# Free and Open Source Software in Healthcare 1.0

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Abstract: The possible benefits of widespread adoption of Electronic Health Record/Electronic Medical Record (EHR/EMR) technologies are widely documented, yet progress is slow and few propose a viable mechanism to achieve shared goals. Multiple problems of cost, interoperability, vendor lock-in, standardization and longevity have been identified and have persisted. Even "successes" have problems. While multiple initiatives and much money is spent on finding answers, Free/Open Source Software (FOSS) licensing holds promise for solving these problems or at least making them more tractable. Multiple deployments, novel applications, and multiple companies offering support appear to be occurring. Interoperability and connectivity may be an area of particular proliferation. By vendor and site self-report there are a substantial number of patient records, 3,959,065 in 898 non-Federal government sites and 24,442,000 patient records in 1607 Federal government sites that use FOSS or public domain software EHR/EMR's. To date, 232 Open Source titled works on various aspects are listed in PubMed. Local and national education is needed to ensure that equal attention be given to FOSS licensed EHR/EMR software.

Keywords: Free and Open Source, Electronic Health Record, Electronic Medical Record.

**Introduction**

The American Medical Informatics Association (AMIA) Open Source Working Group (OS-WG) has created this consensus paper on Free/Open Source Software (FOSS) definitions, FOSS licensing, preferred FOSS licenses, major problems with Health Information Technology (HIT) and Electronic Health Records/Electronic Medical Records (EHR/EMRs) and how FOSS licensed EHR/EMRs can solve these problems. The purpose of this paper is to provide a basic introduction to these concepts and terminology, dispel myths and to explain the possible benefits of this software in medicine.

The benefits of the widespread use of Electronic Health Record/Electronic Medical Record (EHR/EMR) are generally recognized (Institute of Medicine (U.S.). Committee on Quality of Health Care in America, 2001) yet few propose mechanisms for proliferation of these technologies(Jones et al., 2008). Decades of literature exist documenting barriers to proliferation of EHR/EMRs (Valdes, et al, 2004). Major problems of EHR/EMRs are: cost (Shekelle, Morton, & Keeler, 2006), interoperability, standardization, fragmentation, longevity, ethics and multiple organizational issues. Most EHR/EMR software costs too much, delivers too little and does not have adequate safeguards for privacy and security. Furthermore, they have difficult ethical and generational issues such as practicing 'black box medicine' (Herb, 2002), vexing autonomy issues for both patients and practitioners, and serious doubts about using corporations alone for custodianship of EHR/EMR software (Trotter, 2007b).

Free and Open Source licensed EHR/EMR software holds the possibility of solving difficult problems that proprietary EHR/EMR software historically has not(Allbritton, 2003). There is evidence that use of FOSS EHR/EMR software can result in superior health care at a lower cost (Goldstein, 2007)(Longman, 2007)(Weiss, 2007), sometimes at a dramatically lower cost ($4,000 vs. $26,000 per Full Time Equivalent) (Kost, 2007). FOSS licensed software offer the possibility of reducing costs of EHR/EMR software by

shifting the economics of these software's from that used for private goods like cars or furniture to a public goods model such as a lighthouse (Foreman, 2007). FOSS licenses can also create true markets by reducing the information asymmetry between buyers and sellers created by proprietary software in health care. The "noise effect" of too many competitors is a characteristic of EHR/EMR software market failure, yet establishment of a monopoly or cartel is similarly inefficient (Foreman, 2007). FOSS licensed software allows competition on the basis of service and support, not licensing and tends toward being inclusive not exclusive. Licensing can account for at least 1/3$^{rd}$ of the cost of the software in small office settings (Miller, West, Brown, Sim, & Ganchoff, 2005).

FOSS licensed EHR/EMRs have additional flexibility and far more transparency than proprietary EHR/EMRs since important user rights to the software are safeguarded. This flexibility and transparency directly impacts a number of issues such as interoperability as it opens many more avenues for achieving interoperability. Fragmentation is still a problem with FOSS software; however, the problem becomes more of a technical one, not a political or contractual one. Finally, the open nature of FOSS licensing for EHR/EMRs solves many ethical problems of EHR/EMRs since the software can be readily examined by anyone, particularly third parties, and no single corporate entity point of failure need exist. Despite its open nature, software security can be as good as or better (Boulanger, 2005) than proprietary software.

The term FOSS originates from a MITRE report (Bollinger & MITRE Corp., 2003) which resulted in the use and treatment of these software as equal with proprietary software within the Department of Defense. FOSS ideas are not new. The Free Software Foundation was established in 1985 in response to the disruption by proprietary software of the ability of software engineers to cooperate and collaborate (DiBona, Cooper, & Stone, 2006). Historically, software has been developed in a FOSS manner nearly since its inception(Levy, 1994; Raymond, 2001). FOSS licensed software safeguards users' rights and freedoms such as the rights to

run, copy, distribute, study, change and improve the software (Free Software Foundation, 2007b). These rights are critical for widespread adoption of EHR/EMR technology because they make many difficult problems such as interoperability, standardization, longevity, ownership and ethical issues such as privacy, and security solvable. FOSS definitions that will be covered are: Free software licensing, Open Source software licensing, and their major differences. The GNU General Public License (GNU GPL) as it relates to medicine will be covered in-depth.

**General definitions**

Free software and Open Source software have specific definitions and legally enforceable licenses. 'Free' refers to the liberty to use, modify, and or distribute the licensed software, not necessarily the price or value. They include the rights to run, copy, study, distribute and extend the licensed software (Free Software Foundation, 2007a). These rights are specifically granted with Free software licenses. Proprietary software licenses usually take away rights. They frequently take away some or most of the rights listed above. Proprietary licensed software is privately owned and the owner can legally exclude virtually any party it wishes from the use, examination, copy, distribution, or extension of the software. The inner-workings of proprietary software are trade secrets. Frequent confusion occurs with the terms ‘proprietary’ and ‘commercial’. Many FOSS licensed health information technology software is absolutely commercial, as good as, better, or clearly superior than proprietary counterparts, and some proprietary licensed software while considered ‘commercial’ is un-competitive and poor quality.

Open Source licensed software practitioners share many of the same goals of the Free Software Foundation but emphasize more pragmatic issues such as access to source code, economics, and improved software development technique. Open Source de-emphasizes the user rights aspect of the software. Licenses that are considered free are determined by the Free Software Foundation (Free Software Foundation, 2008) and

licenses that are considered Open Source are determined by the Open Source Initiative (Open Source Initiative, 2006). If a given work of software claims to be Free or Open Source but does not use licenses approved by one of these two organizations, it probably isn't Free or Open Source.

Public Domain software has no copyright restrictions or license at all. Public Domain software can be repackaged and sold or modified and licensed as proprietary, Free or Open Source. Public domain software has no requirements or obligations on sharing or distributing whatsoever. An example is the Veterans Affairs VistA Electronic Health Record software which is in the public domain under the Freedom of Information Act (FOIA). It has been re-licensed as both proprietary in the case of the DSS corporation, and FOSS versions by different organizations such as the WorldVistA organization (WorldVistA, ).

While Free and Open Source licenses can be interchangeable, their subtleties have important ramifications for the communities they serve. For instance the FreeBSD (FreeBSD Foundation, 2008) license has few or no restrictions on distributing mixed proprietary source code with FreeBSD source code whereas the GNU GPL (Free Software Foundation, 2007d) does not allow this practice. Less restrictive licenses such as the Lesser GPL (LGPL) (Free Software Foundation, 2007e) may provide for a wider implementation of a library or application because LGPL software can be linked with proprietary applications without violation of either the Free or the proprietary licenses. The Affero GPL license adds an additional safeguard in that the source code for Affero GPL licensed software running on a publicly accessible server must be made available.(Free Software Foundation, 2007c). An example of an Affero licensed EHR/EMR is the Medsphere™ OpenVistA™ product which is based on FOIA VistA. An example of a Open Source license is the Eclipse Public License (EPL)(The Eclipse Foundation, ) which has specific provisions for indemnification of contributors and handling of patents among its contributors and users. Some (Trotter, 2005) consider the GNU GPL as the preferred license in medicine for many reasons both practical and ethical.

FOSS software licensing may be an especially good fit for medicine and medical practice because of medicine's fast-changing nature, relatively small market, and ability by third parties to readily and directly scrutinize software for privacy, security and interoperability problems. In addition, the community building and sharing aspect is akin to the publishing and sharing of medical knowledge for the greater good. Despite these qualities, there persist a number of myths regarding FOSS. Recurring ones are that FOSS software EHR/EMR's are not used in healthcare, one cannot make a living with FOSS software, only proprietary businesses and corporations can be trusted to create software that has value, FOSS organizations and software engineers are amateurs and do not work full-time, service contracts and warranties are not available, and more. Table 4 presents some FOSS myths versus realities.

Examples of FOSS successes are the Internet, Google, Web 2.0, the GNU/Linux operating system, courseware such as Moodle, and the Veterans Affairs VistA hospital system(Goldstein, 2007). Some FOSS disadvantages are:

- Frequently weak marketing.
- Its open nature means that it can be criticized and compared.
- Some features may be available with proprietary software that are not with FOSS licensed software and vice-versa.
- New features may appear slowly due to possibly reduced capitalization of new feature development. (Jones et al., 2008)

**Active Software Systems**

Despite the above mentioned flaws, numerous projects now have thriving commercial ecosystems including companies and service contracts built around them. (Samuel & Sujansky, 2008). Active FOSS EHR Projects identified in a recent California Healthcare Foundation study can be seen in Table 1. Deployments are occurring, some of them are quality award winning (HIMSS Analytics, 2008). The extent and character of deployments of both FOSS EHR/EMR's and Health Information Exchanges (HIE's) is not well studied.

**Standards**

Defining standards in medicine is an important but complex task. However, it is generally recognized that an abstract standard making process without rigorous real-world clinical testing is probably a futile exercise. An advantage of FOSS is that the software itself can become a test bed for evolving standards. An example is the de-facto standard of Veterans Affairs Freedom of Information Act (FOIA) VistA or the Center for Certification of Health Information Technology (CCHIT) certified WorldVistA EHR/VOE 1.0 software. WorldVistA EHR/VOE 1.0 is based as much as is possible on FOIA VistA with additions for use in the private sector. Both FOIA VistA and WorldVistA implement a large number of Health IT standards within them. Both Veterans Affairs and WorldVistA are committed to implementing as many standards as possible (Brown, Lincoln, Groen, & Kolodner, 2003). WorldVistA is committed to implementing relevant standards (e.g., Health Level 7 2.x, ICD-9, CPT 4, LOINC, SNOMED CT). Work on implementing standards such as the Continuity of Care Record (CCR) is currently underway (Lilly, 2008). Thus WorldVistA EHR/VOE 1.0 provides the unique opportunity of serving as a platform that can simultaneously serve as a reference implementation of a wide range of standards, allowing us to see them acting in concert.

**Selection Planning for FOSS Software**

Planning is important for all health information technology implementations. Planning guides are available such as the Texas Medical Association Electronic Medical Record Implementation Guide(Marcus, Lubrano, Katz, & Cowan, 2007). The guide is of some utility but like many guides that have a proprietary bias; it has serious structural flaws in that it completely omits FOSS and does not consider the success rate, sustainability, or adverse effects of proprietary EHR/EMR software in medical practice. Planning questions that are rarely considered in the proprietary world but should be asked are:

1. Is the license one that is approved by the Free Software Foundation or the Open Source Initiative?

2. Does a thriving, support community exist around the FOSS EHR licensed software?
3. Are the goals for the software realistic? For example, any EHR software could result in seeing fewer patients in a particular day which is independent of whether a system is FOSS system or proprietary.
4. Will the corporate agenda of the EHR/EMR Company always be in harmony with the healthcare organization?
5. Will the electronic records be readable in the distant future? (Trotter, 2007b)
6. Can the healthcare organization itself, fix or grow the software and control its own destiny with the software?
7. Does the healthcare organization understand the FOSS ecosystem and is it willing to 'give back' code or money donations to the profession or community?
8. Has the EHR/EMR software actually been shown by an independent source to actually improve patient care?
9. Can the software be easily audited by a disinterested 3rd party for privacy and security flaws?
10. Are code escrows for failed EHR/EMR companies' adequate protection against business failure, buyouts or bankruptcy?

**Methods**

This consensus paper was authored and approved by vote of the American Medical Informatics Association (AMIA) Open Source Working Group (OS-WG) membership with input from members of the association, working group from an e-mail list as well as business meetings. The larger FOSS community outside of AMIA was also invited to comment through solicitation on email lists. A survey was undertaken as to the absolute number of patients that have been entered into FOSS based EHR/EMR software systems in actual deployments. A self-report call for general location, software version, and number of patients entered into FOSS EHR/EMR systems was posted on e-mail lists and groups such as OpenHealth, HardHats and the Linux Medical News http://www.linuxmednews.com website. International totals were not measured. To

allay concerns among vendors regarding divulgence of customer lists, exact geographic location, type of site (hospital, clinic) was not asked for or counted. Follow-up phone calls were placed to some but not all known deployment personnel and totals were asked for independent of vendor information. More site specific details from vendors than is shown in the results were supplied. Checks for duplicate patient entries were not done. No qualitative difference was made between more ambulatory care oriented software such as ClearHealth and more hospital capable software deployments such as VistA. A PubMed query was constructed and run for all papers that had 'open source' in the title. Papers were classified based upon the interpreted subject matter as well as the type of publication the paper was published in. A leading distributor of novel Open Source 'middle-ware' and connectivity 'appliances' Webreach, Inc. was asked about its number of paid support deployments as well as software downloads.

**Results**

As table 3 shows, there are 3,959,065 patients entered into Non-Federal government sites using FOSS EHR/EMR software, 939,065 patients in Veterans Affairs VistA-based or derived Non-Federal sites, an estimated 24,442,000 patients in Federal VistA-based sites including the Indian Health Service RPMS variant and a total of 28,401,065 patients in all FOSS or public domain EHR/EMR software based sites. 13.9% of total patients are in Non-Federal sites. 10.6% of the total patients are in Non-Federal ClearHealth software sites. Number of sites is 898 in non-Federal locations with the bulk of these sites being ClearHealth with 68 locations being VistA variants. Federal sites numbered 1607 and the total number of non-Federal and Federal sites was 2505. The overall density of patients of ClearHealth versus VistA was lower with the overall density of ClearHealth sites being 830/3,020,000 or 3638.55 patients per site and the overall density of non-Federal sites is 68/ 939,065 or 13809.78 patients per site.

At the time of this writing, 232 PubMed papers have the words 'open source' in the title. The number of papers with 'open source' in the title has grown steadily year by year since 1999 as shown in Figure 1. The

papers are characterized in Table 1. There were 17 review articles. Webreach, Inc. reports 203 current paid support clients for its Mirth Open Source connectivity software and appliance. Thousands of downloads of the Webreach Mirth™ software are reported on the Sourceforge.org website.

**Discussion**

The survey of patients in FOSS systems may be the first data of its kind that attempts to gauge the extent that FOSS based EHR/EMRs are being deployed and used. The number of patients entered into FOSS or public domain based EHR/EMR systems and deployments are likely to be under-stated because of existing sites that either did not respond to the public call or were not contacted. Duplicate patients may have occurred. A conservative and skeptical interpretation of the data in Table 3 and the survey methodological shortcomings would still permit the conclusion that a non-trivial number of deployments have occurred and patients have been entered into these systems both Federal government and non-Federal government.

Un-answered questions are how many total patients are entered into all EHR/EMR systems, velocity of new FOSS deployments and patients being entered, geographic distribution of deployments, characterization of deployment (hospital, clinic, etc.), the true total number of FOSS deployments and more cost data regarding these deployments. The comparatively large number of patients in non-Federal government ClearHealth systems but lower density compared to VistA based systems is likely due to ClearHealth's more lightweight private practice management orientation with excellent outpatient GUI scheduling and billing versus VistA based systems which have a vast amount(Toppenberg, 2004) of software functionality needed to run large hospitals or clinics and include enterprise features such as Computerized Patient Order Entry (CPOE), pharmacy, dietetics, cafeteria, work orders and much more.(United States Department of Veterans Affairs, 2005)

There is growing activity in the medical literature on open source software. It was no surprise that many

papers were devoted to open source in bioinformatics. What was unexpected was the relatively fewer papers devoted to clinical research, quality and clinical informatics. The literature search undoubtedly missed important papers. However, there appears to be a trend in the medical literature towards more publications of open source topic papers in recent years.

The number of paid support customers from Webreach, Inc. is an indication of the commercial viability and proliferation of novel open source software in the interoperability and connectivity space. This area may be an emerging strength for FOSS licensed health IT software. These data provides additional evidence to dispel the myths that viable companies and paid careers cannot be had with FOSS, warranties and support are not available and that only proprietary software is 'commercial'.

FOSS licenses such as the GNU General Public License as well as other FOSS licenses as determined by the Free Software Foundation and the Open Source Initiative create software ecosystems that appear to be a good fit for health care given its public good economic nature. Including FOSS software and asking important questions in selection planning are important. Possible adverse consequences of proprietary software, success rates and FOSS are completely omitted from at least one major guide to EHR/EMR software in a large, populous state. While not perfect, FOSS development has resulted in viable software, companies offering support and a substantial number of deployments and actual patient records that hold the possibility of a mechanism for the large-scale computerization of medicine with fewer problems than proprietary software has. However, under-capitalization of development may be an issue.

**Conclusions**

Free and Open Source licensed software is a possible mechanism to access the widely expected but elusive power and benefits of EHR/EMR software while safeguarding patient, developer and practitioner rights. There are at least several thriving FOSS software ecosystems. Large scale, clinically used implementations

exist in non-trivial numbers. A sizable number of United States patients are entered into FOSS EHR/EMR software systems. Education and inclusion of FOSS in selection planning for EHR/EMR software is important. Activity and attention to the subject is growing in the medical literature but is lacking in the area of clinical research. Successes with connectivity may be an emerging strength of FOSS licensed software in medicine. More studies are needed to determine total number of deployments and velocity of adoption.

Table 1: California Healthcare Foundation Report: Active FOSS EHR Projects (Samuel & Sujansky, 2008)

| Project | URL |
|---|---|
| ClearHealth | www.clear-health.com |
| IndivoHealth | www.indivohealth.org |
| FreeMED | www.freemedsoftware.org |
| GNUmed | www.gnumed.org |
| Medsphere OpenVista | www.medsphere.org |
| OpenEMR (managed Model) | www.openemr.net |
| OpenEMR (Community Model) | Sourceforge.net/projects/openemr |
| OSCAR | www.oscarcanada.org |
| PrimaCare | Pcdom.org.my |
| Res Medicinae | Resmedicinae.sourceforge.net |
| Tolven Healthcare Innovations | www.tolven.org |
| Ultimate EMR | www.uemr.com |
| WorldVistA HER | www.worldvista.org/World_VistA_EHR |

Table 2: Classification of 211 Open Source Titled Papers.

| Category | Number of PubMed listed works |
|---|---|
| Bioinformatics | 91 |
| Imaging | 34 |
| Other | 25 |
| Clinical Informatics | 23 |
| Health Education | 14 |
| Public Health | 10 |
| Spectrometry | 10 |
| Clinical research | 6 |
| Pharmacology | 6 |
| Behavioral health | 3 |
| Biomedical engineering | 2 |
| Ontology | 2 |
| Quality assurance | 2 |
| Interoperability | 1 |
| Molecular Biology | 1 |
| Text processing | 1 |

Table 3: FOSS deployments and aggregate numbers of patient records in deployed system.

| Software | Data Source | Patient Records in Deployed Systems | Number of Sites |
|---|---|---|---|
| **Non-Federal Government:** | | | |
| ClearHealth | ClearHealth, Other. | 3,020,000 | 830 |
| WorldVistA EHR/VOE 1.0 | Sequence Managers, Clinica Adelante, Other. | 293,195 | 16 |
| RPMS EHR 1.1 | Community Health Network of WV. | 242,816 | 30 |
| OpenVistA 1.5 | Medsphere Corp. | 213,948 | 18 |
| FOIA VistA | DSS Corp., Family Physicians of Greeneville, Other. | 189,106 | 4 |
| Subtotal Non-federal | | 3,959,065 | 898 |
| | | | |
| **Federal Government:** | | | |
| FOIA VistA | Veterans Affairs www.va.gov | 23,442,000 | 1007 |
| RPMS EHR 1.1 | Indian Health Service | 1,000,000* | 600 |
| Subtotal Government | | 24,442,000 | 1607 |
| | Total | 28,401,065 | 2505 |

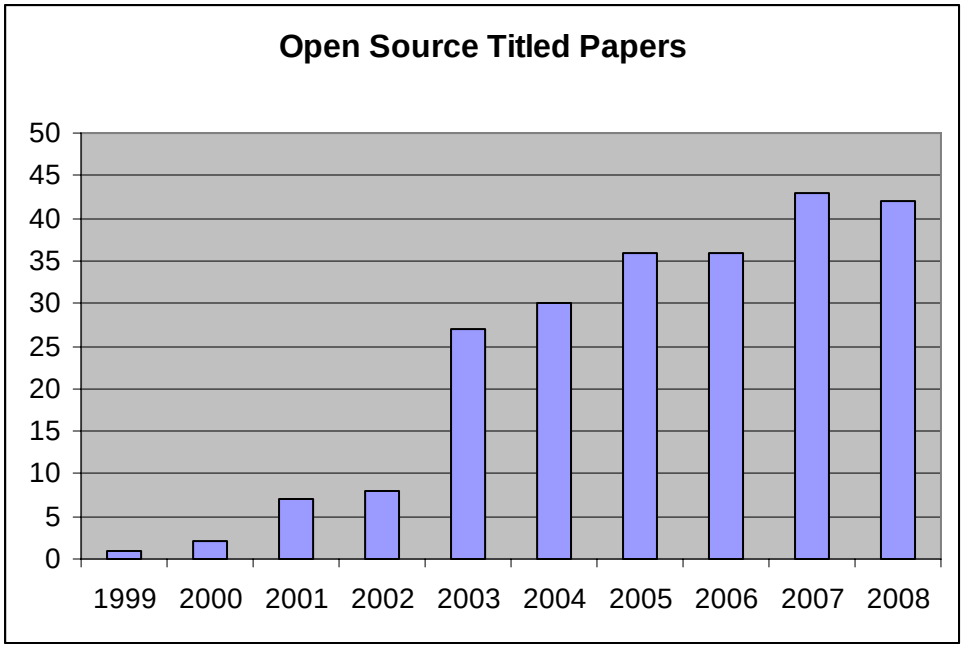
*Estimated number in the RPMS EHR system, various other configurations exist.

Table 4: FOSS Myths and Realities.

| Myths (adapted from (Byfield, 2008)) | Realities |
|---|---|
| You cannot make a living with FOS licensed software. | Multiple corporations and full-time software engineers exist in the FOSS Health Information Technology space. Most companies and individuals make the bulk of their income from installation, maintenance, enhancement and education, not licenses.(MacCormack, 2003) |
| Only proprietary software businesses can be trusted, are ‘real’ or self-sustaining. | Numerous proprietary EHR/EMR software companies have failed and their customers stranded.(Dorenfest, 2000; Trotter, 2007a) FOS licensed software lives on even if a corporation that services and supports it is gone. |
| 'If it is free, it isn't any good'. | Millions and in the case of the Veterans Affairs VistA software billions (Maduro, 2007) of dollars have been invested in FOSS EHR/EMR and middle-ware. |
| You have to run Linux. | FOSS software can be run on proprietary systems and vice-versa. |
| End-users will have to write software themselves. | Users need not write FOSS software unless they want to. |
| It is less secure than proprietary. | FOSS code is available and subject to intense scrutiny by security experts, security problems are often found and fixed before they become problems.(Boulanger, 2005) |
| Any changes to FOSS software MUST be shared. | Private fixes, enhancements and extensions are |

| | |
|---|---|
| | usually not required to be distributed to the community but are strongly encouraged to do so. |
| There is no one to sue, support or warranty the software. | Many companies offer support and warranties on FOSS software and they can be sued. (See Table 1) |
| It isn't being used in medicine. | See Table 3. |

Figure 1: Number of PubMed Papers with ‘Open Source’ in the title by year. 2008 data incomplete.



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