Open Source Digital Health Software for Resilient, Accessible and Equitable Healthcare Systems

Contribution from the IMIA Open Source Working Group

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Summary

Objective: To assess the impact of open-source projects on making healthcare systems more resilient, accessible and equitable.

Methods: In response to the International Medical Informatics Association (IMIA) call for working group contributions for the IMIA Yearbook, the Open Source Working Group (OSWG) conducted a rapid review of current open source digital health projects to illustrate how they can contribute to making healthcare systems more resilient, accessible and equitable. We sought case studies from the OSWG membership to illustrate these three concepts and how open source software (OSS) addresses these concepts in the real world. These case studies are discussed against the background of literature identified through the rapid review.

Results: To illustrate the concept of resilience, we present case studies from the adoption of District Health Information Software version 2 (DHIS2) for managing the Covid pandemic in Rwanda, and the adoption of the OpenEHR open Health IT standard. To illustrate accessibility, we show how open source design systems for user interface design have been used by governments to ensure accessibility of digital health services for patients and healthy individuals, and by the OpenMRS community to standardise their user interface design. Finally, to illustrate the concept of equity, we describe the OpenWHO framework and two open source digital health projects, GNU Health and openIMIS, that both aim to reduce health inequities through the use of open source digital health software.

Conclusion: This review has demonstrated that open source software addresses many of the challenges involved in making healthcare more accessible, equitable and resilient in high and low income settings.

Keywords

Open source software, health system, resilience, accessibility, equity

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Intoduction

In response to the International Medical Informatics Association (IMIA) call for working group contributions for the IMIA Yearbook, the Open Source Working Group (OSWG) conducted a rapid review of current open source digital health projects to illustrate how they can contribute to making healthcare systems more resilient, accessible and equitable.

We sought case studies from the OSWG membership to illustrate how open source software (OSS) addresses these concepts in the real world. These case studies are discussed against the background of literature identified through the rapid review.

2 Resilience

To illustrate the concept of *resilience*, we present case studies from the adoption of District Health Information Software version 2 (DHIS2 [33]) for managing the COVID-19 pandemic in Rwanda, and the adoption of OpenEHR.

2.1 Open Source Software for Health Systems Resilience facing the COVID-19 Pandemic in Rwanda: a Case Study

Resilience in health information technology (IT) has been defined as "institutions' and health actors' capacities to prepare for, recover from and absorb shocks, while maintaining core functions and serving the ongoing and acute care needs of their communities" [1]. The resilience of health systems in low- and middle-income countries (LMICs) has be-

come an increasingly important research topic since the 2014 Ebola Virus Disease (EVD) outbreaks in West Africa [2] and is now magnified with the current Covid pandemic.

In response to the COVID-19 pandemic, a 2020 World Health Organization (WHO) policy brief highlighted the need for effective 'information systems and flows' and strong epidemiological surveillance as key resilience-building strategies [3]. The pandemic has been characterized by high levels of uncertainty with rapid changes in policies and urgent demand for data and digital technology responses. In early 2020, Sri Lanka developed an effective digital platform for responding to the emerging pandemic using the open source DHIS2 platform. The system provided an effective and agile response, with the ability to support case surveillance and contact tracing, and integrating disparate information systems to ensure critical lab test results could be used in the COVID-19 response [4].

Sharing solutions and experience from the Sri Lanka case through the DHIS2 global network, Rwanda also embarked on a process to develop a digital health response to COVID-19 using the DHIS2 platform. From March 2020, the Rwanda DHIS2 team implemented a case surveillance and contact tracing systems, using software developed through the Sri Lanka initiative and enhanced through global collaboration, and included in the new WHO digital health packages [5]. These open source packages consist of health program specific standardised metadata sets that can be downloaded and installed in DHIS2. The Rwandan Ministry of Health (MoH) reported that they saved considerable time by downloading the WHO metadata and then adding additional data variables they already used in their paper-based reporting, and which were not part of the standard package:

> "We saved time by not having to argue too much with multiple stakeholders on what data to include or not, since the standards were recommended by WHO and it was easy to include additional needed data variables."
>
> *Rwanda MoH Team Member*

The lab system work-process, from taking the sample, transporting to the lab, and the dissemination of results, however, turned out to be the biggest bottleneck. Turnaround times of up to one week made real time surveillance impossible. The MoH team then embarked on a full revamp of the lab system at the Rwanda Biomedical Centre, reducing and optimising the work-processes, deploying Android tablet computers for end users, installing workstations in the labs, and establishing a public portal for booking a COVID-19 test, online payment, and checking of results. The entire system was based on the Open Source DHIS2 platform.

When vaccination became possible in March 2021, the MoH team started to develop a vaccination support module in DHIS2 linked to the lab module with the same unique identifier. There were initially several competing systems suggested by development partners and one of these was first selected as the Covid vaccination system. With developers based in the United States (US) and with little local knowledge, this "development from a distance" approach, however, failed to respond to the needs of the MoH and the evolving requirements of the COVID-19 vaccination campaign, such as the need for Quick Response (QR) coded certificates and interoperability with the lab system. Given this development, and the positive results from the implementation of the DHIS2 lab system, the MoH selected the DHIS2 platform for COVID-19 vaccination support and also later decided that all COVID-19 related systems should be based on the DHIS2 platform. The need for local ownership, control and experience of the technology were seen as key reasons leading to this decision.

An entire ecosystem of COVID-19 related apps, modules and services has now been developed and are currently in operation for such tasks as: tracking of cross-border trucks and drivers, QR coded certificates, self-registration for travellers to Rwanda for their health declaration, uploading of documents, payment for rapid test at arrival, and for Short Message Service (SMS) text messaging of results. The vaccination campaign targeted the adult population of approximately 7.5 million people and had reached 7 million doses by mid-November, 2021. Several vaccines were used, including: Pfizer, Moderna, Johnson & Johnson, and Sputnik, with the majority requiring two doses.

During one week in November 2021, 1 million doses were given, providing pressure on the server and team, as the approach of using real-time online registration of vaccination, meant that if the server was down, users had to change their work process and keep notes on paper, which is complicated because each dose is to be linked to a unique identifier. Response time was critical, and the global DHIS2 open source network was engaged in supporting the Rwanda team in addressing server bottlenecks, such as to "kill" processes lasting more than one minute, and removing the autocomplete function on search fields which can create high server loads.

The Rwanda DHIS2 team has provided an effective and agile information and digital response to the pandemic and thereby contributed greatly to the resilience of the Rwanda health system and society in the Covid pandemic (see rbc.gov.rw for daily updated data on cases and vaccination). The open source capacity and quality of the DHIS2 platform have been a prerequisite for building capacity in developing and mastering systems in the Rwanda team as well as for establishing a reciprocal collaborative global network for sharing digital solutions, best practices, support and learning. The platform aspects of DHIS2 has also been important in building the plurality apps needed for responding to the pandemic on top of DHIS2 and interacting through the open API.

2.2 EHRbase: an Open Source openEHR Platform for Health System Resilience

Another aspect that influences resilience is the ability to substitute a health IT system that has been critically compromised. With this regard, there has been a debate over the need for open platforms that allow developing data representation from the system in a way that allows different systems to operate over the same set of data. An advocate for this approach is the openEHR open standard which separates clinical information models from the software domain model. While openEHR provides an open standard with free to access specifications and publishes

validated information models for interoperability in its Clinical Knowledge Manager (CKM) [6], the availability of open source openEHR-based systems has been very limited. For example, Slovenia and three health regions in Norway rely on openEHR standards, but they are implemented through proprietary software applications.

Inspired by the need for new open source options that could increase the availability of openEHR-based systems, the Ripple foundation developed the open source openEHR database, Ethercis [7]. Ethercis has now evolved into the EHRbase platform [8] developed by the German HiGHmed consortium [9] in collaboration with industry partners. These developments have provided an open platform where both the software and the information models for interoperability are widely available for any organization that wants to adopt them. In this way, openEHR has increased the resilience of its approach by allowing health organizations to choose open source options or proprietary openEHR-based platforms if they require extended functionality. Additionally, in the event of a critically compromised system, the information layer still can be used by replacing the software layer since the underlying data representation formalism is the same.

Another relevant topic related to resilience is cybersecurity. Currently, digital health systems suffer from an upward trend in data breaches, with thousands of patient records compromised by different types of cyberattacks [10]. Many of these cybersecurity risks include high-impact actions such as ransomware attacks which can result in a critical impact on the health information infrastructure. Most open source software projects rely on the network infrastructure for their cyberdefense, but they will need to adapt their designs to more resilient architectures including the security-by-design and zero trust approaches in order to deal with future cyber risks [11].

Previously, we discussed the open source initiatives in the context of openEHR. Although these initiatives are clearly contributing to realize the open platform ecosystems, there is still a path to walk in order to make them fully accessible. Currently the developments are mostly back-end systems that require highly trained personnel to deploy and operate them. Developments that facilitate the use of openEHR backend services and offer comprehensive accessible GUI to run them are needed for these developments to contribute in contexts with limited resources.

3 Accessibility

To illustrate the concept of *accessibility*, we show how open source design systems for user interface design have been used by governments to ensure accessibility of digital health services to patients and healthy individuals, and by the OpenMRS community to standardise their user interface design.

3.1 Open Source Design Systems for Digital Health

When individuals access digital health services such as digital vaccine passports, appointment booking systems, or personal health record systems, they should be able to expect an accessible, user friendly and equitable standard of service [12]. Clinicians too, should be able to expect that the digital systems they use have been designed to meet their needs and to have high standards of usability and interoperability [13].

In recent years, governments around the world have begun to introduce open source design systems that enable service design teams to follow commonly-agreed and tested sets of design principles, user interface (UI) components, and design patterns that aim to ensure that digital health services can deliver on national service standards for all users (patients and healthcare providers). Many open source global digital health projects, such as OpenMRS [4, 14–16], OpenIMIS, GNUHealth and DHIS2 [17] have also adopted open source design systems (or frameworks) that aim to achieve high-levels of usability while following international best practice to ensure equitable access to users.

A design system is "a complete set of standards intended to manage design at scale using reusable components and patterns" [18]. For large scale projects, such as DHIS2 and OpenMRS, and for governments providing health services to large populations, ensuring a consistent user interface across services helps users to quickly learn how to use new services and enables service design teams to avoid "reinventing the wheel", freeing up resources to focus on testing and improving the overall design system. Design systems usually consist of a set of design principles, a style guide (which colours, icons, layouts and typography to use), components (sets of user interface elements frequently used together such as a search box) and patterns (sets of components commonly used together such as a multi-page form).

A key element in providing accessible and equitable digital services in the healthcare sector is the ability of users (clinicians and patients) to be able to access online services without needing to constantly relearn how to use the user interface. Open source design systems can help address this challenge while also providing economies of scale to governments and open source digital health projects.

The adoption of open source design systems has standardised the usability, accessibility and equality of access to a wide range of digital services in the countries where they have been implemented to replace a diverse range of existing user interfaces used by government services. By adopting an open source approach to designing user interfaces for healthcare services, government agencies and suppliers can reduce the considerable overhead of reinventing designs whilst benefiting from ongoing user research that is continuously improving the open source systems.

3.2 The NHS Design System

The National Health Service (NHS) open source design system is based on the United Kingdom (UK) government's GOV.UK design system established following a strategic review of the "Directgov" website that was then used to allow UK citizens and residents to access a limited number of government services. The review was carried out by Martha Lane Fox and recommended a sweeping overhaul of all UK government websites and centralisation of the teams that design and manage online services [19]. The result was a new "Government Digital Service"

(GDS) and a set of core design principles [20] based on Fox's success developing commercial websites such as lastminute.com. These principles formed the basis of the GOV.UK design system and were subsequently adapted to create the NHS Design Principles (Table 1).

Using their respective sets of principles, both design systems have developed a similar set of design styles, components and patterns, with the NHS system geared more towards healthcare services resulting in similar designs but with clearly recognisable differences such as the colour scheme used for the header banner (black for GOV.UK and NHS Blue for NHS) (Fig 1).

The NHS Design system is now used across a wide range of NHS services including the NHS website, NHS.UK, which receives over 50 million visits every month [21] allowing users to look up information on their health conditions and access NHS services.

3.3. The United States Web Design System (USWDS)

The USWDS was developed by the 18F, US government design agency (named after the address of the Government Service agency building in Washington DC - 1800 F Street). 18F was established around the same time as the UK's GDS by a group of Presidential Innovation Fellows with a similar background in industry and a drive to transform the usability and accessibility of government digital services. Similarly to the UK GOV and NHS design systems, the USWDS has a set of principles and components. It uses 'design tokens' and 'utilities' as the style guide and a set of templates for common design patterns such as 'authentication pages' and '404 pages'.

3.4 The GOLD AU Design System

In a similar vein to the UK and US design systems, in 2018 the Australian Government developed a 13-point digital service standard and set of open source components and templates to enable Australian Government agencies to develop consistent digital services. In 2021, the Australian Government decommissioned the service leaving government agencies to develop their own design systems [22]. However, a group of stakeholders have now taken over the GitHub repositories under the banner of a new group called Design System AU [23] who maintain the design system now rebranded as GOLD AU design system.

While some may argue that providing an open source design system undermines the competitive marketplace for new designs, individual digital health services may not have the budgets or skill sets required to design optimal user experiences independently. In the healthcare sector, this can result in reducing access to services for some of the most vulnerable members of the community who have the highest needs for accessibility and standardisation. A non-government approach, such as the new Gold AU system, can draw lessons from open source projects such as OpenMRS, DHIS2, GNUHealth and OpenIMIS, who have implemented design systems and frameworks across their projects achieving high levels of usability and accessibility for patients and healthcare providers.

3.5 OpenMRS

The OpenMRS electronic health record (EHR) is deployed clinically in at least 44 low and middle income countries particularly supporting care for HIV, TB, maternal child health and non-communicable diseases [15]. Whilst early implementations of OpenMRS often relied on collection of clinical data on paper forms for back entry, there is strong interest and need for easy to use point-of-care user interfaces with good workflow mapping.

OpenMRS is undergoing a major rebuild of the user interface using a MicroFrontEnds architecture [24] to improve ease of use, and better map clinical workflows. This incorporates the IBM Carbon Design System "a complete set of visual, user experience, and code guidelines and standards" that is available as open source, along with extensive use of user testing and critiquing in multiple countries [25]. High usability and easier modification and combination of UI components should help with the challenges of adapting EHR systems and in training and support of staff with limited IT experience.

The new UI architecture will also provide the environment for new data visualization and clinical decision support components. These in turn will support deployment of AI and machine learning models, for example those created by recent research projects in Kenya working to improve HIV care with data from OpenMRS [26]. This will also build on the support for the latest Fast Healthcare Interoperability Resources (FHIR) data exchange standards in OpenMRS allowing UI components to access clinical data in the OpenMRS backend [27]. This architecture should allow data access from alternative EHR databases that support FHIR.

Table 1 Comparing the UK GDS and NHS Design Principles.

Principle	GDS Principles	NHS Design Principles
1	Start with needs	Put people at the heart of everything you do
2	Do less	Design for the outcome
3	Design with Data	Be inclusive
4	Do the hard work to make it simple	Design for context
5	Iterate. Then iterate again.	Design for trust
6	Build for inclusion	Test your assumptions
7	Understand context	Make, learn, iterate
8	Build digital services, not websites	Do the hard work to make it simple
9	Be consistent, not uniform	Make things open. It makes things better
10	Make things open: it makes things better	

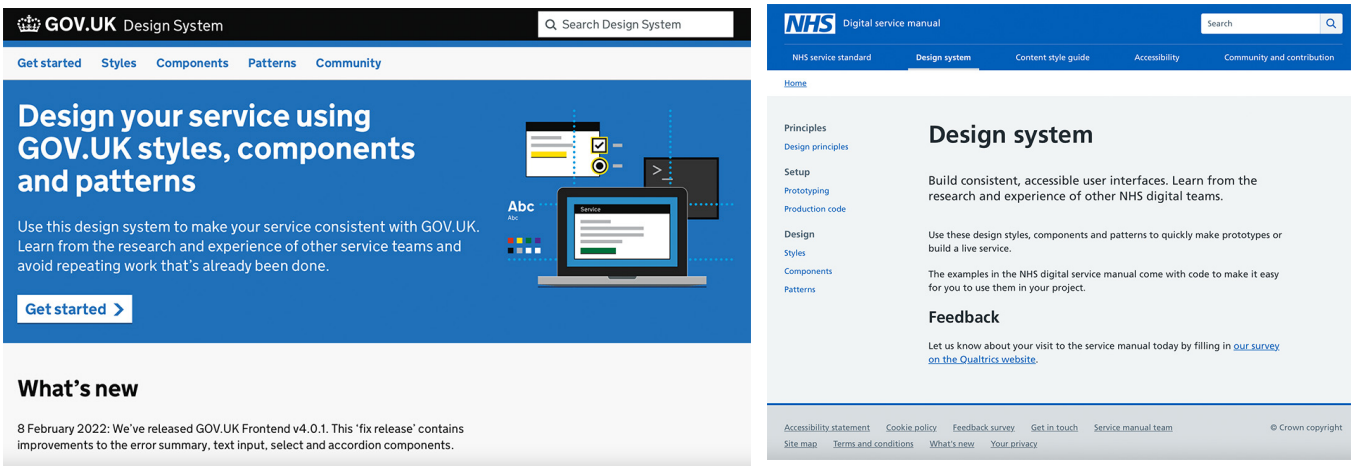

Fig. 1 Comparing the colour schemes of the GOV.UK Design System and the NHS Design System.

4 Equity

To illustrate the concept of *equity*, we describe the OpenWHO framework and two open source digital health projects, GNU Health and openIMIS, that both aim to reduce health inequities through the use of open source digital health software.

4.1 Open Source Software for Digital Health Equity

Open source digital health systems are usually freely available for governments and health systems enabling them to provide more equitable access to healthcare services. In this section we describe three large-scale open source digital health programmes that are supporting equitable health systems around the world.

4.2 World Health Organization (WHO) and OpenWHO, an Open Source Communication Channel

OpenWHO [28] is an interactive web-based platform from the WHO that launched in 2017 to respond to emerging frontlines of epidemics, pandemics, and health crises [29]. OpenWHO provides a variety of educational online courses available for caregivers and decision makers with multilingual settings. Users can take part in learning networks developed by WHO and discuss health experiences in-depth online. WHO is also developing its public health platform for four open source software projects [30] for early detection, verification and risk management of public health. They are ready for communication and contribution from the open source software community on GitHub.

4.3 openIMIS

The Open Insurance Management Information System was established in 2012 with the Swiss Development Cooperation (SDC) supporting the Community Health Funds (CHF) in two regions of Tanzania. The Swiss Tropical and Public Health Institute (Swiss TPH), the Micro Insurance Academy (MIA), and Exact Software were the partners who provided technical expertise. Although it was launched initially in Tanzania, Cameroon and Nepal soon followed suit. With increasing adoption, the SDC shifted to an open-source software licensing regime under the Affero General Public License version 3 (AGPL3) license and partnered with the German Development Cooperation to launch the openIMIS initiative. Since then, the openIMIS community has expanded and has demonstrated various ways open source software can contribute towards universal health care.

openIMIS is premised on ensuring that information technology plays a major role in preserving equity in health financing schemes through the support of appropriate technology. Many health insurance scheme operators in low- and middle-income countries (LMICs) will struggle to achieve efficiencies unless they have the knowledge, skills, and tools to manage their data. openIMIS aims to address these challenges by offering accessible free and open-source software that LMICs can use right out of the box.

openIMIS was born from an understanding that developing software from scratch is resource-consuming, expensive, and error-prone. While commercial, off-the-shelf software packages are available, they come with royalties and prohibitive service fees. By positioning itself as a global public good, openIMIS makes the software accessible to as many stakeholders as possible, including communities of practice, who in turn can improve and develop their experiences and contributions of existing implementations. For example, A key innovation in Nepal is the use of HL7 FHIR to communicate data from OpenMRS to openIMIS, with the potential to send data from other FHIR

compliant electronic health records (EHRs). This exchange of ideas on software, health financing workflows and implementation experiences keeps this growing community vibrant and functional.

4.4 GNUHealth

GNU Health is a Libre digital health ecosystem from GNU Solidario, a non-profit humanitarian organization focused on Social Medicine. The following are the main components that make up the GNU Health ecosystem:

- Hospital Management (HMIS);
- Laboratory Management (Occhiolino);
- Personal Health Record (MyGNUHealth);
- Bioinformatics and Medical Genetics;
- Thalamus and Federated health networks (The GNU Health Federation);
- GNU Health embedded on Single Board devices.

The GNU Health ecosystem provides the tools for individuals, health professionals, institutions and governments to proactively assess and improve the underlying determinants of health, from the socioeconomic agents to the molecular basis of disease. From primary health care to precision medicine. GNU Health has been adopted by health organizations and national public health systems around the world.

GNUHealth has been designed with the ideas of interoperability and accessibility. The GNU Health Federation facilitates the integration of individuals and heterogeneous health informatic systems into a regional or national health network. The GNU Health federated network permits the deployment of large, nationwide health networks, while ensuring the continuity of operations at the local nodes, a key factor in areas where the Internet network connectivity is sub-optimal.

MyGNUHealth, the GNU Health Personal Health record application, provides a tool for individuals to be part of the system of health. MyGNUHealth is a convergent application, that is, the user interface (UI) adapts to desktops and mobile devices (phones, tablets). MyGNUHealth is a health tracker and diary. This allows the person to be in contact with their health professionals from their own home.

In addition, the integration of MyGNUHealth into the GH Federation permits the user sharing their health information and status with professionals. MyGNUHealth covers the main spheres of health (bio-psycho-social). From the last blood pressure and glucose readings, nutrition, sleeping patterns, mood and energy levels, to name a few.

Privacy is another key factor in health informatics. All the GNUHealth components respect the user's privacy. The user is in charge of the application, so they can share with their health professionals only the data that they consider appropriate. GNU Health integrates libraries to encrypt and digitally sign documents and medical acts.

5 Conclusion

Open source software addresses many of the challenges involved in making healthcare more accessible, equitable and resilient. The case studies presented in this paper demonstrate how open source digital health can contribute these goals for both individual people trying to access and use healthcare services and healthcare staff trying to deliver high-quality care. The advantages of collaborative innovation, shared software and sharing of meta-data and implementation experience can help organisations in a wide range of environments. More data is required on how well these tools lead to software that is well used and contributes to improved health care processes and outcomes. This includes more evaluation studies to determine how effective these approaches are in real world deployments at scale. These should include measuring improvements in accessibility and use of systems by a range of users including remote or vulnerable groups and including age, gender and ethnic background [31, 32]. This will allow optimal designs to be shared and adopted at scale, ready for evaluation of their broad impact.

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