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IFLA Journal is an international journal publishing peer reviewed articles on library and information services and the social, political and economic issues that impact access to information through libraries. The Journal publishes research, case studies and essays that reflect the broad spectrum of the profession internationally. To submit an article to IFLA Journal please visit: journals.sagepub.com/home/ifl

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Special issue: Health information transforming lives

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The Health and Biosciences Libraries Section (HBS) of the International Federation of Library and Information Associations (IFLA) is the IFLA ‘voice’ on health and biosciences information and libraries. The HBS, therefore, acts as a forum for special libraries concerned with all aspects of information management and services in relation to the medical, health and other biological sciences. The HBS aims include: the implementation of and support for better management and provision of health care information to health practitioners, researchers, academics and consumers; facilitating the development and application of new technologies relevant to the health and biosciences libraries; supporting the next generation of health information professionals; strengthening and/or initiating the cooperation between HBS and related libraries, organisations, institutions and associations at national, regional and international levels. The HBS, therefore, focuses on Sustainable Development Goal number 3. As part of its activities, HBS has an active research programme and has just concluded a study on the educational needs for health librarianship in the East, Central and Southern Africa region. The HBS recently sponsored a Special Interest Group on Evidence for Global and Disaster Health, which in addition to SDG 3, addresses SDG 6 and 11.

In view of the above, the HBS has prepared this special issue of the *IFLA Journal* on the theme of ‘Health information transforming lives’. The issue highlights the transforming effect of health information in society. For example, library outreach, in all its forms, requires that the librarians leave their own traditional space, enter someone else’s space, learn about the people occupying that space and create a connection between the two. For health librarians wishing to connect with traditionally underserved and hard-to-reach populations, this requires not only learning about and appreciating the cultural differences that may distinguish those populations from

other sections of society, but also about the many health disparities that are likely to exist. For those who may be members of more than one traditionally underserved community, this may also involve understanding and navigating multiple layers of discrimination and their effect on the person’s health, on their sources of information, health information needs as well as their information behaviour.

Long viewed as safe places and spaces, libraries serve as hubs of information services for students, researchers, academics, practitioners and the entire society including underprivileged communities. In both the developed and developing countries, new ideas and services keep emerging, some simultaneously and others adapted and contextualised as being more appropriate for a developing country setting. This Special Issue includes specific examples of innovative projects that have been implemented by health information professionals reaching out to the hard-to-reach areas, giving evidence of what was learnt and demonstrating that a specified group of people was reached and supported. The contribution of public librarians to health information provision is also highlighted in two papers. The successful projects reported in this issue can be replicated in other areas in line with IFLA’s Global Vision of ‘powering literate, informed and participative societies’.

Furthermore, this Special Issue has explored and demonstrated alternative ways of measuring impact beyond traditional scholarly metrics. Conventional bibliometric analysis of output can indeed be complemented by metrics that assess the dissemination and impact of medical/health research through social media, usage of biomedical devices, disease

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epidemiology, and/or other methods that engage the public to improve health. Hence, new roles undertaken by health information professionals in supporting research and the practice of health care have been highlighted. It is, therefore, important to continue building the capacity of librarians to increase their knowledge and skills to be able to perform the new and multiple roles.

In addition, three authors have grounded their papers theoretically using models or theories that are relevant to the theme of transforming lives and society in general. Such theoretical underpinning is important in advancing our understanding and shaping future efforts in research and practice.

The Special Issue has seven papers that embrace a broad geographic coverage. The papers have reiterated the value of information and its transformative effect to health care. This confirms what several authors had reported (Goel, 2015; Mbondji, 2014; Musoke, 2016; Palsdottir, 2010; Wyber, 2019). We congratulate the successful paper authors for bringing us update on the various ways health information has transformed lives.

We are grateful to the reviewers of the papers who supported the peer-review process that enabled the authors to improve the quality of papers. Many thanks to Shane Godbolt and Martin Morris who have worked tirelessly with me to produce the Special Issue on time.

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Transforming lives: Combating digital health inequality

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Abstract

For those who are connected digitally, the digital health revolution is an enormous opportunity for patient empowerment. However, half the world's population are not online. Those who are least likely to be online are exactly those who experience the greatest burden of ill health. As information about health and illness is increasingly (and often exclusively) available in digital form, we face a new public health challenge – digital health inequality. Libraries are ideally placed to reach these population groups who may be hardest to reach. The IFLA (2017) *Statement on Digital Literacy* recognises that with libraries' mission to help all their users access and apply the information they need for personal and community development, digital inclusion is an important part of the practice of librarianship. Successful interventions to improve digital inclusion involve targeting connecting, and transforming lives. This article focuses on initiatives to combat digital exclusion in England and Wales.

Keywords

Consumer health information, digital inclusion, digital literacy, health inequalities, health literacy, library outreach, social deprivation

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Introduction

A revolution in digital health is going on all around us. 80% of Internet users regularly search for health information (Amante, 2015; Fox, 2011). One in 20 Google searches are for health content (Gibbs, 2015). Over 300,000 apps are available to support self-diagnosis and self-management (Pohl, 2017) – 47,000 health apps are available in the Apple App Store (Statista, 2018) with even more for Android.

Patients are being helped to make decisions and navigate healthcare systems through apps and decision aids. Electronic transactions such as appointment bookings, repeat medication and access to online personal health records are increasingly the norm in developed healthcare systems. Remote consultations using Skype and other video technologies are improving access and convenience, particularly for those less able to travel. Artificial intelligence is driving increasingly sophisticated symptom checkers and diagnostic advice tools. Consumer technologies and networks are being used to encourage healthy behaviours and long-term lifestyle change through

coaching, motivational reminders, and communities of like-minded people (Topol, 2012).

Access to consumer health information online has been associated in a number of studies with a range of positive health outcomes, including empowerment of people in their own healthcare and greater involvement in shared decision making (Pluye, 2019).

The World Health Organization recognises the potential of digital technologies to advance sustainable healthcare development, and in particular to support health systems in all countries in health promotion and disease prevention, and by improving the accessibility, quality and affordability of health services.

In May this year, the World Health Assembly adopted a *Resolution on Digital Health* (WHO, 2018) with 11 actions to drive forward digital health

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adoption. It is encouraging that WHO sees digital inclusion of citizens as central to achieving the benefits of digital health. One of the 11 actions urges member states to:

Improve the digital skills of all citizens, including through working with civil society to build public trust and support for digital health solutions, and to promote the application of digital health technology in the provision of, and access to, everyday health services.

Leaving nobody behind

The US institute Pew Research sought the views of 2500 experts and members of the public on what our digital life would be like in 2025 (Anderson and Rainie, 2014). They concluded:

In ten years the internet will be readily available, everywhere, at low cost – embedded in people's lives for good & ill. The greatest impact will be on personal health. Health care will become self-administered. We will detect, monitor, diagnose, get advice & treatment, through mobile, wearable & implanted network devices.

But despite these exciting opportunities there is a significant challenge:

We risk a dangerous divide between the digital haves & have-nots. Networked transactions may benefit smaller & smaller segments of the global population.

The challenge for healthcare services in the 21st century is to ensure that nobody is left behind in this digital health revolution. Of EU citizens 76% go online weekly – but this still means a quarter of the European population do not. In Europe 63% of disadvantaged people use the Internet weekly, with older people (53%) and less educated (55%) still further behind. Lack of use and access to digital resources (often called digital exclusion) is closely related to social deprivation and health inequalities. Among Europeans 47% have insufficient digital skills to make best use of websites, apps and tools. Amongst socially disadvantaged people this rises to 64% (European Commission, 2017).

In the USA, 89% of the population are online, and 11% are not. Age is the most likely indicator for people not using the Internet. Use of the Internet is almost universal in the young population (98% of 18–29 year-olds) but falling to 66% of over 65s. Household income and education are also indicators of a person's likelihood to be offline. Roughly one in three adults with less than a high school education (35%) do not use the Internet. Adults from households earning less

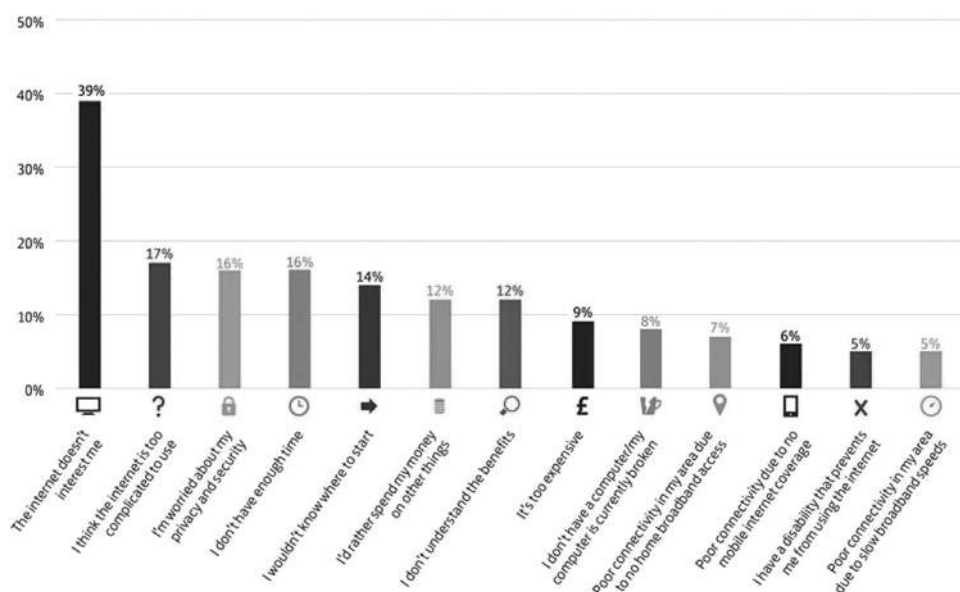
than \$30,000 a year are far more likely than the most affluent adults to not use the Internet (19% vs. 2%). Rural Americans are more than twice as likely as those who live in urban or suburban settings to never use the Internet. Racial and ethnic differences in Internet use are becoming less significant, and today, whites, blacks and Hispanics are all equally likely to be offline (Anderson et al., 2018).

Worldwide, the United Nations has a sustainable development goal of affordable Internet access for all by 2020. The UN's Broadband Commission for Sustainable Development predicted in 2014 that half the world would be online by 2017. In fact, the pace of digital adoption has slowed so that this will not be reached until the middle of 2019 (Sample, 2018). Not only is half the world not online, but there are stark variations: 98% of the population of Iceland have accessed the Internet but only 1.2% in Eritrea and 1.9% in Somalia. Women in low income African countries are the least likely people in the world to be online – yet women are traditionally the main caregivers in families, responsible for everyday healthcare of children and older relatives, as well as for their own health (Alliance for Affordable Internet, 2018).

Those who are least likely to be online are exactly those who make the most use of health services and experience the greatest burden of ill health (older people, people with low incomes, people with long term conditions and disabilities). The rapid growth in digital technologies brings transformative opportunities. Benefits to patients and to health care systems include more involvement of patients in their own care, more convenience and time savings, reduced costs, and better health outcomes (Imison, 2016). But this transformation also threatens to deepen the digital divide between the active users capable of exploiting ever improving technologies, and those who struggle to overcome the barriers to getting online. These digitally excluded people are in danger of being left behind in society, as more and more services, including healthcare services, go online.

The inverse care law was set out by Tudor Hart (1971), who argued that the availability of good health care varies inversely with need. The inverse care law was proposed in the pre-digital world. Today, as healthcare systems progress their digital transformation agenda, there is a real danger of a new digital inverse care law whereby those citizens most in need of accessing new digital services will be left behind again, due to their lack of digital skills and access.

With information about health and illness increasingly (and often exclusively) available in digital form, digital literacy is a key precondition of health literacy.

Table 1. Reasons for not using the Internet.

Source: Lloyds Bank (2018) Consumer Digital Index.

Increasingly this is a public health challenge: low health literacy is closely linked to poor health outcomes and mortality (Kickbusch et al., 2013). Libraries are ideally placed to lead the response to this challenge

Digital inclusion and digital literacy

'Digital inclusion' is the term most commonly used in the UK for people being able to use digital technologies, particularly the Internet, in ways that enhance their lives and help them overcome disadvantage. The term is often used interchangeably with digital skills, digital participation, digital competence, digital capability, digital engagement, digital literacy, etc.

IFLA uses the term 'digital literacy' to describe the ability to harness the potential of digital tools. IFLA promotes an outcome-orientated definition – to be digitally literate means one can use technology to its fullest effect – efficiently, effectively and ethically – to meet information needs in personal, civic and professional lives (IFLA Statement on digital literacy, 2017).

The three main barriers to digital inclusion are:

- Lack of skills
- Lack of access
- Lack of motivation

Today many more people are using digital technologies, helped by cheaper equipment, easier to use touch-screen interfaces and faster broadband speeds.

This is leading to a reappraisal of what we mean by these barriers.

Where once by 'digital skills' we meant the basic skills of carrying out a search or setting up an email account, we are now more likely to mean information literacy skills – being able to distinguish good quality health information from 'fake news'. Where once by 'access' we meant owning or being able to use a device, we are now more likely to mean having sufficient data on a mobile phone contract, access to free wi-fi or high-speed broadband.

These barriers of skills and access still exist for significant numbers of people, preventing them from participating with the digital world. But today lack of motivation, confidence and trust can be the most significant factor preventing a person moving from a reluctant, single-purpose user to someone who truly reaps the benefits of being online.

Data from the Lloyds Bank (2018) Consumer Digital Index in the UK suggests that for the core of those who are not online, lack of interest in what the Internet can do for them is now the major barrier. It seems that too often digital services are not sufficiently compelling and meaningful for them to overcome concerns including privacy and security. See Table 1.

Challenging assumptions

In the UK over 11 million people lack the basic digital skills they need to use the Internet effectively. And over 4 million people never go online at all (Lloyds Bank, 2018). Some sections of the population are more likely to be digitally excluded than others. These are:

- older people – 51% of digitally excluded are over 65;
- people in lower income groups – 45% of digitally excluded earn less than £11.5k a year;
- people without a job – 19% of digitally excluded are unemployed;
- people in social housing – 37% of digitally excluded are social housing tenants;
- people with disabilities – 56% of digitally excluded have a disability or long-term condition (and 22% of adults with a disability have never been online);
- people with fewer educational qualifications – 78% of digitally excluded left school before 16;
- people living in rural areas;
- homeless people;
- people whose first language is not English.

These characteristics of an older, poorer, less educated, rural population who are offline are still predominantly true but the picture is beginning to change. Our assumptions about who is, and is not, online have been challenged in the UK by a timely blog by Scobie and Schlepper (2018) for the Nuffield Trust which tests some of the received wisdom about digital exclusion and health against available data for the UK.

Assumption: Older people do not use digital technology

Facts. Older people are less likely, but the gap is narrowing (although less so in over 75s). Awareness of online primary care services, such as the ability to book an appointment or order repeat medication, is actually highest in the 64–75 age group. And over a fifth of people in this older age group do order repeat medication online – the age group most likely to.

Assumption: Digital services are less accessible to people with complex needs

Facts. Awareness and use of online primary care services by people with disabilities and long-term conditions is similar, or higher depending on the condition, than for people without. But there are important exceptions, including people with learning disabilities, dementia or sight impairment for whom both awareness and use of online services are lower.

Assumption: Ethnic groups are digitally excluded

Facts. Among younger age groups, Internet use is similar between different ethnic groups. Non-white groups have lower rates of use for people over 65.

However overall use of the Internet is actually lowest among white people, reflecting the older age profile of this group.

Assumption: Internet access is worse in rural areas

Facts. There are certainly low levels of digital inclusion in rural areas, due particularly to poor broadband infrastructure and older populations. But some of the worst digital exclusion is still in some urban areas, reflecting worse levels of deprivation.

In July 2018, the Centre for Ageing Better published an important and thought-provoking report on new approaches to supporting people in later life to get online (Mouland, 2018). People in later life stand to benefit hugely from being online – to improve health and wellbeing, save money and keep in touch with family and friends. However, there remains a core of people in later life who are not online and have no intention of getting online. When asked what would prompt them to go online, 74% of people over the age of 65 responded ‘nothing’.

Ageing Better funded Good Things Foundation to conduct research to understand what enables and prevents people in later life from getting online – focusing specifically on people in later life who have never used the Internet, those who used to but have now stopped or those who have limited usage. The report concluded:

- Not using the Internet and being digitally excluded are not the same thing. Some people make a reasoned decision not to be online;
- We need to move on from a focus on basic digital skills to building confidence and motivation to do things online that matter to people;
- We must measure success by outcomes (including health outcomes) rather than just numbers of people attaining basic digital skills.

Digital inclusion for health: National programmes in UK

England

There have been consistent policy commitments to digital inclusion in England for several years, as set out most recently in the *Government Digital Inclusion Strategy* (UK Government, 2014). The Department of Health and Social Care’s (2018) vision for digital health, *The Future of Healthcare* recognises the challenge of delivering an equitable service through digital channels:

Health and care services are for everyone. We need to design for, and with, people with different physical, mental health, social, cultural and learning needs, and for people with low digital literacy or those less able to access technology. We must acknowledge that those with the greatest health needs are also the most at risk of being left behind and build digital services with this in mind, ensuring the highest levels of accessibility wherever possible.

Furthermore, the new NHS Long Term Plan (2019) sets out the vision:

People will be empowered, and their experience of health and care will be transformed, by the ability to access, manage and contribute to digital tools, information and services. We will ensure these technologies work for everyone, from the most digitally literate to the most technology averse, and reflect the needs of people trying to stay healthy as well as those with complex conditions.

And the recent review by Topol (2019: 23) of the digital skills of the healthcare workforce reminds us that digital inclusion is a vital equalities issue:

The NHS is founded on a commitment to the principles of equal and equitable access to healthcare for all UK citizens. Yet use of digital healthcare technologies could undermine these principles by exacerbating inequalities, unless consideration is given to how they affect equality and equity, including the risk that vulnerable groups might be excluded or exploited.

With the rapid growth in digital health products and services, particular attention is now being given to the quality and evidence base of digital technologies. The National Institute for Health and Care Excellence (NICE, 2019) has produced *Evidence Standards Framework for Digital Health Technologies*. The aim of the standards is to make it easier for innovators and commissioners to understand what good levels of evidence for digital healthcare technologies look like, while meeting the needs of the health and care system, patients, and users.

For the past five years in England a National Health Service (NHS) programme called Widening Digital Participation has been mobilising libraries and other community organisations in socially deprived communities to teach digital skills for health, supporting people who may never have used the Internet to get online to take more control of their own health.

NHS England has worked in partnership with a social enterprise, Good Things Foundation, which specialises in supporting digital inclusion and the development of digital skills for socially deprived

people. Good Things Foundation coordinates a network of Online Centres where people who lack digital skills or confidence in using online resources can use computers in a supported environment and gain online skills: 96% of public libraries are part of the Online Centres network, which also includes community centres, health centres, sheltered housing schemes – even a fish and chip shop.

Through the Widening Digital Participation programme, two simple online courses have been developed on the LearnMyWay platform (www.learnmyway.com/what-next/health). The first introduces people with limited digital skills to health information using the NHS website (www.nhs.uk). The second covers online health transactions including booking a doctor's appointment or requesting repeat medication online.

Over the three period 2013–2016, 400,000 people were engaged in the programme through events, workshops and online access to health information resources. Of these 220,000 have been trained in using digital health resources with support in a library or other community setting.

Following the success of the initial three-year Widening Digital Participation programme from 2013–2016, the NHS committed to further action to combat digital inequality in the period to 2020. At the end of 2015, the Secretary of State for Health in England asked the Internet pioneer, digital champion and Twitter board member Martha Lane Fox to advise on next steps to accelerate digital take-up and reduce digital exclusion. Her recommendations (Department of Health, 2015) called on the NHS to:

- Provide accessible, free of charge, infrastructure (wi-fi) throughout all NHS premises to enable patients and carers to access digital tools and technologies at point of care;
- Build the digital skills capability of the NHS workforce at all levels (from leadership to front-line) so staff have the knowledge and motivation to act as digital champions, supporting and encouraging take-up of digital services;
- Embed digital inclusion in all areas of NHS work, nationally and locally, with 'reaching the furthest first' a core principle of all we do. If we can get digital health services right for the hardest to reach groups they will be right for everyone.

Following these recommendations, the Widening Digital Participation programme was extended in 2017, again working with Good Things Foundation. In this second phase there has been a shift away from a focus on digital skills to a discovery and service

design approach, which aims to build a better understanding of the barriers to digital inclusion, and to co-design and test solutions with service users.

To provide evidence for the second phase of the programme, a data driven mapping exercise was undertaken. Using the *Digital exclusion heatmap* (Tech Partnership, 2017) areas of the country with the highest levels of digital exclusion were identified. These were then mapped against data on health inequalities and deprivation (Public Health England, 2017). This enabled prioritisation of localities with both high levels of digital exclusion and health inequalities. On the whole there is a strong correlation between the two – but not always. For example, inner city London has high health inequalities but digital inclusion is good with a young population and good broadband connections. On the other hand, some rural areas have poor broadband and an older population but often better health status.

The data mapping provided the evidence base for identification of sites for Widening Digital Participation Pathfinders. These have now been developed with the involvement of local health and care organisations. The Pathfinders involve working intensively with particular user groups in socially deprived localities to investigate their use of digital health services and information, and how they can best be supported. Up to 20 Pathfinders will be funded, with 11 live to date:

- North London – young people with mental health issues;
- Sheffield – using social prescribing to refer patients to digital training;
- North Somerset – developing a high street healthy living hub;
- Stoke – people with long-term conditions;
- Bradford – young people as carers;
- Wakefield – hearing and visually impaired people;
- Hastings – homeless and insecurely housed people;
- Sunderland – isolated older people
- Thanet – people in social housing;
- Dorset – maternity care, particularly with traveller families;
- Blackpool – users of accident and emergency services.

The Pathfinder work is carried out transparently and can be followed on the programme's Digital Health Lab (Good Things Foundation, 2018a) which includes blogs, case studies, reports of design

sessions, and practical how-to-guides capturing learning. Emerging findings include:

- Although young people are generally digitally confident and use digital tools in their everyday lives, they do not always find digital health resources relevant and meaningful. They are more likely to use health information, apps, etc. if they are involved in their design and development.
- Today older people are often using digital channels such as Skype and Facebook to keep in touch with friends and family. They can be surprisingly ready to use these channels for virtual consultations if they provide convenience (e.g. avoiding need to travel).
- Homeless people often have devices (particularly mobile phones) and often have the skills to use them. Their needs can be more basic – a dry, safe, non-judgemental place where they can charge their phone and get online using free public wi-fi.

The Widening Digital Participation programme has also produced a *Guide to Digital Inclusion* (Gann, 2018a) for local health and care organisations. The Guide provides practical advice on establishing the extent of digital inclusion locally, commissioning and evaluating digital inclusion support, benefits and business case, and partnership working. The content of the Guide was researched through a programme of engagement with health and care organisations, and an agile approach was taken to development with user feedback on alpha and beta versions before the Guide was published online in May 2018.

Wales

Wales has an impressive record in tackling digital exclusion, both in policy and practical action. The Welsh Government's (2016) *Delivering Digital Inclusion: A Strategic Framework for Wales* has an ambitious 15-point delivery plan, and a Digital Inclusion Charter. A dedicated national digital inclusion programme, Digital Communities Wales, is being delivered by the Wales Co-operative Centre. A new *Digital Competence Framework* (Welsh Government, 2018b) is in place in all schools, equipping pupils with the skills they need to be digital citizens in the modern world. Superfast Cymru is bringing broadband access to rural communities which would otherwise miss out.

There are many examples of digital inclusion good practice and innovation in health and care settings, particularly through Digital Communities Wales (Welsh Government, 2018a). In particular, Wales is leading the way in intergenerational support. Through the Digital Heroes initiative, schoolchildren befriend

older people in care homes and introduce them to digital technology, often with inspiring and transformative results.

More than 75% of women and a third of men over 65 in Wales live alone, and a quarter say they are lonely. The cost of social isolation and disconnected communities in Wales has been calculated at £2.6bn per annum (National Assembly for Wales, 2017). Through Digital Communities Wales, people who would otherwise be lonely and isolated are being supported to get online so that they can keep in touch with friends and family. Under the *Ffrind i mi* (or Friend of mine) initiative, Community Connectors befriend anyone who feels lonely or isolated so they can reconnect with their communities

Technologies (including VR headsets) are being used to enable people with dementia to connect with positive memories). Reminiscence sessions in care homes for staff, families and people with dementia, are using digital media (Internet, tablet computers) to help people compile their own life stories.

Digital Communities Wales has also recognised a powerful link between people's motivation to improve both their digital skills and their physical activity. People in a number of settings (housing association tenants, women's fitness group, stroke survivors, workforce) have been loaned Fitbits and shown how to use technology in a fun and informal way.

Remote health care through Skype and online consultations has particular potential in Wales, saving people journeying to hospital where there is often poor rural transport. Digital inclusion support has been shown to create the right conditions for frail older people to use virtual consultations in rural areas (Williams et al., 2017).

A recent report on *Digital Inclusion in Health and Care in Wales* (Gann, 2018b) reviews good practice in Wales, and makes recommendations for future action. In response the Welsh Government has made a new allocation of £3m for a new digital inclusion for health and social care programme from 2019.

In England and Wales we have driven forward digital inclusion through:

- Targeting: using evidence-based, data mapping approaches to identify localities with the greatest health deprivation and low digital adoption so we can focus our efforts;
- Connecting: working with some of the most digitally excluded people in their own spaces, including homeless people and people in long stay mental health units;
- Transforming: carrying out qualitative and quantitative evaluation with compelling case

studies showing the transformative impact of gaining digital skills for individuals, and evidence of significant benefits and cost savings to the health care system.

The role of libraries

Despite the adverse impact of widespread public library closures – 499 libraries closed in the UK between 2012 and 2017 (Onwuezezi, 2017) – libraries remain a crucial community asset for both health promotion and digital inclusion. Libraries are trusted community spaces, whose unique benefits include assisted digital access, health information resources and services, and the volunteering and recreational opportunities they provide. They can deliver a range of health and wellbeing benefits to local communities including those who may not normally access other services.

In August 2017, IFLA issued a *Statement on Digital Literacy*. As the Statement asserts, digital technologies have dramatically transformed our lives but not all can take full advantage of the opportunities created to receive, apply, share and create information. Just as basic literacy – the ability to read and assimilate information – is essential for individuals to participate and flourish in society, realising the potential of digital technologies for personal and community development requires everyone to have the necessary knowledge, skills, attitudes and behaviours.

Given libraries' mission to help all their users access and apply the information they need for personal and community development, this is an important part of the practice of librarianship. The Statement sets out the case for action, defines digital literacy, and makes recommendations to governments and other stakeholders. It also includes examples of library programmes supporting digital literacy in Tampere, Finland; Melbourne, Australia; San Antonio, USA; and Western Cape, Australia.

The American Libraries Association has held a Digital Inclusion Summit leading to the report *After Access: Libraries and Digital Empowerment* (Clark and Perry, 2015). The report recognises the central role of libraries in building digitally inclusive communities, ensuring that nobody is left behind in the digital revolution. The report includes valuable summaries of activities carried out by libraries in partnership with other community organisations.

England

The Society of Chief Librarians (now Libraries Connected) has developed a set of Universal Offers,

including a Universal Health Offer and a Universal Digital Offer. The Universal Health Offer (Libraries, 2017b) includes a commitment for public libraries to provide a range of services including:

- Creating Reading Well self-help reading lists and book collections in libraries covering key areas of health and wellbeing such as mental health, dementia and long-term conditions;
- Signposting and referring the public to information and local services who can provide advice and support;
- Providing creative and social reading activities for a range of targeted groups such as dementia sufferers, teenagers and older people.

The Universal Health Offer includes the Reading Well programme, developed with the Reading Agency. Reading Well promotes the benefits of reading for health and wellbeing, and includes Books on Prescription and Mood Boosting books.

The Universal Digital Offer (Libraries Connected, 2017a) aims to narrow the digital divide between those who regularly access information online and those who do not by:

- Ensuring that all public libraries offer a basic level of digital service to the public, to include free wi-fi, computers and online information about library services;
- Working to develop staff so that they have the skills to help customers who do not normally access information and services online;
- Identifying significant digital developments and highlighting how public libraries and their leaders should respond.

Libraries have been key partners in supporting digital inclusion through the NHS Widening Digital Participation programme. In Southampton, the city library service worked with Macmillan Cancer Support to improve the digital and information literacy skills of people with cancer, and introduce them to high quality cancer information resources. (Tinder Foundation, 2015).

NHS library and knowledge services, while primarily focused on the knowledge and information needs of healthcare professionals, have also recognised their vital role in supporting patients, carers and the general public. Knowledge for Healthcare (2018) has produced a vision statement which includes:

Healthcare library and knowledge services... work in partnerships with key stakeholders to enrich the information offered to patients and carers, to enable people to

better manage their health and wellbeing and make fully informed decisions about their treatment and care.

Knowledge for Healthcare has also produced an Ideas Bank with practical examples of how healthcare libraries can contribute to patient information activities.

Wales

The quality framework for Welsh public library standards, *Connected and Ambitious Libraries* (Welsh Government, 2017), introduced a specific quality indicator for health and wellbeing. Libraries must ensure that the following are offered in all static service points open for 10 hours a week:

- Books on Prescription Wales;
- Better with Books Scheme;
- Designated health and wellbeing collection;
- Information about healthier lifestyles;
- Signposting to health and wellbeing services.

And must report on the number of service points where the following are available:

- Macmillan Cancer or other health information partnerships;
- Dementia friendly services;
- Mental health awareness services.

Public libraries in Wales have been working with Digital Communities Wales to provide digital skills training and support information literacy. A half-day digital inclusion training course has been developed for staff and volunteers in libraries, as well as a fuller two-day digital champions course. Many libraries in Wales are now holding Digital Fridays, where users are introduced to digital technology and tools.

For example, during 2018 Newport Libraries delivered two health-related pilot projects, in partnership with a social housing association and the mental health support organisation MIND. Tea & Tech sessions for social housing residents were based around using the Internet to look at ways of improving health and wellbeing, visiting recognised safe sites for support and guidance. Users had the opportunity to complete an online health assessment form and to be signposted to support groups that could give information on their condition. The project with MIND started in August 2018, encouraging the use of apps to support health and wellbeing. As apps are becoming more popular the Library Service is beginning to promote their use within the digital literacy support programme.

Kenya: UK partnership

In addition to working in the UK, specialist digital inclusion organisations are helping to support digital literacy in other countries. Digital health in Kenya is in its infancy. High costs of digital health systems, poor infrastructure in rural areas and low digital literacy of the population are all barriers to digital health adoption. However, submarine fibre optic cables and connection of major towns to broadband has led to marked improvements in infrastructure.

The real game changer is mobile. Mobile subscriptions in Kenya have surged from 330,000 in 2001 to 38 million in 2016, in a country with a population of nearly 45 million. Many Kenyans have skipped a technological generation, with mobile bringing many online who have never had access to desktop machines or fixed-line broadband (Mutiga and Flood, 2016).

The Kenya National e-Health Policy 2016–2030 aims to ensure that health services are electronically accessible to patients at all levels of the economy, with objectives which look familiar to healthcare systems in other countries:

- Ensure that health information on the eHealth platforms for patients and physicians is multi-lingual, multicultural, multi-professional, and multijurisdiction;
- Ensure affordable broadband Internet connectivity to all parts of the country to enable online access to eHealth services and information;
- Ensure that services are offered across a variety of eHealth access platforms including but not limited to mobile devices and community digital centres;
- Facilitate the use of telemedicine by caregivers in geographically isolated communities to provide healthcare services;
- Promote cross-border sharing of health information about the medical incidences and history of a particular patient by healthcare professionals without compromising his/her privacy.

Last year, a new project to help develop digital literacy was launched by the UK-based Good Things Foundation in partnership with the Kenya National Library Service. Digital Life: Kenya (Good Things Foundation, 2017) has been working with librarians to develop their digital skills, which were often low, so that they could act as digital champions with library users. Libraries are now providing outreach sessions to teach digital skills, with over 60 libraries in the scheme.

At Kinyambu Library, over 50 library users have registered on the Learn My Way online digital skills learning platform. The library now runs a Community Digital Club on Saturdays. Some library users have successfully found jobs after completing Learn My Way.

The Kenya National Library Service has been sponsored by a development corporation to provide laptops and wi-fi, with 640 new devices provided along with local cabling. There are also successful partnerships with international agencies including Book Aid International and EIFL (Electronic Information for Libraries).

Measurable benefits of digital inclusion

Digital inclusion is a social and moral imperative, but there are also compelling economic reasons. Evaluation of the Widening Digital Participation programme in England has produced very encouraging results with people trained in digital skills through libraries in socially deprived communities showing greater confidence in managing minor ailments, reduced dependence on health services and improvements in lifestyles (Tinder Foundation, 2016).

Results include

- 82% of learners were socially disadvantaged and likely to be experiencing health inequalities;
- 41% of learners learned to access health information online for the first time;
- 54% of learners would now go online for non-urgent medical advice;
- 52% of learners now feel less lonely or isolated.

The impact on primary care services was particularly encouraging. One in five of people trained can now book appointments with their general practitioner (GP) online and one in five now order their medication online, saving time and cost for themselves and the NHS. And one in five (21%) say that because they now know how to access online health advice, they now make fewer visits to their GP for minor ailments: 6% say the same about fewer visits to hospital accident and emergency departments. Good Things Foundation has calculated that this represents an annual cost saving to the NHS of £6m in avoided GP and A&E visits – paying for the £1m annual cost of the Widening Digital Participation programme six times over.

The level of savings for the NHS has now been revised in a report from Cebr: Centre for Economics and Business Research, *The Economic Impact of Digital Inclusion in the UK* (Good Things

Foundation, 2018b). Cebr calculate savings to the NHS through individuals learning digital skills and so being able to use the NHS website for self-care advice, as well as booking appointments and requesting prescriptions online. These amount to savings of £141m by 2028 through reduction in GP visits and reduction in use of offline services. Reduction in avoidable GP consultations alone could save £10m within a year.

Of course, increasing digital inclusion has benefits for society as a whole as well as for the NHS. It is important to take these benefits into consideration when considering the impacts for public health. Analysis of Scottish data carried out by Ipsos MORI for Carnegie UK Trust (White, 2016) illustrates the wider societal benefits how Internet use is associated with better health and wellbeing. Those who use the Internet are more likely to have:

- been to a cultural event;
- visited outdoors for recreation;
- taken part in sport;
- volunteered.

Conversely those who are not online are more likely to have visited their doctor once a month or more.

There is a particularly strong benefits opportunity in digital inclusion relieving loneliness and isolation. The National Assembly for Wales (2017) *Inquiry into Loneliness and Isolation* includes powerful evidence on the impact:

- There is a strong link between loneliness and depression. 60% of older people who report being depressed also say they are lonely.
- Lonely and isolated people tend to smoke and drink more, have a poorer diet, and skip medication.
- Falls among lonely and isolated people tend to go unnoticed and unreported.
- Lonely and isolated older people are at an increased risk of dementia.

The cost of social isolation and disconnected communities in Wales has been estimated as £2.6bn per annum, which included:

- £427m – demand on health services;
- £10m – demand on policing;
- £8m – cost of stress and low self-esteem

Disconnected communities are linked to a loss of productivity, with a net cost to the Welsh economy of over £1bn every year. Economic modelling of the cost

effectiveness of actions to reduce loneliness to promote better mental health carried out for Public Health England and submitted as written evidence to the National Assembly for Wales (2018) *Inquiry into Loneliness and Isolation* ‘concludes conservatively that substantial costs to health and social care systems potentially may be avoided if poor health associated with loneliness can be avoided’. This modelling suggests that these costs conservatively may be in the region of £1700 to £6000 per case of loneliness avoided over a 10-year period for people aged 65–75.

If people are online they have better opportunities to keep in touch with friends and family, so reducing loneliness and isolation. The Widening Digital Participation evaluation in England showed 52% of people provided with digital inclusion support felt less lonely and isolated. Work in Wales to combat loneliness through improved digital adoption, including Digital Heroes, is demonstrating a significant return on a very small investment.

Conclusion

Universal access to digital health tools and services, with the skills to use them, has the potential to be one of the great public health advances of the 21st century. The great public health advances of the 19th century came not from medicine but from infrastructure improvements in housing, water supply and sewers. In the 21st century, those who lack access to the public utility of the Internet will, like those who lacked access to the public utility of clean water and sanitation in the 19th century, be at risk of increasing inequality and poorer health status. Libraries are on the front line in combating digital health inequality. In an era of austerity, libraries are having to justify their role. Today, they are showing the way as agents of equality – bridging the gap between the digital haves and the digital have-nots.

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Author biography

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Towards new ways of assessing the impact of local medical journals: A proposal and call for change

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Abstract

The relevance of research output to the local community is critical to changing practice. Research relevance has to be determined using measurements that show that the knowledge that arose from that research has made an impact on society. This paper, based on a literature review and preliminary research results, advocates for research impact measurements which take account of local contexts when evaluating the relevance of a journal article or indeed any research output. It concludes that a journal should go beyond traditional measurement metrics of citation analysis and bibliometrics alone as a measure of research impact. Although it is important to standardise measurements, it is also important that local communities should be encouraged to choose measurements of research output that matter to them. The proposed ways of assessing research impact are: (a) change in policies in the health sector, (b) effect on local medical treatment guidelines, (c) effect on case management, (d) use in continuous professional development, and (e) impact on local knowledge production.

Keywords

Assessment, bibliometrics, citation analysis, impact factor, knowledge production, research, research output, Zambia

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Introduction

African researchers are faced with a myriad of problems when it comes to publishing and to making the impact of their research output felt both within their country and internationally. The problems of inadequate infrastructure and finance, and a lack of publication outlets and post-publication dissemination channels, are just some of the problems faced by African researchers. There is also a lack of knowledge and competencies, such as authorship skills, copyright, where to publish, what choices to make when the manuscript is finally ready for publishing, and which journal to finally submit the manuscript to, whether

locally or internationally. These problems were clearly articulated at a meeting organized by the Planet Earth Institute and held in October 2013 at the House of Lords, and chaired by the Rt Hon Lord Paul Boateng. Lord Boateng indicated that “African research should be assessed using a broad range of metrics as recommended by the San Francisco Declaration on Research Assessment” (Schemm,

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2013) whilst Dr Alicia Wise stated that “much critical research remains unpublished as ‘gray literature,’ largely inaccessible beyond the walls of an institution. Much African research is also published in local, regional and national journals that are not yet indexed” (Schemm, 2013).

As argued by Smart et al. (2004: 330) “apart from financial problems, there are many infrastructural and cultural factors that affect the dissemination of quality information and have resulted in a poorly developed information economy and a lack of representation within the international research community”. It follows, therefore, that after one has been able to publish an article despite these problems, it is important that we know how that article has been utilized. For the authors, an important question to ask would be: what has been the impact of that one published article on Zambian society? This question cannot be adequately answered by traditional measurement metrics, or more recently by the alternative measurement metrics of altmetrics.

Objectives of the paper

The aim of this paper is to review various ways of measuring the impact of research output in the African context, and to propose alternative measurements, using the *Medical Journal of Zambia* as an example.

Methodology

The paper adopted a theoretical review of the literature, using the *Medical Journal of Zambia* as a case study, and combined with the personal reflections of the authors. An earlier version was presented at the International Federation of Library Associations and Institutions (IFLA) Annual Conference held in Kuala Lumpur, Malaysia from the 24th to 30th August 2018.

The Medical Journal of Zambia

The *Medical Journal of Zambia* (MJZ) is published quarterly by the Medical Association of Zambia (ZMA), a membership body of medical doctors in Zambia, and features articles from different medical specialties as well as those that are at the junction of medicine, health, and the social, economic, environmental, and political spheres. It is a “peer-reviewed quarterly journal intended for the publication of papers from all specialities of medicine (Internal Medicine, Surgery, Paediatrics and, Obstetrics and Gynaecology) and their subspecialties, basic sciences, public health, social medicine and medical politics”. Its mandate is to be the:

- dissemination forum for medical and allied research as well as clinical opinion and practice;
- source of medical information for evidence-based patient care and public health for its readership;
- provide medical researchers, biomedical scientists, clinicians and all allied health worker professionals with a forum to enhance their publication skills; and
- source of local continuing education to almost all health care professionals in Zambia (Kachimba, 2010).

The MJZ was first published three years after Zambia gained its independence on behalf of the ZMA in Ndola in 1967, by the Associated Reviews Limited. This also occurred one year after the University of Zambia (UNZA) Medical School was established; the journal has long been associated with the school although it has been, and is still, owned and published by the ZMA. This association with the UNZA Medical School has been established mainly because, for a long time, the Editor-in-Chief of the journal was a faculty member of the UNZA School of Medicine. What that means is that the journal secretariat has been held by the UNZA School of Medicine. However, the UNZA School of Medicine’s site of practice is the University Teaching Hospital, the largest tertiary-level hospital in Zambia. They share the same physical premises. The journal is currently published online only, with the print version ceasing publication in 2010. Among the major international databases MJZ is only indexed in African Journals Online (AJOL) which is a very important African database. Due to this lack of exposure it does not enjoy the benefits of traditional research impact metrics.

Research impact

Research impact is a subject that is of interest to many people in the knowledge production process. This interest applies **both at** society, institutional, and at a researcher level. People do not produce knowledge just for the sake of producing knowledge; they want to know whether that knowledge has been utilized, implemented by society, and ultimately changed their lives. What then is the meaning of research impact? Research impact may mean different things to different people and audiences. A comprehensive definition of research is offered by the United Kingdoms’ Research Excellence Framework (REF), who define research impact as “an effect on, or change or benefit to the economy, society, culture, public policy or

services, health, the environment or quality of life, beyond academia” (REF 2014, 2014: 26). The Research Councils of the United Kingdom (RCUK) define research impact as “the demonstrable contribution that excellent research makes to society and the economy” (UK Research and Innovation, n.d.), a definition that does not focus only on academic impact but also on societal impact as a whole. The London School of Economics (LSE) Public Policy Group (2011: 5) say research impact is a “recorded or otherwise auditable occasion of influence from academic research on another actor or organisation”. According to Greenhalgh et al. (2016: 1) research impact “occurs when research generates benefits (health, economic, cultural) in addition to building the academic knowledge base”. Dunikowski and Freeman (2016: 266) have argued that:

[the] meaning of impact for funders and policy makers might be conceived of as influence on policy, health service delivery, and population health outcomes. Academic institutions are more interested in how a discipline is represented in the academic milieu. For researchers, impact might mean the influence of their work on other researchers and practitioners in the field. For clinicians, the focus will be on the effect on daily practice.

All the above definitions emphasize the importance of research making an impact in people’s lives, whatever the sphere of activity they may be involved in.

In the health sector, just like any sector of society, knowledge production is critical to the success of patient care. Knowledge production requires a publication outlet in which the knowledge product may be published and made available to the relevant constituency. Once knowledge is produced, it requires utilization. In knowledge utilization, journals play a major role, as they are the publication outlets for most of the knowledge produced by scholars and researchers in the biomedical field. After the knowledge has been produced, it must see the light of day through a journal or other media platform. It is at that point that evaluation becomes relevant, because that knowledge now needs to be evaluated on its impact at all levels of society – researcher level, institutional level and indeed the general society as well. Measuring the impact of research output is pivotal to the exercise of knowledge production. In other development fields, this process is sometimes referred to as monitoring and evaluation. This means, that even in scientific knowledge production, it is imperative that the knowledge that is produced is evaluated on its

impact, not only on society in general, but on its relevance to the local community in which that knowledge has been produced. The definitions of research impact cited above bring to the fore the argument that research impact goes beyond the academic.

Research impact evaluation

Moving beyond traditional research impact evaluation

In academia, the benchmarks that have been available to evaluate knowledge production are based on criteria that have been set by the academic community themselves. This evaluation is based on a system of peer review and may not be applicable in all instances of measuring the impact of research. Peer review which, according to Ware (2008: 4), is the “process of subjecting an author’s scholarly manuscript to the scrutiny of others who are experts in the same field, prior to publication in a journal”. In peer review, peers evaluate the likely impact of new knowledge before publication. It is grounded on the assumption that because peers are subject specialists and knowledgeable in that particular scientific field, they are best placed to judge the quality of that knowledge.

Other criteria for evaluating knowledge in academia are the impact factor and citation metrics. According to Cross (2007:1) “journal impact factors give the average number of citations to articles in a particular journal; essentially, the average number of times that articles in a journal are referenced by other articles”. This number is derived from “dividing the number of times a journal is cited by the number of articles that it publishes” (Brown, 2007: 562). The impact factor is used to measure the importance or rank of a journal by calculating the number of times its articles are cited.

In academia, impact factor metrics have been used as one of the ways of measuring research output impact. However, this has not been accepted by everyone and has led some to argue that a “journal’s impact factor says nothing at all about how well read and discussed the journal is outside the core scientific community or whether it influences health policy” (PLOS Editors, 2006: 0707). Alternative journal measurement metrics have been recommended to help highlight that impact achieved by journal articles which is not captured by traditional academic databases. These alternative measurement metrics, called altmetrics, have been enabled by the increasing usage of online platforms which has been made possible by the advent of the Internet. Altmetrics

measures the number of times a research output gets cited, tweeted about, liked, shared, bookmarked, viewed, downloaded, mentioned, added to favourites, reviewed, or discussed. It harvests these numbers from a wide variety of open source web services that count such instances, including open access journal platforms, scholarly citation databases, web-based research sharing services, and social media. (Loria, n. d.)

These article-level metrics offer a “wide range of metrics about the uptake of an individual journal article by the scientific community after publication” (Fenner, 2013: 1).

Further recognition of the inadequacy of the traditional impact factor is demonstrated by the San Francisco Declaration on Research Assessment (n.d.), which recommends that the two-year impact factor should be used with other factors such as the “5-year impact factor, EigenFactor, SCImago, h-index, editorial and publication times, etc. that provide a richer view of journal performance”.

Research impact evaluation: The Zambian context

Since some journals in Africa, just like the MJZ, are not indexed in major databases such as those of the Medline, Scopus, Web of Science, and other internationally-recognized indexing databases, it is sometimes difficult to measure and track its impact by using traditional measurement metrics of citation impact. Making local research output visible has been problematic for both researchers and institutions especially in sub-Saharan countries. This is because of a myriad of factors, such as the difficulty with which researchers in most African countries find themselves in, that is, to break through and have their articles published in ‘high-impact’ international journals. It is important therefore that the MJZ considers other alternative journal measurement metrics in order to be able to indicate its impact.

Studies that make the linkage between research output and impact are required so that the benefits that knowledge production brings to society are well articulated. Journals are produced for the same reasons: that articles published in those journals are used by people to make a positive change in their lives. In this case, the knowledge contained in a journal such as the MJZ should be utilized by medical and health practitioners to improve their clinical practice and ultimately for the continued well-being of Zambian society. When medical and health practitioners improve their clinical practice by utilizing the knowledge obtained in local journals, they improve the services they offer to both patients and the general public.

Although traditional measurement metrics of bibliometrics, citation analysis, and other alternative measurement metrics are important in trying to establish the impact of a journal, it is critical that measurements that are qualitative in nature are also taken into consideration. This is even more so when researchers are involved in tackling local issues that may not be relevant to international audiences. For instance, in Zambia, such research may be on Konzo disease, a neglected disease of limited interest to health professionals in other countries. Konzo disease is a “distinct neurological entity with selective upper motor neuron damage, characterised by an abrupt onset of an irreversible, non-progressive, and symmetrical spastic para/tetraparesis” (Nzwalo and Cliff, 2011). According to Zambian studies, this disease has been diagnosed in people who eat a lot of cassava, especially in the western part of Zambia. An article in the MJZ reporting “Increased sensitization of health workers leading to detection of unintended cases of acute flaccid paralysis: A case of a ‘Konzo’ outbreak in Western Zambia” (Mtonga et al., 2016) would be of particular interest to the Zambian medical community. Statistics on its citation patterns might be useful, but for Zambians, the interest would be whether health workers are able to learn from the research about the management of Konzo disease. Additionally, there might be need to change local treatment guidelines so that any health worker in Zambia who comes across a case of Konzo disease would know how to handle the patient anywhere in Zambia.

How then does one decide how important such a journal is to its local community? Should we use traditional measurements metrics to decide the impact of the journal? Whatever measurements are adopted, they should be tied to the aims and objectives in which that particular knowledge was produced. This paper argues that it is imperative that measuring the impact of a journal goes beyond metrics. In discussing these measurements this paper is cognizant of the manner in which the journal itself sees its impact would be felt by their constituents by focusing on alternative ways of measuring the impact of local research.

It is clear that, from the onset, the MJZ saw itself as going beyond academia; and perhaps the fact that it is published by the ZMA demonstrates that its focus is mainly on impacting health care delivery in the country. A relevant question to ask is that one that has been alluded to by Maeseneer et al. (2007: 402) that; “journal impact factor has an impact on how research and researchers are valued by their academic peers and on the allocation of research funds, but does it have an impact on what research is ultimately about,

improving quality of life for all citizens?”. There are arguments advanced that advocate for measuring a journal’s worth by looking at its contributions to society in general (Maeseneer et al., 2007). How do we arrive at a point where we can say: this is how the local community benefitted from the information coming from a journal article where a journal is geographically located?

Suggested ways of measuring research impact

Although traditional measurement metrics such as citation analysis, and the related field of bibliometrics, are important in trying to establish the impact of a journal, this paper argues that it is essential to go beyond these, particularly in the context of Africa or the global South. In discussing these alternative metrics, this paper puts forward some ways of measuring research impact. In this regard, Kachimba (2010) at the African Journal Partnership Project Annual Review and Planning Meeting held from 8th to 19th May 2010 in Atlanta, Georgia, (United States) looked at the impact of the MJZ through several perspectives, namely:

- Impact with respect to its publication scope;
- Impact with respect to its readership and circulation;
- Impact with respect to calibre of its authors. (Kachimba, 2010)

Following on from the above yardsticks, we argue that the following aspects are important in measuring the impact of the MJZ

Impact on policies in the health sector. Use of the research output contained in the MJZ can change policies in the health care sector. These changes can either be targeted towards the health care provider, officials in the Ministry of Health, health care seekers, patients, or the general population. The information in the MJZ informs the Ministry of Health and other policy makers on the problems and progress that happen in Zambia’s health system through research and thereby help in changing the policy direction of the country. However, these changes are not always definite; as it has often been argued by Cruz Rivera et al. (2017: 16) who quote van Driel et al. (2007) stating that:

whilst it is true that wider dissemination, especially when delivered via world-leading international journals, may well lead eventually to changes in healthcare, this is by no means certain. For instance, case studies evaluated by Flinders University of Australia demonstrated that

some research projects with non-peer-reviewed publications led to significant changes in health policy, whilst the studies with peer-reviewed publications did not result in any type of impact.

These findings indicate that sometimes research published in leading international journals may not meet the specific local needs. This is why this paper strongly makes the assertion that the MJZ’s impact be measured according to how its articles influences local policy, i.e. if its contents are being used to change policy direction. Others such as Ravenscroft et al. (2017), claim that Altmetric.com and other altmetrics providers already examine some policy documents as part of their offerings. However, there are some concerns about the coverage, or lack thereof, of policy providers with respect to geographical regions and scientific fields (Ravenscroft et al., 2017: 2). The major criticism of altmetrics is similar to the criticism of the citation analysis and bibliometrics. They are based on metrics that do not respond to the core needs of the local community. This is because most often the “recipients of research can reliably assess the relevance of publications in a practical context” (Bornmann and Haunschild, 2017: 941). It has further been alleged that “research funders and science politicians are interested in the broad impact of science, i.e. the impact of the sciences beyond the sciences” (Haunschild and Bornmann, 2017: 1210), and that “data can be used for assessing policy impact, but there are clearly still problems with how the software identifies and attributes research papers” (Tattersall and Carroll, 2018: 10). Specifically, there are no measurement metrics that respond to the need of the local community. They further argue that existing analysis of policy documents is based on counting references in these documents to scholarly articles (Tattersall and Carroll, 2018: 10), while this paper argues that counting references in the documents to scholarly articles is not good enough, but utilization of policy contents will show appreciation of its existence.

Impact on local medical treatment guidelines. Local articles should reflect changes in treatment guidelines as adopted by the country’s Ministry of Health. This is helpful as medical practitioners can reflect on the treatment regimens in their practice. A local article discussing the treatment of a particular ailment might be more relevant to the local context than to the international context. Studies such as ‘A Review of the 2010 WHO Adult Antiretroviral Therapy Guidelines: Implications and Realities of these changes for Zambia’ (Patel et al., 2010) can bring significant changes in policy and benefit to the local population. The

article speaks more to the local context as it brings out issues that are specifically relevant to Zambia. Consequently, the article can be used to change treatment guidelines to meet the needs of the local people; then its impact should be rated high as it has a substantial impact on the general health of the locals. Weiss (2007) states that measuring the penetration of research into the clinical domain is thus a complex but important first step in assessing the impact of science on patient health. Weiss further contends that “measuring awareness of a particular research finding is insufficient, for one simple reason: there is a tremendous difference between knowing and doing” (Weiss, 2007: 210). Weiss (2007) cites Wilson et al. (2008) who noted that:

the naive assumption that when research evidence is made available it is routinely accessed by practitioners, appraised, and then applied in practice is now largely discredited. While awareness of a practice guideline or a research-based recommendation is important, it is rarely, by itself, sufficient to change practice. (Weiss, 2007: 210)

This then demands a concern about the extent to which results are implemented or/and utilized, as high citation rates, likes, tweets and referencing may not mean usage.

Impact on local case management. Case management may sometimes differ; and, therefore, the relevance of local articles discussing the management of a particular disease in one part of Zambia might be more relevant to another area or town in Zambia than a city in other regions of the world such as Asia, Europe, Latin America, United Kingdom, or the United States of America. The MJZ publishes articles on diverse medical conditions, some which are Zambia specific or rare cases in the tropics. The rare disease called Konzo, identified in the Western province of the country (Mtonga et al., 2016) and reported in the MJZ, was discussed above. This may serve as a notification to the rest of the Zambian medical community to look out for the disease as well as to learn about its management. Such publications may not come out in the traditional measurement metrics and alternative measurement metrics of altmetrics but may be significant in the local journal measuring metrics, as their importance may only be felt by the locals. This is why this calls for a more comprehensive way of measuring a journal’s impact to include utilization of evidence from such publications in policy and in practice.

Impact on continuous professional education. Research output is important in the knowledge management chain. In order for health practitioners to perfect their practice, they require access to knowledge. It is also important for health practitioners to access information that is relevant to their studies, be they ordinary studies, specialist studies, or continuous professional development (CPD). CPD requires access to empirical evidence in order for it to be successful (Collin et al., 2012). CPD is a stage that is necessary to research, as it is a stage where the evidence arising out of knowledge production is to be utilized.

Impact on knowledge production. Medicine is a very dynamic field that requires one to keep up to date with recently-validated information. It is important that Zambia’s local knowledge not only impacts the health care delivery process, but is continuously used in the local knowledge production process. This is only possible if Zambian authors are encouraged to write on Zambian health issues, issues that affect Zambians, and that these articles are published in a local Zambian journal such as the MJZ. Eriksson (2000: 248) notes that there is a “need for learning and knowledge-production using both quantitative and qualitative approaches for developing the evidence base for public health action”. Knowledge production is a continuous cycle that needs both learning and research to feed into the process of knowledge production so as to produce new evidence.

Conclusion

The need for publishing locally by Zambia authors cannot be overemphasized when one looks at the publishing focus of the MJZ. It is important that local authors publish in local journals for their local audience, but this should not mean that 100% of a local journal’s authorship should only be from within the country. There should be a balance between local articles and those coming from international authors; it is critical that there is a cross pollination of ideas. It follows, therefore, that local Zambian authors should also be encouraged to publish in international journals. In this context, Smart et al. (2004: 330) have argued that:

Most African journal editors and African scholars see potential advantages in publishing within their own region. If academic publishing is seen as an exchange of ideas and information among scholars working in the same area rather than as a tool for promotion up the academic ladder, it is clear that a regional pool of ideas governed by the interests of those living there is desirable. If this sounds parochial, consider how surprised

Canadian scholars would be to find their publications largely dominated by the interests and theories of Malaysians rather than their own.

Local journal production is important to the success of any local knowledge production process. It is generally agreed that knowledge production underpins any profession and medicine is no exception. However, knowledge once produced needs to be utilized, and in order to know what the impact of the produced knowledge is on society, it needs to be measured. The measurements must be appropriate to the context that it is measuring. Although it is important that the assessment of the impact of knowledge on society is standardized, we argue that it should be a combination of measurements that are cognizant of the local environment. In recognition of the local context, it is significant that the MJZ considers other alternative journal measurements in order to be able to indicate its impact to Zambian society. It is also critical that metrics that look at citation data, page views, and downloads are used in conjunction with qualitative evaluation to indicate the true impact of a journal and its responsibility to its local community. The knowledge contained in a journal such as the MJZ should be utilized by medical and health practitioners to improve their clinical practice and ultimately for the continued well-being of the Zambian society. And by improving their clinical practice, they improve the services they offer to both patients and the public. In the end, a traditional evaluative research conducted over time intervals would be able to indicate the impact and relevance of the MJZ to Zambians. It might be apt to proclaim that “inadequacies of simple bibliometrics and altmetrics illustrate the adage that not everything that counts can be counted” (Dunikowski and Freeman, 2016: 268), but rather quantitative statistics must be combined with qualitative data to measure the true value of a journal to its local community. The San Francisco Declaration recommended that we “challenge research assessment practices that rely inappropriately on Journal Impact Factors and promote and teach best practice that focuses on the value and influence of specific research outputs” and “consider a broad range of impact measures including qualitative indicators of research impact, such as influence on policy and practice” (San Francisco Declaration on Research Assessment, n.d.).

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Health information literacy awareness and capacity building: Present and future

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Abstract

Health literacy is increasingly important in today's complex information ecosystem, both nationally and globally. Across the world, whether people live in "information rich" or "information poor" societies, the role of our profession is a vital one. In the developed world, the ubiquitous nature of health information creates a wealth of accessible content and simultaneously has created confusion as to what information is reliable, how health information can be utilized, and whether or not information is produced in a meaningful manner. In the developing world, content may be non-existent, culturally inappropriate or inaccessible in terms of language and other barriers. In order to mitigate the health information crisis we are now facing, we need to collaborate and respond to the challenges raised by the complexity of health information. Librarians and other information professionals can and must play an important role in improving health literacy in their communities. This paper considers international efforts towards improving health in both information poor and information rich settings, including work showcased in recent years at IFLA's Health & Biosciences Libraries Section Open Sessions at the World Library & Information Congress (WLIC). It discusses health literacy in the US and other developed economies, and looks in detail at innovative work by the University of North Carolina at Chapel Hill (UNC) where the Health Sciences Library (HSL), a part of the University Libraries, has strengthened efforts surrounding health literacy in local communities and throughout the state. This paper provides examples of how to partner with multiple constituencies on health literacy and discusses future opportunities for growth and engagement.

Keywords

Community engagement, consumer health, health information, health literacy, healthy communities, population health

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International efforts in health literacy

Health literacy is increasingly important in today's complex information ecosystem, both nationally and globally. Across the world, whether people live in "information rich" or "information poor" societies, the role of our profession is a vital one (Feather, 2017). However, in a report from the Roundtable on Health Literacy regarding health literacy efforts around the world, Andrew Pleasant (2013) notes that

"There is not a global organization for health literacy researchers, practitioners, and policymakers. Therefore, there is no known structure through which to contact practitioners, researchers, academics, and

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policymakers working with health literacy". Last year, at the Institute for Healthcare Advancement (IHA) Annual Health Literacy Conference in May 2018, this was addressed when a new health literacy association was formed, called the International Health Literacy Association (IHLA, 2018). At IHLA, a call for the formation of interest groups was announced, which led the Community Engagement and Health Literacy Librarian at the University of North Carolina at Chapel Hill, Health Sciences Library (HSL), to form the "Librarians Advancing Health Literacy" interest group. It is hoped that this group will serve in a networking and advisory capacity for other librarians interested in health literacy. This group could serve as a sounding board for new ideas, identification of health information resources, and sharing best practices from a global perspective that includes cultural awareness.

A variety of health literacy awareness initiatives and programs are occurring around the world. In the first European Health Literacy Survey, data were gathered in 2011 in eight countries: Austria, Bulgaria, Germany, Greece, Ireland, the Netherlands, Poland, and Spain. The survey was implemented as a population study, with 1000 randomly sampled members of the public aged 15 years and older, for each country, with a total sample population of 8000 people. The survey established four levels of health literacy: "insufficient", "problematic", "sufficient", and "excellent". Findings include that "at least 1 in 10 (12%) respondents showed insufficient health literacy and almost 1 in 2 (47%) had limited (insufficient or problematic) health literacy" although this varied by country (Sørensen et al., 2015: 1053). These findings demonstrate the internationality of the issue, as well as the challenge facing health professionals and policy makers throughout the world. In the publication *Health Literacy: The Solid Facts*, the World Health Organization (Kickbusch et al., 2013) highlights that most evidence, until recently, has been generated from the US. However, the European Health Literacy Survey has "generated a rich new source of high-quality data on the comprehensive health literacy of general populations that enables comparisons both within and between countries and has made major inequities visible" (Kickbusch et al., 2013: iv).

In this context, IFLA is playing a leading role. Over the last two years, it has been consulting on a new Global Vision to shape the future of our profession. Significantly, the Global Vision discussion includes among its top 10 highlights the observations that libraries are:

- deeply committed to core roles in supporting literacy, learning and reading;
- focused on our communities;
- eager to work more collaboratively and develop strong partnerships.

Apart from the book by its Chair, Professor Maria Musoke (2016), IFLA's Health & Biosciences Libraries section has showcased work in health information literacy in the developing world including Musoke and Namugera (2014), Naidoo (2016), Namuleme et al. (2017) and Nwafor-Orizu (2018).

Interesting collaborative projects that aim to improve health literacy and enable informed medical decision-making exist. In the UK, the CILIP Health Libraries Group and Health Education England's Library and Knowledge Services began "A Million Decisions" joint campaign to ensure that the more than one million healthcare-related decisions made each day in the National Health Service are evidence based (CILIP, 2016). Another important organization to note is Healthcare Information for All (HIFA), which is a global health network of over 18,000 members from diverse fields including health workers, librarians, publishers, researchers, and policy makers who are "committed to the progressive realization of a world where every person has access to the healthcare information they need to protect their own health and the health of others" (Healthcare Information for All, n.d.). Launched by the Association for Health Information and Libraries in Africa (AHILA), Global Healthcare Information Network, and other partners, at the 10th AHILA Congress in Mombasa, Kenya in 2006, HIFA is now comprised of more than 2500 organizations across 178 countries worldwide, with one-third based in Africa, one-third in Europe, and one-third in the rest of the world. A particular initiative, the HIFA Voices Database, aims to tackle information poverty by capturing the collective knowledge of participants in the HIFA discussion forums (Pakenham-Walsh, 2014).

Health literacy in the United States

The ubiquitous nature of health information is both a benefit and burden for health consumers; freely available health information on the Internet and a wide variety of media platforms allow access to multitudes of information. However, that wealth of information can be questionable, inaccurate, and overwhelming, particularly for those with low health literacy or fluency. In their systematic review of health literacy interventions and outcomes, Berkman et al. (2011) found that low health literacy is linked to higher risk

of death and more emergency room visits and hospitalizations. Furthermore, beyond individual impact low health literacy also significantly impacts the larger society and the healthcare system as a whole, with a cost to the US economy estimated between \$106 and \$238 billion per year (Vernon et al., 2007). Librarians can help by promoting awareness of the issue of low health literacy as well as help to increase health literacy skills by building capacity for understanding where and when to seek health information and how to effectively evaluate information found.

Libraries of all types contribute in myriad ways to the quality of life of communities. Libraries are a welcoming place, for the benefit of everyone, which makes them a natural location for people to connect and seek answers and assistance to help function in society. Public libraries provide training in the critical skills of literacy and lifelong learning and have stepped up to answer questions and provide technical assistance with navigating the health insurance marketplace, especially after the Affordable Care Act was enacted (Malachowski, 2014; Vardell, 2015). It is a natural extension of these capacities for public libraries to also support the health literacy needs of communities. Health literacy is unique in that possessing these skills can mean the difference between poor and good health (Kickbusch et al., 2013). However, only about 12% of the English-speaking adult population in the United States is considered proficient in health literacy skills (Kutner et al., 2006). Librarians have an important role to play and can assist people in locating health information, learn to critically evaluate whether information is authoritative and reliable, and to support health literacy in their communities. Given the focus on preventative medicine and increase in patient participation in shared decision making with health care providers, patients are now grappling with more complex health information needs. This paper serves as a call to information professionals and librarians working in all types of libraries throughout the world to become proactive and involved in health information literacy training in order to empower their communities.

What is health literacy?

Various definitions of health literacy exist, though a widely used definition by the US Department of Health and Human Services is “the degree to which individuals have the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions” (Ratzan and Parker, 2000). In 2008 the internationally-attended Calgary Institute on Health Literacy Curricula developed a

definition and rationale for the development of a health literacy curriculum. The Calgary Charter on Health Literacy defines health literacy as:

the use of a wide range of skills that improve the ability of people to act on information in order to live healthier lives. These skills include reading, writing, listening, speaking, numeracy, and critical analysis, as well as communication and interaction skills (Coleman et al., 2010: 1).

In the manual for clinicians, *Health Literacy and Patient Safety: Help Patients Understand*, Weiss (2007: 13) explains that “most clinicians are surprised to learn that literacy is one of the strongest predictors of health status”. He reports (p.13) that “all of the studies that investigated the issue report that literacy is a stronger predictor of an individual’s health status than income, employment status, education level, and racial or ethnic group”. As every individual will face a health issue at some point in our lives, health literacy skills are crucial in order to make informed health decisions and to navigate and interact with the health care system. As health care gets more complex and places more demand and participation in decision making on patients and their families, health literacy skills become increasingly important, impacting the overall health status of people.

Over time, there has been growing recognition that health literacy is an interaction; a two-way communication process that requires health professionals to have an awareness of the problem of low health literacy and its impact on their patients. Writing on “The evolving concept of health literacy”, Nutbeam (2008) emphasized that achieving good health literacy is not simply a matter of getting health information to those that need it; it also requires developing the confidence to act on that gained knowledge to make informed health care decisions. The idea is to use community-based educational outreach to help the individual with their personal health decisions, but also to tackle the social determinants of health that can impact the larger population. Nutbeam argues that improving individual health and health literacy skills can have additional positive effects on communities and the social determinants of health. Through this education, librarians can help people understand the effects of low health literacy on their personal health status and empower them to use information to reduce health disparities.

Roles for librarians and other information professionals

With increased access to freely available databases and websites, today’s information environment has

shifted from one of patron dependence on libraries and librarians as gatekeepers to information and knowledge, to one of self-driven information seeking. Patients have shifted from passive recipients to active consumers of health information (McMullan, 2006). Instead of relying on librarians for mediated searches of the literature, often in books and journals behind paywalls, a great majority of people now have access to a wide range of freely available databases like PubMed/MEDLINE, consumer health sites such as MedlinePlus, and online support groups. As more information becomes freely available, this can have both positive and negative impact on information users. Increasingly, patients want to be able to read what their doctors are reading, look at new research being conducted on a health issue, or engage in a meaningful discussion with members of their health care team in order to make informed choices to improve their health status. With the abundance of information available, many people are facing information overload, which requires adapting to and processing of never-ending streams of new information. Another factor compounding the problem of health literacy is the disparity in access to technology. Limited access to technology in turn, exacerbates literacy-related disparities, “with lower literate patients being less likely to own smartphones or to access and use the Internet, particularly for health reasons”, according to Bailey et al. (2015: 3083). The authors also found that patients with adequate health literacy are more likely to access the Internet from their home and use the Internet for accessing health information and communicating with providers than patients with marginal or low literacy. Libraries help to reduce this disparity by providing access to computers and other technology as well as assistance in their use; therefore, programming on health literacy is an equally natural fit.

Libraries are a natural place for community members to get access to the wide range of information available, and to seek assistance from librarians to support lifelong learning and skill development. Long before the term “health literacy” was applied to this area, librarians actively answered consumer health questions and provided patient education (Whitney et al., 2017). Librarians know their local communities and can engage people and connect them to resources. A Digital Inclusion Survey conducted in 2014 by the Information Policy & Action Center found that 60% of public libraries surveyed helped patrons identify health insurance resources, 58% helped patrons locate and evaluate free online health information, and 48% helped patrons understand specific health or wellness topics, while 23% of those libraries surveyed, offered

fitness classes and 18% offered selected health screening services (Bertot et al., 2015). Public librarians have positive impact on individuals, which in turn may contribute to better overall health in the community’s population. According to a survey conducted in 2018 on Pennsylvania public libraries, respondents indicated they frequently interacted with patrons around health and social concerns. “Public libraries are free and accessible to all and are centers of community engagement and education, making them logical choices as partners for improving population health. Library staff members routinely assist patrons with unmet health and social needs” (Whiteman et al., 2018: 1). The report also focuses on the impact libraries might have on the social determinants of health, which includes housing, employment, and education. The study investigated the frequency and methods library staff members use and are familiar with to address the social determinants of health in order to “establish the feasibility of partnering with public libraries to improve population health” (Whiteman et al., 2018: 2). The authors believe that their research can be extended nationally to inform future partnerships between public libraries and the public health sector. In the conclusion of the paper, it was found that “Although at least 40% of respondents offered some health programming at their library branch, their offerings did not meet the high level of need reflected in common patron inquiries” (Whiteman et al., 2018: 1). This indicates there is enormous potential for librarians to serve a critical need in their communities, which will continue to evolve and will require training and collaboration.

Public libraries

Public librarians can provide training on finding and evaluating reliable and authoritative health information on the Internet, as well as helping people be prepared to interact with their health care providers through asking questions and engaging in clear communication techniques with practice and role-play. One example of this is the “Engage for Health” program in Pennsylvania. This was a community health program designed to encourage people to take an active role in their health care. The program was piloted in 16 Pennsylvania public libraries and the toolkit is freely available for other libraries to use in their communities (National Network of Libraries of Medicine, 2017). In June 2013, attendees at the American Library Association were called to action by President Barack Obama to support the public’s health information needs and assist with signing up for health insurance on the online marketplace created

by the ACA (Whitney et al., 2017). Public libraries met the call with varying capacities for support, with very few (only 5%) thinking they should not play a role in the ACA (Kohn, 2013). In 2017, during National Public Health Week, the Public Library Association (PLA) highlighted the work public libraries do in advancing the health and health literacy of Americans. PLA encouraged public libraries to post and share their health-related success stories and program examples on social media and pointed to the National Action Plan to Improve Health Literacy for more ideas and information on doing more health-related programming (Deutsch, 2017). The National Action Plan to Improve Health Literacy is based on two core principles: all people have the right to health information that helps them make informed decisions; and health services should be delivered in ways that are easy to understand and that improve health, longevity, and quality of life (US Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2010).

Health sciences libraries

To address patient needs around health information, health care practitioners have drawn upon the expertise of librarians in accessing, evaluating, and critically appraising scientific literature in order to make evidence-based decisions. Formalized roles for librarians in health literacy are emerging; several institutions have hired “health literacy librarians” who are responsible for outreach to consumers and health care professionals. These health literacy librarians might collaborate on a health literacy project, such as reviewing patient education discharge materials to help reduce post-surgical readmissions, or guest lecturing in credit-bearing courses on topics such as common patient signs of limited health literacy, the importance of using plain language and Teach Back, and online resources for patient education (Ottofen, 2017). Medical librarians working in academic or healthcare settings provide training, services, and resources for clinicians and health professionals to improve their ability to communicate clearly with patients (Barr-Walker, 2016). Academic health sciences librarians are also partnering with public librarians to provide health literacy training directly to members of the public and to train public librarians to build their capacity for providing health information services (Barr-Walker, 2016). For example, academic health sciences librarians provide train-the-trainer instruction on searching consumer health websites like MedlinePlus and mental health resources (Malachowski, 2014; Radick, 2015).

Building health literacy awareness and capacity at UNC

The Health Sciences Library (HSL) at the University of North Carolina at Chapel Hill (UNC) began building its capacity for health literacy in 2017 when two new positions were created: one with responsibilities that include both community engagement and health literacy, and the other dedicated to health literacy, global health, and community outreach. At HSL, librarians have focused their health literacy efforts on both consumers and health care professionals. The consumer-focused activities include community and targeted health literacy workshops and developing online resources for health information, and translating scientific information into lay language. Services targeted to health care professionals include reviewing patient education materials and training for professionals and students on clear patient communication strategies. These activities and services help to solidify concepts and the awareness of the need for conversion of scientific or health science/medical literature into information that is understandable and potentially actionable on the patient level. These services also echo the health literacy programs that Barr-Walker (2016) identified in a literature review on health literacy and librarianship, the first literature review on this topic.

To provide health literacy training to members of the public, the HSL recognized the need to partner with groups on campus and in the community. One of the key points of contact with consumers is via a partnership with three public library systems in the surrounding counties and the School of Library and Information Science (SILS). Since 2005, SILS students have been working with HSL librarians to co-lead a series of computer and information literacy classes at public libraries, called the Community Workshop series (CWS) (Community Workshop Series, n.d.). The series is mostly attended by older adults, but all members of the public are welcome. HSL Librarians worked with library science students interested in health librarianship to lead classes on finding and evaluating health information. The workshops included online consumer health resources such as NLM’s MedlinePlus. Xie (2012) successfully implemented a similar model of library science graduate students partnering with public libraries for health literacy instruction. The health literacy librarians also partnered with the Undergraduate Library in Fall 2018 to pilot an “Adulting 101” workshop series targeted to first-year and undergraduate students on life skills and topics they may not learn through formal coursework such as managing finances and navigating local elections. The health literacy session

titled, "Is There a Doctor in the House? Your Prescription for Finding Quality Health Information" was attended by a mixture of undergraduate and graduate students and a second session is planned for spring 2019 focusing on mental health literacy.

Health literacy services for and collaborations with health care professionals and students focus on improving understanding between providers and their patients. By partnering with UNC's Interprofessional Education & Practice (IPEP) office, located in the HSL, we designed a health literacy workshop which was offered and sponsored by the IPEP that included instruction on clear health communication, both using the teach-back method for verbal communication and assessing written documents, such as patient education materials. In addition, librarians review patient education materials and handouts created by providers or departments in the UNC Health Care System. Reviews focus on ascertaining reading grade level using freely available online calculators and applying the Patient Education Materials Assessment Tool (PEMAT) for suggestions on how to improve understanding through plain language and other changes to increase readability (Agency for Healthcare Research & Quality, 2017). HSL also offers instruction for health care providers on best practices in verbal communication with patients in workshops. For example, the teach-back method ensures patients' understanding of instructions by asking, "What questions do you have?" or "Tell me how you're going to take your medicine when you get home," rather than, "Do you have any questions?" which may lead to nodding or a yes if patients are ashamed to admit they do not understand (Brega et al., 2015). Further examples of successful collaboration have included reviewing and providing suggestions and considerations for patient brochures and websites and helping a group of researchers write a plain language summary of their research for their article submission to a scholarly journal.

The UNC HSL also manages two websites in support of health literacy throughout the state. NC Health Info (Health Sciences Library at UNC-Chapel Hill, 2018a) which was launched in 2003, is HSL's consumer health website, which helps people find reliable and easy-to-understand health and medical information and services that are pertinent to North Carolinians. It links to many reputable health information sites like MedlinePlus and includes sections on managing your healthcare, providers, and services, staying healthy and safe, and medications and therapies. The other site we have been asked to lead, is specifically on health literacy for health professionals, NCHSL.org, which was recently transferred to the

HSL by a health literacy physician expert on campus. This has afforded the library an opportunity to provide much needed health literacy tools, information, and techniques in an online environment that will be easily accessible and utilized.

Future opportunities and health literacy engagement

There are numerous ways to engage in health literacy efforts moving forward. For HSL, we plan on furthering our health literacy initiative by engaging on our campus and in our community in a variety of ways. For example, we plan to design a workshop and develop interactive online modules for teaching best practices in writing plain language or lay summaries of health or scientific information for the public or for those in health or scientific fields other than their own. Beginning in the summer of 2019, the European Union will begin requiring plain language summaries of all clinical trials. Some European journals already require these for journal article submissions. There is growing demand for access to and understanding of medical research for medical decision making and knowledge synthesis and it is anticipated that this demand will continue to grow. The US Food and Drug Administration drafted a document on guidance on the provision of plain language summaries, which is intended to "facilitate the voluntary provision of plain language summaries" for research subjects and the general public (MRCT Center, 2017).

The HSL also plans to develop interactive modules and/or videos on the teach-back method and health literacy for the health care professional. Use of the teach-back method allows healthcare providers to assess patient understanding and helps to cement the information given in patients' minds. In addition, continual work and improvements will continue for the NCHSL.org website (Health Sciences Library at UNC-Chapel Hill, 2018b), which is targeted to healthcare professionals and students in the health sciences. This website was previously maintained by the Sheps Center for Health Services Research at UNC Chapel Hill and served as the home to the NC Program on Health Literacy. Responsibility for its maintenance and re-envisioning was transferred to HSL where a team of librarians will be updating the site with the intent of providing a central online location for health literacy efforts and outreach to the University and statewide. Information on the site will include stories from around the state of how health literacy is applied, testimonials and tutorials, specific projects and partnerships, and professional resources at the HSL and beyond, to help healthcare

practitioners incorporate health literacy best practices in their everyday work with patients and their families. Another segment of the population we plan on engaging is in the K-12 arena. In an effort to help build health literacy skills and capacities of the K-12 and teen population, a health curriculum for underserved populations in North Carolina will be implemented. It will utilize and modify existing curricula developed in other successful projects such as Project SHARE at the University of Maryland (University of Maryland Health Sciences & Human Services Library, 2018) or Nemour's Children's Hospital in Florida (Wilson, 2018). This curriculum will encompass various aspects of navigating the health-care system, building health literacy skills and the capacity to evaluate online health information and to be active participants in their own health and wellness journeys. Our hope is that if we can start building strong health literacy skills in our students, they will build lifelong habits around information inquiry, utilization, and evaluation.

Whether you are serving members of the public, students, or health professionals, it is important for librarians to offer instruction in the search and utilization of reliable and trustworthy information. Developing critical thinking and evaluation skills in the digital environment is increasingly important in this age of information abundance and potentially biased resources. Even with limited ability to add personnel, current staff can be encouraged to participate in continuing education or other courses that will enable a base level of engagement around patient education, health literacy, and clear health communication. The Medical Library Association (MLA) has a Consumer Health Information Specialization (CHIS), which along with MLA membership is available to information professionals throughout the world (Medical Library Association, 2018). This specialization, which can be earned through taking classes approved for the CHIS, serves as an overall guide on providing consumer health information services at a library, and helps public librarians feel more comfortable with serving the general public in terms of their health information needs. Additionally, through the National Network of Libraries of Medicine (NNLM), select classes are available for free, and in some instances, regions within the NNLM offer to pay a participant's CHIS fee to MLA. NNLM also provides funding awards to libraries or community organizations to offer health information services and/or programming to increase access to and use of reliable, authoritative health information (National Network of Libraries of Medicine, n.d.).

Health information is flourishing in the online environment and information professionals are critical partners in helping to identify optimal ways of communicating complex scientific information at a level which patients and consumers will be able to understand. To be able to participate in one's own health care, patients need to know what questions to ask and how to interpret information regarding conditions and diagnoses that are pertinent to health care decision making. Librarians and information professionals can partner with health care teams to help formulate better approaches to converting complex scientific information to lay language, can help redesign patient-centered pamphlets or informational videos, design instructional approaches, provide better communication protocols for clinicians, and can partner with other institutions and organizations to help improve overall health status and reduce health disparities.

Librarians, along with community partners (e.g. school nurses, community pharmacists, utilizing dramatic arts), can have a significant impact on the promotion of health and health information fluency (Mani, 2004). Just as learning is a continual process; the same holds true with health information fluency. We need to build habits of inquiry and learning if we hope to mitigate the health literacy crisis we are now facing. Many librarians are already providing services and assistance, however, there is an overwhelming untapped opportunity for greater involvement. Libraries have always been very responsive to the needs of members of their communities and are needed now more than ever to enhance and improve the quality of life for the community they serve. All librarians and information professionals can play an important role in helping to educate and empower their communities through health literacy training and programming. The question remaining is: *wherever you are*, are you ready to answer the call?

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The importance of public libraries in education for health literacy: A case study on diabetic patients

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Abstract

Public libraries can play a major role in improving health literacy of clients by offering special services. Educating diabetic patients through public libraries can improve the dissemination of health information. The objective of the study was to evaluate the effect of education on the level of health literacy among diabetic patients referring to a public library, and the relationship between health literacy level, age and gender of patients. This research is a quasi-experimental study with pre-test and post-test. The study population included 48 diabetic patients referring to the public library. The research tool is a nationalized adult health literacy questionnaire in Iran. Results showed that 14.5% of samples had the maximum access to the required information in terms of accessibility. In terms of reading skill, 20% of samples had the maximum skill needed to read the information resources. In terms of information comprehension, 27% of samples had a maximum comprehending of the information they needed. In terms of evaluation, 13.5% of samples had completely correct evaluation of the information they needed. In terms of decision making, 24.5% of the people made decisive decisions about their information demands. The mean health literacy of diabetic patients before and after education showed a significant difference. In addition, no significant relationship was found between the level of health literacy and the age of diabetic patients referring to the public library before and after education ($r < 0.05$). The health literacy level of diabetic patients increased before and after education in both males and females. It was concluded that as one of the tasks of public libraries is teaching citizens, the use of educational capacities in public libraries in the health sector can improve community health.

Keywords

Diabetic patients, education, health literacy, public library

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Introduction

One of the centers which have been able to take steps to improve health knowledge of people in many

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countries, is public libraries. The central public library is a local place for information which provides all kinds of knowledge and information to users. The most vital health issues and demands of the different classes of the society in the health area can be handled by libraries. The public library, as a service institution, plays an important role in collecting, organizing and exploiting, providing and accessing to information resources which is why public libraries have a responsibility in improving the health literacy of communities. In other words, health literacy is the most important issue which can be improved by using the capacity of public libraries (Cobus, 2008; Flaherty, 2013; Malachowski, 2011, 2014). Health literacy is defined as one's capacity to gain, interpret and comprehend the basic health information needed to make proper decisions (Berkman et al., 2010; Kumar et al., 2010; Rudd, 2010; Speros, 2005).

Based on a WHO report, people lacking the health literacy skills, show **less** preventive health behaviors, are not able to comprehend the health recommendations, their control and prevention are weaker, they show low self-care skills, have a higher rate of hospitalization, and finally, incur more medical costs (Kickbusch et al., 2013). The concept of health literacy was first developed in developed countries in the 1960s and 1970s with the aim of promoting a healthy life. Then, a specific framework was determined for this concept including the three levels of functional, communicational and critical. Basic or functional health literacy includes basic reading and writing skills required for effective performance in the health area. Interactive or communicational health literacy includes more advanced literacy and social skills, enabling an individual to participate actively in health care, extract information, understand the meaning of various forms of communication, and use information to change the situations. Critical health literacy includes the ability to analyze critically and use information to participate in actions overcoming the structural barriers of health (Nutbeam, 2000).

Poor health literacy is associated with a lack of knowledge and understanding health conditions and health services, inability in conducting self-care activities, difficulty in comprehending medicine guidelines, inappropriate medicine consumption, not following physicians' orders, increase in hospitalization and health care costs, poor health status and increased mortality, less screening for early diagnosis of diseases, the inability to communicate with physicians and medical staff (Sihota et al., 2004). In developed countries such as US, health literacy is an important issue which in this regard, various plans and projects are developed and implemented. For example, National Plan for

Improvement of Health Literacy is one of these plans, developed and implemented by the US Department of Human Health and Services seeking to interact with organizations, professionals, policymakers, communities, individuals and families to improve the various aspects of health literacy (Malachowski, 2014). If we consider health literacy as a set of skills, abilities and capacities which involves obtaining health information and comprehending them, processing, interpreting, and using this updated information, these skills and capacities can be the basis for measuring health literacy tools (Speros, 2005). The Test of Functional Health Literacy in Adults (TOFHLA) is one of the most important tools. Parker et al. (1995) designed a reliable and valid tool for assessing functional health literacy in patients. This tool included 50 questions related to comprehending the concepts of words when reading and 17 items related to testing the ability of counting comprehension. To complete this questionnaire, 22 minutes is required (Parker et al., 1995). The shortened form of TOFHLA (S-TOFHLA) is used to measure patients' ability to read and comprehend health-related concepts. The research conducted by Baker et al. (1999) designing a shortened version of TOFHLA was aimed at reducing to 17 items in the numerical domain, 3 items in the conceptual domain, 4 items in the counting domain. Its completion time also was reduced from 22 minutes to 12 minutes (Baker et al., 1999). Studies have shown that S-TOFHLA is a practical tool for measuring functional health literacy. It can be used by health educators to identify individuals who need special help to achieve learning goals (Baker et al., 2008; Morris et al., 2006).

Rapid Estimate of Adult Literacy in Medicine (REALM) is another screening instrument to assess an adult patient's ability to read common medical words and lay terms for body parts and illnesses. It is designed to evaluate medical professionals in estimating a patient's literacy level so that the appropriate level of patient education materials or oral instructions may be used. The test takes two to three minutes to administer and score (Davis et al., 1993).

The Health Literacy for Iranian Adults (HELIA) questionnaire is one of the normalized questionnaires in this area, which has been considered more in comparison with the other questionnaires because of its comprehensiveness of measuring various aspects of health literacy. Its reliability and validity to measure the health literacy in Iran's context have been confirmed. This research was an attempt to design a tool to measure the public health of adult Iranian people (18 to 65 years) living in Iran's cities. It has been developed based on the socio-cultural characteristics of Iranian people to be used in other studies. After reviewing

various scientific documents on health literacy in the present research, the related definitions were determined in order to develop the tool's conceptual framework. In addition, according to the health area's priorities in the country and some important public information about health, the questions were provided.

Then, several items were developed in the mentioned subjects based on the concepts of health literacy dimensions including access, reading skill, comprehension, evaluation and decision making, and applying health information by using existing tools and consulting with experts (66 questions). The content validity of the questionnaire was evaluated by 15 different health professionals and suggested reforms were applied. It included 47 questions. After collecting the information from 336 people selected randomly from 22 districts of Tehran, its construct validity (using exploratory factor analysis) and reliability (by calculating the internal correlation coefficient) were evaluated.

The final results of factor analysis revealed that the questionnaire had 33 questions in 5 specific domains, including 1 – access (6 questions); 2 – reading skill (4 questions); 3 – comprehension (7 questions); 4 – evaluation (4 questions), and 5 – decision making (12 questions). The Cronbach's alpha of the items in the related constructs was acceptable and varied from 0.72 to 0.89, so the reliability of the questionnaire was confirmed. Results of this research can be used to measure the health literacy of the urban population in Iran (Haghdoust et al., 2015; Montazeri et al., 2014).

Today, the number of diabetic people is growing increasingly in the world. One of the factors affecting diabetes prevention and control is having adequate knowledge about the occurrence and prevention of this disease. In addition, one of the factors affecting the level of knowledge and more effective control and prevention of diabetes is health education through public libraries (Gillaspay, 2005).

Several studies have been carried out on the importance of health literacy education by librarians in foreign countries (Berkman et al., 2004, 2011b; Eichler et al., 2009; Parker and Kreps, 2005; Shipman et al., 2009). However, no independent study was found to evaluate the educational role of public libraries to enhance the level of health literacy. According to the aforementioned, researchers aim to evaluate the health literacy status of diabetic patients referring to the public Andisheh Cultural Library by using the HELIA questionnaire and evaluate their health literacy before and after training. Results of this study not only can explain the effect of education on the health literacy of the patients and the role of public libraries in this process, but also can clarify the value and status of these libraries in promoting health culture.

Methods

The present study is a quasi-experimental study with pre-test and post-test. The research population included diabetic patients referring to Tehran Municipality Cultural and Art Organization (Andisheh Cultural Center) from April to November 2015. The sample population was 48 people using this formula:

Fifty-two participants were selected for the pilot study (6.5 mean difference questionnaire score before and after intervention, with 0.05 significance level and 80% power and 10% dropout). Four persons missed a follow up. We therefore analyzed data for the remaining 48 participants.

$$n = \frac{1}{1-f} \frac{\left(z_{1-\frac{\alpha}{2}} + z_{\beta}\right)^2 (s_d)^2}{d^2}$$

$$= \frac{1}{1-0.1} \frac{(1.96 + 0.84)^2 (7.35)^2}{(3)^2} \cong 52$$

$$52 - 4 = 48$$

The tool applied to collect data was HELIA Normalized Questionnaire, published in 2015. The validity of this tool was confirmed by 15 experts in different fields of medicine. Cronbach's alpha was used in order to confirm the reliability reported as 0.72 to 0.89. The questionnaire includes 33 questions in 5 domains, including access (6 items), reading skill (4 items), comprehension (7 items), evaluation (4 items), and decision making and application of health information (12 items). The current study evaluates the health literacy of the community before and after the direct and indirect education. The questionnaire was distributed among the research subjects and was collected after completion.

Then, direct and indirect education was provided for the subjects. Direct education was provided for the subjects in four two-hour sessions by the head of the Iranian Association for Diabetes according to the required information for diabetic patients, including self-care, control, treatment, maintaining and promotion of health and so forth. The indirect education included selecting and preparing a brochure, pamphlet, and educational booklets for diabetic patients by a librarian and with the consultation of experts in this area. The questionnaire is scored between 0 and 100, in which a health literacy's score between 0 and 59, suggests inadequate literacy, score between 60 and 74 suggests borderline health literacy, and score between 75 and 100 suggests adequate health literacy. Data were analyzed by using SPSS21 software. Paired t-test and chi-square tests were

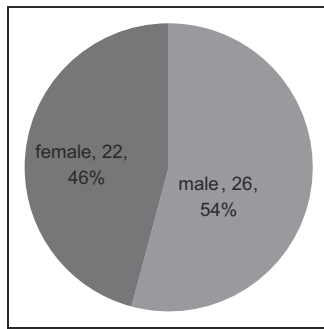


Figure 1. Background information of the population under study (gender).

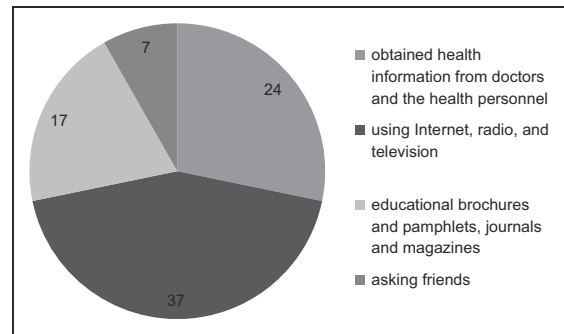


Figure 4. Background information of the population under study (source of information).

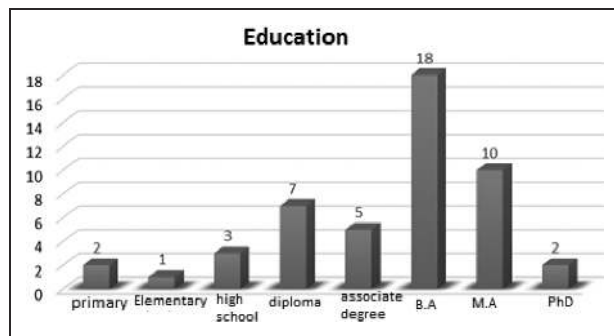


Figure 2. Background information of the population under study (education).

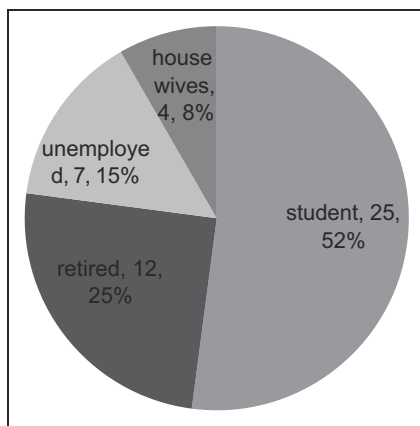


Figure 3. Background information of the population under study (employment).

applied for pre-test and post-test comparisons. Correlation between variables was also determined by using Pearson correlation coefficient.

Results

Figure 1 indicated that the number of women and men was 22 (45.8%) and 26 (54.2%) respectively. Mean age of individuals was 10.61 ± 54.62 .

Figure 2 indicated that three individuals had a high school degree (6.25%), two had a primary degree

(4.17%), seven had diploma degrees (14.9%), five had associate degrees (10.42%), 18 had BA degrees (37.5%), 10 had MA degrees (2.1%) and two had PhD (4.17%).

Frequency distribution of employment shows (Figure 3) that the highest frequency associates with students (25 persons (52%)) followed by retired individuals (12 (25%)), unemployed individuals (7 persons (15%)), housewives (4 persons (8%)).

Some participants had experienced more than one source of information (Figure 4). Thus, 24 participants (28.24%) obtained health information from doctors and health personnel, 37 (43.53%) through using Internet, radio, and television, 17 (20%) from educational brochures and pamphlets, journals and magazines, and 7(8.23%) by asking friends.

Table 1 revealed that:

- 14.5% of samples had the maximum access to the required information in terms of accessibility while 2.5% of them had the minimum rate of access.
- In terms of reading skill, 20% of samples had the maximum skill needed to read the information resources while 8.5% of them the minimum rate.
- In terms of comprehension skills, 27% of samples had a maximum comprehension of the information they needed while 4% of them had the minimum rate of these skills.
- In terms of assessment skills, 13.5% of samples had completely correct evaluation of the information they needed while 4% of them had the minimum rate of these skills.
- In terms of decision-making skills, 24.5% of the samples made decisive decisions about their information demands while 6% of them had the minimum rate of these skills.

According to Table 2, the mean score of the health literacy level before intervention was 72.45 ± 9.99

Table 1. The frequency of five variables in health literacy.

| Variables frequency | 1 (Never) | 2 (Rarely) | 3 (Some times) | 4 (Often) | 5 (Always) |
|--------------------------------------|--------------|---------------|-------------------|--------------|---------------|
| Health information access | 2.5% | 11% | 33% | 39% | 14.5% |
| Reading skills | 8.5% | 7.5% | 25.5% | 38.5% | 20% |
| Understanding/comprehension skill | 4% | 8% | 17% | 44% | 27% |
| Assessment skills | 4% | 19% | 31% | 32.5% | 13.5% |
| Communication/decision making skills | 6% | 13.5% | 19.5% | 36.5% | 24.5% |

Table 2. Mean comparison of health literacy level before and after education.

| Score of health literacy | Before education | | After education | | P |
|--------------------------|------------------|--------------------|-----------------|--------------------|---------|
| | Mean | Standard deviation | Mean | Standard deviation | |
| | 72.45 | 9.99 | 79.85 | 10.22 | < 0.001 |

Table 3. Health literacy level of diabetic patients based on their gender.

| | Borderline health literacy | | Adequate health literacy | | Total | |
|--------|----------------------------|---------|--------------------------|---------|--------|---------|
| | Number | Percent | Number | Percent | Number | Percent |
| Female | 5 | 23 | 17 | 77 | 22 | 100 |
| Male | 5 | 19 | 21 | 81 | 26 | 100 |
| Total | 10 | 21 | 38 | 79 | 48 | 100 |

Table 4. Comparing mean score of health literacy before and after education based on gender.

| | Female | | Male | | P |
|---|--------|--------------------|-------|--------------------|-------|
| | Mean | Standard deviation | Mean | Standard deviation | |
| Score of health literacy before education | 72.43 | 10.42 | 72.47 | 9.8 | 0.989 |
| Score of health literacy after education | 79.69 | 10.24 | 79.99 | 10.41 | 0.920 |
| Score differences of health literacy before and after education | 7.26 | 10.83 | 7.52 | 10.43 | 0.932 |

which increased to 79.85 ± 10.22 (p -value < 0.001) after intervention. The mean score difference before and after education was 7.40 ± 10.50 .

Table 3 shows that 23% of women under study had borderline health literacy and 77% had adequate health literacy. 19% of men had borderline health literacy and 81% had adequate health literacy. Generally, 79% of participants had adequate health literacy and 21% had borderline health literacy.

According to Table 4, mean health literacy of women before education was 119.51 (standard deviation: 17.20) and it was 131.49 after education (standard deviation: 16.89), while mean health literacy of men before education was 119.57 (standard deviation: 16.20) and it was 131.99 after education (standard deviation: 17.18). It can be seen that health

literacy of male and female diabetic patients increased before and after education. Therefore, there is no significant relationship between health literacy of patients referred to Andisheh Cultural Center and their genders.

Discussion

As there are several tools to measure health literacy, different tools have been used in various studies to measure health literacy skills in patients. The results of various studies around the world have reported wide range of inadequate health literacy (Duong et al., 2015; Palumbo et al., 2016; Sørensen et al., 2015).

The current research reported that the maximum rate of the main areas of health literacy, including

accessibility, reading skill, comprehending, evaluation, and decision making are at a low level, while the acceptable level of these areas allows people to interpret and understand the issues related to their health and be able to take care of themselves and others against pathogens. The findings of different studies suggest that in communities with a high level of public health literacy, people are more vibrant, healthier, and dynamic and lower costs are imposed on governments to treat the patients. Hence, treatment costs will be spent on the prevention and health of the people, leading to an improvement in quality of people's lifestyle. People with inadequate health literacy are less likely to comprehend the written and spoken information provided by health professionals and less likely to follow the instructions given to them. They also have weaker health status and incur more medical costs (Berkman et al., 2011a; Howard et al., 2005; Nutbeam, 2008). Although the population in this study had relatively high health literacy at the start of the process; the impact might not have been the same if the group had lower general literacy and health literacy at the outset.

Considering the importance of public health knowledge and its key role in reducing the cost of treatment, new paths can be developed to improve the health knowledge of the community (Hamzehei et al., 2018). Health education is one of these methods that can lead to a change in lifestyle and help individuals, families and communities to make informed decisions about issues that are effective in retrieving, accessing, and maintaining health. This style of education can be implemented through public libraries. Public libraries have always been places to access information and are tied to education and learning in the community. Learning services in these libraries are available for all potential and actual people who are referring to the public libraries. This is a clear case for diabetic patients, because it is a commonly known disease of the century (Sanghera, 2016). Many studies have referred to the public libraries as a platform for education as we mention it this study too. In fact, if we notice the educational role of public libraries as a platform in the community, it can be lead to the better managing and controlling the complications of diseases (Linnan et al., 2004; Luo and Park, 2013). In other words, public libraries can extend healthy lifestyles and promote health literacy through their educational role. The results of the present study, like other similar studies, indicate that patient education is very effective in increasing the health literacy of patients (Kandula et al., 2009; McCleary-Jones, 2016; Nutbeam, 2000; Schillinger et al., 2004; Seligman et al., 2005; Sharp and Lipsky, 1999; Toronto and

Weatherford, 2015; Yehle et al., 2016). The results are especially important for diabetes which has been recognized as the most prevalent disease of the century (Graham, 2013; Griffin, 2005; White et al., 2010). In many previous studies, the research setting was hospitals and clinics. However, the library has not been used as the setting in any of the studies conducted in this area although library space, compared to hospital, plays a positive role for education. In the hospital, people are placed in a context related to illness and disease, while in the library they feel more relaxed.

In the present study, the intervention was implemented directly and indirectly, which was different from many previous studies. Those referred to the library obtained information about training methods and self-care (via educational pamphlets) in educational workshops and places other than workshops such as at home, in the workplace, while commuting and so on. It seems that studying pamphlets before attending workshops prepared participants to accept the materials referred to in the workshop. If we believe in the capabilities of public libraries in promoting culture and levels of public literacy, such social institutions can be easily used for public training. It is important to focus on training self-care behaviors, control, and informed prevention, especially with regard to diabetes. It is more efficient to promote patients' health literacy by leveraging all the advantages of public libraries, although it should be noted that there were some difficulties during the present study, such as identifying and explaining the goals to the participants, holding regular classes based on their time-table, and preparing appropriate and accurate outline for the related intervention session. Therefore, ongoing patient education can reduce the risk of long-term complications (American Diabetes Association, 2011).

Conclusion

Politicians concerned with health and health education can use potential facilities of public libraries, achieve the goals determined in their programs, and set the ground for health promotion in society.

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article was presented to IFLAWLIC 2018 (Kazerani et al., 2017) with some changes.


Declaration of Conflicting Interests

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Health information services: Engaging women in cervical cancer screening awareness in Nigeria

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Abstract

Around the world, a woman dies of cervical cancer every two minutes. In Nigeria, it is the second leading cause of cancer deaths, which could be avoided with proper access to health information. This mixed methods study, which employs a questionnaire, interviews, observations and discussion, examined women's awareness on cervical cancer, screening status, sources, attitude and willingness, factors deterring them from being screened, and lessons learnt. Screening was done using visual inspection with acetic acid (VIA). The study involved two librarians, two medical doctors, a pharmacist and a laboratory scientist: 90 women participated in the cervical screening exercise in non-standard settings – an e-library and a cathedral. It was discovered that 90% of the women had never been screened. Thus, if the women are not sensitized on cervical cancer they may never go for screening and more casualties will be recorded. The paper concludes with recommendations and a call to action for all, especially librarians.

Keywords

Cervical cancer, health information, Nigeria, screening, Sustainable Development Goal 3, visual inspection with acetic acid (VIA), women's engagement

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Introduction

Cervical cancer is a leading cause of mortality in women, especially in sub-Saharan Africa. Human papilloma virus (HPV) infection is a well-established cause of cervical cancer (Bruni et al., 2018), with likely exacerbating factors being a lack of health insurance in most African countries, and poor access to information about the disease.

The World Health Organization (WHO) has reported that the number of Nigerian women suffering from cervical cancer annually totalled 14,089 (Agbo, 2018). In Northern Nigeria, cervical cancer accounts for 65.7%, making it the leading cause of all gynecological cancers (Oguntayo et al., 2011). Studies have also been carried out in Onitsha and Abakaliki (Nigeria) on the issues of health information on cervical cancer (Chinaka and Nwazue, 2013;

Nwozor and Oragudosi, 2013). In the same vein, Ntekim (2012) reports that none of the 500 women attending maternal and child health clinic in a poor area of Lagos (Nigeria) in 1999 had ever had a Pap smear. Only 9% of healthcare workers in the two health institutions studied have had a Pap smear. There are similarly shocking stories of low participation of women in cervical cancer screening, even among professionals, in medical fields across other African countries like Tanzania and Uganda (Mutya et al., 2006). A recent study by Bruni et al. (2018) reveals that:

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About 14,943 new cervical cancer cases are diagnosed annually in Nigeria (estimates for 2018). Cervical cancer ranks as the 2nd leading cause of female cancer in Nigeria. Cervical cancer is the 2nd most common female cancer in women aged 15 to 44 years in Nigeria.

HPV can be easily detected through visual inspection of the cervix with acetic acid (VIA), which has the same sensitivity as the Pap smear (Urasa and Darj, 2011) and is highly recommended in low-resource countries (Eguzo et al., 2017; Jeronimo et al., 2016). To access this screening, women must be made aware of the opportunity for early detection of cancer through such screening, avoiding the circumstances that can cause the disease to develop, as well as the possibility to take advantage of treatment and HPV vaccination (Chinaka and Nwazue, 2013; Nwozor and Oragudosi, 2013).

Access to health information gives people opportunities to live healthy lives, and seek help when they notice abnormal signs in their bodies. It is therefore critical to engage women with health information services and create awareness of cervical cancer screening. These aims, naturally flow from the UN's Sustainable Development Goal 3 (SDG 3), which emphasizes the importance of ensuring healthy living and promoting well-being for all, as well as combatting gender discrimination, which systematically undermines women's access to health care (UN Women, 2018). In view of this, librarians have a key role to play in promoting knowledge of cervical cancer, and thus improving lives by facilitating information awareness in their communities (Lankes, 2016). The right to equitable access to health information, which libraries and librarians promote, is therefore crucial.

Clearly, Nigerians and Africans need access to health information to reduce the burden of terminal diseases. This is, no doubt, why Anasi (2012) stressed the importance of the synergy between health and information professionals and the adoption of best strategies for the dissemination of health information. The need to control cervical cancer is critical and should not be left for the government alone. It is a matter of general concern because only a healthy woman can carry pregnancy, give birth, nurture babies, nurse, cook and take care of all members of her family. Additionally, society needs women to participate and contribute in nation building and in achieving the aims of the SDGs.

Promoting and disseminating community access to health-related information is a vital activity (Anasi, 2012; Chipungahelo et al., 2015). The library holds the key to facilitating access to information

irrespective of class, gender, location and tribe. When the information is disseminated, right steps will be taken and there will be safe communities with sustainable health. This study therefore examined women's awareness on cervical cancer, sources of information, screening status, attitude and willingness and factors deterring them from being screened. For these reasons, we conducted this study in Anambra State (in SE Nigeria) and Delta State (in SS Nigeria).

Research questions

The following research questions guided the study:

1. Are women aware of cervical cancer in Anambra and Delta States in Nigeria?
2. What is the screening status of the women in Anambra and Delta States?
3. What are their sources of information awareness?
4. What are their attitudes and willingness to be screened for cervical cancer?
5. What factors deter the women from being screened?

Literature review

Health is critical to human development. Improved access to information plays a strong role in linking people to reliable and informed health decisions. The ability of libraries to partner with organizations and community health workers to give access to vital health information has been harnessed. Chipungahelo et al. (2015), Anasi (2012) and Obidike (2011) have stressed the importance of dissemination of health information in the prevention and treatment of diseases. In the same vein, health information services have provided cancer patients and their families with additional information and resources, empowering them with health literacy services. Full access to health information increases health awareness and knowledge, and saves lives, and libraries are providing cancer patients and their families with such information (Health Library News, 2019; Summa Health, 2019; Yoo-Lee et al., 2016).

There is need to engage women on health issues because many women do not know their statuses nor are they aware of HPV and the dangers of cervical cancer. In Onitsha for example, 35.56% of a sample (160 women) were aware while only 1.78% (8 women) had been screened (Nwozor and Oragudosi, 2013). Similarly, 85.0% of the women assessed in Lagos were not aware of cervical cancer while only a few (13.3%) of the respondents had ever been screened and none in the previous three years

(Oluwole et al., 2017). At the University College of Ibadan, only about 3000 women were screened in the three-year period from 2005–2007 (Nigeria Health Watch, 2015). This is why librarians are taking action to engage women through access to health information on appropriate cervical cancer screening and vaccination.

Relevant health information sources are important in preventing sicknesses. Memorial Healthcare (2018) emphasized that with health information, most deaths from cervical cancer can be prevented as regular screening and follow-up can help detect abnormal (changed) cells early, before they turn into cancer. Therefore, women need education, information engagement and services to be able to make good decisions about their health. Inadequate access to health information diminishes awareness of preventive health measures. In other words, little knowledge of health issues and incorrect information on medical conditions and treatments have negative results for individuals, communities and the society (Ukachi, 2011). The observed gap in awareness and access to cancer-related information is one of the ideas behind the commemoration of World Cancer Day, to create opportunities to advocate and raise awareness on the growing need for women to protect themselves from cervical cancer and HPV.

Considerable efforts have been made by librarians to address these needs by empowering patients and giving direction, through information provision, contributing to improved patient care indicators, potential usefulness of the information in the future, clinical value, better informed clinical decisions and higher quality care (Anyaku, 2014; Marshall et al., 2013; Nwafor-Orizu, 2014). Furthermore, in a study by Oluwole et al. (2017) a majority (86.7%) of respondents expressed willingness to undergo cervical cancer screening. Librarians offer insights that save women from cervical cancer and get them willing to participate in cancer screening and other preventive measures, and a calming influence at a naturally stressful time. When a woman is well informed on health issues, she will likely talk about it in her groups and enjoin others to access the treatment. It is likely that the same reasoning holds for the findings of McCarthy et al. (2017), in which almost all the women (97%) were willing to undergo cervical cancer screening.

That notwithstanding, certain factors deter women from being screened for cervical cancer. Cultural beliefs, the health care system, the physician's attitudes towards women, fear, pain, the gender of health workers, embarrassment about undergoing a gynecological examination, lower socio-economic

background, lack of health insurance and low literacy (Abdullahi et al., 2009; Ackerson, 2010; Mutyaba et al., 2006; Ntekim, 2012; Tavafian, 2012) pose challenges. In the same vein, Ndikom and Ofi (2012) in their research identified ignorance, illiteracy, belief in not being at risk, a nonchalant attitude to health, financial constraint, and fear of having a positive result. Information remains the key to open and relevant insight to all health issues.

Methodology

This is a mixed methods research that used a questionnaire, interviews, observations and discussion. The study started following the 2018 International World Cancer Day, when women who attended the event at the Onitsha Divisional Library, Anambra State revealed during the interactive session that they had never been screened for cervical cancer. The authors met with the doctor who delivered a cancer talk show and began discussion on partnering to reducing the screening cost to enable many women to know their statuses. The doctor agreed to reduce the cost if the authors could get 30 women. The authors started sensitization in schools and existing women's meetings in churches, social groups and work places to create awareness on cervical screening and vaccination. Names and phone numbers were collected after which the authors started to share cancer information through the WhatsApp platforms which allowed for free interaction and maximum participation. This online engagement began in February 2018.

Target groups were adult women of any occupation. The authors opened a bank account specifically for payment for screening. Every payment was acknowledged in the Whatsapp group which increased trust and confidence between the authors and the women. The cervical screening was performed using visual inspection with acetic acid (VIA), a simple and inexpensive test used extensively in low resource settings: 90 women participated in the screening which took place in non-standard but convenient settings. Information about the exercise spread beyond Anambra State when some participants requested to include their friends from Asaba, in Delta State. Arrangements were therefore made for a convenient place in Asaba. The cervical screening exercises took place at Prof. Ken Dike State Central e-Library in Awka (the Anambra State Capital) and St Peter's Cathedral in Asaba (Delta State Capital). These places were used to demystify the fear of VIA screening and for ease of participation for the women. Ninety women participated in the cervical screening exercise. 11 women were not screened but all of them

listened to the cervical cancer lecture, completed the questionnaire, and participated in the discussion and interview. The reasons for not participating in the screening were that three participants were virgins, two were on their menstrual cycle, two were pregnant while four asked for permission to leave, saying they had emergencies, and did not return. The study took place between March and May 2018. In Awka Anambra State, cervical screening sessions took place on 23 March and 24 May 2018 while in Asaba Delta State, they took place on 2 and 29 May 2018. Each cervical screening exercise took an average of four hours including lecture, screening and documentation of events.

The study involved two librarians, two medical doctors, a pharmacist and a laboratory scientist. Dates were fixed as soon as payments for at least 15 women were received. Names were published on WhatsApp and convenient times fixed. At least one of the authors was always present to coordinate every activity and offer refreshment to the participants. A doctor gave lectures on cervical cancer, prevention, treatment, management and vaccine before every screening. Payment for the screening was N1500 each but during sensitization in different groups, some women donated money to cover expenses for those who wished to be screened but could not pay. Hence, 52 women benefited from the donations while 27 women paid for their own screenings. The screening instruments were mobile and were easily taken to the scheduled venues. Follow-up procedures were issued immediately for progression, counseling and referral. Simple frequencies and percentages were used to present the findings. Results were presented in tables and figures.

Findings

Table 1 shows the characteristics of women that participated in the cervical screening activities in the two cities. Women from various occupations participated. The greatest number came from civil servants with 50%, followed by self-employed women 16.7%, professionals 13.3%, traders 11.1%, students 6.7% and unemployed 2.2%.

On their level of education, 61.11% women had an HND/BSC, 13.33% had a School Certificate, 10% had neither, 10% had MSC, 3.3% had a PhD and 2.2% had an OND/Diploma.

The age range shows that 50% of the women were between 41–50 years, followed by 22.22% of women within 31–40, 14.44% represented women below 30 years and 13.33% represented women above 50 years. The data for characteristics of women studied show

Table 1. Characteristics of the women that participated in the cervical cancer activity.

| Serial/ Number | Status | Participants | | |
|-------------------|--|-------------------|------------|-------|
| | | N | % | |
| 1. | Occupation: | | | |
| | Trading | 10 | 11.1 | |
| | Self employed | 15 | 16.7 | |
| | Professional | 12 | 13.3 | |
| | Civil service | 45 | 50 | |
| | Students (Undergraduates) | 6 | 6.7 | |
| | Unemployed | 2 | 2.2 | |
| | Total | 90 | 100 | |
| 2. | Education: | | | |
| | Below School Certificate Examination | 9 | 10.01 | |
| | School Certificate | 12 | 13.33 | |
| | OND/Diploma | 2 | 2.22 | |
| | HND/BSC | 55 | 61.11 | |
| | MSC | 9 | 10 | |
| | PhD | 3 | 3.33 | |
| | Total | 90 | 100 | |
| | 3. | Age range: | | |
| | | Below 30 | 13 | 14.44 |
| 31–40 | | 20 | 22.22 | |
| 41–50 | | 45 | 50 | |
| 51 and above | | 12 | 13.33 | |
| Total | | 90 | 100 | |

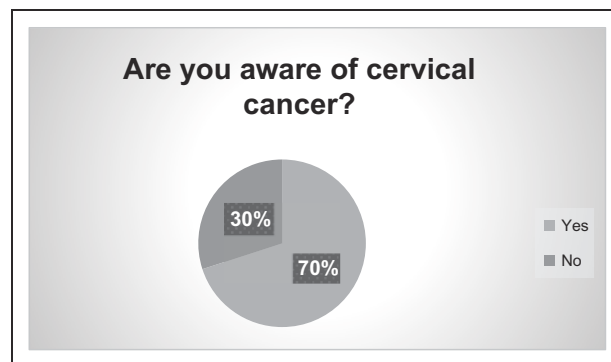


Figure 1. Awareness of cervical cancer.

that women in all statuses, educational background and age ranges need health information.

The chart in Figure 1 shows the rate of response on awareness of cervical cancer: 70% of the women noted that they were aware of cervical cancer while 30% stated that they had no knowledge of cervical cancer.

The interview and discussion revealed that some of the participants had heard of other types of cancer, especially breast cancer, but were unaware of cervical

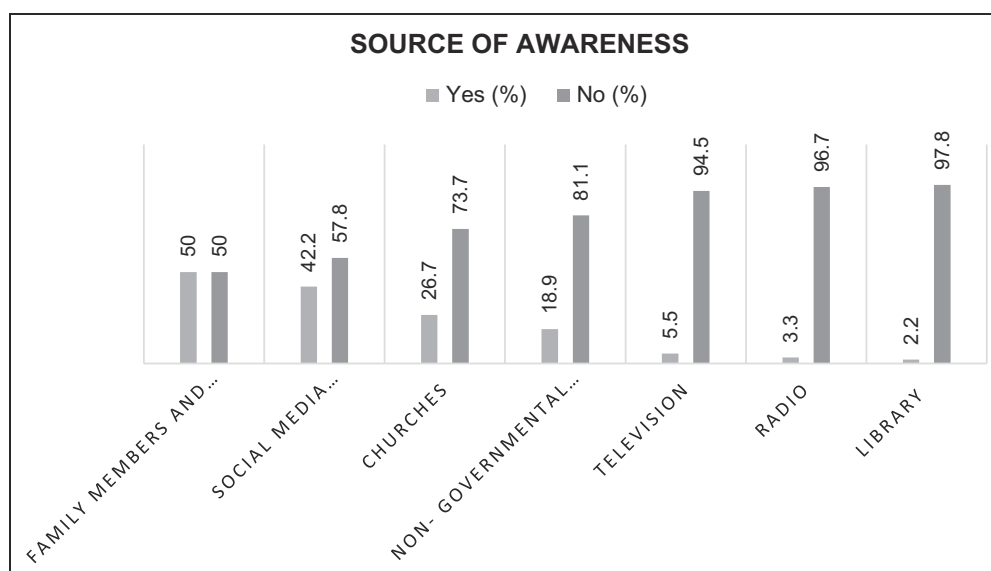


Figure 2. Sources of awareness.

Table 2. Attitude/willingness to undergo screening.

| Item | Yes | | Undecided | | No | |
|---|-----|------|-----------|------|----|------|
| | F | % | F | % | F | % |
| Attitude toward screening prior to discussion on cervical cancer with the women | | | | | | |
| Are you willing and ready to undergo cervical cancer screening? | 19 | 21.1 | - | 0 | 71 | 78.9 |
| Attitude toward screening after discussion on cervical cancer with the women | | | | | | |
| Are you willing and ready to undergo cervical cancer screening? | 72 | 80 | 13 | 14.4 | 5 | 5.6 |

F is frequency.

cancer. It was also revealed during discussion that none of the women knew about HPV or about factors that could cause cervical cancer.

Enquiry on source of awareness as reflected in Figure 2 reveals that 50% of the women gained awareness of cervical cancer through their family members, 42.2% learnt about it through social media platforms, 26.7 through their churches, 18.9% through NGOs while the library served as the least awareness source at 2.2%.

To ascertain whether the participants had been screened for cervical cancer previously, the question was asked. It was revealed that only 10% of the women had been screened prior to our interaction with them while 90% had never been screened.

Further verbal enquiry revealed that almost all women who had been previously screened did so because of the recommendation of their doctor during a medical review. Some reported that their doctor had noticed something during an ante-natal visit and told them to go for screening. They admitted that they would not have gone if the doctors had not told them about cervical cancer. Two of the women stated that

cervical cancer screening was part of their routine medical checkup whenever they traveled abroad. They affirmed that they had never had it done in Nigeria until they heard of this opportunity.

Table 2 shows that 21.1% of the women were willing and ready to undergo screening even before the interactive discussion with them on cervical cancer, while the remaining 78.9% were unwilling. However, the rate of acceptance and willingness to undergo screening drastically changed after the interaction with them, which exposed them to enhanced knowledge of what cervical cancer is, including the benefits associated with its early detection. This is shown in the acceptance rate which increased to 80% while 14.4% remained undecided on whether to accept it or not. It was only 5.6% of the entire population that refused screening after the interaction as against the initial rejection rate of 78.9% prior to the interaction.

From Table 3 it can be seen that the factor that had the highest acceptance rate is “being scared of the outcome/result” which had agreement percentage rate of 83%. This is followed by “being uncomfortable and apprehensive about the screening” with the agreement

Table 3. Factors that deter participating women from undergoing cervical cancer screening.

| Factors | Strongly Agree | | Agree | | Disagree | | Strongly Disagree | |
|---|----------------|----|-------|----|----------|----|-------------------|----|
| | Agree | % | Agree | % | Disagree | % | Disagree | % |
| I am uncomfortable and apprehensive about it | 23 | 25 | 43 | 48 | 21 | 23 | 4 | 4 |
| I am scared that it might be very painful | 14 | 16 | 38 | 42 | 27 | 30 | 11 | 12 |
| I do not want to open my body to a male doctor | 13 | 14 | 32 | 36 | 30 | 33 | 15 | 17 |
| I am scared of the outcome/result | 34 | 38 | 41 | 45 | 15 | 17 | - | - |
| Unaware of the existence of cervical cancer screening | 28 | 30 | 2 | 2 | 61 | 68 | 9 | 10 |
| I do not have money to pay for the screening | 12 | 13 | 43 | 48 | 21 | 23 | 14 | 16 |
| Unpleasantness of the screening | 9 | 10 | 44 | 49 | 16 | 18 | 21 | 23 |
| Religious faith and belief | 3 | 3 | 48 | 53 | 33 | 37 | 6 | 7 |

percentage rate of 73%. The others in the order of rate of acceptance are: not having money to pay for the screening (61%), unpleasantness of the screening (59%), scared that it might be very painful (58%), and religious faith and belief (56%).

Lessons learnt from the cervical screening

- Many women are eager to be screened after getting information on cervical cancer.
- Women are also very interested in cervical cancer vaccines and want their young children to be vaccinated.

Some women wanted to be screened last. They were asking others who were screened before them how it felt and what really happened.

Many of them visibly relaxed when they were told before screening that the male doctors would not be part of the screening. They very much preferred women to screen them.

- The excitement on being declared negative was infectious. They were flaunting their negative results and smiling happily.
- Although those with negative results were understandably quiet, their mood changed following counseling.

Discussion of findings

The demonstration of interest in the program by different categories of women from different occupations, level of education and age range shows that health information is relevant and should be inclusive. This buttresses the statement of Solanke and Osuchukwu (2018) on the importance of facilitation and access to information regardless of age, income, race, ethnicity, religion, physical limitations, language, education or social status. The indication is that women need health information to improve their

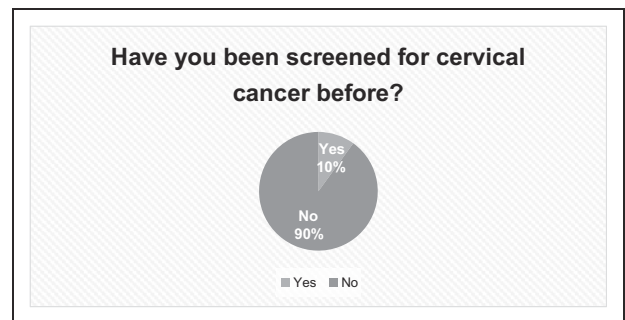


Figure 3. Screening status.

health knowledge base and also be able to make informed decisions on things that affect their lives. Ukachi and Anasi (2018) also emphasized that health information is needed to reduce levels of uncertainty and enable people to take the right health decisions.

The disclosure on the awareness of cervical cancer as shown in Figures 1 and 2 reveal that many of the women knew about it even though a small percentage admitted that they did not know about cervical cancer. Although the women admitted hearing of cervical cancer from family members, media, churches and non-government organization. The lowest source of awareness is the library and the indication questions the relevance of library to facilitation of access to health information (Popoola, 2019). It is not surprising that some women are unaware of cervical cancer in this age and time. The total lack of knowledge of HPV and how cervical cancer could be transmitted during discussion buttresses the concern of Anasi (2012) on the urgent need for strategic massive information awareness on cervical cancer.

The study also revealed that there was a low participation rate in cervical cancer screening among the women studied, which is confirmed by the results shown in Figure 3. This outcome is disheartening when weighed against its obvious consequences with the negative implications. This result corroborates

with reports of studies previously carried out which revealed that more women in sub-Saharan Africa are dying of cervical cancer (Ferlay et al., 2012; Ibekwe et al., 2010; Ntekim, 2012). It is also noted in this study that the women who had been screened according to the interview and discussion did not even go of their own volition but went because their doctors discovered something and sent them for the screening. The other two went because their annual medical checkup included it.

Conversely, the study also documented a shift in their attitude to and willingness to undergo cervical cancer screening after they were exposed to the knowledge of what causes cervical cancer, including the benefits inherent in early detection which can only be achieved through screening. This outcome relates to the findings of Jayasinghe (2017) and Ntekim (2012) whose studies established that providing positive provider-client relationships, confidentiality, privacy, compassion, respect and dignity for the women will make them participate willingly in the screening.

In the area of factors that deter the women from undergoing cervical cancer screening, the most notable ones are: being scared of the outcome/result, being uncomfortable and apprehensive about the screening, and not having money to pay for the screening. Besides the formal expression of these deterrents by the participants, personal observations by the researchers during the screening exercise showed apprehensiveness and uneasiness among the women. These deterrents were alleviated by counseling and demystifying the screening process for them. This approach was acknowledged by the Majorie Bash Foundation et al. (2018) in their cancer control program which emphasized the sharing of experiences about cancer and engaging different media in promoting cancer control in Nigeria. The problem of not having enough money to pay for the screening is not surprising considering the high cost of undergoing the process as well as the fact that most African countries do not have effective and efficient health insurance schemes for their citizenry like other developed countries, coupled with rate of poverty.

Implication of the findings

The findings indicate that if women are not offered health information on cervical cancer, they may never go for screening nor have knowledge of prevention and vaccination. It is clear that lack of information on cervical cancer is a contributing factor to women in Nigeria and sub-Saharan Africa having very high rates of cervical cancer. This should be a matter of grave concern to all stakeholders: librarians,

government, society at large, communities, families and individuals. Libraries, especially, should reach out to women in all communities and sectors, building partnerships for effective sensitization programs. If women are not properly sensitized on cervical cancer, they may never visit the hospitals for screening and will continue to die unnecessarily. Women need help in the area of awareness, information availability and accessibility, and screening support assistance to meet this devastating health challenge just like their counterparts from the developed parts of the world. The findings in this study indicated that libraries and health information providers, health policies makers and primary health care providers could do more towards curbing this escalating menace in Nigeria. The study has also shown that women are keen to know more and participate in cervical cancer programs.

Conclusion and recommendation

Cervical cancer is a serious health issue that should not be viewed as a women's problem only because everyone has a mother, sister, wife, daughter and female colleagues. Additionally, the roles that women play in families and society make them key players in the achievement of Sustainable Development Goals.

The importance of libraries and librarians in making health information available and accessible should be viewed critically. Figure 2 showed libraries scoring lowest as a source of information. The time for taking ownership of information and ensuring people are aware of library services on health information delivery is now.

Therefore, the study makes the following recommendations:

1. Health libraries are important players in the process to achieve SDG-3, but must promote their role and make this more visible.
2. Libraries in Nigeria should counteract the effect of the low resource status of their health care system on knowledge of cervical cancer by proactively facilitating access to reliable information,
3. Health libraries must make themselves relevant to Nigeria's health care system and SDG3 plans by working to share successful initiatives implemented towards tackling the urgent health issue of cervical cancer.
4. Librarians should collaborate with other health care professionals to be more effective noting that cervical cancer screening can be arranged in informal venues and with flexible time other

than the hospital, which will help to attract women for counseling and lectures.

5. Libraries should assist in cervical cancer awareness creation by repackaging information in formats other than books and also translate them into local languages spoken in the communities.
6. Libraries should help to share cervical cancer success stories, which have the potential to reduce fear and unnecessary tension.
7. Libraries should collaborate with other health care professionals and help in providing materials for:
 - lobbying government to organize massive health information education and awareness on cervical cancer across the States in the country including using radio and various electronic and social media to broadcast information acting in collaboration with different professional bodies and organizations concerned with cervical cancer;
 - setting up a program to open National Cancer Center centers and make screening free and accessible to all.

This is an appeal for urgent action to start now and build on the modest initiative described in this study.

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Advancing scholarly publishing through open access biomedical repositories: A knowledge management perspective

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Abstract

Scholarly publishing has undergone major changes over the past 50 years. Funder mandates and organisational reporting obligations have heralded the creation of open access repositories, such as institutional and subject repositories. This research draws upon the US PubMed Central (PMC) and Europe PMC, also known as PMC International, as a role model to inform the concept and opportunity for an Australasia open access biomedical repository. PMC International is a leader in making citations and research output, which link to research data, Findable, Accessible, Interoperable and Reusable (FAIR). As repositories approach two decades of development, this paper reports on the potential for an Australasia open access biomedical repository through a knowledge management lens and explores the opportunities for future open access biomedical repositories.

Keywords

Australasia, Europe PMC, evidence-based healthcare model, knowledge management, open access biomedical repositories, open science, PMC, PMC international, PubMed Central, scholarly publishing

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Introduction

Open access repositories worldwide have emerged as a trusted platform for accessing and managing scholarly research output. In late 2000, institutional repositories were set up in Australian universities to provide access to research collections (Steele, 2013). In line with the US and Europe, in pursuing open access publishing, the requirement of key Australian funding bodies for authors to publish the results of their research openly put the pressure on universities to manage this process using institutional repositories.

Another significant repository development occurred in 2000, when the US PubMed Central (PMC) commenced as a disciplinary repository of

full-text biomedical research, making the results of the National Institutes of Health's research openly and permanently available (Roberts, 2001). PubMed linked to PMC makes research evidence in the biomedical sciences accessible throughout the world (Williamson and Minter, 2019).

A decade later, PMC nodes were established in Europe and Canada, forming the PMC International

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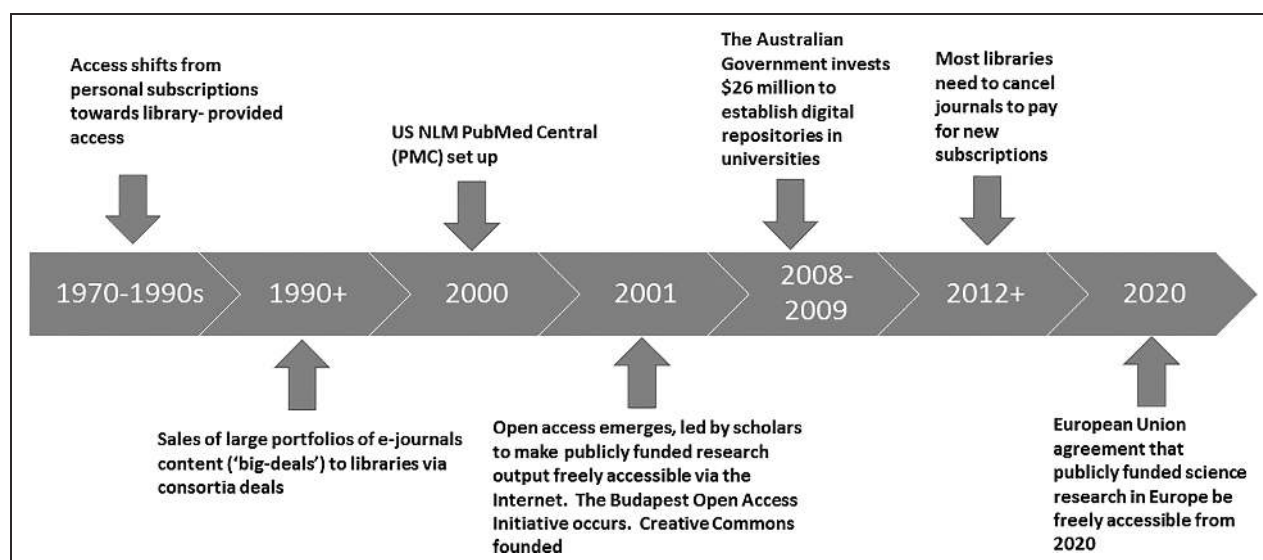


Figure 1. Chronology of scholarly publishing trends and developments (Compiled by L Kruesi).

(US National Library of Medicine, National Institutes of Health, 2018b). Whilst Australian university institutional repositories exist, the Australasia region lacks a consolidated repository to make biomedical and health sciences research accessible, discoverable, interoperable and permanently findable.

This paper reports on an investigation into the concept and opportunity for establishing an open biomedical repository in the Australasian region, such as a PMC repository, from a knowledge management (KM) perspective. An Australasia PMC could potentially include biomedical research output with an Australian, New Zealand and Pacific Islands focus. The Evidence-based Healthcare (EBHC) pyramid is the model adopted to investigate the knowledge transfer and dissemination role of a PMC.

Background

For over 350 years, scholarly journal articles have been the chosen means to disseminate new knowledge, register research findings, review and certify results, preserve a record, add to the existing body of knowledge and act as a measure for determining academic promotion (Fyfe et al., 2015).

Over the period from 1970 until the 1990s, there was a shift from personal subscriptions towards library-provided journal access (Tenopir and King, 1998). Around this time sales of large portfolios of electronic journal content sold through consortia arrangements to libraries was the major means to acquire research collections. Figure 1 provides a chronology of scholarly publishing trends and developments since 1970.

Academic libraries throughout Australia spent approximately \$282m in 2017 on access to subscription journals to support students, researchers and practitioners (Council of Australian University Librarians and Australasian Open Access Strategy Group, 2018). Over the past decade, many academic libraries have needed to cancel subscriptions in order to free up funds for new titles. In addition to the struggle to maintain subscriptions, library managers are required to sign contracts that forbid them disclosing publisher fees (Sample, 2012) therefore the costs of the existing scholarly publishing system are not transparent.

Presently aggregator online library search platforms that evolved from library catalogues are set up to adhere to publisher contracts. The library search systems lock down collections and databases using paywalls, ultimately restricting the access, reading, citing and translating of research into practice.

Advancing scholarly publishing literature review

This review highlights key research articles that explain and distinguish the roles of repositories providing research output. The status of research repositories in Australia and the world perspective are summarized. Key research articles on PubMed and PMC's evolution are included to give perspective on their role in advancing scholarly publishing.

Repositories

In early 2000, around the time of the Budapest Open Access Initiative, the focus was on making peer-reviewed scholarly journal articles accessible via the

Internet from institutional and subject repositories such as PMC (Sequeira et al., 2001). By late 2000, in addition to journal articles, the content of books and book chapters, conference papers, theses, working papers, preprints, learning objects and rich media files were becoming openly accessible from repositories. The fundamental goals of opening up research output relate to pursuing transparency of research methods, reusability of research processes, open communication and public accessibility via the Internet (Gezelter, 2009).

A digital repository is a set of systems and services that ingest, store, manage, display, retrieve and allow reuse of digital objects (Pinfield et al., 2014). Institutions, subject communities and research funders predominantly set up repositories to provide access to digital objects (Pinfield, 2009). Aggregators actively harvest data from multiple sources such as repositories, and make repositories searchable and available in a uniform way (Przybyła et al., 2016). Open access literature is content that is online, digital, free of charges and without most of the copyright and licensing restrictions (Suber, 2015).

A subject or disciplinary repository is defined as a repository ‘that collects and provides access to the literature of a single subject or a set of related subjects’ (Huber and Swogger, 2014: 71). According to Björk (2014), subject repositories may contain article metadata, as well as research data and full text of scholarly publications which is available free of charge and is searchable by web robots.

Subject and national repositories help scholars to navigate the vast amount of knowledge, though institutional repositories have been less successful as outlets for this endeavour (Armbruster and Romary, 2009). Institutional repositories, such as those developed in Australia, do aggregate with the National Library of Australia’s repository TROVE. Most institutional repositories harvest quality metadata and full-text articles from subject repositories such as Europe PMC. Repositories exist to provide value and relevance of research; they do not exist to archive every research output (Armbruster and Romary, 2009).

An institutional repository is a recognition that scholarship of universities and organizations is in digital form. An institutional repository is a means to make research output available to members of their communities and the public (Huber and Swogger, 2014: 71). Examples of subject repositories that work effectively alongside institutional repositories, include ArXiv (an open access e-prints repository in Physics, Mathematics, Computer Science, Quantitative Biology, Quantitative Finance and Statistics) (arXiv.org), PMC

(<https://www.ncbi.nlm.nih.gov/pmc/>), and RePEc (Research Papers in Economics <http://repec.org/>).

Status ‘Down Under’ and world perspective

Library services in the medical sector are a small part of a massive healthcare system in Australia that consumes over \$147bn a year (Australian Government Productivity Commission, 2015; Brooks, 2011). It is currently difficult to report comprehensively on the state of health sciences research output throughout Australian universities, hospitals, medical institutes and health care centres. Australian health practitioner information is stored in silos and because of this doctors, nurses and allied health professionals make clinical decisions based on an array of sources (Four Corners ABC, 2015). Australia publishes on average 50,000 biomedical and health sciences research articles annually (Elsevier BV, 2017). Medical research consumes a significant investment of \$5.9bn annually of Australian public money (Research Australia, 2016).

In 2007–2009, the Australian Government administered the Australian Scheme for Higher Education Repositories (ASHER) programme, during which digital institutional repositories throughout Australian universities received \$26m. ‘Enhancing access to research through the use of digital repositories’ was the aim of ASHER, though at the time much of the allocation was assigned to developing closed collections for the Excellence in Research Australia (ERA) project (Steele, 2013).

Regardless of the vast investment in establishing and operating repositories throughout Australia, most of the university repositories, according to the Director of the Australian Open Access Strategy Group, achieve around 20–25% compliance with open access mandates (Barbour, 2017). Europe PMC achieves much higher compliance with making research papers openly available on behalf of their 29 research funders (e.g. Wellcome Trust reports compliance of around 80%) (Lariviere and Sugimoto, 2018).

There is no government long-term funding for Australian university institutional repositories and no oversight of their development at a national level (Barbour, 2017). Heriyanto (2018) reports on the difficulties authors experience in complying with funder mandates. He explains that authors are confused by the concept of publication versions (e.g. preprint, post print, publisher versions) and this hinders their ability to submit publications to their institutional repository. Other challenges include low author motivation and limited participation in submitting content to institutional repositories (Cullen and Chawner, 2011; Joo

et al., 2018). Fragmentation is another issue highlighted in our recent research (Kruesi et al., 2019). For instance, a user locating a reference without the accompanying full-text article in an institutional repository may need to search in numerous repositories. This fragmentation creates flow on challenges with accessibility, discoverability, interoperability and permanency (Kruesi et al., 2019).

At a time when major world universities and institutions are taking the initiative and developing an ‘open’ infrastructure, it is important to undertake studies on the open biomedical repositories to help guide the future direction for library services and the wider research ecosystem (Dizikes, 2016; Science Europe, 2015).

From 2006 onwards, major world institutions have introduced open access mandates and plans, such as:

- Wellcome Trust (Wellcome Trust, 2006);
- US National Institutes of Health (US Department of Health and Human Services, National Institutes of Health, 2008);
- NHMRC (National Health and Medical Research Council (Australia), 2018);
- ARC (Australian Research Council, 2013);
- European Union (Science Europe, 2015);
- cOAlition S, Plan S (cOAlition S, 2019).

In 2015, the importance of Findable, Accessible, Interoperable and Reusable (FAIR) data and research output principles were established by a group at a workshop in Leiden in the Netherlands and later adopted by major world bodies (cOAlition S, 2019).

PubMed and PMC

The US National Library of Medicine (NLM), creator of PubMed, established an open biomedical and life sciences repository of freely accessible full-text journal literature, PMC, in 2000. PubMed is an aggregator database, the precursor of which was the printed *Index Medicus* that began in 1879 (Greenberg and Gallagher, 2009). PMC, as an open biomedical repository, enables the publications resulting from the funded research of the National Institutes of Health, the Health Research Alliances (75 non-profit research funders) and other private and international partners to be openly and permanently available from the NLM’s website (US National Library of Medicine, National Institutes of Health, 2018b).

According to Richard Roberts, executive editor of the journal, *Nucleic Acids Research* and Nobel Prize winner for medicine in 1993, the goal of PMC is not to replace the journal. The objective of a PMC is to distribute knowledge as widely as possible (Roberts,

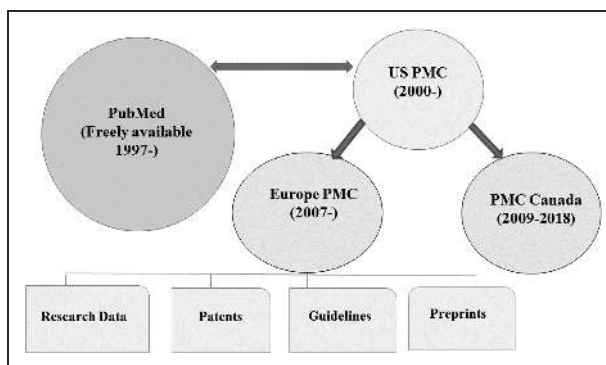


Figure 2. PMC International landscape.

2001). The US NLM PMC is the parent site of Europe PMC. The purpose of Europe PMC, established in 2007, is to expand the participation in the PMC repository and add to the increasing corpus of open access research. PMC Canada was operational over the period 2009–2018, as another child site of the US PMC.

The most successful repositories are disciplinary or national in scope rather than institutional repositories (Poynder, 2016). Two Australian PhD studies (Kennan, 2008; Kingsley, 2010) traced the open access scholarly publishing transformation over recent decades and the role of institutional repositories. Whereas Kennan’s research focused on the introduction of institutional repositories, Kingsley raised the need for institutional repositories to ‘adapt dramatically’ in order for the academic community to adopt them into practice and suggested the alternative is for communities to develop subject-based repositories (Kingsley, 2010: 210).

PubMed is an openly accessible aggregator database with over 29.2 million biomedical literature citations from MEDLINE, life science journals, and online books (see Figure 2). PubMed citations may include links to full-text, peer reviewed articles that are accessible from the repository PMC.

PMC is a free repository of biomedical and life sciences journal literature. PMC was an initiative of the Nobel laureate NIH Director, Harold Varmus, set up in 2000 (Sequeira et al., 2001; US National Library of Medicine, National Institutes of Health, 2011).

PubMed and MEDLINE, and PMC as a subset of PubMed, all of which are part of the Entrez series of repositories, is one of the world’s largest and freely available biomedical databases (Yoo and Marinov, 2010). Healthcare practitioners rely on PubMed as an important and trusted digital biomedical library (Nankivell et al., 2001). A major ‘objective of the databases is to make the path from basic research findings to clinical applications as smooth as

possible' (McEntyre and Lipman, 2001: 1319; US National Library of Medicine, 2018). The 'tentacles' of PubMed are far reaching, with at least 28 by-products of PubMed existing to optimize searching of this resource, to help create meaning when extracting results from the 29 million plus bibliographic records (Lu, 2011). PMC is dependent upon PubMed for bibliographic metadata. In 2019, there are over 5.2 million articles in PMC.

In 2018, PMC Canada ceased operation and institutional repositories took over the management of author submissions. Europe PMC in contrast to PMC Canada continues to expand functionality and content. In 2018 Europe PMC was one of the few repositories that has most of the technical requirements specified by the open access publishing initiative Plan S (cOAlition S, 2019). In addition, many of the cOAlition S funders use Europe PMC as their repository for managing their publication outputs from life science funding projects (Europe PMC, 2019).

Statement of the problem

Even though funding bodies such as the NHMRC and the ARC have open access mandates, less than 50% of their funded research outputs are accessible as open access articles from Australian institutional repositories. A repository such as Europe PMC, in contrast to PMC Canada, has achieved open access compliance rates of 80% on behalf of their funders such as Wellcome Trust (Lariviere and Sugimoto, 2018).

In the Australasia region, there has not been a concerted effort to address the problems of fragmentation, accessibility, discoverability, interoperability and permanency of biomedical research output (Kruesi et al., 2019). An Australasia PMC Working Group comprising librarian members from Australian and New Zealand major universities, set up in 2016, is providing advice and feedback on an Australasia PMC investigation.

An Australasia PMC could be a biomedical regional repository to access research output and a means to demonstrate the value and impact of the annual investment in health care by Australians (Australian Government Productivity Commission, 2015). An Australasia PMC could mirror and contribute to other world PMCs and potentially include biomedical research output with an Australian, New Zealand and Pacific Islands focus. It could apply to become a 'child' of the US PMC. The research output in an Australasia PMC could include openly available journal literature, preprints, guidelines, conference proceedings, reports, patents, books, images and could link to research data, such as the world clinical trial

registries. It could consolidate biomedical research findings and provide an outlet for linking research and data to clinical outcomes. The core of an Australasia PMC could potentially be PubMed, US PMC and Europe PMC. There are various options available to populate an Australasia PMC. Harvesting citations from existing repositories and inviting Australasian researchers to deposit their research papers directly in an Australasia PMC are options for consideration. An Australasia PMC could be a permanent repository of a high standard for now and into the future.

Research design

This research is the basis of an exploratory study on the establishment of an Australasia open access biomedical repository. Based on action research commenced in 2016, the intervention is PMC International, as a role model open access biomedical repository. Knowledge management (KM) theory underpins the research on the concept and opportunity for an Australasia PMC repository. In addition, the Evidence-Based Healthcare (EBHC) pyramid is the model adopted to investigate the biomedical knowledge transfer and dissemination role of a PMC.

The study comprises three cycles. The first action cycle identified significant interest in an investigation on an Australasia PMC (Kruesi, 2018). This paper is based on the second research cycle, which adopts KM theory to develop a conceptual design for an Australasia open access biomedical repository. During the third and final cycle KM theoretical models will be used to guide and evaluate the functional design for a potential Australasia open biomedical repository system.

KM theory and the EBHC model

KM systems aim at getting the right knowledge to the right user and using this knowledge to improve organizational and/or individual performance (Jennex et al., 2009). A set of techniques and technologies for getting the most out of knowledge resources underpins the KM system architecture (Becerra-Fernandez and Sabherwal, 2015). There is a prolific amount of research literature on KM with a focus on achieving competitive advantage for organisations (Argote and Ingram, 2000; Halawi et al., 2005; Mårtensson, 2000).

Based on a thorough search of the literature and discussions with leaders in healthcare, biomedical research and open access fields, there are no previous academic studies on the concept, viability and potential for an Australasia PMC repository from a KM perspective. A vast amount of academic research on

Table 1. Summary of KM process models aligned with biomedical research activities.

| References | | Knowledge management processes | | | |
|---|---|--------------------------------|---|--|-------------------------|
| Grouping | | 1. | 2. | 3. | 4. |
| Nonaka (1994) | Socialization | | Externalization | Combination | Internalization |
| Alavi and Leidner (2001) | Creation | | Storage and retrieval | Transfer | Application |
| Becerra-Fernandez and Sabberwal, (2015) | Discovery | | Capture | Sharing | Application |
| Maier (2007) | Discovery | | Publication | Collaboration | Learning |
| Biomedical research activities | | | | | |
| NHMRC (Australia) (2016) | Conception, planning and commencement of the research | | Data collection, processing, analysis, storage and management | Dissemination of results and data access | Translation of research |
| Kramer and Bosman (2017) | Preparation, discovery and analysis | | Writing and publication | Outreach | Assessment |

more generic open access publishing and repositories is available.

KM is concerned with the discovery of tacit and explicit knowledge from data and information or from the synthesis of prior knowledge (Becerra-Fernandez and Sabherwal, 2015: 59). The discovery activity of research involves iterations of searching and reading (Kramer and Bosman, 2017).

Four groupings of KM processes are summarised in Table 1.

The groupings are based on KM theory and their alignment with biomedical research activities, as defined by the Australian National Health and Medical Research Council (NHMRC) and the authors Bosman and Kramer (Kramer and Bosman, 2016; National Health and Medical Research Council (Australia), 2016). Each of the knowledge creation modes identified by Nonaka (1994) is vital to the transformation of research by health practitioners, industry, or consumers to adopt the findings as knowledge. A social process, which often involves checking with other practitioners and gaining insight from a range of sources occurs to form part of a 'mindline', the knowledge in context that is used in practice. This social activity underpins the constant and repeated process to transform research into knowledge (Gabbay and le May, 2010: 102).

Information systems that support collaboration, coordination and communication processes can increase a researcher's contact with colleagues. These information systems underpin knowledge creation activities (Alavi and Leidner, 2001). Conception, planning and commencement of research (National

Health and Medical Research Council (Australia), 2016) and preparation and analysis (Kramer and Bosman, 2016) are key activities in knowledge discovery and creation processes.

KM processes align with biomedical knowledge creation activities. For example, there is correlation of the KM storage and retrieval processes with the biomedical research activities: data collection, processing, analysis, storage and management (National Health and Medical Research Council (Australia), 2016) in addition to writing and publication (Kramer and Bosman, 2017).

KM processes provide the theoretical perspective for this research. KM processes are fundamental to developing world open biomedical research systems. According to Tuomi (1999), when we explicitly address processes that underpin the establishment of shared understanding, it is then we develop KM systems.

KM processes are important throughout key research activities (Saito et al., 2007). The conduct of clinical trials is a major biomedical research activity that requires registration of data and report planning at an early stage of the research. KM is concerned with data, when knowledge discovery occurs through data mining techniques, and biomedical repositories are becoming a major means to manage and disseminate research data (Becerra-Fernandez and Sabherwal, 2015: 40).

In addition, the Evidence-Based Healthcare (EBHC) pyramid model, developed by Haynes (2001, 2006), is the lens adopted to explain the use of biomedical repositories for retrieval of quality research findings.

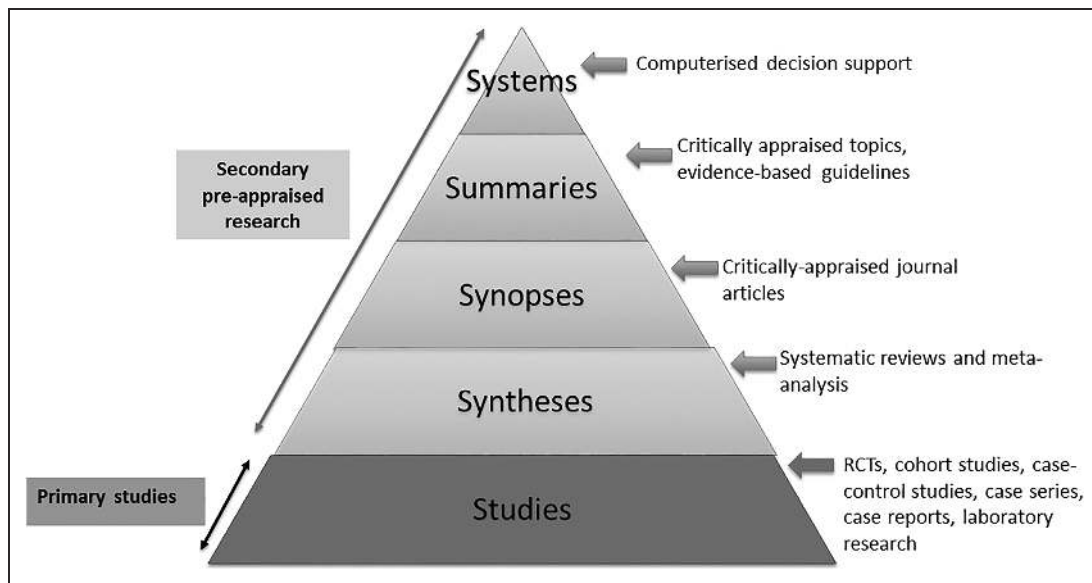


Figure 3. Evidence-Based Healthcare (EBHC) pyramid.

PMC predominantly comprises individual, primary research studies that are the foundation of the EBHC pyramid. For example, Europe PMC, when accessed on 26 October 2017, comprised 4.4 million articles of which 430,168 were reviews, 11,060 were books and documents, and the remainder were primary studies (Europe PMC, 2017). The primary studies form a pyramid within the EBHC pyramid (Figure 3). The studies hierarchy commences with laboratory research, followed by expert opinion in the form of case reports and case series, case-control studies, cohort studies, randomized controlled trials (RCT) and has systematic reviews and meta-analyses above the individual studies (Petrisor and Bhandari, 2007; Sackett, 2000; Shaneyfelt, 2016). RCTs are the gold standard in clinical research, based on a rigorous methodology that helps to eliminate bias (Grimes and Schulz, 2002). Primary studies, based on the EBHC model, are located at the bottom of the pyramid (Figure 3). The pyramid is the model adopted to explain the biomedical knowledge transfer and dissemination role of a PMC.

Progressing beyond systematic reviews in the pyramid, the next level includes synopses, such as critically appraised primary studies. Continuing upwards in the pyramid evidence-based guidelines, and then synthesized summaries (evidence-based textbooks) and systems are at the apex. The apex represents the integration of evidence within hospital clinical decision systems, which along with digitized patient health records help to achieve individualized healthcare. Knowledge synthesization is not typically included in generic KM processes though is essential for users of a PMC.

Discussion

The United Nations International Scientific Information System (UNISIST) model of scientific and technical communication is an example of a proposed universal international communication structure. Authors who have reviewed the UNISIST model argue that national or regional information substructures exist, and it is important to consider regional developments in particular, when US databases are developed based on US standards and culture (Fjordback Søndergaard et al., 2003). Development of a regional open access repository presents an opportunity to address the imbalance, such as the bias of indexing language and focus on local systems design needs.

The need for archiving and making openly accessible national and regional substructures of research output is evidenced by the establishment of Europe PMC in 2007, followed by PMC Canada in 2009 (Figure 2), as PMC International (Europe PMC Consortium, 2015; National Research Council Canada, 2017). In 2018, PMC Canada ceased operation, alleging that institutional repositories could replace their role. In Australia not all institutional repositories achieve satisfactory levels of compliance; they have no coordinating authority and often suffer from lack of resources (Council of Australian University Librarians, 2017).

PMC Canada commenced in 2009, as a service within the Canadian Institute for Health Research (CIHR). In 2010, CIHR lost 60% of their staffing during a restructure. For several years though there were at least 20 employees assigned to PMC Canada.

Table 2. Top six open access repositories with health and medicine content based on record count.

| Name | Metadata records | Full text |
|---------------------------------------|------------------|-------------|
| 1. Europe PMC | 35 million | 5.2 million |
| 2. PMC | 28 million | 5.2 million |
| 3. German Medical Science | 77,496 | 77,496 |
| 4. bioRxiv | 40,558 | 40,558 |
| 5. APO: Analysis & Policy Observatory | 38,626 | 16,372 |
| 6. LENUS (Irish Health Resources) | 29,082 | 29,082 |

In the later years of PMC Canada, there were significant staff reductions. Information technology (IT) staff were lost and IT service was devolved to central services, constraining the maintenance and development of PMC Canada. There were major difficulties with KM processes associated with the creation, storage, retrieval, transfer and application of knowledge. For example, creation of records in PMC Canada was difficult for researchers due to an antiquated submission system and confusion with processes such as the alternative avenues for depositing their articles in either PMC Canada, the US PMC or Canadian institutional repositories. There was no collaboration between PMC Canada and Europe PMC. Most of the communication with the US PMC was for technical support (Landa, 2017).

In the planning for the development of an Australasia PMC, the current research is building on the foundation of KM theory. A thorough understanding of knowledge processes and their related biomedical research activities is informing the design of such a repository. It is anticipated that this systematic analysis will help avoid some of the operational challenges experienced by PMC Canada.

The Directory of Open Access Repositories (OpenDOAR) 'is a quality-assured global directory of academic open access repositories' (University of Nottingham (UK), 2019). OpenDOAR provides information on sites that fully embrace open access to full-text resources that are of use to academic researchers; sites that require authentication and are metadata only are not included. A search of OpenDOAR on the subject, 'Health and Medicine' returns a listing of 359 open repositories. Of these repositories, 45 are disciplinary; this grouping includes PMC and Europe PMC. Within the disciplinary grouping PMC and Europe PMC provide vastly more metadata and full text content than the other 43 repositories in the disciplinary category.

The majority of the databases in OpenDOAR are institutional, though these have fewer than 5000 items

in their collection (Loan and Sheikh, 2016). OpenDOAR states their focus is on sites that embrace open access to full-text resources for an academic audience. The top six OpenDOAR repositories based on record count of health and medicine content is summarized in Table 2. Of these top six repositories, it is important to note that even though they are individual repositories in OpenDOAR, some of the repositories contain duplicate content, such as Europe PMC, being a mirror site of the US PMC and bioRxiv (a biological sciences preprint repository) that is discoverable from the Europe PMC repository. The Analysis & Policy Observatory (number five in the list) is a multidisciplinary repository, with a focus on public policy research, that includes medical and health content. LENUS (number six in the list) is the Irish Health Research repository and according to their website is the leading source for Irish research in health and social care. The opportunity to complement, collaborate and standardize services between regional open access biomedical repositories, in addition to institutional repositories, is essential for the future (Dr Stevens' Library, n.d.).

One of the authorities for the German Medical Science site advised that this resource was not a repository; however, the German open access biomedical repository is the Repository for Life Sciences which has 9395 metadata records and the same amount of full text (ZB Med Information Centre for Life Sciences, 2018). The OpenDOAR health and medicine repositories reveal a wide lack of standardization within the field of open biomedical repositories worldwide. The Table 2 figures are from the repository website or a contact working for the repository or the OpenDOAR database entry for the repository; January 2019 is the date of the figures.

The open science movement has gained significant momentum over the past two decades. During this time, institutional and disciplinary repositories have significant KM process roles throughout the biomedical knowledge creation stages of discovery, creation, representation, storage, retrieval, transfer and application (Kruesi et al., 2018). There are further opportunities for repositories to work together to achieve the FAIR principles.

Plan S, an initiative for open access publishing, released in 2018 and supported by cOAlition S, requires that from 2020, scientific publications resulting from research funded by public grants, be published in journals or platforms that are open access compliant (cOAlition S, 2019). Europe PMC fully supports the mission of Plan S to drive universal open access for research articles (Europe PMC, 2019). Many of the cOAlition S funders use Europe PMC

as their repository for deposit of their publication outputs from publicly funded biomedical projects. Europe PMC meets all the requirements outlined in the implementation plans and points out that this approach provides the best opportunity for discovery, interoperability and reuse of the full-text content of research articles, and therefore contributes effectively to open science (Europe PMC, 2019).

Over 600 organizations have responded to Plan S from over 40 countries (cOAlition S, 2019). One of the responses from the United Kingdom Council of Research Repositories (UKCORR) (2019) raises concerns over the potential for Plan S to marginalize. UKCORR (2019) argues:

Open access repositories add to the diversity of open research platforms and should therefore be nurtured and supported by funding bodies to become an essential component of the scholarly communication landscape. Failure to do so will exclude a large proportion of ‘APC poor’ authors from their participation in scholarly discourse, as well as inhibit the growth and exposure of high-value grey research literature.

The vast majority, if not all, Australasian repositories at present do not comply with the technical requirements of Plan S. Nevertheless, Europe PMC is one of the few repositories that does comply with Plan S and its adoption in the Australasia region would be a means to achieve immediate open access to publications from publicly funded research.

AmeliCA’s (Ameli, open Knowledge for Latin America and the Global South) goal is to achieve a non-commercial open access, multi-institutional platform to develop technology and generate knowledge (AmeliCA, 2019). In Australia, universities place great importance on their global rankings. In some cases, publication and citation in the leading journals determines a major part of university rankings, e.g. the Shanghai Jiao Tong University rankings (Marginson, 2007). There are some synergies with the situation in Latin America for researchers in the Australasia region; in particular, by researchers who are unable to publish in the top journals, such as the journals indexed by MEDLINE (Kruesi et al., 2019). Plan S necessitates we continue to work with publishers. Establishment of an Australasia PMC would be a start to establishment of a regional open access biomedical repository infrastructure that could potentially fuse traditional approaches to scholarly publishing with innovative approaches, to help encourage academic institutions to retain ownership and disseminate their research output as widely as possible.

KM processes can inform the design for a successful regional or national repository such as an Australasia PMC; this will be tested in the third cycle of this action research. According to senior staff from the National Library of Australia, KM process principles were a key reason for the success of their legal deposit online system. Senior National Library of Australia staff indicated the balance of technology, people, content and process were essential to the legal deposit system that is being implemented throughout the National and State libraries in Australia.

In November 2018, the Council of Australian University Librarians (CAUL) and the Australasian Open Access Strategy Group’s (AOASG) submission on establishing a strategic approach to open scholarship was recognized in a report by a Standing Committee on Employment, Education and Training. According to Ginny Barbour (2018), AOASG Director:

we should publish research as a fully interconnected, purposefully designed, equitable, global scholarly ecosystem supported by a wide variety of open access publishing models, underpinned by sophisticated linking of well-curated, interoperable research articles and other outputs, including data and software.

The emphasis is on removing barriers to the effective dissemination of knowledge.

Evidence exists of the success and pervasive nature of PMC International as a repository. Reports include PMC being able to satisfy funder requirements to publish open access articles within 12 months or earlier (Lariviere and Sugimoto, 2018). Other evidence of Europe PMC International’s effectiveness is evident from the ongoing development of system features and services that are wide ranging, such features that allow reporting on grants and research findings, author profiles linked to ORCID, text mining, related articles and an annotations service (Europe PMC, 2018; Europe PMC, 2019).

A PMC itself is not a panacea for all regions. A PMC requires a very significant investment and strict qualifications exist to become a member of PMC International. It is the PMC model that is available to all open access biomedical repositories and is worthy of attention.

A limitation of this research is the focus on biomedical research output and not multi-disciplinary research output. However, we proposed and successfully tested the use of a KM perspective as a general approach to describe how academic publications are serving the purposes of systematic management of scientific knowledge and the role of open access publications in complementing and addressing the challenges of the regional KM.

Conclusion

The research based on action research methodology is proving an effective approach to producing new knowledge about scholarly communications whilst also addressing practical problems. The problems include an inadequate system for researchers to comply with funders' open access requirements, fragmentation of institutional repository content, along with challenges of accessibility, discoverability, interoperability and permanency of biomedical research output in the Australasia region. Requirements to achieve open access publishing highlighted by Plan S are rigorous and controversial. High standards for open access publishing are essential and collaborating with publishers to achieve innovation in scholarly publishing is vital. Working with Europe PMC may be a suitable starting point to commence development of an open access biomedical repository for the Australasia region.

'An old tradition and a new technology have converged to make possible an unprecedented public good' (Budapest Open Access Initiative, 2002). There is great opportunity to accelerate the advancement of scholarly publishing through open access biomedical repositories.

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The role of the university library in creating inclusive healthcare hackathons: A case study with design-thinking processes

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Abstract

Librarians can utilize design-thinking practices to develop instructional materials, in the development of new products and services, and in prototyping novel solutions to problems. This paper will explore the role of design thinking in teaching and learning via the use of the Blended Librarians Adapted Addie Model (BLAAM), and will illustrate how well-designed learning approaches can be used to create inclusive learning environments. It will present a case study showcasing how an academic health sciences librarian utilized a design-thinking process to create a health data literacy instruction service that encourages diverse participation in healthcare hackathons.

Keywords

Data literacy, design thinking, diversity, hackathons, health

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Introduction

This study was conducted at a large, STEM-focused research university in the United States. Librarians at the university hold tenure-track faculty status and frequently collaborate with faculty and instructors in other disciplines across campus and as a result, a range of interdisciplinary and multidisciplinary information literacy, research data management, and data literacy services have been offered for well over a decade. The university's teaching philosophy centers around student-centered learning, an instructional approach that seeks to actively engage students in the learning process. (Maybe et. al, 2017) Though the university hosts many extracurricular data challenges each year, students from health sciences disciplines are often underrepresented at those events. But, big data in healthcare has become a prominent issue and is being used to identify and manage high-risk and high-cost patients, and used in the development of precision medicine services (Ellaway et. al., 2014). Health sciences graduates with experience transform- ing large biomedical datasets into usable information,

products, and services have a valuable, in-demand addition to their academic experience (Schneeweiss, 2014). Additionally, the health sciences disciplines at this university tend to be diverse, particularly in terms of having higher percentages of women and members of minority ethnic groups when compared to other STEM disciplines, offering the opportunity to recruit participants from diverse backgrounds and participants frequently underrepresented in traditional data hackathons (Decker et. al., 2015).

Can librarians develop extracurricular activities that encourage health sciences students to participate in health data challenges? This paper will seek to answer that question by applying design-thinking processes, specifically the Blended Librarians Adapted Addie Model, to the creation of a new library service that encourages a more inclusive learning

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environment for health sciences students interested in working with large biomedical datasets.

Healthcare hackathons as data literacy instruction opportunities

Hackathons offer a means to gather an interdisciplinary group of participants to solve a specific real-world problem and learn from one another. They encourage participants to utilize design-thinking approaches to innovate, require a successful pitch that convinces stakeholders of the usability of a solution, and require participants to quickly respond to feedback and adjust their proposed solutions accordingly (Silver et. al., 2016). Though hackathons have roots in the technology industry, they have been embraced by academia and by libraries (Burton et. al., 2018) as a vehicle for inquiry-based and student-centered learning, and have been used in health-related disciplines as a means to encourage students to be both information seekers and knowledge creators as they find and analyze biomedical data to create an end-product (Camacho et. al., 2018; Decker et. al., 2015; Duhring, 2014; Kienzler and Fontanesi, 2017). To make it easier to describe hackathons to healthcare professionals – healthcare administrators, physicians, nurses, etc. – unfamiliar with the concept but whose buy-in would be needed to support such events, Silver et. al. (2016: 177) define the term *healthcare hackathon* as:

a competitive event (live or virtual) that has three specific goals – accelerating the innovation of medical solutions, improving the design in the beginning stages, and supporting educational training for all participants – and aims to accomplish them by focusing on a specific problem (pain point), bringing together in an open innovation format (internal and external resources) an interdisciplinary group of individuals (hackers) that include, but are not limited to, physicians and other healthcare professionals, data scientists, engineers, user interface designers, business professionals, students and other stakeholders who work in teams and follow a process to develop initial prototypes, pitch them to a panel of judges experienced in innovation and quickly alter them according to the feedback (pivoting).

Participation in healthcare hackathons helps current and future health professionals identify, consider, and develop solutions to challenges associated with how big biomedical data influences patient well-being, and hackathons are particularly useful for better understanding challenges associated with the underuse of uniform data standards and challenges associated with navigating siloed data (Schneeweiss, 2014; Silver et. al., 2016). Health professionals who

can overcome such challenges to design care responses based on data generated from the healthcare systems in which they work and in which their patient data was originally created, can provide more tailored care, improve their understanding of the effectiveness of treatments, and improve the prediction of health outcomes (Schneeweiss, 2014). This ability to transform data into actionable knowledge can supplement the information provided by research studies, where patient populations might be different or which might have been conducted in a controlled research environment (Schneeweiss, 2014). In his exploration of learning from big biomedical data, Professor of Medicine and Epidemiology Sebastian Schneeweiss suggests that health care professionals should understand how to analyze the data being collected in their local health care systems to inform patient care, using the same hospital information systems that already generate that data. Schneeweiss offers a few considerations to facilitate learning from such health data outputs:

1. Methods should ensure that the patient groups used in comparison groups are similar;
2. Aspects of analyses should be automated without losing validity;
3. Automated analyses should be repeated in cycles synced to data refreshes;
4. Software solutions should be intuitive and require only minimal investment of time and training to set-up and use;
5. Analysis results should be easily digestible for both busy clinicians and patients.

These considerations are useful for hackathon participants designing software applications and for judges evaluating hackathon participant submissions. Schneeweiss suggests that learning to treat patients with the data that they themselves generate and understanding the aforementioned considerations will lead health professionals to actionable practices that improve patient treatment and outcomes (Schneeweiss, 2014).

Applying design thinking to promote inclusion in hackathons: The BLAAM model

Criticisms of hackathons include that they promote a culture unwelcoming to women and underrepresented minorities by:

1. fostering an overly competitive environment;
2. using a format or following a schedule that potential participants might find unappealing, i.e. staying up for days on end; and
3. lacking in diversity, which leads to feelings of otherness. (Decker, et. al., 2015)

The proposed library service seeks to alleviate these issues, using design thinking to guide the creation of inclusive activities that leverage current interest in hackathons and extend that appeal to members of minority communities. To achieve this goal Rune Pettersson's information design principles guided the marketing and promotion efforts, while Steven Bell's design-thinking approaches guided the service formation (Bell and Shank, 2007; Pettersson, 2014; Petterson and Avgerinou, 2016). Service formation and related outcomes are addressed in this paper.

Utilization of design-thinking approaches are the basis of Steven Bell's *Academic Librarianship by Design*, in which Bell offers an academic librarian's perspective of design thinking: "we want to optimize the user's satisfaction, and our motive is deeper learning. We too can creatively develop those design elements [performance, quality, durability, appearance, and cost] to benefit our user communities" (Bell and Shank, 2007: 43). Bell suggests that design takes place in three ways within libraries: (1) across products, (2) across environments, and (3) in communication. He introduces a model created specifically for use by librarians to design instructional products and user-centered services, the Blended Librarians Adapted Addie Model (BLAAM) (Bell and Shank, 2007).

BLAAM acknowledges that instructional librarians often lack the time, staff, and money for full-scale design projects, but encourages the use of design-thinking processes to develop services. The model is an adaptation of the ADDIE (analyze, design, develop, implement, and evaluate) model, modified for the library instruction environment and consists of five phases:

1. Assess
2. Define Objectives
3. Develop
4. Deliver
5. Measure.

A description of each phase is summarized below.

Assess

Understand the needs of the learners by discussing anticipated outcomes and goals with the stakeholder, then assess students via an informal needs assessment. Use the results of the stakeholder interview and needs assessment to develop a problem statement that identifies gaps in service, or highlights needs for instructional tools (Bell and Shank, 2007).

Define objectives

Establish objectives that set measures for product or service success. Each project should have 3–4 objectives. Bell recommends the A-B-C-D technique for developing objectives:

- A. Audience: who is the intended audience?
- B. Behavior: at the end of the instruction or service, what behavior changes should the learner have made?
- C. Condition: what condition do learners need to execute the learned behavior?
- D. Degree: establish a standard for deciding when the learner has achieved the objective. (Bell and Shank, 2007)

Develop

Produce learning or service materials. Develop a plan for the new service or product, share it with colleagues and stakeholders, and collect their feedback. Edit the plan as needed, then develop the final product. Formal evaluation can be done after the product or service is launched, via a survey of the learners (Bell and Shank, 2007).

Deliver

Use the instructional tool or service. Instructors should be trained and comfortable with the new product or service (Bell and Shank, 2007).

Measure

Measure how well the predetermined outcomes and objectives were achieved. This step provides evidence that learning occurred and helps to highlight needed changes or adjustments (Bell and Shank, 2007).

BLAAM in action: Designing an inclusive hacking service for health sciences students

With Bell's BLAAM model as a guide, the librarian designed a library service aimed at improving health sciences students' participation in data-hacking activities.

Assess

The idea for a new service emerged from an undergraduate, health sciences evidence-based practice course where students explored datasets but where course restraints did not allow for manipulation or combination of datasets. An observation of campus

data challenge offerings, extracurricular activities that would allow students to practice data skills, highlighted an emphasis on engineering, technology, and computer science disciplines. The assessment phase focused on better understanding learner needs by discussing anticipated outcomes and goals with stakeholders, including health sciences faculty, instructors, and students. An informal needs assessment via casual conversation and reference interviews with students suggested that health sciences students thought data literacy was important but were not participating in the many data-hacking challenges going on in other areas of campus for various reasons, including discomfort in a competitive hacking environment and time restraints. At the end of a librarian-led class discussion on research data management, a group of health sciences students were asked if they had considered participating in a data hacking challenge. These two quotes summarize the group's response:

I learned Javascript because I think that knowing at least one programming language and knowing how to work with data will become even more important throughout my career, but I don't think my skills are good enough to compete with, for example, someone getting a degree in computer science. That's why I haven't attended any of the hackathon events on campus. (quote from an undergraduate student majoring in a health sciences discipline).

I don't know how to code, no programming languages at all, but I think understanding how to manage raw data is important. I would be interested in a class or workshop or special event, something that would teach me to work with raw data despite my not having programming knowledge. (quote from an undergraduate student majoring in a health sciences discipline).

Based on the needs assessment, a problem statement was developed:

How can librarians encourage health sciences student participation in health data-hacking challenges?

Define objectives

Bell's A-B-C-D technique, as previously explained under the "Define Objectives" phase of the BLAAM model, was used to define service objectives:

1. Audience: The intended audience was undergraduate students in health sciences disciplines. Many of these targeted disciplines – nursing, nutrition, and psychology, and speech, language, & hearing sciences – provided an opportunity to recruit from a diverse pool that included significant numbers of

women and members of underrepresented minority groups, audiences often underrepresented in data-hacking challenges.

2. Behavior: By the end of the service, learners should be able to locate relevant open-source datasets, clean and organize raw data, combine data from multiple sources and in multiple formats, and use their cleaned and formatted data to build an application using the Javascript programming language.
3. Condition: To execute the learned behavior, learners should be comfortable searching the web for open datasets, finding datasets in library-provided databases, be able to select the appropriate tools to clean and combine data in various formats, and have a beginner's knowledge of the Javascript programming language.
4. Degree: Learners will be assessed by the quality of their project deliverable – a functioning Javascript application prototype using at least one open data source. They will also be assessed by the improvement of their application over the course of the data-hacking event (for individual hacks) or by peer evaluation of their contribution to their data hacking team (for team hacks).

Service objectives.

1. The proposed service aims to motivate health sciences students to participate in health data-hacking challenges by providing opportunities complementary to the interests, skills, and experience of students and professionals in health-related professions.
2. Participants will demonstrate an ability to execute data literacy-related competencies, including the management of large biomedical datasets, to create an application, service, or tool.

A healthcare hackathon service was conceptualized, and a sample hackathon challenge was created:

Scenario. Diseases and viruses are common in the US media landscape and public mindset; public awareness, and knowledge tend to be easily affected and directed by news stories. This often shapes a discourse of fear. Imagine you are hearing the news about the return of a disease or virus (you can choose a specific virus) and you want to figure out the probability of it spreading to your area. This could be based on geography, proximity to cities, mountains, lakes, plains, traffic connectivity, climate, airports, etc.

Task. Using open data from the CDC and mapping it to environmental and travel conditions, build an application that will make the public more educated about the current state and impact of viruses so they can make better-informed choices as they travel inside the US.

Mandatory requirements.

1. Your application must use the mandatory dataset: Climate Data Online;
2. Your application must use at least one or more datasets from Data.gov;
3. Your application must be written in the JavaScript language;
4. Your website must integrate a mashup;
5. The code submission must be complemented with a readme file;
6. The readme file must have metadata: keywords, a brief description, a unique identifier of the author, a browser within which it was tested (must be Chrome);
7. Your application must use one of the suggested libraries: arbor.js, D3.js, or sigma.js.

This sample challenge was shared with colleagues for review, including fellow librarians with data science interests, faculty in health sciences disciplines, and faculty with interest in open digital innovation. Their feedback was used to help visualize a challenge model.

Develop

After the needs assessment was conducted and a clear idea of service objectives was defined, the librarian used the BLAMM model to develop a plan for a new health data-hacking service. A collaboration was forged between the Libraries and the Research Center for Open Digital Innovation, where a research team had designed and tested a new hacking competition design appropriate for beginner hackers called IronHacks, three-week competitions where each participant worked independently with integrated feedback from technical and user experience experts (Brunswick et al., 2017). A plan to collaborate to host a healthcare hackathon began with a recruitment strategy that encouraged the participation of novice developers and data scientists by providing pre-hackathon training that would allow all participants to meet the basic level of coding and data science skills needed to actively participate in the hack. This provision of introductory data literacy training to attract novice developers and data scientists combined with a self-paced hacking model that provided iterative feedback

formed the heart of the hackathon service's diversity commitment. The service, then, consisted of two integrated parts:

1. pre-hackathon workshops that introduced the data literacy competencies needed to compete in a health data hacking challenge; and
2. hacking events with iterative feedback that allowed participants to practice and execute the data literacy competencies learned in the workshops.

Pre-event training opportunities included a Data Hacking Workshop Series that included research data management workshops, an OpenRefine workshop for cleaning and combining datasets, a Gephi workshop for data visualization, and Javascript training. The workshops encouraged participants to research and develop the methods, software, and tools needed to analyze biomedical big data in advance of the hacking challenge. Participants were recruited from a range of backgrounds through campus and community promotional activities – via campus activity fairs, through student organizations, and via recruitment in entry-level computer science and health sciences courses. To encourage diverse participation, outreach efforts were tailored to organizations like the regional Clinical and Translational Science Institute (CTSI) and campus cultural centers, as well as local civic hacking organizations and makerspaces. A budget was created and funding was sought, resulting in the receipt of a National Institutes of Health (NIH) Big Data to Knowledge (BD2K) Hackathon Award, for which the Librarian was the primary investigator.

Deliver

After receiving the NIH BD2K Hackathon Award, the proposed library hacking service was formally titled the Biomedical Big Data Hacking for Civic Health Awareness Project. To better meet the award requirements, the target audience for the hackathons was expanded to include graduate students, faculty, staff, local health professionals, and members of the public. The BD2K Hackathon Award funded two projects – Black Ironhack in Fall 2016 and the Libraries Health Data Hackathon in Spring 2017. Black Ironhack was co-hosted by the Libraries and the Research Center for Open Digital Innovation and utilized a pre-existing hackathon structure. The IronHacks model is a 21-day, 4-stage self-directed hacking initiative that allows hackers the time and flexibility to create well-developed applications. At the end of each stage, participants receive feedback from experts and future app users. Black Ironhack asked participants to use

open health and travel data to address health challenges, specifically to create a tracker for travelers interested in evaluating their risk of virus exposure. Participants were required to create a web application and mashup (or combine) at least two open datasets.

Guidelines for the IronHacks are:

1. Submit at least one application at each of the 4 hacking phases.
2. Discuss general questions on the IronHack forum only. Do not communicate solutions with competitors or others.
3. Do not work in teams. IronHack is an individual competition.
4. The code you submit in the first phase does not have to be a fully working application, it can be a non-interactive prototype (even an image).
5. You must be the originator of the code. Be ethical!

The event timeline was as follows:

August–September 2016: Data Hacking Workshop Series

September 14, 2016: IronHack Training Session

September 21–23, 2016: Self-Directed Hacking Phase

September 24–26, 2016: Expert Evaluation Phase 1

September 27–29, 2016: Self-Directed Hacking Phase 2

September 30–October 2, 2016: Evaluation Phase 2

October 3–5, 2016: Self-Directed Hacking Phase 3

October 6–8, 2016: Evaluation Phase 3

October 9–11, 2016: Self-Directed Hacking Phase 4

October 12–18, 2016: Evaluation Phase 4

October 19, 2016: Awards Ceremony and Announcement of Final Winners.

There were 89 participants registered for the hackathon and 43 participants attended at least one of the pre-hackathon training sessions. In the first phase 36 projects were submitted, 13 submitted in the second phases, nine submitted in the third phase, and six projects were submitted for final review at the end of the 21-day hackathon. Expert evaluations and feedback were based on usability, technological performance, and user experience.

The Purdue University Libraries Health Data Hackathon was a 2-day hackathon hosted by Purdue University Libraries in Spring 2017. Participants were asked to use open-source data to identify health trends and opportunities, then work as a team to design an app to track behavior and enhance communication

between consumers and health information sources. Each team was assigned an early-career healthcare professional to advise on current challenges related to working with biomedical data. There were 25 participants registered and 7 participants submitted final projects, with the winning team including a nurse who blended clinical experience, patient communication knowledge, and computing expertise to develop a pharmaceutical drug distribution app. The winning project codes and presentations are available on Github: <https://github.com/anajaved/Heath-Data-Hackathon> <https://github.com/will1397/Health-Data/tree/master/HealthDataApp/app/src/main>

Measure

In his discussion on learning from big health care data, Schneeweiss (2014) identified navigating siloed data and consistent lack of use of uniform data standards as two major obstacles for health professional's utilization of big health data. These are both issues in which librarian expertise and instruction can be instrumental. Though Schneeweiss focused specifically on data from electronic health records, these issues are also reflected in open datasets from government agencies and private organizations, proprietary data in subscription databases, and NGO datasets. Though the study findings for this service represent a single site case study and are limited as such, both issues identified by Schneeweiss emerged as the most popularly reported challenge for hackathon participants. Qualitative feedback from post-event interviews with participants who submitted final projects revealed the desire for further training in data management, particularly data organization, data collection, and data analysis. For example, one winning participant expressed such concerns during his post-event interview, recorded at the Black IronHack awards ceremony: <https://vimeo.com/188211462>. Participants also reported wanting to improve the efficiency of their data collection and data analysis practices with either pre-hackathon training or a guided data management component during the first day of hacking.

Participants noted a few logistical concerns. Downloading multiple large datasets caused the wi-fi to be slower than expected during the first day of the Libraries Health Data Hackathon, which was especially problematic and frustrating for hackers working with a short timeline. And, a sponsor provided snacks for the Libraries Health Data Hackathon, but participants reported that lunch, even just pizza or sandwiches, would have been more useful as they would not have needed to break for lunch.

Next steps

Instructors interested in communicating with, and teaching for a diverse audience will discover that applying a design-thinking approach to the creation of instructional services is valuable for guiding their development and for prototyping novel solutions to problems. Launching services without a clear context can disable the learning cycle, but instructors able to present clear outcomes and objectives in relatable culturally-sensitive and audience-specific ways, have a greater capacity to launch sustainable services. For this project, the goal was to create a service that encouraged diverse participation in healthcare hackathons by offering extracurricular data hacking challenges that health sciences students would participate in. That goal was met with over a quarter of total participants, 28%, being from a health sciences discipline. Considering registrants for both hacks, 38% were women and 46% were members of a racial minority group. There was, however, a high rate of attrition between the number of registrants and the number of participants submitting final projects. This was true for both hacks – Black IronHack began with 89 participants registered and concluded with only six final projects submitted, and the Health Data Hackathon was capped at 25 registrants, with only seven participants actually attending. However, all attendees who participated on the first day of the hackathon felt invested enough to return for the second day. To improve retention rates, future action will include research to better understand causes for failure and rates of attrition in hackathons and similar data challenges.

Both hackathons were extracurricular activities and participant motivation was likely incentivized by the prestige of participating in an NIH-sponsored hackathon event and by the offering of monetary awards for winners; however, funding for the Biomedical Big Data Hacking for Civic Health Awareness Project was limited. To sustain this Libraries hackathon service, present and future action will include continued collaboration with the Research Center for Open Digital Innovation, collaboration with the Health and Human Sciences Office for Diversity and Inclusion, and the continued pursuance of grant and award funding. Since launching these hackathons, the librarian has helped to launch a multidisciplinary undergraduate learning community focused on critical data studies, addressing the ethical and social aspects of big data. This living and learning community offers a readily-accessible pool of potential participants for health data hacking challenges. The hackathon service will continue although its name will likely change.

Relatedly, healthcare hackathons introduce the opportunity to explore issues related to critical data studies. Specifically addressing questions regarding who collects biomedical data; where does biomedical data come from; what challenges are associated with combining, formatting, storing and analyzing big biomedical data from different systems; and who controls and owns biomedical data. Also, what privacy concerns need to be addressed by health professionals using data from patient health records and hospital information systems?

Conclusion

This study revealed that health sciences students are interested in working with big data, but do not always have the coding expertise to compete in hackathon competitions. Results from the initial needs assessment at the beginning of the service design project suggest that there are students interested in learning to manage data, but not particularly interested in learning a programming language. Future action might include expanding services to include data-related challenges that do not require coding, such as datathons, humanitarian mapping events, ideation challenges, case competitions, and policy challenge competitions.

To improve attrition rates, future action might include either integrating a hackathon model, like IronHacks or a similar approach, into existing health sciences courses or creating a hackathon-based course for upper-level health sciences undergraduates to provide health sciences students with experience wrangling big data and with a tangible deliverable they can share with potential employers.

When asked in post-event conversations, participants consistently reported either finding or formatting data as the most difficult challenge. Addressing this issue ahead of or during hackathons might provide an additional means to reduce attrition rates. This also provides librarians, even those uninterested in hosting hackathons, the opportunity to offer data management training in various forms. These might include hosting a data management workshop series prior to hackathons, hosting pre-hackathon training that focuses on data management practices, and librarian involvement in data-centric health sciences courses or labs as data management experts.

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Author biography

Bethany McGowan is Assistant Professor of Library Science and Health Sciences Information Specialist at Purdue University in West Lafayette, Indiana, USA. Professor McGowan holds degrees in Library & Information Science (MLIS) and Human-Computer Interaction: Interaction Design and Information Architecture (MS).

Abstracts

قطفات

Transforming lives: Combating digital health inequality

تغيير الحياة: مكافحة عدم مساواة الصحة الرقمية

بوب جان؛ مسنول الإدراج الرقمي – NHS Digital، المملكة المتحدة

مجلة إفلا، 3-45،

مستخلص

تعد ثورة الصحة الرقمية فرصة عظيمة لمستخدمي التكنولوجيا الرقمية من أجل تمكين المرضى، ولكن نصف سكان العالم غير متصلين بالإنترنت. فأقل الأشخاص قدرة على الاتصال بالإنترنت هم بالأخص أكثر من يعانون من سوء الصحة. وبتزايد وجود المعلومات المتعلقة بالصحة والمرض (وعادة بشكل حصري) في شكل رقمي، نواجه تحديًا جديدًا للصحة العامة، وهو عدم المساواة في مجال الصحة الرقمية. إن وضع المكتبات يؤولها إلى الوصول إلى تلك المجموعات السكانية التي قد يصعب الوصول إليها. ويعترف بيان إفلا عن محور الأمية الرقمية (2017) أن الإدراج الرقمي جزء أساسي من ممارسة أمانة المكتبة نظرًا لدور المكتبات في مساعدة جميع مستخدميها في الاتصال بالإنترنت، وتطبيق المعلومات التي يحتاجون إليها للتنمية الشخصية والمجتمعية.

تشتمل الإجراءات الناجحة لتحسين الإدراج الرقمي على استهداف الاتصال وتغيير الحياة. ويتناول هذا المقال مبادرات لمكافحة الإقصاء الرقمي في إنجلترا وويلز.

Towards new ways of assessing the impact of local medical journals: A proposal and call for change

من أجل طرق جديدة لتقييم أثر الدوريات العلمية: مقترح ودعوة للتغيير

كريستين وامونيما كاتينجو، وميرسي وامونيما موند وأكاكانديلوا أكاكانديلوا

مجلة إفلا، 3-45،

مستخلص

تعد ملاءمة نتائج الأبحاث العلمية للمجتمع المحلي ضرورة لممارسات التغيير، حيث يجب تحديد علاقة الأبحاث عن طريق

مقاييس تظهر أن المعرفة الناجمة عن البحث قد تركت أثرًا في المجتمع. يتناول هذا البحث – المبني على أدبيات ونتائج أبحاث سابقة – مقاييس تأثير تأخذ في الاعتبار السياقات المحلية عند تقييم علاقة مقال في دورية علمية أو أي نتائج بحثية. يختتم البحث بأن الدوريات العلمية يجب أن تتخطى الانحصار في معايير القياس التقليدية الخاصة بتحليل الاقتباس وتحليل الاستشهادات المرجعية باعتبارها الوسائل الوحيدة لقياس التأثير البحثي.

رغم ضرورة توحيد القياسات، فمن الضروري أيضًا تشجيع المجتمعات المحلية على اختيار مقاييس نتائج الأبحاث التي تعنيها. والطرق المطروحة لتقييم تأثير الأبحاث هي: (أ) تغيير السياسات في قطاع الصحة. (ب) التأثير في إرشادات العلاج الطبية المحلية. (ج) التأثير في إدارة الحالات. (د) استخدامه في التنمية المهنية المستمرة. (هـ) أثره في إنتاج المعرفة المحلية.

Health Information Literacy Awareness and Capacity Building: A Call to Action

الوعي بمحو الأمية المعلوماتية في مجال الصحة وبناء القدرات: دعوة للمعمل

تيري أوتوسن ونانديتا س. ماني وميجان ن. فرااتا

مجلة إفلا، 3-45،

مستخلص

لقد زادت أهمية محو الأمية الصحية في النظام البيئي الحالي المعقد القائم على المعلومات، سواء على الصعيد الوطني أو العالمي. وتؤدي مهنتنا دورًا محوريًا في جميع المجتمعات حول العالم الغني معلوماتيًا منها والفقير. ففي العالم المتقدم صنع انتشار المعلومات الصحية ثروة من المحتويات في متناول الناس، ولكنه في الوقت نفسه صنع التباين حيث لم يعد من السهل معرفة أي المعلومات يمكن الاعتماد عليها، وكيفية استخدام المعلومات الصحية، وما إذا كانت المعلومات تنتج لهدف معين. أما في العالم النامي، فقد لا يكون هناك أي محتوى على الإطلاق. حيث يكون غير مناسب ثقافيًا أو لا يمكن الوصول إليه بسبب اللغة أو أي عوائق أخرى. وللتخفيف من حدة تلك الأزمنة الخاصة بالمعلومات الصحية التي نواجهها الآن، نحتاج إلى التكاتف من أجل مواجهة التحديات التي تفرضها الطبيعة المعقدة للمعلومات الصحية. ويمكن، بل يجب على المكتبيين والعاملين في مجال المعلومات أداء دور محوري في تحسين محو الأمية الصحية في مجتمعاتهم. ولهذا يتناول هذا البحث الجهود الدولية لتحسين الصحة في المجتمعات الغنية والفقيرة معلوماتيًا على حد سواء، بما في ذلك الأعمال التي تم

طرحها في السنوات الأخيرة في جلسات إفلا المفتوحة للصحة والعلوم الحيوية ضمن فعاليات المؤتمر العالمي للمكتبات والمعلومات WLIC. وكذلك يناقش البحث محو الأمية الصحية في الولايات المتحدة وغيرها من الاقتصاد المتقدم، ويدرس بدقة الأعمال المبتكرة لجامعة كارولينا الشمالية في تشابل هيل UNC، حيث قامت مكتبة العلوم الصحية (HSL) – قسم من مكتبات الجامعة – بتعزيز الجهود الخاصة بمحو الأمية الصحية في المجتمعات المحلية عبر الولاية. كذلك يعرض هذا البحث أمثلة عن كيفية الشراكة مع العديد من الجهات القائمة على محو الأمية الصحية، ويناقش فرص النمو والمشاركة المستقبلية.

The Importance of Public Libraries in Health literacy: A Case Study for Diabetic Patients

أهمية المكتبات العامة في محو الأمية الصحية: دراسة حالة على مرضى السكري

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مجلة إفلا، 3-45،

مستخلص

خلفية البحث: يمكن للمكتبات العامة لعب دور رئيسي في دعم محو الأمية الصحية للعلاء، من خلال تقديم خدمات خاصة. ومحو الأمية الصحية هو قدرة الإنسان على الوصول إلى المعلومات وفهمها وتطبيقها؛ من أجل الحفاظ على الصحة وتحسينها. ولا يمارس من ليس لديهم المعلومات الصحية الكافية سلوكيات وقائية كافية. ويعتبر مرض السكري أحد أكثر الأمراض انتشارًا في الدول النامية. ويؤثر الحصول على المعلومات الضرورية الكافية تأثيرًا كبيرًا في سبيل التعايش الصحيح مع المرض وأنشطة العناية الشخصية. فتعليم مرضى السكري من خلال المكتبات العامة قد يعزز من نشر المعلومات الصحية. الأهداف: إن الهدف من هذا البحث هو تقييم تأثير التعليم في مستوى محو الأمية الصحية؛ بين مرضى السكري التابعين لمكتبة أنديشة الثقافية، وتقييم العلاقة بين مستوى محو الأمية الصحية وسن المريض وجنسه.

المنهجية: يعتبر هذا البحث دراسة شبه تجريبية ذات مرحلتين؛ الأولى قبل الاختبار والأخرى بعده. وقد أجريت الدراسة على 48 مريض سكري ممن يترددون على المكتبة العامة. ويُستخدم كأداة للبحث استبيان عن محو الأمية الصحية، يُضفى عليه الطابع الإيراني المحلي. ويتكون هذا الاستبيان من 33 سؤالاً في 5 موضوعات مختلفة: 1- الوصول (6 أسئلة). 2- القراءة (4 أسئلة). 3- الاستيعاب (7 أسئلة). 4- التقييم (4 أسئلة). 5- اتخاذ القرار (12 سؤالاً). وقد تم التدخل التعليمي للأفراد قيد الدراسة بطرق مباشرة وغير مباشرة. وتم تحليل البيانات باستخدام برنامج SPSS21. النتائج: تبرز النتائج أنه:

- في موضوع الوصول، حظي 14.5% من العينات على أعلى درجات الوصول إلى المعلومات المطلوبة.
- فيما يتعلق بقدرات القراءة، أظهر 20% من الأفراد أعلى مستوى للمهارات المطلوبة لقراءة مصادر المعلومات.
- في مجال استيعاب المعلومات، كان 7% من العينات قيد الدراسة أعلى مستويات استيعاب المعلومات التي يحتاجونها.

- فيما يخص التقييم، استطاع 13.5% من العينات القيام بتقييم صحيح تمامًا للمعلومات المرجوة.
- في أسئلة اتخاذ القرار، اتخذ 24.5% من الأفراد قيد الدراسة قرارات حاسمة فيما يتعلق بمتطلباتهم من المعلومات.

وقد ظهرت اختلافات كبيرة في متوسط محو الأمية الصحية لدى مرضى السكري قبل التعليم وبعده. ولكن لم تتضح أية علاقة بين مستوى محو الأمية الصحية وسن مرضى السكري المترددين على مكتبة أنديشة الثقافية قبل التعليم أو بعده (بمعدل $0.05 >$). أما مستوى محو الأمية الصحية فقد ارتفع بمقارنته قبل التعليم وبعده في المرضى من الجنسين.

الخاتمة: حيث إن تعليم المواطنين يعد إحدى مهام المكتبات العامة، فإنه يمكن من خلال استخدام القدرات التعليمية في المكتبات العامة في قطاع الصحة تحسين صحة المجتمع.

Health Information Services: Engaging Women in Cervical Cancer Screening Awareness in Nigeria

خدمات المعلومات الصحية: إشراك النساء في الوعي بفحوص سرطان عنق الرحم في نيجيريا

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مجلة إفلا، 3-45،

مستخلص

يتسبب سرطان عنق الرحم في موت سيدة كل دقيقتين بالعالم. ويُعد هذا النوع ثاني أكبر مسبب للوفاة في نيجيريا بين مرضى السرطان، ويمكن تجنب ذلك بالحصول على معلومات صحية. تتحقق هذه الدراسة من وعي السيدات بسرطان عنق الرحم وحالة الفحص والمصادر والترتيبات والعوامل التي تؤثر عليهم وقت الفحص. تم جمع وتحليل البيانات باستخدام بحث متعدد المنهجية – استبيان وحوار وملاحظة ومناقشة – تم الفحص البصري باستخدام حمض الخليك. اشتملت الدراسة على مكتبيين وطبيين وصيدي وعالم مختبر، وقد تم فحص 90 سيدة في مواضع غير اعتيادية، مثل: مكتبة إلكترونية وكاتدرائية. كشفت الدراسة أن 90% من النساء لم يتم فحصهن من قبل، بالتالي إن لم تستشعر المرأة وجود سرطان عنق الرحم لن تذهب للفحص مطلقاً مما سيزيد من عدد الخسائر المسجلة. يختم البحث بتوصية ودعوة للعمل موجهة للجميع ولاسيما المكتبيين.

Advancing Scholarly Publishing through Open Access Biomedical Repositories: a Knowledge Management Perspective

تتمية النشر العلمي من خلال المستودعات الطبية البيولوجية ذات النفاذ الحر: منظور إدارة المعلومات

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مجلة إفلا، 3-45،

مستخلص

لقد شهد النشر العلمي تغييرات هائلة في الخمسين عام الأخيرة، حيث تبشر صلاحيات الممول والتزامات الإبلاغ التنظيمية بخلق مستودعات ذات نفاذ حر، مثل المستودعات المؤسسية ومستودعات المواد. يعتمد

هذا البحث على قاعدة البيانات الأمريكية PubMed Central (PMC) والأوروبية Europe PMC – التي تعرف أيضًا باسم PMC الدولية – باعتبارها مثالاً يحتذى به لتقديم المفهوم والفرصة لمستودع بيولوجي طبي أسترالاسي بنفاذ حر. تعتبر PMC الدولية في الصدارة فيما يتعلق بالاقتباسات ونتائج الأبحاث حيث يسهل الوصول والنفاذ إليها، وتتسم بتبادلية التشغيل وإعادة الاستعمال. يقرر هذا البحث إمكانية قيام مستودع بيولوجي طبي أسترالاسي بنفاذ حر واستكشاف فرص قيام مستودعات بيولوجية طبية بنفاذ حر.

The Role of the University Library in Creating Inclusive Healthcare Hackathons: A Case Study with Design Thinking Processes.

دور المكتبات الجامعية في خلق هاكاثون شمولي للرعاية الصحية: دراسة حالة ذات عمليات تفكير تصميمي

بيثاني مكجوان

مستخلص

يمكن للمكتبيين استخدام ممارسات التفكير التصميمي لتطوير مواد إرشادية وتقديم منتجات وخدمات جديدة ونمذجة حلول جديدة للمشكلات. يستكشف هذا البحث دور التفكير التصميمي في التعليم والتعلم من خلال استخدام نموذج Blended Librarians Adapted Addie Model (BLAAM) ، ويوضح كيف يمكن استخدام مقاربات التعلم جيدة التصميم لخلق بيئات تعلم شمولية. وكذلك يقدم دراسة حالة تبرز كيف استخدم أحد المكتبيين الأكاديميين في مجال علوم الصحة عملية التفكير التصميمي لتوفير خدمة إرشادية لمحو الأمية في مجال البيانات الصحية لتشجع على المشاركة في هاكاثون الرعاية الصحية.

IJ 45-3 - 英语语言翻译摘要

变革中的希腊图书馆：持续的对话

Transforming lives: combating digital health inequality

改变生活：抑制数字健康不平等

Bob Gann

国际图联杂志，45-3，187-198

摘要：

对于那些能够接触数字化的人来说，数字健康革命对于患者赋能是一个巨大的机遇。然而，世界上有一半的人口无法获取网络，而这些最不可能上网的人却承受着最沉重的健康负担。随着有关健康和疾病的信息越来越多的(而且通常是仅有的)以数字化的形式呈现，我们面临着一个新的公共健康挑战—数字健康不平等。

图书馆是帮助这些弱势人群的理想地点。国际图联的《数字素养声明》(2017)中明确了图书馆的使命，就是帮助所有图书馆用户，获取和使用他们所需的个人和社区发展的信息，而数字包容就是图书馆实践的一个重要部分。

提升数字包容的成功干预包含目标连接和改变生活。这篇文章将会关注在英格兰和威尔士地区抑制数字排斥的各项倡议。

Towards new ways of assessing the impact of local medical journals: a proposal and call for change

评估当地医学期刊影响力的新方法：一份提案和变革呼吁

Christine Wamunyima Kanyengo, Mercy Wamunyima Monde, Akakandelwa Akakandelwa

国际图联杂志，45-3，199-206

摘要：

研究成果对当地社区有很强的相关性，能够改变社区的实践，而这种研究的相关性需要一些标准来衡量，以此来显示研究所得出的成果对社会产生的影响。这篇文章基于文献综述和初步的调研结果，主要关注研究影响力的衡量，在评估一篇期刊文章，或任何研究成果的相关性时，会将当地作为背景环境。文章总结出在评估研究的影响力时，应不仅仅以传统的引证分析和文献计量作为衡量标准。

虽然将衡量标准化很重要，但是鼓励当地社区选择与其相关的衡量标准也很重要。本文提出的衡量研究影响力的主要方面有：a)健康领域政策的变化，b)对当地医疗指南的影响，c)对病例管理的影响，d)对职业发展的作用，和e)对当地知识生产的影响。

Health information literacy awareness and capacity building: A call to action

健康信息素养意识和能力建设：行动呼吁

Terri Ottosen, Nandita S. Mani,
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国际图联杂志, 45-3, 207-215

摘要：

在当今复杂的信息生态系统中，不论是在国家层面还是国际层面，健康素养变得越来越重要。世界范围内，无论人们是生活在“信息富余”的社会中，还是“信息贫瘠”的社会中，我们这个职业的作用都是很重要的。在发达国家，健康信息的普遍存在性衍生出许多内容制造者，他们能够获取信息，同时也给信息的可靠性，怎样使用信息，以及制造信息的方式是否有意义带来了扰乱。在发展中国家，健康内容可能是缺失的，或在文化上不适合，或因为语言或其它障碍而无法获取。为了缓和我们现在所面临的这场健康信息危机，我们需要共同合作，来应对由健康信息的复杂性引发的挑战。图书馆员和信息专家能够，而且必须要在各自的社区发挥作用，提升社区的健康素养。本文将思考在“信息富余”和“信息贫瘠”的环境中，国际社会对提升健康素养所做的努力，包括在近几年国际图联的世界图书馆和信息大会(WLIC)上，健康和生物科学会议所展示的工作成果。文章还会探讨美国和其他发达国家的健康素养，会详细论述北卡罗来纳大学教堂山分校的创造性成果，作为大学图书馆的一部分，健康科学图书馆对提升当地社区，乃至整个州的健康素养都做出了巨大的努力。文章会列举例子，阐述如何就健康素养问题同多个选区建立伙伴关系，并且会讨论未来发展和参与的机遇。

The importance of public libraries in health literacy: A case study for diabetic patients

公共图书馆在培养健康素养中的重要作用：糖尿病患者实例研究

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国际图联杂志, 45-3, 216-223

摘要：

研究背景：公共图书馆通过提供特殊服务，能够在提升读者的健康素养中发挥重要作用。健康素养是个人获取、理解和利用健康信息的能力，从而实现保持和提升个人的健康水平。健康素养不足的人，就会缺少预防性的健康行为。糖尿病被认为是发展中国家最常见的疾病之一，拥有必需和足够的健康信息，对于正确应对疾病和自我保养有很大的影响。通过公共图书馆对糖尿病患者进行教育，能够有效提升健康信息的传播。

研究目标：本研究的主要目标是评估教育对于到访安迪舍尔文化图书馆的糖尿病患者健康素养水平的影响，并且评估健康素养水平和患者年龄和性别之间的关系。

研究方法：本研究采用准实验研究方法，有先期测试和后期测试。研究对象为48名到访公共图书馆的糖尿病患者。研究工具采用的是伊朗全国成年人健康素养调查问卷，问卷共33个问题，分为5个不同的部分：1-访问(6个问题)2-阅读(4个问题)3-理解(7个问题)4-评价(4个问题)5-决策(12个问题)。研究对象会接受直接或间接的教育干预。调查问卷获得的数据使用SPSS21软件进行分析。

研究结果：结果显示：

- 在访问方面，样本的14.5%；最大程度上获得了所需信息
- 在阅读技巧方面，样本的20%；拥有阅读信息资源所需的阅读技巧
- 在信息理解方面，样本的27%；能够理解他们所需的信息
- 在评价方面，样本的13.5%；能够完全正确评价他们所需的信息
- 在决策方面，24.5%；的人能够对他们所需的信息做出果断的决策

糖尿病患者的平均健康素养水平，在接受教育的前后有明显的不同。此外，在接受教育前后，到访安迪舍尔文化图书馆的糖尿病患者的健康素养水平和他们的年龄不存在明显的关联性。在接受

教育前后，男性和女性糖尿病患者的健康素养水平都得到了提升。

结论：公共图书馆的任务之一就是教育大众，而在健康领域利用公共图书馆的教育职能，可以提升社区整体的健康水平。

Health information services: Engaging women in cervical cancer screening awareness in Nigeria

健康信息服务：增强尼日利亚女性对宫颈癌筛查的意识

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国际图联杂志, 45-3, 224-232

摘要：

世界范围内，每两分钟就有一名女性死于宫颈癌。在尼日利亚，宫颈癌是导致癌症死亡的第二大癌症，而它却可以通过健康信息的获取而避免。本研究调查了女性对宫颈癌的意识，接受筛查的情况，筛查的来源，筛查结果的处置，和阻止她们接受筛查的因素。数据的收集和分析采用了混合方法研究—调查问卷，采访，观察和讨论。宫颈癌筛查使用的是乙酸目视检查(VIA)。参与研究的人员有两名图书馆员，两名医生，一位药剂师和一名实验室科学家。90名女性在非常规地点接受了筛查，分别是一个电子图书馆和一座教堂。研究发现，90%的女性从没接受过筛查。因此，如果女性对宫颈癌不敏感，那么她们可能从来都不会去进行筛查，进而更多的伤亡将被记录在案。文章得出结论，建议并且呼吁大家采取行动应对，尤其是图书馆员。

Advancing scholarly publishing through open access biomedical repositories: a knowledge management perspective

通过开放获取的生物学资源库推进学术出版：从知识管理的角度分析

Lisa M Kruesi, Kerry J Tanner, Frada V Burstein

国际图联杂志, 45-3, 233-245

摘要：

在过去的五十年中，学术出版经历了巨大的变化。资助者授权和机构报告义务已经预示着开放获取资源库的设立，如机构资源库和学科资源库。本研究以美国公共医学中心(PMC)和欧洲公共医学中心，也称国际公共医学中心，作为例子，来解释建设澳大拉西亚开放获取生物学资源库的概念和机遇。国际公共医学中心在创造引文和科研成果方面处于领先地位，可以连接研究数据，使其可查找，可访问，可操作，可重复使用(FAIR)。资源库已有二十年的发展历史，此篇文章将会论述建设澳大拉西亚开放获取生物学资源库的潜在可能性，以及探讨未来开放获取生物学资源库的机遇。

The Role of the University Library in Creating Inclusive Healthcare Hackathons: A Case Study with Design Thinking Processes.

大学图书馆在创造包容性的医疗编程马拉松中的作用：设计思维过程实例研究

Bethany McGowan

国际图联杂志, 45-3, 246-253

摘要：

图书馆员可以利用设计思维的实践来编写指导性材料，开发新产品和新服务，以及为问题设计创新解决方案。这篇文章将会通过使用适应图书馆员的混合艾迪模型(BLAAM)，探索设计思维在教与学中的作用，并且将会阐释设计良好的学习方法如何能用来创造包容性的学习环境。文章会列举一个实例，展示一位学术健康科学图书馆员如何利用设计思维程序创造了一项健康数据素养指导服务，鼓励了多元化参与的医疗编程马拉松。

Sommaires

Transforming lives: combating digital health inequality

Transformer des vies : combattre l'inégalité face à la santé numérique

Bob Gann

IFLA, 45-3, 187-198

Résumé :

Pour tous ceux qui sont connectés, la santé numérique est une véritable révolution qui permet aux patients de devenir autonomes. Cependant, la moitié de la population mondiale n'a pas accès à internet. Et ce sont justement ceux qui sont les moins susceptibles d'avoir accès à internet qui sont les plus touchés par les problèmes de santé. Comme l'information concernant la santé et la maladie sont de plus en plus (et souvent exclusivement) disponibles sous forme numérique, nous devons faire face à un nouveau défi sanitaire – l'inégalité face à la santé numérique.

Ce sont les bibliothécaires qui sont les mieux placées pour atteindre ces populations difficiles d'accès. Dans la *déclaration pour la maîtrise du numérique* (2017), l'IFLA reconnaît qu'en dehors de sa mission d'assistance aux utilisateurs pour leur permettre d'obtenir et de mettre en œuvre l'information nécessaire à leur développement personnel et à celui de leur communauté, l'insertion numérique est une composante essentielle du métier de bibliothécaire.

Les interventions en faveur de l'insertion numérique ciblent la connectivité, et transforment des vies. Cet article porte sur les initiatives en faveur de la lutte contre l'exclusion numérique en Angleterre et au Pays de Galles.

Towards new ways of assessing the impact of local medical journals: a proposal and call for change

Vers de nouveaux outils de mesure de l'impact des journaux médicaux au niveau local : une proposition et un appel au changement

Christine Wamunyima Kanyengo, Mercy Wamunyima Monde, Akakandelwa Akakandelwa

IFLA, 45-3, 199-206

Résumé :

La pertinence des résultats de recherche pour la communauté locale est un facteur essentiel dans le changement des pratiques. La pertinence des recherches doit être définie au moyen d'outils de mesure relevant l'impact des connaissances issues de cette recherche sur la société. Cet article, basé sur une analyse

bibliographique et sur des résultats préliminaires de recherche, milite en faveur d'une mesure de l'impact des recherches qui prendrait en compte le contexte local pour l'évaluation de la pertinence d'un article de journal ou de tout autre résultat de recherche. Il conclut qu'un journal devrait aller au-delà des outils de mesure traditionnels d'analyse des citations et de la bibliométrie pour mesurer l'impact de ces recherches.

Bien que la standardisation des outils de mesure soit importante, il est tout aussi important d'encourager les communautés locales à opter pour des outils de mesure des résultats de recherche qui correspondent à leurs besoins. Les moyens proposés pour mesurer l'impact des recherches sont les suivants: a) les changements dans la politique de santé publique, b) l'effet sur les directives thérapeutiques locales, c) l'effet sur la gestion des dossiers, d) leur utilisation dans le cadre de la formation professionnelle continue, et e) l'impact sur la production locale des savoirs.

Health information literacy awareness and capacity building: A call to action

La vigilance vis-à-vis de la maîtrise de l'information médicale et le développement des compétences : un appel à l'action

Terri Ottosen, Nandita S. Mani, Megan N. Fratta

IFLA, 45-3, 207-215

Résumé :

L'information médicale occupe une place de plus en plus grande dans l'écosystème complexe d'information de nos jours, tant sur le plan national qu'international. Dans le monde entier, que les gens vivent dans des sociétés où l'information est « riche » ou « pauvre », le rôle de notre profession est vital. Dans les pays développés, l'ubiquité de l'information médicale crée une abondance de contenus accessibles à tous et en même temps une confusion quant à la fiabilité et à l'utilité de ces informations, ainsi que la question de la pertinence de la production de cette information. Dans les pays en voie de développement, le contenu peut être non-existant, culturellement inapproprié ou inaccessible du fait de la langue ou d'autres freins. Pour atténuer cette crise de maîtrise de l'information sur la santé à laquelle nous sommes confrontés, nous devons collaborer et proposer des réponses aux défis soulevés par la complexité de l'information médicale. Les bibliothécaires et les professionnels de l'information peuvent et doivent jouer un rôle important dans l'amélioration de la connaissance médicale au sein de leurs communautés. Cet article s'appuie sur des

efforts internationaux pour améliorer la santé, aussi bien dans les secteurs où l'information est « pauvre » que dans ceux où elle est « riche », dont des travaux présentés au cours des Séances Publiques sur la Santé et les Biosciences (Health & Biosciences Open Sessions) du Congrès Mondial des Bibliothèques et de l'Information (WLIC, World Library & Information Congress) de l'IFLA. L'article aborde la connaissance médicale aux USA et dans d'autres économies développées, et détaille le travail innovant effectué à l'Université de Caroline du Nord à Chapel Hill (UNC). Dans cette université, la Bibliothèque des Sciences Médicales (Health Sciences Library, HSL) qui fait partie des Bibliothèques Universitaires, a intensifié ses efforts autour de la connaissance médicale dans les communautés locales et dans tout l'état. Cet article donne des exemples de partenariats regroupant plusieurs circonscriptions autour de la connaissance médicale, et présente des opportunités à venir pour qu'elle grandisse et soit mieux ancrée.

The importance of public libraries in health literacy: A case study for diabetic patients

L'importance des bibliothèques publiques dans la connaissance médicale : une étude de cas chez les diabétiques

Hamed Pirialam, Maryam Kazerani,
Maryam Shekofteh, Zahra Razzaghi

IFLA, 45-3, 216-223

Résumé :

Contexte de l'étude : Les bibliothèques publiques peuvent jouer un rôle majeur dans l'amélioration de la connaissance médicale de leurs clients en proposant des services dédiés. La connaissance médicale est la capacité des individus à améliorer leur capacité à trouver, comprendre et appliquer des informations dédiées pour leur permettre de préserver et d'améliorer leur santé. Les personnes qui ne disposent pas d'une connaissance médicale satisfaisante adoptent moins de comportements préventifs pour leur santé. Le diabète est considéré comme étant l'une des maladies les plus courantes dans les pays en voie de développement. Disposer d'une information adéquate peut avoir un effet significatif sur la bonne prise en charge de la maladie et la mise en place de soins personnels. Eduquer les patients diabétiques grâce aux bibliothèques publiques peut améliorer la dissémination de l'information médicale.

Objectif : L'objectif de cette étude est d'évaluer l'effet de l'éducation sur le niveau de connaissance médicale des patients diabétiques fréquentant la Bibliothèque

Culturelle d'Andisheh, et d'évaluer la relation entre le niveau de connaissance médicale, l'âge et le sexe des patients.

Méthodologie : Cette étude est effectuée de manière quasi-expérimentale avec des pré-tests et des post-tests. La population étudiée comprend 48 patients diabétiques fréquentant la bibliothèque publique. L'outil de recherche est un questionnaire national de connaissance sur la santé pour les adultes en Iran. Ce questionnaire est constitué de 33 questions couvrant 5 domaines différents: 1- L'accessibilité (6 questions) 2- Compréhension écrite (4 questions) 3- Compréhension de l'information (7 questions) 4- Evaluation (4 questions) 5- Prise de décision (12 questions). L'intervention éducative a été fournie de manière directe et indirecte aux sujets. Le logiciel SPSS21 a été utilisé pour l'analyse des données.

Résultats: Les résultats ont révélé ce qui suit:

- 14,5% des individus disposait d'un accès maximal aux informations nécessaires en termes d'accessibilité.
- En ce qui concerne la compréhension écrite, 20% des individus disposait des compétences maximales requises pour lire les sources d'information.
- Concernant la compréhension de l'information, 27% des individus disposait de la compréhension maximale de l'information dont ils avaient besoin.
- Pour ce qui est de l'évaluation, l'évaluation de l'information dont ils avaient besoin était totalement satisfaisante pour 13,5% des individus.
- En termes de prise de décision, 24,5% des individus avaient pris des décisions déterminantes concernant les informations qu'ils avaient recherché.

La connaissance moyenne sur la santé des patients diabétiques avant et après l'intervention éducative a changé de manière significative. De plus, aucune relation significative n'a été trouvée entre le niveau de connaissance médicale et l'âge des patients diabétiques fréquentant la Bibliothèque Culturelle d'Andisheh avant et après l'intervention éducative ($r < 0.05$). Le niveau de connaissance médicale des patients diabétiques a progressé à la fois chez les hommes et les femmes après l'intervention éducative. Conclusions: Comme l'une des missions des bibliothèques publiques consiste en l'enseignement des citoyens, l'utilisation de capacités éducatives au sein des bibliothèques publiques dans le domaine de la santé peut améliorer le niveau de santé de la communauté.

Health information services: Engaging women in cervical cancer screening awareness in Nigeria

Service d'information santé : encourager les femmes au dépistage du cancer du col de l'utérus au Nigéria

Ngozi P. Osuchukwu, Ngozi B. Ukachi

IFLA, 45-3, 224-232

Résumé :

Une femme meurt du cancer du col de l'utérus toutes les deux minutes dans le monde. Au Nigéria, c'est la seconde cause de mortalité due au cancer qui peut être évitée grâce à l'accès à l'information médicale. Cette étude porte sur la prise de conscience du cancer du col de l'utérus, son dépistage, ses origines, ses caractéristiques et les facteurs empêchant le dépistage. Les données furent réunies et analysées au moyen de « méthodes de recherche variées » - questionnaires, entretiens, observations et débats. Pour le dépistage, on a utilisé l'Inspection Visuelle à l'Acide Acétique (IVA). Deux bibliothécaires, deux médecins, un pharmacien et un scientifique de laboratoire ont collaboré à l'étude. Le dépistage a été effectué sur 90 femmes dans un cadre inhabituel: une librairie numérique et une cathédrale. Il s'est avéré que 90% des femmes n'avaient jamais effectué de dépistage. Par conséquent, si les femmes ne sont pas sensibilisées au cancer du col de l'utérus, il est possible qu'elles ne se feront jamais dépister et qu'on enregistrera une augmentation du nombre de décès. La conclusion de l'article comprend des recommandations et un appel à l'action pour tout le monde, et en particulier pour les bibliothécaires.

Advancing scholarly publishing through open access biomedical repositories: a knowledge management perspective

Améliorer la publication académique grâce aux dépôts biomédicaux en accès libre : une perspective de gestion des savoirs

Lisa M Kruesi, Kerry J Tanner, Frada V Burstein

IFLA, 45-3, 233-245

Résumé :

La publication académique a subi des changements majeurs ces cinq dernières années. Des mandats proposés par des bailleurs de fonds et des déclarations d'organisation obligatoires sont des signes

annonciateurs de la création d'un libre accès aux dépôts numériques telles que les dépôts institutionnels et disciplinaires. Cette étude s'appuie sur la base de données bibliographique PubMed Central (PMC) Américain et le PMC Européen, également connue sous l'appellation PMC International, qui devient un modèle et une source d'informations pour concevoir la création d'un dépôt numérique biomédical en accès libre en Australasie. PMC International est un leader dans le domaine des citations et des résultats de recherche, avec des liens vers des données de recherche, afin qu'ils soient Trouvables, Accessibles, Interopérables et Réutilisables (FAIR pour Findable, Accessible, Interoperable and Reusable). Etant donné que les dépôts se développent maintenant depuis près de deux décennies, cet article étudie la possibilité de créer un dépôt numérique biomédical en accès libre en Australasie et explore les opportunités pour la création de dépôts numériques biomédicaux en accès libre.

The Role of the University Library in Creating Inclusive Healthcare Hackathons: A Case Study with Design Thinking Processes.

Le rôle des Bibliothèques Universitaires dans la Création de Hackatons Inclusifs sur la Santé : Une Etude de Cas utilisant le processus du « Design Thinking »

Bethany McGowan

IFLA, 45-3, 246-253

Résumé :

Les bibliothécaires peuvent utiliser le « Design Thinking », une synthèse entre la pensée analytique et la pensée intuitive, pour développer des matériels éducatifs, de nouveaux produits et services et pour prototyper des solutions innovantes aux problèmes. Cet article explore le rôle du « Design Thinking » dans l'enseignement et l'apprentissage en utilisant le modèle BLAAM (Blended Librarians Adapted Addie Model), et illustre le fait que des démarches d'apprentissage bien conçues peuvent être utilisées pour créer des environnements d'apprentissage inclusifs. Il présente une étude de cas montrant comment un bibliothécaire universitaire en sciences médicales a utilisé un processus de « Design Thinking » pour créer un service de formation à la maîtrise des données médicales qui favorise une participation diversifiée à des hackatons sur la santé.

Zusammenfassung

Transforming lives: combating digital health inequality (Lebensverändernd: Bekämpfung der Ungleichheit bei E-Health)

Bob Gann

IFLA-Journal, 45-3, 187-198

Abstrakt:

Für alle, die digital vernetzt sind, ist die digitale Gesundheitsrevolution eine große Chance für das Patienten-Empowerment. Während jedoch noch immer die Hälfte der Weltbevölkerung nicht online ist, kämpfen gerade diejenigen, die kaum Chancen auf einen Internetanschluss haben, mit den größten Gesundheitsproblemen. Da Informationen über Gesundheit und Erkrankungen immer mehr (und oft sogar ausschließlich) in digitaler Form verfügbar sind, stehen wir vor einer neuen Herausforderung im Gesundheitswesen, einer Ungleichheit im Bereich der digitalen Gesundheit.

Bibliotheken sind der ideale Ort, um den am schwersten erreichbaren Bevölkerungsgruppen doch Zugang zu E-Health-Angeboten zu verschaffen. Das *Statement on digital literacy* (2017) von IFLA erkennt, dass im Rahmen der Mission von Bibliotheken, ihre Nutzer beim Zugang und der Anwendung der Informationen zu unterstützen, die sie zur persönlichen Entwicklung und zur Entwicklung ihrer Gemeinschaft benötigen, die digitale Inklusion einen wichtigen Teil des Aufgabenfelds von Bibliothekaren darstellt.

Erfolgreiche Interventionen zur Verbesserung der digitalen Inklusion sind die gezielte Zielgruppenansprache und Verbindung und die Veränderung von Leben. Dieser Artikel befasst sich schwerpunktmäßig mit Initiativen zur Bekämpfung der digitalen Exklusion in England und Wales.

Towards new ways of assessing the impact of local medical journals: a proposal and call for change (Neue Wege zur Messung des Einflusses lokaler medizinischer Fachzeitschriften: Vorschlag und Aufruf zur Veränderung)

Christine Wamunyima Kanyengo, Mercy Wamunyima Monde, Akakandelwa Akakandelwa

IFLA-Journal, 45-3, 199-206

Abstrakt:

Die Relevanz von Forschungsoutput für die lokale Gemeinschaft ist ein kritischer Faktor für Veränderungen

der Praxis. Die Forschungsrelevanz lässt sich mithilfe von Messungen ermitteln, die belegen, dass die durch die Forschung gewonnenen Erkenntnisse etwas für die Gesellschaft bewirkt haben. Diese auf Literaturforschung und vorläufigen Forschungsergebnissen basierende Arbeit plädiert für Messungen zum Einfluss von Forschungsergebnissen, und zwar unter Berücksichtigung des lokalen Kontexts wobei bei der Bewertung der Relevanz eines Zeitschriftenartikels oder von Forschungsoutput. Fazit ist, dass eine Fachzeitschrift über die herkömmlichen Messungskriterien der Zitationsanalyse und Bibliometrik allein als Messung des Einflusses von Forschungsergebnissen hinausgehen sollte.

Auch wenn eine Standardisierung von Messungen wichtig ist, so sollten doch lokale Gemeinschaften dazu ermutigt werden, Messungen von Forschungsergebnissen zu wählen, die eine Bedeutung für sie haben. Zur Messung des Einflusses von Forschungsergebnissen werden folgende Verfahren vorgeschlagen: a) Veränderung der Vorgehensweise im Gesundheitssektor, b) Einfluss auf lokale Richtlinien im Gesundheitssektor, c) Einfluss auf das Case Management, d) Einbindung in die kontinuierliche professionelle Weiterentwicklung, und e) Auswirkungen auf die lokale Wissensproduktion.

Health information literacy awareness and capacity building: A call to action (Aufbau von Gesundheitskompetenz und -kapazität: Aufruf zum Handeln)

Terri Ottosen, Nandita S. Mani, Megan N. Fratta

IFLA-Journal, 45-3, 207-215

Abstrakt:

Informationskompetenz im Bereich Gesundheit wird in dem heutigen komplexen Informations-Ökosystem auf nationaler und weltweiter Ebene immer wichtiger. Die Rolle unseres Berufsstands weltweit, ob in „informationsreichen“ oder „informationsarmen“ Gesellschaften, ist dabei von großer Bedeutung. In der entwickelten Welt liefern die überall verfügbaren Gesundheitsinformationen einen reichen Schatz an Informationen, auf den die Nutzer zugreifen können. Gleichzeitig aber führt diese unübersichtliche Datenflut zu Fragen darüber, welche Informationen zuverlässig sind, wie sie zu nutzen und ob diese Informationen aussagekräftig sind. In Entwicklungsländern sind solche Inhalte entweder nicht vorhanden oder können kulturbedingt unangemessen oder aufgrund von Sprach- und sonstigen Barrieren unzugänglich sein. Um die Folgen dieser Gesundheitsdatenkrise, in der

wir uns gerade befinden, zu mildern, müssen wir zusammenarbeiten und uns den Herausforderungen stellen, welche die Komplexität der Gesundheitsinformationen uns aufgeben. Bibliothekare und Informationsexperten können und müssen in ihrem jeweiligen Umfeld eine wichtige Rolle bei der Verbesserung der Gesundheitskompetenz spielen. Diese Arbeit befasst sich mit den internationalen Anstrengungen zur Verbesserung der Gesundheit in „informationssarmen“ und „informationsreichen“ Umgebungen, unter anderem mit Arbeiten, die bei den Health & Biosciences Open Sessions auf dem IFLA-WLIC-Weltkongress (World Library & Information Congress) präsentiert wurden. Diskutiert wird die Gesundheitskompetenz in den USA und anderen Industriestaaten, und es werden innovative Arbeiten der University of North Carolina in Chapel Hill (UNC) detailliert betrachtet, wo sich die zur dortigen Universitätsbibliothek gehörende Health Sciences Library (HSL) intensiv für die Gesundheitskompetenz vor Ort und im gesamten Bundesstaat einsetzt. Die Arbeit liefert Beispiele für Partnerschaften mit mehreren Kreisen zur Gesundheitskompetenz und diskutiert künftige Möglichkeiten für Wachstum und Engagement.

The importance of public libraries in health literacy: A case study for diabetic patients (Die Bedeutung öffentlicher Bibliotheken für die Gesundheitskompetenz: Eine Fallstudie für Diabetespatienten)

Hamed Pirialam, Maryam Kazerani, Maryam Shekofteh, Zahra Razzaghi

IFLA-Journal, 45-3, 216-223

Abstrakt:

Hintergrund der Studie: Öffentliche Bibliotheken können durch ein spezielles Dienstleistungsangebot eine bedeutsame Rolle bei der Verbesserung der Gesundheitskompetenz ihrer Nutzer bieten. Unter Gesundheitskompetenz wird die Möglichkeit von Personen verstanden, Informationen zu finden, zu verstehen und sie zu nutzen, um ihre Gesundheit zu erhalten und zu verbessern. Menschen mit unzureichender Gesundheitskompetenz weisen weniger Präventionsverhalten in Bezug auf ihre Gesundheit auf. Diabetes gilt als eine der häufigsten Erkrankungen in Entwicklungsländern. Der Zugang zu notwendigen und adäquaten Informationen kann signifikante Auswirkungen auf einen angemessenen Umgang mit der Erkrankung und auf die Selbstpflege haben. Durch die Schulung von Diabetespatienten

mithilfe von Bibliotheken kann sich die Verbreitung von Gesundheitsinformationen verbessern.

Aufgabe: Die Aufgabe dieser Studie bestand darin, die Auswirkungen von Schulung im Bereich der Gesundheitskompetenz auf Diabetespatienten an der Andisheh Cultural Library und das Verhältnis von Gesundheitskompetenzlevel, Alter und Geschlecht der Patienten zu bewerten.

Studiendesign: Es handelte sich um eine quasi-experimentelle Studie mit Vortest und Nachtest. Die Studienpopulation bestand aus 48 Diabetespatienten bezogen auf die Bibliothek. Das Studieninstrument war einer nationalisierter Fragebogen zur Gesundheitskompetenz von Erwachsenen im Iran. Der Fragebogen beinhaltete 33 Fragen zu 5 Themen: 1- Zugänglichkeit (6 Fragen) 2- Lesekompetenz (4 Fragen) 3- Verständnis (7 Fragen) 4- Bewertung (4 Fragen) und 5- Entscheidungsfindung (12 Fragen). Die Schulung wurde den Studienteilnehmern direkt und indirekt geboten. Zur Datenanalyse wurde die Software SPSS21 verwendet.

Ergebnisse: Die Ergebnisse zeigten, dass:

- 14,5% der Befragten in Bezug auf die Zugänglichkeit maximalen Zugang zu den notwendigen Informationen hatte.
- Bei der Lesekompetenz verfügten 20% der Befragten über die maximalen Fertigkeiten zum Lesen der Informationsquellen.
- 27% der Befragten verfügten im Bereich Verständnis über die maximalen Fähigkeiten, die benötigten Informationen auch zu verstehen.
- In Bezug auf die Bewertung konnten 13,5% der Befragten die benötigten Informationen auch korrekt und vollständig bewerten.
- 24,5% der Befragten traf wichtige Entscheidungen über ihre Informationsbedürfnisse.

Im Schnitt wies die Gesundheitskompetenz der Diabetespatienten vor und nach der Schulung einen signifikanten Unterschied auf. Zwischen dem Gesundheitskompetenzlevel und dem Alter der Diabetespatienten der Andisheh Cultural Library zeigte sich vor und nach der Schulung kein signifikanter Unterschied ($r < 0.05$). Sowohl bei Männern als auch bei Frauen stieg der Gesundheitskompetenzlevel nach der Schulung.

Schlussfolgerung: Im Zuge einer der Aufgaben öffentlicher Bibliotheken zur Fortbildung von Bürgern kann der Einsatz von Schulungsinstrumenten zu Gesundheitsfragen in Bibliotheken die Gesundheit der Bürger vor Ort verbessern.

Health information services: Engaging women in cervical cancer screening awareness in Nigeria (Gesundheitsinformationsdienste: Bewusstmachung bei Frauen der Wichtigkeit von Vorsorgeuntersuchungen für Gebärmutterhalskrebs in Nigeria)

Ngozi P. Osuchukwu, Ngozi B. Ukachi

IFLA-Journal, 45-3, 224-232

Abstrakt:

Alle zwei Minuten stirbt irgendwo in der Welt eine Frau an Gebärmutterhalskrebs. In Nigeria ist dies die zweittödlichste Krebsart. Mit Zugang zu Gesundheitsinformationen wäre dies allerdings vermeidbar. Im Rahmen dieser Studie wurde das Bewusstsein von Frauen für Gebärmutterhalskrebs sowie Vorsorgestatus, Quellen, Disposition und Faktoren zu deren Beseitigung durch Vorsorgeuntersuchungen analysiert. Zur Sammlung und Analyse von Daten wurden mehrere Forschungsmethoden eingesetzt, nämlich Fragebögen, Interviews, Beobachtung und Gespräche. Die Vorsorgeuntersuchung wurde mithilfe der visuellen Inspektion mit Essigsäure (VIA) durchgeführt. Das Studienteam bestand aus zwei Bibliothekaren, zwei Ärzten, einem Apotheker und einem Laborwissenschaftler. In einem unüblichen Umfeld, nämlich einer E-Bibliothek und einer Kathedrale, wurden 90 Frauen gescreent. Dabei stellte sich heraus, dass dies für 90% der Frauen das erste Screening war. Werden Frauen nicht für Gebärmutterhalskrebs sensibilisiert, erhalten sie womöglich niemals eine Vorsorgeuntersuchung, was zu mehr Todesfällen führt. Der Artikel schließt mit Empfehlungen und einem Aufruf zum Handeln für alle, insbesondere Bibliothekare.

Advancing scholarly publishing through open access biomedical repositories: a knowledge management perspective (Förderung wissenschaftlicher Publikationen mittels biomedizinischer Open-Access-Repositorien: eine Wissensmanagementstrategie)

Lisa M Kruesi, Kerry J Tanner, Frada V Burstein

IFLA-Journal, 45-3, 233-245

Abstrakt:

In den vergangenen fünfzig Jahren hat sich die Art der wissenschaftlichen Publikation umfassend

verändert. Verpflichtungen in Bezug auf Aufträge von Geldgebern und organisationale Berichterstattung haben die Schaffung von Open-Access-Repositorien begünstigt, beispielsweise institutionelle und disziplinäre Repositorien. Diese Studie stützt sich auf die Datenbanken US PubMed Central (PMC) und Europe PMC, auch als PMC International bezeichnet, als Rollenmodell zur Förderung des Konzepts und der Chance für ein biomedizinisches Open-Access-Repositorium für ganz Australasien. PMC International ist führend für Zitationen und Forschungsoutput, die mit Forschungsdaten nach dem FAIR-Prinzip (Findable, Accessible, Interoperable and Reusable) verknüpft sind. Nachdem Repositorien inzwischen auf fast zwanzig Jahre Entwicklung zurückblicken können, stellt dieser Artikel das Potenzial für ein biomedizinisches Open-Access-Repositorium für Australasien dar und untersucht die Möglichkeiten für künftige biomedizinische Open-Access-Repositorien.

The Role of the University Library in Creating Inclusive Healthcare Hackathons: A Case Study with Design Thinking Processes (Die Rolle der Universitätsbibliothek bei der Schaffung inklusiver Gesundheits-Hackathons: Eine Fallstudie mit Design Thinking Prozessen)

Bethany McGowan

IFLA-Journal, 45-3, 246-253

Abstrakt:

Bibliothekare können Design-Thinking-Methoden bei der Entwicklung von Schulungsmaterial, der Entwicklung neuer Produkte und Dienstleistungen sowie bei der Musterentwicklung neuer Lösungen anwenden. In diesem Artikel wird die Rolle des Design Thinking beim Lehren und Lernen mithilfe des Blended Librarians Adapted Addie Model (BLAAM) untersucht. Außerdem wird illustriert, wie gut gestaltete Lernansätze zur Schaffung inklusiver Lernumgebungen eingesetzt werden können. Der Artikel enthält eine Fallstudie, in der demonstriert wird, wie ein Bibliothekar einer medizinischen Fakultätsbibliothek einen Design-Thinking-Prozess zur Erstellung einer Anleitung für Gesundheitskompetenz genutzt hat, die eine breitgefächerte Teilnahme an Gesundheits-Hackathons fördert.

Аннотация

Transforming lives: combating digital health inequality

Преобразуя жизнь: борьба с цифровым неравенством в области здравоохранения

Боб Гэнн

IFLA Journal, 45-3, 187-198

Аннотация:

Тем, кто связан посредством цифровых технологий, цифровая революция в сфере здравоохранения открывает колоссальные перспективы в плане расширения возможностей для пациентов. Однако половина населения планеты не подключена к цифровым сетям. Именно на долю тех, кто имеет наименьшие шансы выйти в режим онлайн, ложится наибольшая нагрузка, вызванная проблемами со здоровьем. Поскольку информация о вопросах здоровья и о заболеваниях доступна все в большем объеме (а зачастую - исключительно) в цифровой форме, перед нами встает новая проблема общественного здравоохранения - цифровое неравенство в области здравоохранения.

Библиотеки имеют идеальное расположение с точки зрения воздействия на те группы населения, которых особенно тяжело достичь. В *Заявлении ИФЛА о цифровой грамотности (2017)* признается, что в связи с тем, что миссия библиотек заключается в оказании помощи всем своим пользователям в доступе к и в применении информации, которая необходима для личного и общественного развития, расширение внедрения цифровых технологий является важным аспектом библиотечной деятельности.

Успешные мероприятия в области расширения внедрения цифровых технологий включают в себя целенаправленные действия по цифровому соединению и преобразованию жизней. В настоящей статье рассказывается о программах борьбы с отсутствием доступа к цифровым технологиям в Англии и Уэльсе.

Towards new ways of assessing the impact of local medical journals: a proposal and call for change

Ну пути к новым методам оценки влияния локальных медицинских журналов: предложение и призыв к переменам

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IFLA Journal, 45-3, 199-206

Аннотация:

Применимость результатов исследований в рамках местного сообщества имеет критическое значение для изменения действующей практики. Для оценки применимости результатов исследований необходимо использовать такие методы измерения, которые демонстрируют, что знания, полученные в результате исследования, оказали влияние на общество. Данная работа, основанная на обзоре литературы и предварительных результатах исследований, призывает к использованию таких методов измерения влияния проводимого исследования, в рамках которых учитывается местная специфика, для оценки актуальности статьи в научном журнале или даже фактически любого результата исследований. Вывод заключается в том, что журналу следует выйти за рамки традиционных методик измерения на основе анализа цитирования и библиометрии вообще как метода оценки влияния исследований.

И хотя стандартизация методов оценки имеет большое значение, еще одним важным фактором является мотивация местных сообществ для выбора тех методов оценки результатов исследований, которые имеют значение именно для них. Предлагается использовать такие способы оценки влияния результатов исследований, как: а) изменение политики в сфере здравоохранения, б) влияние на локальные инструкции в области медицинского обслуживания, в) влияние на индивидуальное ведение клиента, г) использование в рамках непрерывного профессионального развития и е) воздействие на формирование местных знаний.

Health information literacy awareness and capacity building: A call to action

Просвещение и развитие потенциала в области медицинской грамотности: Призыв к действию

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IFLA Journal, 45-3, 207-215

Аннотация:

В современной сложной информационной экосистеме растет значимость медицинской грамотности как на национальном, так и на глобальном уровнях. По всему миру, вне зависимости от того, является ли общество "информационно богатым" или "информационно бедным", наша профессия

играет жизненно важную роль. В развитых государствах общедоступность медицинской информации приводит к возникновению обилия материалов из открытых источников, но при этом создает неуверенность относительно того, какой информации можно доверять, каким образом медицинскую информацию можно применять, и преподносится ли информация в конструктивном ключе. В странах развивающегося мира информация может отсутствовать вовсе, быть неприемлемой в культурном плане или быть недоступной в связи с языковым или иными барьерами. С целью снижения влияния кризиса в сфере информации о здоровье, с которым мы столкнулись в настоящий момент, нам необходимо сотрудничать и решать вопросы, возникающие в связи со сложностью медицинской информации. Библиотекари и специалисты в области информации могут и должны играть важную роль в деле повышения медицинской грамотности в своих сообществах. В настоящей работе рассказывается о международных усилиях, направленных на улучшение общего состояния здоровья в обстоятельствах как «информационной бедности», так и «информационного богатства», включая работу, которая освещалась в последние годы в рамках Открытых заседаний ИФЛА по вопросам здравоохранения и биологических наук на Всемирном библиотечном и информационном конгрессе. Здесь говорится о медицинской грамотности в США и других экономически развитых странах, а также подробно рассматривается инновационный проект Университета Северной Каролины в Чапел-Хилле (UNC), где Библиотека медицинских наук (HSL), которая входит в состав Университетских библиотек, направила свои усилия на повышение медицинской грамотности как в рамках местных сообществ, так и по всему штату. В работе приводятся примеры взаимодействия в области медицинской грамотности с различными группами населения, а также обсуждаются возможности для роста и укрепления взаимодействия в будущем.

The importance of public libraries in health literacy: A case study for diabetic patients

Важность публичных библиотек для медицинской грамотности: Анализ ситуации с больными диабетом

Хамед Пириалам, Мариам Казерани, Мариам Шекофтех, Зара Раззагхи

IFLA Journal, 45-3, 216-223

Аннотация:

Контекст проведения исследования: Публичные библиотеки могут сыграть существенную роль в повышении уровня медицинской грамотности своих клиентов путем предложения специальных услуг. Медицинская грамотность - это возможность человека получать, осмысливать и применять информацию таким образом, который ведет к поддержанию и улучшению его здоровья. Те, кто имеет недостаточный уровень медицинской грамотности, менее склонны к деятельности, направленной на сохранение здоровья. Диабет считается одним из наиболее распространенных заболеваний в развивающихся странах. Наличие необходимой и достоверной информации может существенно повлиять как на эффективность борьбы с болезнью, так и на мероприятия по уходу за собой. Просветительская работа среди пациентов, страдающих диабетом, осуществляемая библиотеками, может способствовать распространению медико-санитарной информации.

Цель: Цель настоящего исследования заключается в оценке влияния образования на уровень медицинской грамотности среди больных диабетом, обращающихся в Библиотеку культурного центра Андише, а также в выявлении связи между уровнем медицинской грамотности, возрастом и полом пациентов.

Методы: Данная работа является квазиэкспериментальным исследованием с предварительным и послеэкспериментальным тестированием. Исследуемая группа включала в себя 48 больных диабетом, посещающих публичную библиотеку. В качестве инструмента исследования использовалась национальная анкета для определения уровня медицинской грамотности в Иране. Данная анкета включает в себя 33 вопроса из 5-ти различных областей: 1- Доступность (6 вопросов) 2- Чтение (4 вопроса) 3- Восприятие (7 вопросов) 4- Оценка (4 вопроса) и 5- Принятие решений (12 вопросов). Обеспечивалось прямое и косвенное представление субъектам образовательных материалов. Для анализа полученных данных использовалось программное обеспечение SPSS21.

Результаты: В результате исследования выяснилось, что:

- 14,5% испытуемых имели максимальный доступ к необходимой информации с точки зрения ее доступности.
- Что касается способности читать, то 20% испытуемых обладали максимальным

уровнем, необходимым для чтения информационных ресурсов.

- В части восприятия информации, 27% испытуемых имели максимально необходимый уровень восприятия требуемой им информации.
- Что касается оценки, то 13,5% дали абсолютно верную оценку необходимой им информации.
- В плане принятия решений, 24,5% респондентов принимали определяющие решения относительно своих информационных потребностей.

Была выявлена существенная разница между средним уровнем медицинской грамотности больных диабетом до и после образовательных мероприятий. Кроме того, не было обнаружено ощутимой взаимосвязи между уровнем медицинской грамотности и возрастом больных диабетом, обращающихся в Библиотеку культурного центра Андисе до и после образовательных мероприятий ($t < 0,05$). Уровень медицинской грамотности больных диабетом вырос перед и после образовательных мероприятий как среди мужчин, так и среди женщин.

Вывод: Поскольку проведение образовательных мероприятий среди населения является одной из задач публичных библиотек, использование возможностей публичных библиотек в плане просвещения в области здравоохранения может способствовать укреплению общего здоровья населения.

Health information services: Engaging women in cervical cancer screening awareness in Nigeria

Информационные услуги в области здравоохранения: Повышение уровня осведомленности женщин Нигерии о скрининге на предмет рака шейки матки

Нгози П. Осучукву, Нгози Б. Укачи

IFLA Journal, 45-3, 224-232

Аннотация:

Каждые две минуты в мире от рака шейки матки умирает женщина. В Нигерии это заболевание стоит на втором месте среди причин смерти, вызванной раком, и ее можно избежать, если обеспечить доступ к медико-санитарной информации. В рамках данного исследования рассматривается осведомленность женщин о раке шейки матки, ситуация со скринингом, источники, предрасположенность, а также факторы, удерживающие женщин

от прохождения процедуры скрининга. При сборе и анализе данных использовались “смешанные методы исследования” - анкета, интервью, наблюдения и обсуждение. Скрининг проводился методом визуального осмотра с использованием уксусной кислоты (антивирусное средство). В исследовании принимали участие два библиотекаря, два врача, фармацевт и работник лаборатории. 90 женщин прошли скрининг в необычных условиях: в электронной библиотеке и в соборе. Выяснилось, что 90% женщин никогда ранее не проходили этой процедуры. Следовательно, если не привлекать внимания женщин к заболеваемости раком шейки матки, они, возможно, никогда не пройдут скрининг, что приведет к росту числа жертв. В завершительной части документа приводятся рекомендации, а также призыв к действию, адресованный всем, особенно библиотекарям.

Advancing scholarly publishing through open access biomedical repositories: a knowledge management perspective

Медико-биологические репозитории открытого доступа как средство продвижения научных публикаций: взгляд на управление знаниями

Лиза М Круэси, Керри Д Таннер, Фрада В Берштейн

IFLA Journal, 45-3, 233-245

Аннотация:

За последние пятьдесят лет процесс распространения научных публикаций претерпел существенные изменения. Требования спонсоров и обязательства организаций по представлению отчетности привели к возникновению репозиториев открытого доступа, таких как репозитории отдельных учреждений или тематические репозитории. В настоящей работе речь идет об электронных архивах US PubMed Central (PMC) и Europe PMC, известных также как PMC International, как о наглядном примере, который является средством для ознакомления, а также источником возможностей для медико-биологического репозитория открытого доступа для Австралии. PMC International является лидером в части размещения цитат и результатов исследований, связанных с научными данными, отвечающими требованиям концепции FAIR: удобными для поиска, доступными, совместимыми и допускающими многократное использование. История развития репозиториев приближается к своему двадцатилетию, и в этой работе говорится о перспективе создания медико-биологического

репозитория открытого доступа для Австралии, а также о возможностях будущих медико-биологических репозиториях открытого доступа.

The Role of the University Library in Creating Inclusive Healthcare Hackathons: A Case Study with Design Thinking Processes

Роль университетской библиотеки в создании инклюзивных медицинских хакатонов: Анализ жизненной ситуации с применением дизайнерского мышления

Бетани Макгоуэн

IFLA Journal, 45-3, 246-253

Аннотация:

Библиотекари могут пользоваться приемами дизайнерского мышления для разработки учебного

материала, развития новых продуктов и услуг, а также для моделирования новых подходов к решению проблем. В данной работе рассматривается роль дизайнерского мышления при преподавании и обучении с использованием BLAAM (адаптированной для библиотекарей широкого профиля модели ADDIE (анализ, дизайн, развитие, реализация, оценка)), а также показывается, как можно использовать качественно разработанный подход к обучению для создания инклюзивной учебной среды. В работе содержится анализ конкретной ситуации, демонстрирующей, как библиотекарь из сферы академических медицинских наук использовал приемы дизайнерского мышления для создания сервиса по обучению медицинской грамотности, который мотивирует к разностороннему участию в медицинских хакатонах.

Resúmenes

Transforming lives: combating digital health inequality (Transformando vidas: lucha contra la desigualdad en la salud digital)

Bob Gann

IFLA Journal, 45-3, 187-198

Resumen:

Para los que están conectados digitalmente, la revolución de la salud digital constituye una oportunidad excepcional para el empoderamiento del paciente. Sin embargo, la mitad de la población mundial no está conectada. Y los que menos probabilidades tienen de estarlo, son precisamente los que tienen peor salud. A medida que crece la disponibilidad de la información sobre salud y enfermedad en formato (casi exclusivamente) digital, afrontamos un nuevo reto de salud pública: la desigualdad de la salud digital.

Las bibliotecas ocupan un lugar privilegiado para llegar a estos grupos de población de tan difícil acceso. El *Statement on digital literacy* de la IFLA (2017) reconoce que, debido a la misión de las bibliotecas de ayudar a todos sus usuarios a acceder y aplicar la información que necesitan para su desarrollo personal y comunitario, la inclusión digital desempeña un papel importante en la práctica de la biblioteconomía.

Las intervenciones eficaces para mejorar la inclusión digital comportan la promoción de la conexión y la transformación de vidas. Este artículo se centra en

iniciativas para combatir la exclusión digital en Inglaterra y Gales.

Towards new ways of assessing the impact of local medical journals: a proposal and call for change (Hacia nuevos métodos de evaluación del impacto de las publicaciones médicas locales: una propuesta y una llamada al cambio)

Christine Wamunyima Kanyengo, Mercy Wamunyima Monde, Akakandelwa Akakandelwa

IFLA Journal, 45-3, 199-206

Resumen:

La importancia de los resultados de la investigación para la comunidad local es esencial para cambiar la práctica. La relevancia de la investigación debe determinarse utilizando indicadores que demuestren que los conocimientos que surgen de dicha investigación tienen un impacto para la sociedad. Este artículo, basado en una revisión bibliográfica y en resultados de investigaciones preliminares, aboga por indicadores de impacto de la investigación que tengan en cuenta los contextos locales a la hora de evaluar la importancia de un artículo o de cualquier otro resultado. Concluye que una publicación debería trascender los indicadores tradicionales de análisis de citas y bibliometría para medir el impacto de la investigación.

Si bien es importante normalizar los indicadores, también lo es que se anime a las comunidades locales a elegir los indicadores de los resultados de la investigación que más les importen. Los métodos propuestos para evaluar el impacto de la investigación son: a) el

cambio en las políticas del sector sanitario, b) el efecto sobre las directrices de tratamientos médicos locales, c) el efecto sobre la gestión de casos, d) el uso en el desarrollo profesional continuo, y e) el impacto sobre la producción local de conocimientos.

Health information literacy awareness and capacity building: A call to action (Concienciación sobre la alfabetización en ciencias de la salud y creación de capacidades: una llamada a la acción)

Terri Ottosen, Nandita S. Mani, Megan N. Fratta

IFLA Journal, 45-3, 207-215

Resumen:

La alfabetización en ciencias de la salud es cada vez más importante en el ecosistema de la información actual, tanto a escala nacional como global. En todo el mundo, tanto si las personas viven en sociedades «ricas en información» como «pobres en información», el papel de nuestra profesión es vital. En el mundo desarrollado, la naturaleza ubicua de la información sanitaria crea un caudal de contenido de acceso público y ha creado simultáneamente cierta confusión sobre qué información es fiable, cómo se puede utilizar, y si esa información se produce o no de una forma significativa. En el mundo en vías de desarrollo, el contenido puede ser inexistente, culturalmente inapropiado o inaccesible en términos de idioma y otras barreras. Para mitigar esta crisis de información sanitaria que estamos sufriendo, debemos colaborar y responder a los desafíos planteados por la complejidad de dicha información. Los bibliotecarios y los profesionales de la información pueden y deben desempeñar un papel importante en la mejora de la alfabetización en ciencias de la salud de sus comunidades. Este artículo considera iniciativas internacionales destinadas a mejorar la salud en contextos «ricos en información» y «pobres en información», incluido el trabajo expuesto en los últimos años en las Health & Biosciences Open Sessions celebradas por la IFLA en el World Library & Information Congress (WLIC). En él se evalúa la alfabetización en ciencias de la salud en los EE. UU. y en otras economías desarrolladas, y se analiza en detalle el innovador trabajo de la Universidad de Carolina del Norte en Chapel Hill (UNC), donde la Biblioteca de Ciencias de la Salud (HSL), que forma parte de las bibliotecas universitarias, ha redoblado sus esfuerzos en torno a los conocimientos en esta materia en las comunidades locales y en todo el estado. Este artículo ofrece ejemplos de cómo aliarse con varias comunidades de usuarios en la alfabetización en ciencias de la salud

y se analizan oportunidades futuras de crecimiento y compromiso.

The importance of public libraries in health literacy: A case study for diabetic patients (La importancia de las bibliotecas para la alfabetización en ciencias de la salud: un estudio de caso para pacientes diabéticos)

Hamed Pirialam, Maryam Kazerani, Maryam Shekofteh, Zahra Razzaghi

IFLA Journal, 45-3, 216-223

Resumen:

Antecedentes de la investigación: Las bibliotecas públicas pueden desempeñar un papel importante en la mejora de la alfabetización en ciencias de la salud de sus usuarios ofreciendo servicios especiales. La alfabetización en ciencias de la salud es la capacidad de los individuos para acceder a información, y comprenderla y aplicarla para mantener y mejorar su salud. Las personas con una alfabetización inadecuada en ciencias de la salud muestran menos conductas preventivas. La diabetes es una de las enfermedades más comunes de los países en vías de desarrollo. El hecho de tener la información necesaria y adecuada puede tener un efecto notable en el abordaje correcto de la enfermedad y de las actividades de cuidado personal. Educar a los pacientes diabéticos a través de las bibliotecas públicas puede mejorar la difusión de información en materia de salud.

Objetivo: El objetivo de esta investigación es evaluar el efecto de la educación sobre el nivel de alfabetización en ciencias de la salud entre los pacientes diabéticos que visitan la Andisheh Cultural Library y evaluar la relación existente entre el nivel de alfabetización en ciencias de la salud, la edad y el sexo de los pacientes.

Métodos: Esta investigación es un estudio cuasi-experimental con una prueba antes y otra después de la intervención. La población del estudio constaba de 48 pacientes diabéticos que acudían a la biblioteca pública. La herramienta de investigación es un cuestionario de alfabetización en ciencias de la salud administrado en Irán. Este cuestionario consta de 33 preguntas que se engloban en 5 categorías: 1- Accesibilidad (6 preguntas) 2- Lectura (4 preguntas) 3- Comprensión (7 preguntas) 4- Evaluación (4 preguntas) y 5- Toma de decisiones (12 preguntas). Se proporcionó intervención educativa para los sujetos directa e indirectamente. Para analizar los datos se utilizó el software SPSS21.

Resultados: Los resultados revelaron que:

- El 14,5% de las muestras tenía el máximo acceso a la información requerida en términos de accesibilidad.
- En términos de competencia de lectura, el 20% de las muestras tenía la máxima habilidad necesaria para leer los recursos de información.
- En términos de comprensión de la información, el 27% de las muestras tenía una competencia de comprensión máxima de la información que necesitaba.
- En términos de evaluación, el 13,5% de las muestras tenía una competencia de evaluación correcta de la información que necesitaba.
- En términos de toma de decisiones, el 24,5% de las personas tomó decisiones cruciales sobre sus demandas de información.

La alfabetización media en ciencias de la salud de los pacientes diabéticos antes y después de la educación marcó una diferencia significativa. Además, no se observó ninguna relación significativa entre el nivel de alfabetización en ciencias de la salud y la edad de los pacientes diabéticos que acudían a la Andisheh Cultural Library antes y después de la educación ($r < 0,05$). El nivel de alfabetización en ciencias de la salud de los pacientes diabéticos aumentó antes y después de la educación, tanto en hombres como en mujeres.

Conclusión: Puesto que una de las tareas de las bibliotecas públicas es educar a los ciudadanos, el uso de capacidades educativas en las bibliotecas públicas en el sector de la salud puede mejorar la salud de la comunidad.

Health information services: Engaging women in cervical cancer screening awareness in Nigeria (Servicios de información sanitaria: concienciación de las mujeres sobre el cribado del cáncer de cuello uterino en Nigeria).

Ngozi P. Osuchukwu, Ngozi B. Ukachi

IFLA Journal, 45-3, 224-232

Resumen:

Cada dos minutos muere una mujer de cáncer de cuello uterino en el mundo. En Nigeria es la segunda causa de muerte por cáncer que se puede evitar con acceso a información sanitaria. En este estudio se analizó el nivel de concienciación de las mujeres sobre el cáncer de cuello uterino, el estado de cribado, las fuentes, la disposición y los factores que las disuaden de someterse a cribado. Los datos se recogieron

y analizaron utilizando «investigación con técnicas mixtas»: un cuestionario, una entrevista, observaciones y debate. El cribado se realizó mediante una inspección visual con ácido acético (VIA). En el estudio participaron dos bibliotecarios, dos médicos, un farmacéutico y un científico de laboratorio. 90 mujeres se sometieron a cribado en contextos inusuales: una biblioteca electrónica y una catedral. Se descubrió que el 90% de las mujeres nunca se había sometido antes a un cribado. Por tanto, si no se sensibiliza a las mujeres sobre el cáncer de cuello de útero, estas nunca se realizarán la prueba y se registrarán más muertes. El artículo concluye con recomendaciones y una llamada a la acción para todos, especialmente para los bibliotecarios.

Advancing scholarly publishing through open access biomedical repositories: a knowledge management perspective (Avances en la publicación científica por medio de repositorios biomédicos de acceso abierto: una perspectiva de gestión del conocimiento)

Lisa M Kruesi, Kerry J Tanner, Frada V Burstein

IFLA Journal, 45-3, 233-245

Resumen:

La publicación científica ha sufrido grandes cambios durante los últimos cincuenta años. Los mandatos de los patrocinadores y las obligaciones de notificación organizativas han señalado el comienzo de la creación de repositorios de acceso abierto, como repositorios institucionales y temáticos. Esta investigación se basa en US PubMed Central (PMC) y Europe PMC, también conocidos como PMC International, como modelo a seguir para inspirar el concepto y la oportunidad para un repositorio biomédico de acceso abierto en Australasia. PMC International es líder en citas y producción investigadora, que se vinculan con datos de investigación encontrables, accesibles, interoperables y reutilizables. Como los repositorios cumplen ya casi dos décadas de desarrollo, este artículo informa sobre el potencial de un repositorio biomédico de acceso abierto en Australasia y explora las oportunidades para futuros repositorios de este tipo.

The Role of the University Library in Creating Inclusive Healthcare Hackathons: A Case Study with Design Thinking Processes (El papel de la biblioteca universitaria en la creación de hackatones sanitarios inclusivos: un estudio de caso con procesos de pensamiento del diseño)

Bethany McGowan

IFLA Journal, 45-3, 246-253

Resumen:

Los bibliotecarios pueden utilizar prácticas de pensamiento del diseño para desarrollar materiales educativos en el desarrollo de productos y servicios nuevos, y en la creación de prototipos de soluciones novedosas para los problemas. En este artículo se analiza el papel del pensamiento del diseño en la enseñanza y el aprendizaje a través

del uso del Blended Librarians Adapted Addie Model (BLAAM), y se ilustrará el modo en que se pueden usar enfoques de aprendizaje bien diseñados para crear entornos de aprendizaje inclusivos. Se presentará un estudio de caso que muestra la forma en que un bibliotecario especializado en ciencias de la salud utilizó un proceso de pensamiento del diseño para crear un servicio de alfabetización en ciencias de la salud que promueve la participación en hackatones sanitarios.

