Trust and compliance: today's online environment, pregnancy and personalisation

Perdita Stevens*

School of Informatics
University of Edinburgh

Abstract. In most e-Health systems to date, trust and compliance have been regarded as simple issues (easy to understand, although not easy to produce). In this short paper we argue that in the specific context of pregnancy and childbirth they are more subtle. We discuss the nature of *today's* online resources and communities, and how they are used. We discuss the implications for developers of personalised eHealth systems aimed at pregnant women.

1 Introduction

Over the past decade or so, the growth of the Web, and of its general availability, has transformed the access to information of a large proportion of adults in the developed world. Despite beginning as a repository for geekish information, the Web has become a resource of interest to everyone, and usable by most.

At the same time, medical practitioners and those interested in supporting them have been exploring the possibilities for using the Web and related technologies to allow people to access appropriate, perhaps individually tailored, information at a time and place of their choosing. The vision is that this would help people to have better control of their own health. After an initial surge of commercial enthusiasm in the final years of the twentieth century, however, the growth of this field has been slower than some imagined. Interactive, personalised systems are not yet mainstream.

Thus we have two parallel phenomena: the organic, non-planned growth of the Web and its communities, and the design of a future world of eHealth.

In this paper we will suggest that the first phenomenon has had effects on the attitudes and behaviours of potential users of eHealth systems, which it will be beneficial to take into account in their further development. In particular, the nature of trust in health information, and compliance to health advice, has in important respects been altered.

Ehealth means a variety of things. We focus on systems for people whose health is at stake (not their caregivers), which aim to inform and advise them on decisions relating to their health. Within this category, domains that have been considered include smoking cessation [4], diabetes management and nutrition

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* Email: Perdita.Stevens@ed.ac.uk Fax: +44 131 667 7209

[1]. Naturally, researchers have concentrated first on areas where it is possible to give relatively uncontroversial advice, and where it is clear that the perfectly rational user would trust and comply with the system's advice.

2 Why consider pregnancy and birth in particular?

Health care during pregnancy is a particularly interesting case study for two main reasons.

– There are many affected people worldwide (pregnant women, but also their families and caregivers).
– Women are very highly motivated to seek out and act on health information during pregnancy, because the potential effects on them and their babies are obvious and immediate. Moreover, since pregnancy is not an illness and is often planned, many women have plenty of time to seek information before they make their decisions.

Therefore, there is a large and lively collection of resources and online communities relating to pregnancy and birth. We will discuss the nature and influence of these.

It is an interesting case study for issues of trust and compliance in particular because many of the issues that arise are highly controversial, with usual practices and advice differing systematically between countries (e.g, the US and the UK) and between professional groups (e.g., midwives and obstetricians), as well as unsystematically between individual practitioners.

3 Trust and compliance: a traditional view

One traditional view of trust and compliance in health care has been embodied in the phrase "trust me, I'm a doctor". According to this view, both doctors and patients expect that the doctor will tell the patient what to do, and that the patient will do it. Understanding by the patient is optional; understanding by the doctor is assumed. This has probably always been a caricature. One sign of problems with the view is that patients do not always follow their instructions, even when they have understood and remembered them correctly.

The informal article [3] gives a general discussion of non-compliance and why it occurs, emphasising that it occurs more often than most health professionals imagine. Interestingly, although it discusses the fact that non-compliance may be a deliberate decision, it does not explicitly discuss cases where the patient may have made a judgement *about the advice itself*, for example, concluding that a different health professional would have advised differently and deciding to follow that imaginary advice instead. For example, it mentions that a patient might take less than the prescribed dose of a drug because the patient fears side effects, but it does not mention that a patient might take a lower dose because they know that a different dose was used in a relevant clinical trial.

Most of medicine is based on "informed consent" – a patient should consent to treatment recommended by a doctor, and they should have enough information to make a reasonable yes/no decision about whether to do so. Pregnancy care is different. The UK government report *Changing Childbirth*[2] recommended that the maternity services should be more woman-centred: one result of this is the oft-occurring phrase "informed *choice*" (rather than informed consent, or compliance) to describe the ideal role to be played by the pregnant woman.

In practice, however, a traditional compliance model still holds sway. For example Stapleton et al. write [6]: "We observed a strong hierarchy within the maternity services, with obstetricians at the top, midwives and health professionals other than doctors in the middle, and pregnant women at the bottom ". They conclude: "The hierarchical power structures within the maternity services, and *the framing of information in favour of particular options*, ensured compliance with the "right" choice." (my emphasis).

4 Nature of today's resources

Web sites range from the sites of medical research journals, to one giving the complete text of Enkin et al.'s classic book on evidence-based care, "Effective care in pregnancy and childbirth" (http://www.maternitywise.org/guide/about.html), to many frankly paternalistic sites ("Your doctor will decide..."). More interesting are the newsgroups and mailing lists that give access to other pregnant women and to their caregivers.

4.1 Usenet newsgroups

The main relevant newsgroup is misc.kids.pregnancy (mkp). It has:

– relatively high traffic (hundreds of messages per day);
– small number (say 5-25, depending on definition) of "resident experts" (mostly not health professionals) who regularly answer questions and provide references to sources of information, including abstracts of medical research papers;
– large number of less regular posters;
– US bias, but members worldwide;
– topic drift and off-topic argument, but not so much as to swamp the on-topic posts;
– a mixture of support, chat and factual/scientific traffic.

A typical example thread is that headed "Amniocentesis - cons/pros", which began on February 25 2005, and amassed over 60 followups in the next week. It included scientific and statistical discussion of what amniocentesis can and can't show; emotional and moral discussion of the pros and cons of choosing amniocentesis (including a subthread on whether a post-amniocentesis miscarriage should be considered murder!). It also included some information on practices in different countries concerning when amniocentesis is offered/recommended.

Although there is from the point of view of someone seeking scientific information a rather low signal to noise ratio, someone asking either for scientific information or for contact with others who have similar experiences to herself almost always receives it (even if it pertains to a rare condition or combination of circumstances). Any new study reported in the press is discussed (and often criticised in a scientifically literate manner) on this group. Someone who reads this group over months in preparation for and during pregnancy will at least be aware in advance of many of the issues on which she has to make choices, and will often be aware of controversies that she might not otherwise encounter. She is likely to recognise the fact, if a health professional gives her only one side of a story.

4.2 Mailing lists for professionals

Yahoo group ukmidwifery (http://health.groups.yahoo.com/group/ukmidwifery/ and obstetricians' mailing list http://forums.obgyn.net/ob-gyn-l/ are both available to laypeople. Membership of ukmidwifery has to be approved, but laypeople are explicitly welcomed and invited to ask questions. Laypeople are strictly forbidden to ask questions on OBGYNL, but anybody can read the archives.

Comparing these two is perhaps the starkest demonstration of the systematic differences in approach between obstetrics and midwifery. Almost any issue would serve to illustrate, but we might take VBAC, vaginal birth after caesarean, as an example. Some obstetricians believe that after a woman has had one baby by caesarean section, all subsequent births should also be by caesarean section. Others (and most midwives?) vehemently disagree. Both sides claim to have studies to back up their arguments. ukmidwifery regularly includes support for women seeking VBAC, and a regular poster recently advertised a workshop on the subject. Indeed, a recurring theme on the list is to bemoan the current caesarean rate, which most members of the list consider to be inexcusably high. On OBGYNL, by contrast, a typical recent post on the subject (http://forums.obgyn.net/ob-gyn-l/OBGYNL.0503/0303.html), in a thread entitled "Those crazy VBACs", included the phrase "If I were allowing VBACs".

All groups, particularly those with a relatively stable membership, such as these professional lists, develop their own "tone". The contrast between these two makes any reader aware that there may be disagreement between professionals on many questions that will arise in pregnancy. It is likely to decrease a woman's trust in any single professional's unsupported opinion.

5 Effects on trust and compliance

Women have always had the option of seeking out textbooks and research papers on topics relating to pregnancy and birth. What has changed in recent decades is partly that the Web has made access to such information dramatically easier, but also that qualitatively new sources of information have become available. It is now possible to hear about the advice given by other people's

healthcare providers worldwide, about their experiences, and even to eavesdrop on heated discussion among health care professionals themselves. Moreover, the large membership of the available fora makes it possible to form an impression of the consensus or lack of it on an issue: this is not just an online version of coffee morning chat.

Thus it is now much less likely that a woman who doubts the advice she is given will have no option but to trust it. She may already be aware of whether the advice she is receiving is controversial; she can easily go to a newsgroup or mailing list and ask about others' experiences. Statements of fact, in particular, are often easy to check. Practitioners who say things they are unsure of have always risked being discovered in error, which may damage trust. Many, however, prefer to sound confident and risk being wrong, rather than admitting to being unsure (which might also damage trust). An effect of the growth of online resources and communities is that the balance of risk has changed in such cases. This should actually benefit eHealth systems, since they do not depend on fallible human memory. The implications of more women being aware of controversies within the professions are harder to assess. A good eHealth system probably must be prepared to tackle a controversy head-on if the user is aware of it, but must not confuse the user who is not.

On the other hand, in relationships with human practitioners, a woman is very likely to buy into a particular style of advice because she trusts the individual practitioner. A trusted practitioner will be given the benefit of the doubt if her/his advice does not accord with what is expected: the user may feel comfortable questioning it, or may assume that there is a good reason for the variance. Establishing trust is harder where there is no continuity of care, and this may be expected to be a problem for eHealth systems.

Compliance, even where consent is ostensibly given, is also at issue. For example, screening for gestational diabetes is routine in the USA, but there is a controversy over whether this is appropriate: one school of thought is that gestational diabetes is a misnomer. Misc.kids.pregnancy regularly hears from people about to undergo this screening who are advised on how to "beat the test". Inevitably, some posters exclaim that it would be better to refuse consent to the test than to subvert it, and others explain that their providers are so insistent that they should have the screening that to refuse would be intolerably awkward, so that they prefer to take the test and pass by hook or by crook!

Thus a qualitatively different kind of non-compliance is on the rise: a woman may be non-compliant with a given piece of advice because she is instead choosing to comply with what she perceives as an alternative piece of advice from a "virtual" practitioner: she makes her own choice of what to comply with, *resting on the authority of what other practitioners advise in similar circumstances.* This has obvious risks: there is unlimited scope for misunderstanding about when a piece of advice is valid. It has balancing benefits of defending against unknowingly following advice from a maverick practitioner, one having an off-day, or one whose advice rests on a value system different from a woman's own.

Health practitioners' attitudes to people seeking health information online can be instructive. Almost everybody professes to believe that it is a good thing for people to take responsibility for their own health, and to be informed about it. Nevertheless, there is a stereotype of the informed patient as a non-compliant hypochondriac nuisance. It is interesting, for example, that Harris Interactive's Healthcare News [7] characterises all those who ever go online for health information as "cyberchondriacs". (Incidentally, [7] reports that 74% of all those online have at some point looked for healthcare information online, and that most of those do so using a portal or search engine, not by starting at a specialist site.)

6 Implications for eHealth systems, especially personalisation

In the light of access to this conflicting information, it is unlikely that the internet literate user of an eHealth system can be given one viewpoint and expected to trust it implicitly, even if it is backed up with argument. In order to be trusted, an authority probably needs to acknowledge the existence of opposing viewpoints and explain explicitly why a conclusion has been reached. This has been done to a limited extent: [1] is a good example.

We may ask whether it will ever be possible for a system to credibly claim to be viewpoint-free: will obstetricians and (radical) midwives ever be able to agree on the information and advice presented? Certain documents (NICE guidelines (http://www.nice.org.uk), MIDIRS Informed Choice leaflets (http://www.midirs.org) are already developed with this aim: however, anecdotally their development tends to be fraught.

What might personalisation mean in the context of an e-Health system aimed at pregnant women?

Most obviously, it might include taking account of previous medical and obstetric history. For example, parity – whether a woman has ever been pregnant or given birth before, how many times, and with what result – would almost certainly be considered relevant. Immediately, though, we can see that "here be dragons". We have already mentioned the VBAC controversy. Let us give two further examples, to stand for many more.

Should a pregnancy that lasts longer than average be ended by inducing labour, even when mother and foetus are well? This has become obstetrically routine, but is vociferously disputed. The evidence is discussed in [5], but the controversy continues. The heart of the argument is the disputed level of risk of perinatal death: not an easy issue for a human to handle tactfully, let alone for an eHealth system.

When is home birth a sensible route to consider? Opinions here vary from "never", via "for a totally uncomplicated second or third birth", to "always". Again, each group cites study evidence to support their viewpoint, and each study's methodology has its critics.

A more ambitious use of personalisation might be to start by getting a general picture of someone's ideal birth, and use that to give tailored information which

will be considered relevant. For example, someone whose ideal birth is in hospital with as little pain as possible might be given different advice to someone who prefers to avoid drugs and sees pain as positive. Exactly how to do this would need to be carefully considered, because naturally any system would have to present the risks and benefits of any given option honestly. A different slant on the same information might be justified, however. For example, one might offer information on labour positions that are often found helpful to both groups, but introduce the information differently. The potential drug-free home-birther might be told:

"People who prefer to avoid using drugs for pain control often say that finding good positions for labour is important to them. Some positions which are often found helpful are ..."

whereas the hospital pain-minimiser might be told:

"Even people who plan to use epidural anaesthesia should consider alternative methods of pain control, because there are many reasons why an epidural might not be available immediately. [link: What reasons are there?] What position you are in can make a big difference to how much pain you perceive. Some positions which are often found helpful are ..."

Possibly such matters, having more to do with the mother's comfort than with life and death, would be less daunting to address. Eventually, however, eHealth will need to go further.

7 Conclusion

This short, preliminary paper has aimed to open debate on trust and compliance in situations where people have easy access to information about controversies and different viewpoints. eHealth systems aimed at pregnant women must coexist with today's online resources and communities: to be useful, they must elicit trust in this environment.

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