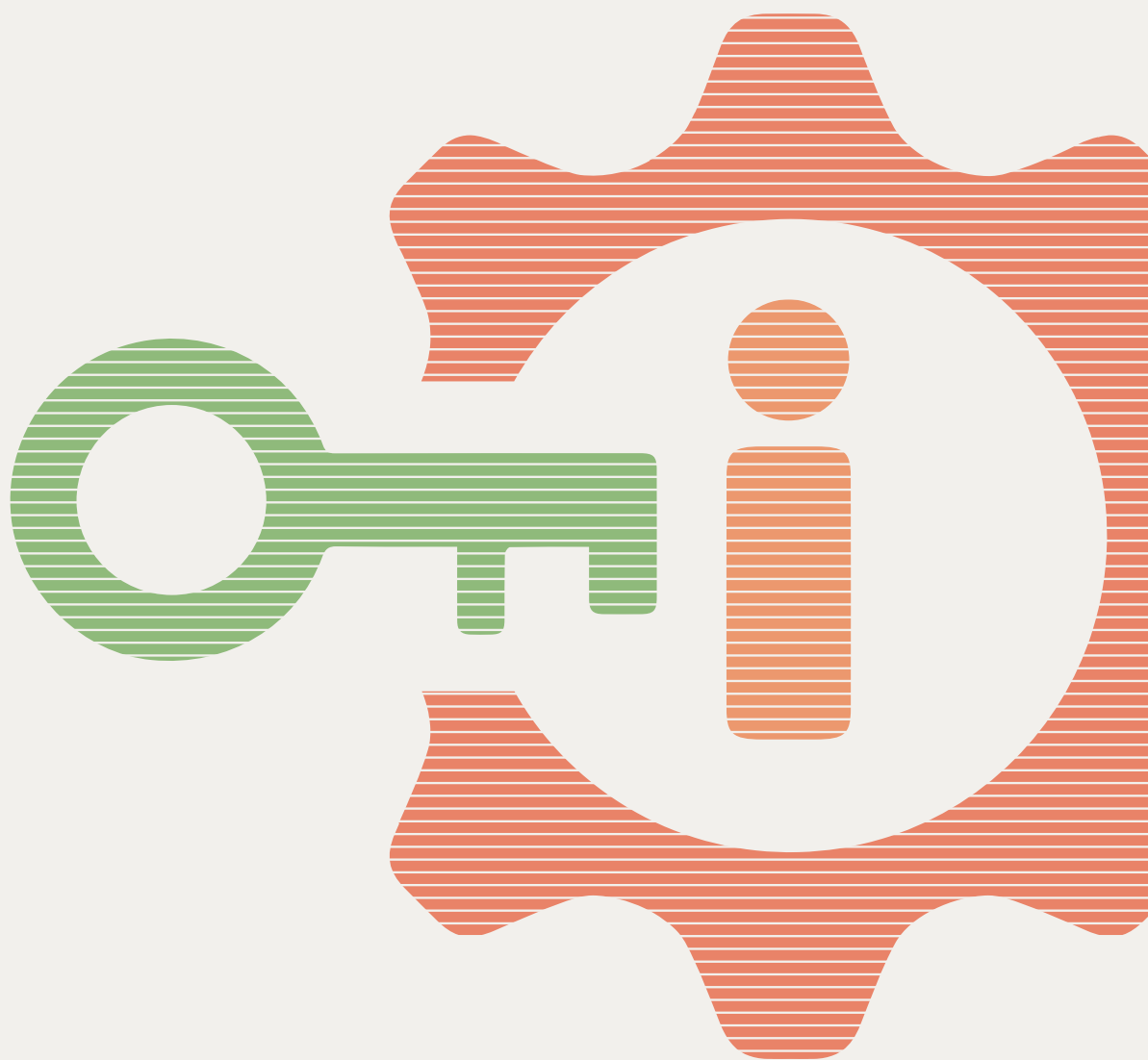




# Development *and* Access to Information

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**The Technology & Social Change Group (TASCHA)** at the University of Washington Information School explores the design, use, and effects of information and communication technologies in communities facing social and economic challenges. With experience in over 50 countries, TASCHA brings together a multidisciplinary network of researchers, practitioners, and policy experts to advance knowledge, create public resources, and improve policy and program design.

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## Chapter 4:

# A2I for Better Health

## *How access to information can help ensure healthy lives and promote well-being*

Simon Chaplin  
Wellcome Trust

Can information make us better? Not simply better informed, more engaged, and better able to contribute to productive, equitable, democratic and sustainable societies, but healthier? What role does access to information play in helping us collectively and individually achieve UN Sustainable Development Goal 3, which seeks to “ensure healthy lives and promote well-being for all at all ages”? And what role do libraries play in this delivery, as reliable information providers, responsible facilitators of access to information, as trusted spaces for engagement, and as active advocates for and agents of good health?

It is hard, of course, to separate the health benefits of A2I from the wider social, cultural and economic benefits it brings. At a fundamental level, A2I helps create and sustain stable, transparent and accountable societies in which basic human rights to health and well-being are more likely to be recognized. Improvements in education, facilitated by A2I, drive economic development. Where the latter is managed responsibly, in balance with concern for long-term sustainability and with economic benefits equitably distributed, it creates the social and structural conditions for a healthy society. Clean water, access to healthy nutrition, security, housing – all have a profound impact on health and well-being, and A2I can have an underpinning role in each. But there also are some more specific health benefits that stem from both A2I and libraries, and it is worth focussing on what these are, and how they can be maximized.

### 4.1 Types of health information

Before looking at the role of libraries, let us reflect on what kinds of information might play a role in improving health. Three categories spring to mind. The first is the fundamental research from across medicine, science,



The Sesigo project in Botswana delivered **Internet-connected computers** and staff training to provide tailored help to people diagnosed with **HIV/AIDS** through libraries.

social science and humanities that helps us understand the biological, social and cultural determinants of health and the pathways to its improvement. The second is material produced specifically for the purpose of improving individual and collective public health and well-being, frequently described as health education or consumer health information. The third category is the contextual information, such as current affairs or national statistics, that enables citizens to hold to account those responsible for delivering health care and provides the background for informed decisions about both personal health and public health policy.

**Health research**

None of these information categories is novel, and in physical form all have traditionally been the stock in trade of libraries. But the transition to digital has fundamentally changed the way we produce, distribute and consume information, while a combination of digital technology and the growth of human society has exponentially increased the amount of information produced. Numerous studies have suggested a long-standing exponential growth pattern in the number of scientific research papers published, with one analysis estimating a doubling every nine years (Bornman & Mutz, 2015). The U.S. National Library of Medicine’s MEDLINE® service, which indexes only biomedical

research papers, shows a similar albeit slower trend, with citations growing from around 400,000 in 1998 to 800,000 in 2015. Increasingly, it is not only the traditional research outputs – scholarly articles and monographs – that are being made available. A combination of the relative ease of sharing supporting datasets in digital format, allied with a desire on the part of researchers and research funders to ensure transparency and reproducibility of research findings, has meant that traditional publication now accounts for only the tip of the iceberg regarding health research. As we look to the future, it is becoming evident that “big data” – massive datasets, generated through programmatic analysis, and manageable only through programmatic manipulation – will fundamentally transform the nature of research, with huge potential benefits to population and individual health, but also profound implications for personal data privacy and accountability (Schadt, 2012; McKinsey & Co., 2015).

#### 4.1.1 Information for health education

Consumer health and health education is a more heterogeneous category. While there is no evidence that the amount of health information has been disproportionately increased by the digital revolution, the simple proliferation of all information forms has had inevitable consequences.

At one end of the spectrum, health education has been both enhanced and complicated by the growth of the internet, allowing more organizations to put more information into the public sphere, but with the inevitable challenge that quantity brings in terms of conflicting messages and variable quality. Health educators have sometimes been slow to recognize the changing patterns of media consumption, especially among younger people, and this affects the targeting of health messages.

At the other end of the spectrum, conventional publishing formats such as books, newspapers, magazines, and broadcast media have been significantly disrupted but not yet eclipsed by digital channels. In some cases, lower barriers to entry – in e-book publishing, for example, or online video – have enabled many more people to participate as producers as well as consumers of information. Again, one consequence has been a challenge to quality and authority. One feature of online platforms such as Amazon is to reduce the value of publisher’s brand as a factor in determining purchase. Similarly, traditional newspaper and magazine publishers have often struggled to sustain editorial models predicated on print sales and advertising, with consequent impact on quality – particularly in science and health content.

An indicator of the scale of the change in terms of information providers is the growth of Wikipedia. Founded in 2001 as a free, collaborative reference resource, Wikipedia in 2017 has grown to include more than 41 million articles in 294 languages. It has become

the de facto primary reference source for internet users – including not only those seeking information about their own health, but among many students of and practitioners of medicine (Aitken, Altmann & Rosen, 2014).



**81% of library authorities** in England offer access to **e-information on health** and wellbeing, and library-taught digital literacy skills play a significant role in supporting health literacy.

#### 4.1.2 Public health data

It is harder to quantify the growth rate of public health datasets, but the amount of accessible information has increased dramatically as, in many cases, information previously only available in printed or closed digital services has been made freely available online. For example, the U.S. Government’s Department of Health and Human Services’ Health Data Initiative, established in 2010, has resulted in the release of more than 2,000 U.S. government datasets. Up until 1991, a researcher wishing to access health data collected by the Organisation for Economic Co-operation and Development (OECD) had to do so physically; from 1991 on, they were distributed on CD-ROM. They are now freely available online, together with previous years’ datasets, thanks to the work of the OECD iLibrary (OECD, n.d.).

Such information plays a critical role in holding actors to account for their ability to deliver good health. At a global level, the World Health Organization’s Global Health Observatory provides a resource to “help governments, policymakers, funders and researchers identify health R&D [Research and Development] priorities based on public health needs and ensure that funds and resources are used to fill R&D gaps,” linking performance directly to the Sustainable Development Goals (WHO, 2017a). Alongside this obvious benefit to member states, it also enables citizens, NGOs and the media to hold governments to account.

The same is true of data shared on a national, regional, and local level: increased access to data improves accountability. An example is the publication of data relating to nitrogen dioxide and particulate pollution in London by the Environmental Research Group at King’s College London (2017). The data has compelled both local and national government to acknowledge the scale of the health impact. As in other areas of society,

restricting access to information becomes a barrier to accountability, even if the health consequences are all too apparent, as with the Chinese government's decision to block access to independent air monitoring data for Beijing during the 2014 Asia-Pacific Economic Cooperation Summit (Branigan, 2014).

The precarious nature of public health data is not only an issue in states where an absence of democratic accountability and restrictions on the free press are longstanding concerns, as testified by the recent decision to remove information from some U.S. federal government websites. Again, libraries have traditionally been one mechanism for ensuring information security, a role now shared with digital archives such as the one maintained by the Environmental Data & Governance Initiative.

## 4.2 Libraries as facilitators of digital access

The Lyon Declaration identified the role of libraries, archives, civil society organizations, community leaders and the media as "information intermediaries," backed by information and communication technologies and by investment in general literacy (IFLA, 2014). The recognition that libraries are only one category of intermediary reflects the changing nature of the digital information economy. The transition from a world of print publishing to one in which many key health information sources are primarily digital has, of course, had profound implications for libraries, but suggestions of obsolescence have proved ill-founded. In many cases, the shift to digital has created a new role for libraries as disseminators and quasi-publishers of health information and data. Examples include HighWire Press, originally developed through Stanford University Library, which now provides a platform for more than 3,000 journals. Perhaps the most notable example is the U.S. National Library of Medicine (NLM), whose various digital literature services – the MEDLINE citation index, PubMed (an extended public interface to MEDLINE) and PubMed Central (a free archive of the full-text subset of PubMed) – have built on the library's historical role as a print repository and indexer (through Index Medicus and the Index-Catalogue of the Library of the Surgeon-General's Office).

The German equivalent of NLM, the Deutsche Zentralbibliothek für Medizin, has similarly adopted a publishing role with its open-access Publisso platform, covering materials such as books and journal articles, conference presentations, videos, and research data across the life sciences. Many university and research libraries have taken on management of institutional repositories, moving from being solely repositories for print to being distributors of digital information and data, working either independently or, more often, as parts of consortia. This is the case in Hong Kong, where the eight main universities work together under the Joint University Librarians Advisory Committee to allow cross-

searching across their individual digital repositories. In Cuba, the infoMED service developed out of a network of health libraries to provide a shared service that now encompasses a virtual health library, training network, health news, and collaboration (Centro Nacional de Información de Ciencias Médicas, 2017).

The adaptive nature of libraries is also evident in the way they have positioned themselves as facilitators of public access to digital health information provided by others, and indeed more fundamentally to the internet itself. Recent estimates suggest that close to half the world's population has direct access to the internet. This is not to underplay the huge disparity that exists between the world's richest and poorest countries, but reflects the rapid growth of mobile data networks, circumventing the need for more costly physical infrastructure. But this still leaves a huge gulf between digital "haves" and "have nots," which libraries have been working to address since the rise of digital communication.

There are many drivers for and benefits from digital access, and these have been formally recognized since at least 2003 when the UN-sponsored World Summit on the Information Society stated that "no one should be excluded from the benefits the Information Society offers" (International Telecommunication Union, 2003). In 2011, a report to the UN Human Rights Council called for internet access to be acknowledged as a fundamental enabler of human rights, something subsequently recognized by states including Finland, Greece, France, and Spain (Beyond Access, 2012).

Through the work of programs such as the Bill and Melinda Gates Foundation's Global Libraries Initiative and the EIFL (Electronic Information for Libraries) project, supported by the Soros Foundation, libraries have been at the forefront of improving public access in countries including Chile, Jamaica, Moldova, Poland, and Vietnam. The IREX (International Research and Exchanges Board) Beyond Access initiative has also been instrumental in enabling community libraries to realize their potential as sustainable information hubs.

A global study conducted for the Technology & Social Change Group (TASCHA) at the University of Washington Information School in 2013 highlighted the general benefits arising from provision of public access to information and communication technologies (ICTs) in three kinds of venue – telecentres, cybercafés, and libraries. The study found that library users were more likely to access health information than users of the other two kinds of venue, and also more likely to report positive impacts from the health information they accessed (Sey, et al., 2013, 111-2). Provision of digital access and skills, and health improvement, have often gone hand in hand. In Botswana between 2009 and 2013, for example, the national library service's Sesigo Project to train staff and provide internet-connected computers was delivered in partnership with the African Comprehensive HIV/AIDS Partnerships and the Bill and Melinda Gates Foundation, recognizing the role that A2I could play both in helping those diagnosed

with HIV/AIDS and in helping to prevent its spread. This link between digital literacy, digital access, and health is relevant not only to libraries in low-resource settings. A study by Arts Council England (2014) found that 81 percent of local government library authorities in England provide access to electronic information on health and well-being, and that digital literacy skills promoted by libraries played a significant role in supporting health literacy and the capacity to access, use, create, and share health information.



Access to information is vital for professionals – **specialist library services to doctors** and others generated a \$5 return on every \$1 invested.



### 4.3 Libraries and open access to health information

It isn't simply a matter of making information available, however. Put simply, if health information is available only to those who can afford to pay for it, the already profound effect of economic inequity on health is only exacerbated. This is the case for much health research, which is published in subscription-only journals or made available through other licensed services.

The critical importance of open sharing of health research and data was reflected in the agreement between the NLM and the publishers of leading medical journals to lift subscription barriers and make articles and datasets relating to the 2014-15 Ebola outbreak freely available (NLM, 2014). A subsequent agreement between research funders and publishers led to a lifting of restrictions on Zika-related research, and a commitment to take similar actions in the face of future global public health emergencies (Statement on Data Sharing in Public Health Emergencies, 2016).

These moves come on top of a longer-standing commitment by many publishers to the World Health Organization's Hinari Access to Health Research program, under which 14,000 journals, more than 50,000 e-books, and more than 100 other information resources are made available for free or at reduced cost to participating health institutions (described as "national universities, professional schools [of] medicine, nursing, pharmacy, public health, dentistry, research institutes, teaching hospitals and health-care centers, government offices, national medical libraries and local non-governmental organizations") in more than 115 countries (WHO, 2017b). While the Hinari program and similar schemes covering agriculture, development

studies and environmental science under the umbrella of the Research4Life program have delivered substantial benefits, they do not provide public access to research for many of the organizations identified as "information intermediaries" under the Lyon Declaration, including non-national libraries. In some countries, local agreements seek to redress this imbalance. In the U.K., for example, a 2012 Working Group on Expanding Access to Published Research Findings chaired by Dame Janet Finch resulted in a consortium of academic publishers establishing Access to Research, a service offering free on-site access to more than 15 million journal articles via libraries (Griffin, 2016).

The problem of inequality in access to information is accentuated if there are disparities in access, such that validated information – such as peer-reviewed research – is placed behind paywalls or otherwise restricted, while unvalidated or unsubstantiated information is freely available. This is true of much health information in the area of complementary medicine, where practices can range from those that are well-established and soundly evidenced to those that threaten both personal and population health. The greatest risks come from movements that seek to undermine well-tested but frequently inaccessible (to a lay user) medical research by providing free access to pseudo-scientific information, as in the U.S. with the anti-vaccination movement, which has frequently been seen as a beneficiary of so-called "predatory" open-access publishing, in which the normal checks of peer review and validation are either not applied or are inadequate.

Libraries – and more importantly trained librarians – are an important means of countering this, by assessing and validating information sources and empowering others, whether they are students, health professionals, members of the public, or policymakers, to do the same. Libraries' role in promoting and enhancing health literacy (and not just general or digital literacy) is therefore an important tool of health promotion. The economic benefits of informed access to information for health professionals have been quantified in research carried out by the Australian Library and Information Association (2014), which estimated a 5:1 return on every dollar invested in specialist health (and also legal) library services.

Yet for those libraries that are not covered by schemes such as Hinari or Access to Research, and which do not have the resources to invest in specialist subscriptions, no amount of health information literacy on the part of either librarians or their users will serve to compensate for inaccessibility of the information they seek. One of the main drivers of the Open Access movement for research publications and data is the recognition that the public good is best served by "worldwide electronic distribution of the peer-reviewed journal literature and completely free and unrestricted access to it by all scientists, scholars, teachers, students, and other curious minds" (Budapest Open Access Initiative, 2002). Enabled by, and closely linked to, the rise of digital publishing, which allows the cost of disseminating research to be shifted from consumers to

producers (or more usually, their funders), open access obviates the need for libraries pay for or manage subscriptions, and creates a level playing field in terms of information availability for anyone connected to the internet. This is not a trivial issue. Many researchers, especially (but not only) those in resource-poor settings, have argued that open access not only enhances the research enterprise but also strengthens the application of evidence-based health policies (e.g. Tambo et al., 2016). Not surprisingly, libraries and librarians have been consistent advocates for open access, and have played an important role in the implementation of open access policies and practices. For example, in Kenya, the Kenya Library and Information Services Consortium (KLISC) links universities, museums, libraries and other research organizations with a common aim of promoting open access (Matheka et al. 2014).

A key precept of those pushing for open access to health research and data has been the application of licences that facilitate reuse, something that is not true of many publisher-led access initiatives, which tend to reserve rights. While many organizations involved in health promotion in low-income settings are likely to regard this as a moot point, it nevertheless represents a barrier to responsible reuse. In a report for the WHO's African Health Monitor, Derege Kebede and colleagues have described two kinds of health information gap: the absence of knowledge, or a basic deficiency in research; and what they call the "know-do gap," or the failure to apply what is known in a way that materially improves people's lives (Kebede et al. 2010).

For example, one of the key barriers to accessibility of health information aside from its free availability is language. The licensing terms for most conventionally published research will usually allow some element of fair use (depending on jurisdiction) but will rarely allow full translation. The impact of this is often disproportionately felt in communities that speak minority languages, which may already have contributed to economic, political or health inequality. Under EIFL's Public Library Innovation program, library workers in the Butaleja district of Uganda delivered a project to train health and community workers in basic ICT skills and provided computers and internet access. However, faced with a local community in which most only spoke a local language, Lunyole, they had to go further and use their newfound access to relevant health information to create resources that were accessible to their target audience – the kind of activity that is technically only possible with non-restrictive licenses (Ehrke, 2013).

#### 4.4 Libraries as trusted social spaces

As the Butaleja project shows, the proposition that creating public access to health information will inevitably yield health benefits is deceptively simple. A report undertaken in the U.K. for the Patient Information Forum (2013), a membership organization representing

health information professionals, highlights the moral argument for providing high-quality information to the public and the economic benefit that derives from the better engagement of, and health outcomes for, those who suffer ill-health. But it also acknowledges that while high-quality information is essential to public or patient engagement, it is not sufficient. The long history of public health campaigns shows that no matter how compelling and unambiguous the evidence is, behavior change is rarely dictated by information alone. Health education professionals speak about a distinction between "clinical" and "public health" models of health literacy. The former treats a lack of health literacy as a risk to be managed; the latter describes the possession of health literacy as a personal asset (Nutbeam, 2008). The models are not mutually exclusive, and both are valid under different circumstances. However, the former can lead to a tendency to assume that the key challenge around health information lies in ensuring that it is available to be accessed: thereafter, it is the failure of the individual that prevents it being acted upon in such a way as to lead to better health outcomes. Conversely, the public health model places greater onus on the act of engaging the public and creating a shared belief in the desired outcome and its fulfilment, which is more likely to lead to preemptive adoption.

In some countries, the role that libraries play in addressing the risks associated with a deficit in public health information is enshrined in law. In Japan, the Cancer Control Act requires national and local government bodies to offer information on cancer treatment and extend advice and aid to those who have been diagnosed with cancer. Libraries play a key role in this provision, with many offering specialist cancer information services that combine digital and physical resources (Miwa et al., 2016). Legal obligation aside, one reason why libraries have continued to play an important part in information access despite the growth in individual access to the internet is therefore their role as organizations that sit within, and are trusted by, their communities, a fact acknowledged by the 2013 TASCHA study. In 2009, South Korea – a country with one of the fastest and most extensive internet networks in the world – announced a major expansion of its public library network (Yoon-mi, 2011). Like many other developed countries, the Korean initiative was designed in part to help libraries become "cultural complexes," offering a range of services underpinned by the libraries' traditional role as information providers (Tack-whan & Jae-un, 2015). Research conducted in 2016 for the European Parliament's Committee on Culture and Education on the "new role" for libraries highlighted their importance as spaces for promoting social cohesion. Among the examples cited was the new public library of Arhus in Denmark, Dokk1 (which opened in 2015), which counts public health department workshops and advice services for food and health as part of its public offerings.

This rethinking of the library as community hub is not restricted to public library services. The same kinds of existential questions have been asked of research



libraries. MIT’s “Task Force on the Future of Libraries,” convened to help MIT “serve as a leader in the reinvention of research libraries,” has posited a future in which its digital collections and services are placed at the service of a global public audience as well as a local academic one, and in which the physical space of the library becomes the nexus of a series of concentric, virtual “gathering spaces” (Smith, 2017).

As trusted spaces, libraries are able to engage people with health information, as well as being facilitators of access to it, thus addressing both the clinical and public health models of health literacy. The U.K. government’s “Libraries Task Force” report *Libraries Deliver: Ambition for Public Libraries in England 2016 to 2021* (2016) describes health and well-being as one of the seven outcomes that libraries can offer their communities. Their research shows that in the U.K. – a country that might be assumed to have relatively high levels of general and health literacy, at least on a global scale – 43 percent of working-age adults did not understand health information given to them (a figure that rose to 61 percent where this health information included statistics). The report argued that by offering access to both general information and health literacy training, often in conjunction with public health services, libraries were well placed to address this deficiency. Moreover, it also noted the importance of libraries as “non-clinical spaces in localities where health and well-being groups can work with the community in a trusted and non-threatening venue,” a feature that has made libraries particularly important for supporting self-management of long-term medical conditions in people who might otherwise have little regular contact with health professionals. In Lithuania, the EIFL-funded Kaunas County Public Library BiblioHealth service works through a network of local libraries to provide internet access and digital literacy skills to older citizens, together with a range of programs including lectures, meditation, yoga, and exercise classes. The service recognizes that the benefits of better access to health information are likely to be greater in a group that is also engaged in community health and well-being activity (EIFL 2013a). The “Health Bridge” project created by the Lori Regional Library in Armenia includes an “e-health” service that combines digital and print resources, backed up by community training, public events and an online forum that enables users to talk with doctors (EIFL 2013b).

In other cases, the nature of the library as a “safe space” takes on more a more literal meaning. Writing in the *Journal of the Indian Library Association*, K. S. Raghavan (2016) argued that one reason why libraries are well placed to lead the country’s digital information agenda is because libraries are “non-threatening environments where people, irrespective of age, gender and other factors, can feel free to have discussions and ask questions” – not a trivial issue in a country where issues of caste, religion and gender can place individuals at risk of violence. Rural Education and Development (READ) Global, which was founded in 1991 in Nepal, has created a network of 91 rural health libraries across Nepal, Bhutan, and India, serving a potential audience of 2.3 million people. READ

centers provide health information resources on a range of subjects, including personal hygiene and sanitation, food and nutrition, disease prevention, and reproductive health. A critical factor in READ’s success, highlighted by an evaluation report carried out in 2013, has been the provision of specialized services and “dedicated safe spaces for women to gather, share information, and learn from each other.” This has led to benefits in terms not just of levels of information, but also the self-confidence to apply this knowledge, contributing to a self-reported 80 percent increase in the empowerment of female users and an increase of 68 percent in their decision-making power regarding family planning and health-care issues.



READ Global’s network of rural health libraries in Nepal, Bhutan and India provided women with information and support, as well as a safe space to gather, share information and learn from each other. Participants recorded **major increases in their ability to take decisions on health issues.**

In health emergencies, libraries can go beyond being information distributors to become part of a two-way communication between those affected and those trying to help. In Nepal in the aftermath of the 2015 earthquake, the READ Global rural health libraries found themselves becoming hubs for medical care and shelter, and providing access to electricity for charging mobile devices as well as internet connections (READ Global, n.d.). When flooding affected more than 1.6 million people in Myanmar in the same year, libraries were at the forefront of providing support to those affected, building on digital services designed to help improve maternal and child health and providing an information conduit back to emergency relief organizations (Turner & Gebhart, 2015). Such activities are not restricted to lower-income countries. In 2012, for example, libraries in New Jersey and Connecticut in the eastern United States were able to provide safe community spaces and access to information for those forced from their homes or left without power or internet connections after a hurricane (Bayliss, 2012).

One consequence of a combination of improved access to health information and a strong sense of community engagement is the transition of libraries into active agents for health improvement. In Romania, staff at one county library were moved to action by comparative data released by Eurostat, the European Union’s statistics agency. This showed that one in three people involved in serious accidents in Romania died as a result of inadequate first aid treatment. A “train the trainer” program backed by an online portal was established,



leading to 90 librarians across 86 sites becoming accredited trainers and more than 2,000 members of the public receiving first aid training. The Kyrgyz Libraries Information Consortium “No to TB!” project was similarly inspired by data that revealed the extent of the tuberculosis infection in Kyrgyzstan. Information centers were created in 190 libraries, 800 health campaign workers were trained, and workshops were held to equip them with the digital literacy and social media skills necessary for them to become effective and informed advocates for health promotion (Turner 2012).

## Conclusion

Programs such as those in Romania and Kyrgyzstan go far beyond simple access to health information. Yet they illustrate the added value that comes from the work of libraries as active agents for achieving the Sustainable Development Goals. Can information make us better? Based on evidence from across the world, it can, but it is not enough for information simply to be available for it to have an impact on health. Instead, it depends on information being mobilized appropriately – the right kinds of information, engaging the right kinds of users, under conditions that allow it to be used appropriately and trusted accordingly. If we regard health and well-being as a fundamental human right, and securing healthy lives and promoting well-being for everyone, at every stage of life, as one of the key conditions for our future prosperity and sustainability, then attention must be paid to where, how, and by whom information is accessible. Correctly mobilized, information empowers us to make better decisions about our own health and the health of others, and creates the potential for research and innovation to transform health for all. It helps us set goals and hold ourselves and others to account for their delivery. Libraries play a crucial role in every part of this ecosystem as organizations that vouchsafe the quality of information and provide routes to ensure that access is open to all, and as community spaces that enable people to access information and share ideas safely.

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