your questions and know exactly what information you're looking for. It's almost like you need to know the answers before you ask the questions. I find a lot of doctors tend to talk at you instead of with you"

Our observations, interviews and feedback from customers who use pharmacies' reaffirm this point and produced interesting evidence about the active role of community pharmacists. Their familiarity with many patients' practices, the problems they experience and patients' appropriation of medical information and technology were some of the observed information. Although our interviewed pharmacists were located in small urban communities and not rural areas, they all confirmed Wathen and Harris' evidence as the next series of extracts from our interviews show:

'Lots of people come here first, not only because they have a small problem but also because they do not want to go to the GP: it takes time and money. Some people also say: I do not like to be treated like a number, I want to be treated like a person…' Elisabeth, Irish Ph.

'…we are probably unique in relation to the other Health Care professionals, you can walk through the door and demand information …you cannot walk to any other HC professional in this way: you have to wait for the doctor, you have to wait for you dietician ...we cannot hide from that, we are here all the time...' Ian, Irish Ph.

What emerges from these extracts support the idea that patients pro-actively build their own health practices and understanding by creating their own local social networks of experts and non-experts and by relying on a series of resources that might not coincide with the institutional setting where patients are supposed to passively adopt prescribed behaviors. Community Pharmacists, in the case we witnessed, turned out to play an often-interesting role that surpasses the simple dispensing of drugs and that might support the development of a patient-centered approach to future HC services. As Wathen et al. (2007) showed by talking of the proactive role of pharmacists:

'Like dieticians, pharmacists are familiar with non-compliant patients...the info(r)mediary work of pharmacists is directed to information accuracy and patient self-determination rather than compliance.'

In discussing the increase in pharmaceutical demand, Cooksey et al. (2002) describes this aspect in term of Pharmacists' shift to a patient focus:

"Shifting from a dispensing focus to a patient focus has been particularly challenging in community and retail pharmacies. Progress in the past five years has included offering expanded patient counselling, immunisations, and medication-dependent disease management for persons with certain chronic conditions (such as asthma, diabetes, hypertension, and high cholesterol). [...] Surveys [...] have reported a wide range of clinical and management functions: tracking adverse drug effects, participating in

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concerning their relations with patients. How different patients might appear, what problems they raise and their nature, what practical aspects emerge in dealing with medical technology, with emergencies, with self-care and self-medication practices. Interview with chronic disease patients revolved around their experience in dealing with their disease and the nature of their interaction with institutionalised actors (such as GP, specialists) and different actors (such as patients with the same disease, pharmacists, online mentors and so on). Interviewees were constantly invited to provide practical examples and stories instead of talking in general terms.

programs to reduce medication errors, monitoring patients' compliance with medication use, and conducting medication management programs [pg.29]

As Keely underlined (2002): *'...Pharmacists are moving from prescription provider to pharmaceutical care provider...'* [33] In a similar study, Sleath (1996) described pharmacists' interaction as participative rather than authoritative, especially with elderly people and with patients who were picking up refill prescriptions[34].

Interviewed community pharmacists seemed to know quire well a good part of their customers and they often feel compelled to act beyond the simple dispensing of drugs. As one pharmacist stressed, "*nobody is paying me for that, but that is my job*". For instance, interviewed pharmacists receive phone calls from patients dealing with their problems, they chat with them and build friendly relationships, and they inform, educate and advise patients on their disease and medicines. They support during emergency situations, they reassure patients and support them with their medications especially when treatments are particularly demanding, they also demonstrate the correct use of certain medical technology among other things. On the patient side, many lay people seem to have found it easier to relate with community pharmacists. From patients' feedback gathered in community pharmacies during participant observation a series of reasons were particularly recurrent: there are no queues to attend to, no GPs bills to pay, a more relaxed and dialogical interaction where patients feel more confident to express their doubts and a more accessible language that does not reaffirm the usually asymmetrical relationship with more and more busy GPs whose consultations tends to become habitual (as shown in Schulz, 1991)[35].

In the next paragraph, we will discuss further and more detailed evidence from our case study. In order to inform our patient centered approach and to envision a participative platform for future service, we now collect instances of patient/pharmacist interactions and practices that help to better characterise the proactive role of patients and the relevance of pharmacists.

4   FURTHER EVIDENCE FROM THE FIELD

4.1   Who do I talk to about my health problems? Patients in search of listeners

As mentioned, interviewed community pharmacists reported many examples of patients who prefer to supplement their interaction with the GP with a more relaxed and dialogical interaction with a local community pharmacist.

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[33] In discussing the role of pharmacists in patient care, Schulz (1991) earlier discussed the mentioned shift in terms of pharmacist' risk management (nonjudgmental, not specific, drug centered) and patient-advocacy role which would serve patients by providing objective information that would help them to create their own medication practice.

[34] Literature offers a limitless amount of researches on the extended role of the pharmacist in both natural and experimental settings that confirm their pro-active role and their importance as relevant resources for patients. Kodkani et al. (1999) discussed the pharmacists' role in providing travel advice (regarding for instance vaccinations). Hudmon et al. (2003) analysed their role in smoking cessation counseling. Lipton (1995) showed their contribution in rationalising drug therapy while Schnipper showed their role in preventing adverse drugs events after hospitalisation (Schnipper, 2006). Delivery influenza vaccinations (Steyer et al (2004)), recognition and management of insomnia (Wincor, 1992), promotion of optimal use of antimicrobial use (Dickerson et al. 2000), rationalise drug therapy of the aged (Adamcik et al. 1993), supporting self-care (McCallian et al, 2002), improving home care for patients with diabetes (Setter, 2000), providing alcohol related advice and education (Harris, 1993), explaining illness and medicine to patients (Schommer, 2000; Williford et al. 1995), caring for patients with reactive airways disease (Weinberger, 2002) are just a few examples. Moreover, according to Babb (2003) hypertension, diabetes, asthma, patient education, smoking cessation or general medication management are just some of the new duties that characterised pharmacists.

[35] This is also quite clear in this extract from an interview reported by Hughes at al. (2003): The pharmacist is bombarded day in and day out with people coming in and out. It's in your face. There are no appointments, you are directly accessible. [...] they (pharmacy's costumers) say "I come in to see what you say rather than them going and bothering the GP as it takes up to three weeks to get an appointment. Because I can't get hold of the doctor, I am coming to you.". Furthermore, Barry et al. (2000) draws on the notion of patients' unvoiced agendas and showed how patients often do not feel comfortable in expressing their doubts or preferences to their GP to which they passively attend to.

'…many customers, especially those who are not fully self assured, save their doubts and question for me, they feel I know their problems better' Giulia, Italian Ph.

'People often do not tell the doctor if they have problem with their dosage schedule: some just realised that when they come in here, but some other do not feel like discussing it with the doctor…and so they ask me when they buy their drugs and I revise the dosage schedule with them…' Claudio, Italian Ph.

The problem of patients growing uneasiness with GPs' consultations has been addressed in literature. It is not only as a result of the increase of medical demand (that put much more pressure on GPs) but also as an effect of the establishment of a scientific method in medicine. Borell (1993) stated: '*As machines provided the precision and new tests proliferated, data rather than the patient claimed the physician's attention'*. Leder (1992), who also critiqued biomedicine as it treats the body as a machine, has addressed a similar point:

'At the core of modern medical practice is the Cartesian revelation: the living body can be treated as essentially no different from a machine. [...] Insofar as the body is modelled upon a lifeless machine, the role of subjective experience in determining one's health history will tend to be overlooked'

Also Radley (1994) defended a similar position and explained:

'The implication here is that the person must take his or her illness and cope with it in his or her own life, removed from the attentions of medical personnel. Where acute illness can be discussed from the perspective of the doctor (that is, from the standpoint of biomedicine), the special problems of living with chronic illness evade these kinds of explanations'

What we learn here is also that – when interacting with their GPs – some patients will probably experience an increasing lack of occasions to talk about their feelings and claims regarding the practicalities of living with their health conditions. In discussing this problem, Levenstein et al. (1986) developed a model of patient centred medicine by introducing the concept of agendas and showed that doctors fail to elicit 54% of patient reasons for consulting and 45% of their worries. As a proactive reaction, many patients already supplement to this condition by saving their doubts for the interaction with the local community pharmacists they know (in addition to - we are inclined to think - people in the family, at work or in the consultation waiting room etc.).

4.2 Get reassured: dealing with difficult treatments and learning from others

Reassuring is another aspect that emerged quite strongly in the analysis of patients/pharmacist interaction that further addresses the need for patients to share their own experiences when dealing with difficult treatments. The next series of extracts show this important aspect:

*'…for many personal points of view you have to interact with people, you do not have to leave them alone…take the triple therapy for the users: that is a terrible stuff to do…and you are supposed to take that for...what…12 days or so…and so you have to explain that that it is a terrible thing to drink and it tastes terrible…but what I am saying is that you reassure them to actually proceed with it, that it is for the benefit of their health…[...] you have to be professional and be careful…*Ian, Irish Pharmacist

'…I always invite people to take their medicine as prescribed. Sometimes prescriptions might be complicated and people get confused…if I see that someone is not complying I try to understand what it is, if I see a problem I ask them to go back to their doctor and tell him…Claudio, Italian Pharmacist

'If I see someone is not complying, I ask and try to talk. Are there any problems with the medication? Then I can ask them to tell the doctor but definitely I talk with the customer first…Giulia, Italian Pharmacist

This series of extracts further show how patients might benefit from informal interactions, with the focus on how to deal with their practical problems. As we can see, pharmacists do not try to necessarily achive or impose compliance but rather to provide patients with room to reflect on their problems, to get reassured about the difficult aspects of their treatment and to possibly relate with the GP in a more

fruitful way. It has been observed also that when possible, pharmacists – who are exposed to this sort of discussions with patients - refer to the experiences of other patients they have already interacted with and through which they become familiar with specific problems.

4.3 Medical Technology demonstration: how am I supposed to use this?

Another interesting aspect that emerges in our case study with all the interviewed community pharmacists is that many patients often need support when using medical technology in their domestic environments. They need to be instructed (as instruction leaflets *are nightmares*) and to have a demonstration of the correct usage. Moreover, patients seem to especially rely on their pharmacists when they experience a technical problem with their medical self-care devices (from blood pressure monitors to inhalers) and need support. In both cases, pharmacists turned out to be a reliable central actor. The next series of extracts regarding inhalers and nebulisers illustrates this aspect clearly:

'usually I show them how it works and I let them try it in the shop. We unpack it together and assemble it…it is extremely simple to use but I prefer not to have them taking the box and go home…if they do not do it like this they often come back for further explanations…Claudio, Italian Pharmacist

'for the Rino-wash for instance I always open the box here in the shop with the patient and I show them how to assemble it and use it. A man come in and wanted to return his Rino-wash because – according to him – it did not nebulise properly. We have assembled it in here, plugged it in and it was working. Giulia, Italian Pharmacist

An interviewed pharmacist in Galway mentioned a previous experience where she was asked to assess the use of inhalers by the local health unit: '*I was amazed by how many people could not use the inhaler properly, for years!!!*' Elisabeth, Irish pharmacist

This aspect seems to be even more concerning when it comes to more complex technologies such as self-testing digital devices and particular elderly users:

'One day an old woman did many tests and she brought the device back to the shop because she got too many different results. This has also to do with their expectations. People say: it is morning, I have not done anything particular, I am home and I feel fine why should I have changes in my blood pressure?' Giulia, Italian Pharmacist

'People come in twice and more…they are afraid to make mistakes. When test results vary a lot they come back here and ask if they perform the test correctly, if the device work properly, they ask if they can double check with my machine here in the shop…' Claudio, Italian Pharmacist

This second series of extracts touch upon a very delicate point we have just mentioned in our introductory framing. Appropriation of technology has a double face, sometimes it is a good thing - as showed by Conrad and confirmed in our interviews with chronic disease patients - but it might also be dangerous and detrimental to good treatments and so it can degenerate into bad habits, misuses and fallacious understanding of what is going on with a medication[36]. Again, the informal support of an expert such as a pharmacist (or whoever might have developed a certain experience in dealing with certain medical technology such as an expert patient) can make a big difference.

'a few days ago a woman came in…she was worried about self-testing her blood glucose because she was afraid of the needle. "Should I really prick my finger?" She said…and I said: "well, yes but just a very little cut, do not worry, let's do this together…"' Giulia, Italian Ph.

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[36] We are not able to quantify how many costumers would appreciate this service. However, we witnesses much appreciation in many cases: two elderly women came in to check their blood pressure monitors, and ask for support in measuring their pressure; a married couple asked for a demonstration when they bought an aerosol, from their feedback they preferred to have a demonstration than to try to rely on instruction leaflets by themselves.

5   TOWARD A PARTICIPATIVE MODEL FOR FUTURE PATIENT CENTERED HIS

Our approach and the evidence from the field have shown many interesting aspects that we intend to take into account for the development of future HC services with a particular attention to patients and their practices. First of all, we have seen that compliance is not always the standard and that sometimes patients proactively develop their own medical practices to let it fit in with their lives. As we have introduced in section 1, some patients (and this is particularly evident in chronic disease patients) will develop their own medication practices to adjust their treatment to the practicalities of their life and gain some control of their disease. Then we have also seen that patients proactively build local social networks when they need to supplement the lack of understanding they might experience with GPs. We witnessed that while many patients feel in need to talk about their feelings and difficulties, some others produce relevant practical knowledge that might be much needed by people who share similar problems. Then, we saw that community pharmacists often play a relevant role that exceed the simple dispensing of drugs and that they often develop friendly interactions with them. Our initial questions about how to support the development of a patient centered approach, how to support good appropriation and how to avoid unsafe practices, ask for a participative model which would add to the already existing vertical channels based on control and compliance (i.e. traditional channels) and a series of new horizontal channels based not on compliance but on appropriation. In order to address this series of issues we have decided to bet on community pharmacists and to envision a patient-centered platform that would support future patients to better develop their own local practices and social networks, but also to share their experiences with other patients. This series of consideration has brought us to look at the Web 2.0 revolution and the emergence of the so-called Health 2.0 as a possible solution (and a trend) that, in our opinion, future Health Information Systems cannot ignore.

5.1   Challenges from the 2.0era: Patient generated content and social networking

The evolution of the Internet is much studied and its future trends much anticipated. In keeping with the terminology of software applications, in particular software upgrades, these have often been characterised in terms of version numbers. Thus we have Web 1.0, Web 2.0 and subsequent attempts to predict what 3.0 and 4.0 might have to offer. These latter two are speculative and are still highly subjective, however we now clearly understand the difference between 1.0 and 2.0 (in retrospect of course) and we have some early indication of what the future may hold. Web 1.0 was largely a passive experience. Users consumed hypermedia with interaction limited to the most basic transactions. Interactions with other Internet users were largely through email and also more anonymously via file sharing networks.

Web 2.0, a term coined at an O'Reilly conference in 2004, heralded a new way of thinking about the network. In this vision the user was center stage and User Generated Content (UGC) would drive the nature of the network and the uses to which it would be put. This phase has seen the rise of social networks (MySpace initially, subsequently overtaken by Facebook and Bebo), weblogs, Instant Messaging services and most recently hybrid services epitomised by the current interest in Twitter. Mobile connectivity has also been a strong feature with increasingly capable mobile devices connecting to the network. The future Internet will see the UGC trend continuing with significantly increased levels of interactivity and connectivity.

As mentioned, within the Health Care domain, this shift has produced a new series of approaches that goes under the name of Health 2.0. Even if there is a lack of consensus on its definition, different authors agree on the fact that Health 2.0 is based on a participatory model where the pro-activeness of patients is taken more seriously than ever before. Staying informed through RSS and podcasts (Giustini, 2006), support medical education of both GPs or the public (Sandard et al. 2007, Crespo, 2007), participating in self-help discussions (Preece, 1998) and managing a particular disease by connecting to an on-line community (Ferguson, 2007) are just some of the first instances of the 2.0 chapter of Health Information Systems. The web is witnessing the rise of patients' blogs (e.g. Diabetesmine.com;

assertivepatient.com), Health social networks (e.g. dailystrengh.com, patientslikeme.com), health wikis (e.g Fluwikie.com; en.wikipedia.org/wiki/health), Health UGC site (e.g. drugs.com), health podcasts (e.g. podcasthealth.com) and video sharing (e.g. health channels in youtube.com or ivillage.com, iheathtube.com, icyou.com).

The buzzword for the approach we propose then becomes that of Patient Generated Content, their health related social networking and their peer-to-peer interaction. It is worth noting the downside of these approaches, as also recently addressed in literature (Hughes, B. et al., 2009), namely, the danger of inaccurate information[37.] What we believe we add to the actual spread of Health 2.0 application derives from what we witnessed by looking at community pharmacists anf the relevance of local interactions. We have seen how people seek for real interactions where – in a relaxed context – they can discuss about their practical problems. Actual Health 2.0 application are always web-based, they certainly provide relevant information, probably a more accessible language and even foster interactions (mostly asynchronous) but they rarely offer the chance to have face to face interactions with people who know about or share similar problems. In this sense, we aim to bet on pharmacists in order to add a local dimension to our take of 2.0 Health Information Systems. In the following part of this work we will proposed an information system based on these assumptions.

6   TECHNOLOGICAL PROPOSITION

The system proposed would embrace and encourage such an approach, with patient-generated content and the local formation of social networks facilitated by community pharmacists. Enabling technology however is the key to making this a realisation. The core technology used needs to feel familiar and not be a barrier to the user. Instant Messaging (IM), is a form of near real time communication between two or more users over a network. Simple IM clients provide the basic functionality for users to communicate in a one to one fashion. Richer IM clients retain the core text based communication but enhance the user experience by integrating audio and video communications, file sharing and context sensitive services.

IM has had a surge of popularity in recent years as the Web 2.0 matured. The paradigm shift to mobile computing saw a new wave of innovation. The core concepts and functionality of early communication orientated computing, was adapted and brought into this new generation. The result was devices became smaller, faster, smarter and ubiquitous. This paradigm shift was aided by the communications platform in place. Phones had long switched from analogue to digital but had now advanced to 3G speeds. Broadband networks were becoming more main stream allowing for higher bandwidth and accessibility for the home user. Public Wi-fi was being established ensuring that an individual could remain connected somehow and someway no matter where they went. The information superhighway was literally at a person's fingertip.

The result of this was the emergence of IM as a primary means of communication for both business and social users. The added benefit of using this means of communication to stay in touch is the presence and group mechanisms which have evolved with the technology. Contextual information such as availability, location and sensor data can be shared seamlessly in a real time manner with online "buddies", the term coined to describe a person's online contacts. Buddies are logically grouped together into user defined "groups". Common groups would be "friends", "family" and "work mates". These groups combined, form the users online roster of friends, commonly known as a "buddylist". A set of services can be offered and shared with visibility set to each group within the users' buddylist. These services can be very dynamic, adapting to status, presence and other contextual information in highly innovative ways. For instance one modern IM application offers the following: standard one to one chat

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[37] In a recent commentary on the Journal of the American Medical Association, Youtube was reviewed as a site of health mis-information (Dec. 2007), a summary is available here: http://blog.highlighthealth.info/social-networks/youtube-as-a-source-of-health-misinformation/

service, multi user chat, media chat (voice + video), file transfer, calendar, maps, games, health & fitness, news, sports, weather, dating, Q&A, yellow pages, shopping and several other user focused services. When one bears in mind that most of these services are to some extent "aware" of aspects of the users' context, and also that these applications are available in mobile and desktop variants, then the potential of these platforms is unlike anything we have seen in the past. Of particular interest is whether these platforms are based on open standards, and can thus be enhanced in innovative new directions.

The services developed on such systems have a strong reliance on open source standards and protocols, enabling highly scalable applications to be built and distributed. The most prominent of these protocols is the eXtensible Messaging and Presence Protocol (XMPP) set of standards, also known as Jabber. XMPP was formally standardised by the IETF and together with its use of the XML data format it makes the protocol the leading choice for near real time communications. Currently over 100 extensions are active or in the testing phase expanding the original concept to include such innovative extensions such as "User Gaming" [XEP-0196], "User Location" [XEP-0080] and "Location Query" [XEP-0255] to name but a few. XMPP would be the underlying technology of choice for driving forward this system[38].

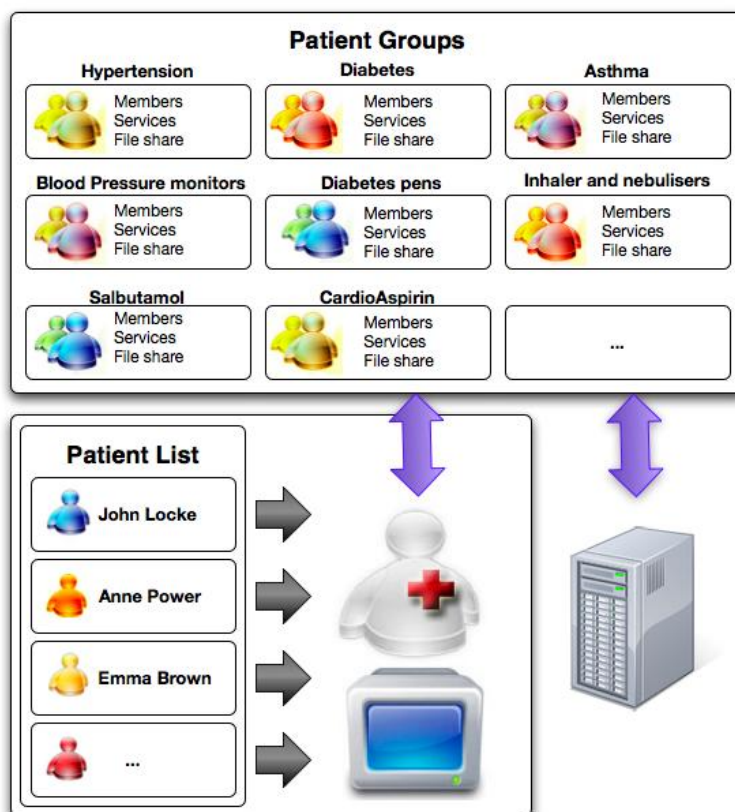## 6.1   Explanation of the Architecture:

Figure 1:Architecture proposed

The architecture highlighted above in figure 1 is what we propose in this paper. A community pharmacy would have an enhanced group focused communications server based on XMPP. The communications server is running the standard XMPP installation as well as several custom schemas to facilitate dynamic group formation, migration, service provision and file sharing. The extensible nature of the system's core underlying components would allow for added functionality to be added in the future. This

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[38] For a more detailed discussion of the architectural structure and its premises see Griffin and de Leastar (2009) and Griffin, Foley and de Leastar (2009)

functionality could be driven by user trends or the desires of the pharmacist. This provides a future proof system with scalability in mind.

This system would be initially set up by a system developer and handed over to the pharmacist who would adopt the role of administrator. The pharmacist registers interested customers as patients of the system. Each customer receives an entry on the system, providing them with unique jabber based identifications with which to authenticate. This identification would be very similar in style to an email address. During the registration process, the pharmacist tags the users profile with key words. These key words will be used to dynamically create the groups and populate them with the correct individuals. Key words or tags, - provided by the patient- can include an overall classification of the patients ailment (such as hypertension, diabetes asthma), the types of medication that the patient is currently prescribed (cardio aspirin, salbutamol) and any external devices required by the patient as part of their prescription (diabetes pens, blood pressure monitors). Customised tags decided upon by the pharmacist are also possible. By associating each patient with such key words, the system can form closely related groups. Patients can and will hold simultaneous membership of groups and group membership can be added to or indeed revoked if need be. A full log of memberships, both past and present are also recorded for the pharmacist.

A number of benefits to having patients logically divided into groups exist for the core users of the system. From the pharmacist's perspective, custom information and specialized services can be tailored at these groups, providing key, relevant and timely information. User generated content can be validated by the pharmacist. From the customer's point of view, they are able to freely interact, share information and even meet with other community members who suffer from a similar ailment or simply look for contents of interest that have been commentented by a pharmacist. Sharing customised services, health tips and obtaining vital peer support would be very important for the interested customer.

Control over data and services would also be limited by group membership. The pharmacist and more importantly the patients could create and publish new content (audio, video, services) to the groups. The content itself could be tagged with the appropriate group names, thereby making it only visible to those it is most relevant to. This would keep data private to an extent and allow for greater customisation, as the content would be patient centric and patient driven.

6.2 User Scenario: an example of system in use

Having signed up for the service and gone through the registration process and a system walkthrough in the pharmacy, a customer, John Doe, receives an information pack from the pharmacist outlining the steps for using the system. Included in the pack are all the details required to install the software on his home device and an instructional video. After successfully installing the client side software, John logs onto the homepage of the system. His homepage shows a number of public and private groups. The private groups are groups which the pharmacist has associated with the user during the registration process. Diabetes, Insulin and Diabetes Pen are the three groups associated with the user. The public groups are special interest topics such as hobbies and sports which enhance the social dimension of the system. The user is prompted to enter his home location. Upon doing this, a new group, geographical neighbours, appears on his homepage. The system has taken John's home location and added him as a member to the geographical group that corresponds to his home area. Within the group are four neighbors of the user who also use the system. Selecting the group, the user is brought to a new page. This page has an Instant Messaging chat room but nobody in this group is online. John notices a news information widget is also available with community notices posted by the users of the group. Backing out and entering the Diabetes group, John notices a lot more activity and content available. Widgets linking to other users blogs on the system are advertised. These blogs serve as a place where they can record an online journal of their daily battle with their illness. John selects the content area, and within here are a number of user generated services and podcasts. A dietary service catches his eye and he downloads it to his home area for later use. This service has a 7 day meal list for diabetes patients who

like to maintain a tough fitness regime. It comes with a disclaimer, "not approved by the pharmacist yet", informing John that the advice given has not been verified and could possibly be misleading.

John backs out and enters the online chat area. Here a group chat is going on with other users enjoying conversations about the weekend's football action. John introduces himself and receives a number of private messages welcoming him to the system. Some users were good enough to send on some links to help him get started. Taking the advice of some of the users he goes about and personalises his homepage and creates his first blog. A quick navigation to his homepage shows a content rich screen. His old homepage was a number of private groups and default public groups. John's new homepage has a cycling group, a rugby group, his geographical group and his original medical groups. Added to this a local newsfeed, two users blogs and his dieterary service are available. Before logging off for the evening John tries the service creation tool and creates a service for cycling enthusiasts mapping out his favorite country cycling track. He is surprised at the ease and usability of the tool. Upon logging in the following day, John is quite pleased to see that another user has downloaded the service and sent him a message. In his inbox is a 2nd message from the pharmacist informing all users who downloaded the dietary service that he has approved the content and advice.

7   FUTURE CHALLENGES AND CONCLUSION

Proposing an architecture that deals with service creation, file sharing and instant communication over several personal network domains poses several challenges. Synchronisation, ease of use, mishandling of information, illegal content, trust and privacy implications are just some of several problems that – although considered in the design - would be encountered in a live system. Addressing these problems before they become an issue is thus the real goal even if we can conclude little before to assess a real system in a real setting. By adopting a popular network architectural style, embracing open source protocols and following good programming practice it might be possible to develop a system that has long term stability, scalability and security. Further work to be carried out would be a full requirements analysis and prototype design of the system in order for a pilot study to be carried out and refined.

We are looking forward to assessing our architecture in the field, we can anyhow draw some initial conclusions to the approach we are proposing and the evidence we are reflecting on. We have initially asked ourselves how to support safe appropriation of medical information, procedures and technologies without fostering the circulation of mis-information, and unsafe practices. We have seen that a bottom-up, patient centered approach would ask to look at patients not so much as passive actors who have to comply with doctors orders but rather as proactive actors that develop relevant, local and practical knowledge on how to deal and live with their disease. We believe that sharing this information is vital in a future HC in need to contains endlessly increasing costs. Research on Health Care information systems has already showed that the identification of actors and their role should be dynamic, iterative and interpretative (Pouloudi, 1998). As Pouloudi and Whitley also showed, actors depend on a specific context and time frame (1997), moreover they cannot be viewed in isolation as their position will change over time (Mantzana and Themistocleous, 2004). In this sense, we have developed a participative model where the role of who is producing relevant knowledge and who is consuming it is not prefigured in the system in a fixed way thus allowing for dynamic role and group formation. The only exception is community pharmacists, who are put in their position to support patients, pointing them to similar ones and supervising their shared contents.

We believe that this is advancement to actual Health 2.0 models for at least two reasons. The first one is that while actual Health 2.0 systems do not have any mechanism that prevent the diffusion of mis-information and unsafe practices (because content can be freely created), the system we propose strongly afford safe content to be shared, with unsafe content flagged for the user. The extra 'validating' work requested to community pharmacists might be a problem but it can be also marginal with respect to the possibilities to further increase their interactions and familiarity with patients and their problems and consequently their customer fidelity and revenues. The second contribution of our proposition

regards the addition of a local dimension to the actual Health 2.0 platforms, which are solely based on remote interactions, and which can rarely allow face-to-face encounters with people with similar health problems. Thanks to the facilitating role of pharmacists our platform would also afford patients to meet face to face as pharmacists are put in the position to point patients to local people in a similar situation.

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