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Consumer & Patient Health Information

Message from the Chair

Erica Lake, MLS, Chair, CAPHIS 2018-2019 Associate Director, Hope Fox Eccles Health Library Associate Librarian, Spencer S. Eccles Health Sciences Library University of Utah



Greetings, CAPHIS members!

I'm looking forward to seeing many of you in two months at MLA '19 Chicago. We'll have some important agenda items to discuss at our business meeting, including the transition to MLA's new caucus structure.

Earlier this month, the co-chairs of the Communities Transition Team asked all Section and SIG leaders to complete a survey about domain hubs. We were ask to identify which hub/s we aligned with, and indicate a point person for each hub startup vision workgroups. I sent a couple of emails to the CAPHIS listserv asking for volunteers – and I didn't get any. But don't worry, it's not too late to participate!

Here's a bit of information on how the survey was completed.

- CAPHIS members were interested in five of the seven domain hubs:
 - Information Services
 - Information Management
 - Education
 - Clinical Support
 - Global Health & Health Equity

Since we had no volunteers to serve as CAPHIS point persons for the hub startup workgroups, I had to "volunteer" some of you – my apologies! I was just going to put my name down as the point person for all of the hubs for now, but I couldn't do that - the survey required a separate person for each hub. (Continued)

(Message from the Chair Continued)

- Instead, I volunteered several CAPHIS leaders for these roles. Leaders, if you are unable to attend the upcoming virtual meetings for your assigned hub, let the group know and we'll find a new volunteer. Virtual meetings for each hub startup workgroup are scheduled for March, April, and June, with a face-to-face meeting planned for MLA in Chicago. You'll find the charge of the workgroups and their rosters on the <u>Communities Transition Team website</u>.
 - Information Services Erica
 - Information Management Mina
 - Education Robin
 - Clinical Support Maggie
 - Global Health & Health Equity Karin

That's it for now. Safe travels, and I'll see you soon!

Erica

Inia Lale

Announcements

Consumer Health librarian of the Year!

Congratulations to Judy Carol Stribling, AHIP, Samuel J. Wood Library and C.V. Starr Biomedical Information Center, Weill Cornell Medical College, New York, NY, who has received the 2019 Consumer Health Librarian of the Year Award from MLA! Well-deserved!!

Member Publications, Presentations, and Conferences of Interest Attended

Presentation

Elisabeth Marrapodi, Library Director at Trinitas Regional Medical Center, Elizabeth, New Jersey conducted a virtual field trip to the Health Hacienda in Second Life at Whole Brain Health on March 1, 2019 for NonProfit Commons, whose mission is to connect communities for social good through education, networking, and collaboration.

The Health Hacienda is part consumer health outreach project based in the virtual reality platform of Second Life. This project began in 2010 with a Small Projects grant from NNLM/MAR and IRB approval. The outreach includes interactive quizzes to help improve health literacy about various health topics, such as heart attack, stroke, medical terminology, pre-diabetes and Alzheimer's, which are all offered in English and Spanish. A textbook chapter and a 2017 article in the Journal of Consumer Health on the Internet have been published about this outreach project.

The health quizzes are also available in web-based format on the library and institutional websites: <u>https://www.trinitasrmc.org/</u>.

Attended a meeting

Adela V. Justice, Senior Librarian, Patient Education - The Learning Center, MD Anderson Cancer Center attended The Library Assessment Conference in Houston Texas December 4–7, 2018.

(Continued)

This was my first time attending the <u>Library Assessment Conference</u>, which is a biennial conference on all things library assessment related.

<u>Day 1</u>: I attended a workshop entitled "Library Spaces: Approaches to Needs Assessment and Post-Occupancy Assessment." This is a timely topic for me, as two of our libraries will be undergoing renovation and relocation. My takeaways include:

- it's important to study non-library users as well as users
- you're not renovating for now, you're renovating for the future
- don't neglect doing a post-occupancy assessment, or did the renovation meet your goals after all?

<u>Day 2</u>: The first plenary speaker was product and service designer Paul-Jervis Heath, and his talk "<u>Unlocking the Power of Design in the Library</u>." He gave a great presentation on the power of design, and how we can use that power in our libraries. He advised us to get to know everything about our users and warned that it takes lots of thoughtful time for the design process.

The rest of the day was spent attending sessions with titles such as "MEASUREMENT AND MEASURES INDICATORS" and "SPACE I." I learned how some libraries conduct assessments on things such as the usage of their physical spaces, including their methods, metrics, and findings.

<u>Day 3</u>: The opening plenary talk was on leadership and assessment in advancing diversity. Three panelists led the discussion and gave us time to discuss our personal experiences with the others sitting at our tables. Takeaways include:

- the data default to measure diversity is to measure people's race, gender, etc. but these things are evolving so do our metrics really reflect these new realities?
- redesigning library spaces is needed for inviting in more diverse populations and being more inclusive
- this quote: "If there is nothing in this library that doesn't offend you, let us know"

Sessions later on in the day that I attended were "DIVERSITY, EQUITY AND INCLUSION" and "SPACE II." In the Diversity session I saw presentations on topics such as power structures and tension, social justice metrics for libraries, assessing the library experiences of underrepresented populations, and assessing/communicating libraries' social value.

<u>Day 4</u>: I ended the conference by attending the workshops "Assessing Librarian Skills for the Future: a Toolkit for Success" and "Loud Librarians! Communicating the Impact of Your Library."

There were also two great poster sessions from which we could learn from other libraries' assessment projects. This conference is good for anyone interested in library assessment, from novice to expert level and will be on my radar from here on out.

New Editor in Chief: JOURNAL OF CONSUMER HEALTH ON THE INTERNET

As you may know, I was appointed Editor-in-Chief of the *Journal of Consumer Health on the Internet* in July 2018. In case you aren't familiar with the journal or haven't looked at it lately, please go to the journal website:

https://www.tandfonline.com/action/journalInformation?journalCode=wchi20

DID YOU KNOW that a number of CAPHIS members are involved in the journal? as Column Editors and Editorial Board Members.

Current Column Editors:

- Kelsey Leonard Grabeel (Patient Education)
- Priscilla Stephenson (WebHealth Topics)

And Mary Katherine Haver (*Book Reviews*) and Kay Hogan Smith (*Consumer Health Resources*) just recently stepped down from their posts after years of service.

Current Editorial Board Members:

- Jackie Davis
- Martha F. Earl
- Sandy Oelschlegel

PLEASE CONSIDER WRITING FOR THE JOURNAL! CAPHIS members are an especially accomplished and dedicated group! Your fellow CAPHIS members would love to hear about

- Any research studies you've worked on
- Any outreach initiatives
- Items for one of the six columns (Health Sitings; Health Literacy; Patient Education; Consumer Health Resources; WebHealth Topics; Book Reviews)

THE JOURNAL OF CONSUMER HEALTH ON THE INTERNET should be a very natural fit to SHOWCASE CAPHIS members work and contributions!!!

Part of the purpose of CAPHIS is to network. Since we're all spread far and wide across the country (and probably beyond!), the Consumer Connections newsletter is our way of networking and sharing between annual conferences. Please send anything, which may be of interest to the members of CAPHIS, to the Consumer Connections editor. See issue deadlines listed at the end of the newsletter.

Original Articles

Here is another article on a poster presentation from the Public Librarians Symposium at MLA '18.

Developing a New Partnership to Support Cancer Patients and Families

Christian I.J. Minter, Community Engagement and Health Literacy Librarian, McGoogan Library of Medicine, Omaha, NE

At MLA'18, I presented a poster titled, "A Pilot Partnership to Provide Health Information to Cancer Patients and Families." My coauthors were Roxanne Cox, Mary Winter, Benjamin Simon, and Rebecca Jackson.

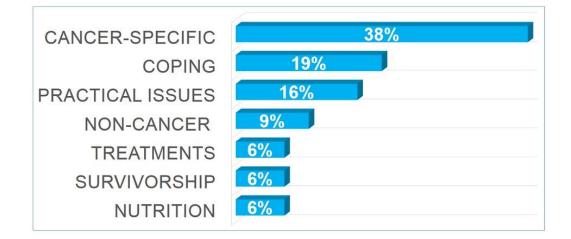
The University of Nebraska Medical Center opened the Fred and Pamela Buffett Cancer Center in June 2017. The Cancer Center provides a Resource and Wellness Center to meet the non-clinical needs of patients and families. Services include health information, wigs, massage therapy, and leisure activities.



McGoogan Library of Medicine was invited to participate in planning meetings for the resource center, and this led to the launch of a pilot partnership. The goals of the pilot were to provide cancer patients and their families with easy access to quality health information, assess their health information needs, and explore the demand for library services in the resource center.

The pilot took place June 2017 through March 2018. During this time, library staff were available 18 hours a week at the Resource and Wellness Center to answer consumer health questions. The Community Engagement & Health Literacy Librarian assisted the resource center staff in selecting a small print collection of books and pamphlets on cancer-related topics. Statistics were collected on the number and type of health information questions received, and feedback on library services were gathered in meetings with clinical staff, health system administrators, and the Oncology Patient and Family Advisory Council.

Over the course of the pilot, the library received thirty-two requests for consumer health information. The most common questions were related to a specific type of cancer, resources for coping with cancer diagnosis or treatment, and practical issues such as financial assistance or community resources. Most questions came from caregivers and were asked in-person.



Following the pilot, the library decided to continue the partnership. Library staff are available at the Resource and Wellness Center for 15 hours each week. Promotion of the resource center and awareness of the library's presence in this space continues to be a challenge. The meetings with various stakeholder groups have provided some insight into the health system's organizational structure and ideas to increase engagement with patients and families. New postcards and bookmarks have been created to promote the consumer health information services, and outreach continues to connect with staff and volunteers who can help refer patients and families to the library.

To view our MLA poster, visit: https://digitalcommons.unmc.edu/mcgoogan_pres/6/

Book Reviews

Lesko, Anita. The Complete Guide to Autism & Healthcare: Advice for Medical Professionals and People on the Spectrum. Arlington, TX: Future Horizons, c2017.

ISBN: 978-1-9417-6544-9.

The strength of this book is found in the subtitle. It truly is a work that strives to provide healthcare professionals with insight on how to best accommodate the needs of people of the spectrum while at the same providing people on the spectrum and their parents with tips on how best to approach healthcare visits.

While it might seem a stretch to tackle both groups, it actually isn't for Lesko, as she herself falls into both categories. As a nurse anesthetist who was diagnosed with autism as an adult, she deftly weaves her healthcare knowledge with her experience as someone on the spectrum. The content addresses such topics as how to deal with meltdowns during a visit, how an office can make adjustments to their environment to ease sensory overload, and how important visual tools and advanced preparation is to a successful visit. Lesko also provides tips for emergency rooms visits and how to prepare for operations, including for anesthesia. It is quite clear when Lesko is providing advice to fellow medical professionals versus when she is providing advice to consumers. Both groups are encouraged to work together, particularly emphasizing how important it is to not to just get a parent or caregiver involved, but to really listen to their input.

Publication Information

Statement

Consumer Connections (ISSN 15357821) is the newsletter of the Consumer & Patient Health Information Section of the Medical Library Association. It is published on the CAPHIS web page of the MLA website quarterly.

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Editor

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Please contact the editor for information on submitting items for publication. The layout of the book clearly emphasis the practical approach. It does not overwhelm, as the text is accompanied by lists and forms that can be easily followed by anyone who would like to implement the strategies discussed. Lesko includes her personal experiences to bring her recommendations and strategies to life. A case study is also included to further illustrate how the strategies can be applied.

Amazon link: <u>https://www.amazon.com/Complete-Guide-Autism-Healthcare-Professionals/dp/1941765440</u>

Reviewed by Elizabeth Irish, MLS, AHIP, Assistant Professor, Schaffer Library of Health Sciences, Albany Medical College, Albany, NY

Call for Submissions

Do you have an interesting consumer health initiative or project taking place at your Library? Have you been spearheading innovative work with consumer health librarianship and want to let the world know? We want to hear from you! Consider submitting a brief article (200-400 words) to Consumer Connections!

Consumer Connections Newsletter considers for review books of interest to librarians, patients, caregivers, and the general public. This column will concentrate on reviews of recently published books about consumer healthcare information available in print and/or electronic formats. General interest titles related to healthcare and medicine may also be considered. It is the purpose of each review to provide a detailed description and critical evaluation of the work. Recommendations for purchase are also included. Book reviews should be 200-400 words. Reviews reflect the opinions of the reviewer, not of the *Consumer Connections Newsletter* Editors.

Persons interested in becoming a book reviewer or suggesting titles for review in the *Consumer Connections Newsletter* should contact the Book Review Editor: Claire Joseph <u>Claire.Joseph@snch.org</u>.

Deadlines for all submissions are March 1, June 1, September 1, and December 1 for publication on the 15th of those months.