HealthTrain
The Open Healthcare Manifesto

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Version 0.1

Thanks to our supporters and reviewers – for everything good about this project. Blame editing by this project's coordinator – for everything bad.

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Table of Contents

I. Introduction

What is in the name?

HealthTrain is shorthand for "Healthcare Cluetrain". At the tail-end of the first Internet boom Cluetrain Manifesto (http://cluetrain.com/), laid out the vision for how conversational media will transform business. The vision proved prescient, but has not yet been translated into the language of healthcare.

What this document is **NOT**

This is not a repudiation of business and legal realities in healthcare. Nor does this effort imply that "Cluetraining" of healthcare will come fast and easy. This is certainly not a call for a financial redistribution of any kind nor for a socialized healthcare system. The idea is to propose a set of principles that will empower individual healthcare stakeholders, while keeping the risks in check, thus starting a movement towards a truly open healthcare system.

Why should you care to read and act upon this document?

Much has been said about the impact of blogs and social media on politics, news, technology and entertainment. But, what will be the impact on healthcare? Will it be a force of good? Who will benefit? Many have praised the potential of "open media", especially as far as empowerment of individuals is concerned. Yet many are afraid of change or concerned about the downsides.

What exactly are you suggesting?

This Manifesto proposes principles under which open media could become a force of positive change in public health and the healthcare system. It steers clear of issues that may favor any stakeholder group over another, aside from promoting greater empowerment of individual healthcare consumers and professionals. The goal of this effort is not to offer specific prescriptions for a healthcare reform, as different people and groups have very different ideas. The objective is to propose general principles under which open expression and discussion can force system change for the better. This is work in progress that will benefit from constructive criticism.

What are the implications of this vision?

As other industries have shown the way, healthcare institutions must radically rethink how they relate with their constituencies. This change will not be easy for some of them, but the individual empowerment afforded by the Internet is changing the rules of engagement and there is no going back. Open media will increase the pressure to draw a line between valid safeguards, serving a legitimate purpose, and unjustified restrictions harmful to the public.

Who is behind this?

This effort is **for, of and by** individual healthcare consumers and professionals, but is designed to engage every institutional healthcare stakeholder in a dialog, with the goal of adding their support along the way. Our group of supporters already represents a broad cross-section of healthcare. The goal is to frame the issues in a "neutral way" so that every stakeholder group could sign on – much like how this happened with earlier eHealth standards.

Why should Open Media or this Manifesto merit any credibility?

This is the whole point of the project, isn't it? Of course not every blog or online media participant is equally credible. But how is this different from credibility of traditional authorities? Proposed set of guidelines is designed to help elevate credibility of open media and spread awareness about its impact and potential. Given open media's ability to self-correct and self-adjust, this Manifesto may in fact raise the bar on credibility well beyond the Internet.

What does this document's version mean?

Answers to complex questions about healthcare cannot be decided quickly by a few and without input from everyone affected. This is reflected in the proposed versioning scheme and process for taking action:

- **v0.0.X:** Pre-public drafting with a core group of like-minded supporters, with the goal of initial framing and solidifying the vision.
- **V0.X:** Release for public comment to stimulate debate about the principles proposed. The goal is to have every stakeholder group weigh in and have their feedback reflected. Support grows from here.
- **vX.Y:** Enough consensus to have these principles well defined and broadly adopted as a policy. Possibly with oversight by a new or existing standards body. Think **"HONcode 2.0"**.

To help give healthcare consumers and professionals a well-deserved seat at the table in shaping healthcare, please read and support this Manifesto!

II. Preamble

1: What is "Open Healthcare"?

The nature of the Internet as a means of disseminating health media is changing. The first wave of online technology enabled organizations to extend their top-down, "command and control" communication methods to a new channel. But a new wave of open publishing technology now enables any individual, with or without professional training, to communicate with global audiences to share health-related information and opinions.

This communication occurs through multiple formats, including blogs, podcasts, wikis, message boards, videocasts, collaboration, community and review sites, as well as other forms of social media and peer-to-peer services. This grassroots media continues explosive growth with or without permission or endorsement from established healthcare institutions. Healthcare is entering a "New Era", foretold by the Cluetrain Manifesto (http://cluetrain.com/), which greatly inspired this "open healthcare" movement.

2: Why is this Manifesto needed?

This tidal wave of open health media is raising questions about its ultimate impact. Everything is in play. How will consumers find and act upon health information? How will professionals incorporate the latest scientific advances into their practice? How will healthcare institutions respond to increasing demands for transparency? How will the entire healthcare delivery and financing system be transformed by grassroots action?

Open media offers tremendous opportunities to improve healthcare at every level. But there are also risks and dangers inherent in greater openness and the Hippocratic principle of **"first do no harm"** is as relevant as ever. There is a great need to declare and spread a strong argument for the benefits of open health publishing, while proposing common standards of conduct aimed to mitigate the new risks and promote greater responsibility.

3: What about existing eHealth standards?

The early Internet health information standards, by HONcode Foundation (www.hon.ch), Internet Healthcare Coalition (www.ihealthcoalition.org) and URAC (www.urac.org) offered the first steps to creating integrity safeguards for Internet health information and remain as relevant as ever. However, they were primarily designed to apply to "command-and-control" communication, top-down from institutions to individuals. They do not sufficiently recognize, promote and address the positive opportunities and potential threats presented by open peer-to-peer exchange of healthcare information and opinion.

The goal of this Manifesto is to complement these early standards and declare the principles for further development of open health media. With this Manifesto we are hoping to kick off a grassroots awareness campaign, which at some point in the future may lead to creation of a more formal standard.

4: What are the goals of this Manifesto?

The Manifesto is put forth to declare a shared vision of how open media can help make a positive impact on healthcare. A vision that could bring together different stakeholder groups, in the system that has been charitably described as "balkanized". Without a doubt, supporters of the Manifesto may hold directly opposing views on a long list of issues, including healthcare policy, politics, finance, incentives, liability, roles of the stakeholders, scope of professional practice, scientific conclusions and moral values to name only a few.

None of these legitimate differences need to be in conflict with a shared understanding that an open exchange of information and opinion can help create a positive change. In the sphere of public life, it has often been said that "sunshine is the best disinfectant". It should be up to any individual, consumer, professional, institution, professional society or advocacy group to decide where to shine the light. Yet it would be up to the audience to decide if an argument is convincing and what to do in response.

5: What action are you hoping to spur?

The early growth in open health media is well underway, driven primarily by individual consumers and professionals, publishing online in a variety of available formats. Yet, there is still significant lack of awareness and recognition of the ongoing changes in health media creation and distribution by the traditional institutions, professional societies and advocacy groups. Many are starting to learn and adapt. Yet others still believe that open media is not important and are ignoring or resisting it. This Manifesto will help rally the early adopters of open health media around a simple set of principles, easy to describe and disseminate. Thus the main actions we hope to spur include:

- Declare a shared vision for "open health media".
- Rally support of the early practitioners of openness by collecting input and endorsements from bloggers and forward-thinking healthcare leaders.
- Stimulate discussions with traditional healthcare institutions, professional societies and advocacy groups about the principles declared.
- Advocate incorporation of these principles in organizational and professional policies and wherever applicable push for legal and regulatory reforms.
- Continuously revise these principles based on community feedback.
- Strive to research and understand the impact and outcomes that result from the growth of open health media.

III. Theses

The principles of the Manifesto are organized into "Theses". Each Thesis starts with naming of a key concept followed by explanation of its role

By design, every Thesis is kept short to only highlight the key ideas. Detailed explanations of their applicability could be longer and are yet to be developed. This is similar to organization of standards like HONcode that separate clear and concise principles from the details on guidance:

1. **Openness**
   The open and democratic nature of the emerging new forms of health media is in the public interest and should be encouraged and promoted in every possible way. While restrictions on open expression may sometimes be legitimate, the burden to justify them should be high.

2. **Empowerment**
   Open health media is empowering individual subjects of the healthcare system: consumers and professionals. Traditional healthcare institutions, professional societies and advocacy groups must embrace individual empowerment or risk their reputations in the court of public opinion.

3. **Conversation**
   Open health media is grounded in "human-to-human" conversations. They are experiential, personal, earnest and often irreverent. They greatly differ from traditional "command-and-control" forms of healthcare communication. They often convey truths that are too inconvenient for traditional channels.

4. **Empathy**
   Many people are driven to participate in open media conversations by a debilitating or life-threatening illness. They are seeking more than merely information, but also support and encouragement. The human dimension of open media should translate into empathy with their pains and fears.

5. **Trust**
   Embracing open health media and these principles offers an opportunity to build trust. No individual or organization should take the public's trust in them for granted but must work hard every day to earn and keep it. Reputations are now very public for anyone to judge, question and act upon.

6. **Critical Thinking**
   In the medium where millions of dissonant voices are a mouse click away, it takes critical thinking to discern who and what to believe. Open media should not be viewed as "ultimate authority". Before accepting opinions you find online think critically and seek out counsel of the people you trust.

7. **Guidance**
Consumers should not entrust their healthcare decisions solely to online media, which is no substitute for patient-physician relationship. However open media may be used to support a patient-physician relationship or provide professionally guided education grounded in experience and training.

8. **Control**
Open media should put consumers in greater control over all aspects of their care, including choice, delivery, documentation and information disclosure. Patients and consumers should be empowered to make their own decisions, informed by professional guidance and vetted by critical thinking.

9. **Credentials**
While open media may turn regular people into "new authorities", it is critical for participants to disclose their healthcare professional credentials or lack thereof. Yet, credentials alone cannot be the basis of trust and healthcare professionals can leverage open media to enhance their reputations.

10. **Transparency**
Open media is increasing transparency of healthcare industry practices. Similar transparency standards should be applied to the authorship and sponsorship of views communicated through the media. The audience will grant or withhold trust based on disclosure or lack thereof.

11. **Privacy**
Support for openness and transparency does not condone disclosure of private and confidential information, as defined by relevant legal, ethical and regulatory guidelines, especially on patient privacy. However, such guidelines should not be abused to prevent disclosures, clearly in the public interest.

12. **Anonymity**
Candid expression is often possible only under a strong protection of anonymity. Thus privacy of the anonymous speech should be protected. Yet, anonymous expression should expect a higher hurdle to earn trust, as it may be used to mask biased, unethical or otherwise improper behavior.

13. **Scientific Validity**
Openness may increase risks of mis-information, quackery and deceit. The level of trust in open media participants should be based on their adherence to scientific methods. Whenever the science itself is in dispute, openness can serve as a mechanism to air, discuss and reconcile different points of view.

14. **Conflicts of Interest**
Everyone's statements are colored by experience, biases and interests that go beyond merely financial. The antidote to any conflict is full disclosure of all relevant information. The audience will grant or withhold trust based on open and candid disclosure or lack thereof, severely punishing any breach of trust.

15. **Sponsorship**
    Commitment to open media expression comes at a cost and participants
    expect to derive a benefit, financial or not. Oftentimes communicated views
    may carry some form of sponsorship, commercial or not. Possibility of conflict
    of interests is inevitable but can be mitigated by full disclosure.

16. **Promotion**
    Self-expression that leads to individual empowerment is inherently self-
    promotion and should not be frowned upon merely on that basis. There is a
    fine line between legitimate self-expression and spam. The difference may
    have to be defined on a case-by-case basis, sometimes as a formal policy.

17. **Controversy**
    Openness invites different viewpoints and therefore disagreement, sometimes
    rising to the level of controversy. While less welcome in the traditional health
    media, heated disagreements or controversies should not be discouraged,
    but used as an opportunity to publicly examine issues from all perspectives.

18. **Civility and Respect**
    Disagreement is no excuse for disrespectful or abusive behavior. Moderation
    of personal attacks, hate speech and foul or demeaning language should not
    be viewed as a violation of the spirit of openness and transparency. When in
    doubt, use a test: "would you say this to a neighbor face-to-face?"

IV. Supporters

1: A Disclaimer

The idea is to make this document easy to support by as broad group of individuals and organizations as possible. Unfortunately the legal environment in healthcare makes many people pause before signing on to anything.

Therefore, endorsement of this Manifesto should only be construed as support for its principles "in the spirit" and **shall not constitute agreement with every word**. The language will get refined as the effort gains traction and incorporates more input. Note the explanation of document versioning in the Introduction.

2: Silent Believers

Even with liability fears aside, many may still have concerns about acceptance of these ideas in their professional environment, What if this thinking is "too-far-too-fast" for my colleagues, partners, clients or neighbors?

Early reviews of this document found quite a few people with this perspective. If you see yourself not yet ready to become on-the-record supporter (or disagree with the vision), you can do service to your organization, professional society or advocacy group by bringing up this Manifesto and discussing its ideas with powers-that-be. They will hear about it sooner rather than later anyway.

So, thanks to all of you too, the Silent Believers.

3: Founding Signatories

The Founders are the individuals who reviewed and provided input and support for this Manifesto, in its early stages of development.

While only symbolic, the "Founder" designation is open to anyone who provides their endorsement and comments before the end of the Year 2006.

When providing your information for addition to the list of Founders, that will be continuously updated online, please include:

- **Name / Degree:** As you want it to appear
- **Personal URL:** To be hyperlinked by name
- **Organization:** If applicable. This does not imply endorsement ***BY*** the organization, unless stated explicitly
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- Frank Hone, Executive VP, Ogilvy Healthworld, author of the book "Why Healthcare Matters".
- Michael Ryan, Managing Partner, Executive Impact Group, http://www.execimpactgroup.com
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Credits:

- To Nedra Weinreich for suggesting the name "HealthTrain"
- To Steve Rubel for coining and promoting the concept of "Silent Blogging Believers" (SBB)
- To Fard Johnmar for proposing the term of "command and control" to describe pre-Cluetrain healthcare communication
- To all authors and supporters of the original Cluetrain Manifesto

Coordinator:
Dmitriy Kruglyak of The Medical Blog Network (www.healthvoices.com) is responsible for coordinating this effort and final editing of **v0.1** document. He did his best to ensure that every relevant perspective got represented.

4: Get Updates

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