Chat transcript

Annalise Sansouci: Opening on Monday

Lisa Scheib: We never close at seattle cancer care alliance

Lori Santoro: Still trying to sort that out

Rania Abdulla: Moffitt never closed, but most worked from home (4k) rest are essential at hospital. Research on campus stopped and rolling out virtual. Outreach events on hold(e.g. no healthfairs) and some virtual like webinars

Janet Papadakos: I have a question for all: have you put any practices in place to limit handling of consumer health information (e.g. pamphlets)?

Lisa Scheib: yes - patients are not allowed to handle our material. I let patients browse and then I give them the materials.

Kathy Jinkins: At MD Anderson, clinical areas have stripped pamphlets in all areas. Trying to figure out how to do that in The Learning Center and still serve patients. The Learning Center remains closed.

Lisa Scheib: we also removed a lot of our pamphlets and put signage up to ask a staff member for resources.

Pat Stahl: we will be working closely with infection control to establish guidelines.

Anne Bidelman: At Moffitt, we've removed all pamphlets from clinics and are patient libraries/resource centers are still closed.

Donna Branson: Welcome to everyone on the call. If you are interested in learning more about CPEN and joining here's a link to find more information.https://www.cancerpatienteducation.org/

Annalise Sansouci: Is anyone on here part of a resource center that was partnered with ACS?

Maritza Nassif: Dana-Farber resource center is having remote zoom workshops (spirituality, caregivers, finances, insomnia etc). Our One-to-One program peer support is still operating remotely.

Ruth Barker: Our physical library has been taken over by emergency operations. Our volunteers had been the folks who staffed our patient resource centre. As they are not allowed in the hospital we no longer have anyone to serve the patients/families and so it is closed. We have started online chemo classes.

tedi brash: Any thoughts on the privacy / health equity aspects of using Zoom or other virtual platforms. Do you have guidelines for educators to ensure this as well as health literacy best practices?

Kathy Jinkins: What platform is everyone using for their online services? How are you providing privacy?

Rania Abdulla: Zoom
Susan Chandler: Zoom

Rania Abdulla: you can set zoom room more private. for example for focus groups patients get a link and an ID. that way other patients cant see names or phone numbers

Lori Santoro: Microsoft Teams

Anne Bidelman: zoom with ID and password'

Ruth Barker: Zoom Health (secure) for support groups.

Susan Chandler: We're struggling with those who don't have internet or hardware resources.

Ruth Barker: Majority of virtual visits by phone currently

Carol Nottingham: about 50% want phone and 50% go virtual via phone when I set up pharmacy contacts

Pat Stahl: I think we are still struggling with what kinds of workshops people need or want the most. We are re-evaluating what kinds of workshops we offer. Maybe a survey or some focus groups? I think the world has changed and people's priorities have shifted..

Susan Chandler: Good suggestion from Pat Stahl

Annalise Sansouci: We have a wig program and are still trying to figure that out

Jennifer Edwards: This looks like it would have been great but I haven't had sound since the beginning so I'm checking out. Maybe provide this program later by recording.

Linda Bily: we are doing wig fittings virtually with TLC catalog

Linda Bily: We ship directly to patient home

Susan Chandler: Our Wig Center is open one day a week by appointment only. Must call; provided staff with cell phone so she can return calls from her home. We are a university base cancer center associated with the Commonwealth of Virginia so we are closed until June 10

Lisa Scheib: we are doing them virtually at seattle cancer care alliance. they send us pictures of what they want and i choose 2-3 wigs, take pics and send them the pictures to choose from.

Janet Papadakos: We have most of our classes online (as well as in-person) but since COVID, cancelled all in-person and quickly got the in-person ones up that weren’t online yet. Our usage statistics are very high â€“ looks like many patients and family are accessing the classes. More than in-person. https://pmcancerclasses.ca/

Linda Bily: I have grant funding for our wigs

Susan Chandler: We use grant funds to provide wigs for our patients; those outside our health system are referred by ACS and we provide wigs for them as well.

Lisa Scheib: we use donated funds

Lisa Scheib: most of our wigs are new

Carol Nottingham: what is the process being used for wig cleaning, is it in house cleaning?

Carol Nottingham: thanks
Janet Papadakos: I am curious about lending policies during COVID.

Maritza Nassif: Dana-Farber, All of our hat donations, book donations etc are on hold. This is on a list of questions we have for infection control, we are going to need to look at policies moving forward.

Ruth Barker: We stopped distributing wigs about two years ago for infection control purposes.

Kathy Jinkins: At MD Anderson, our book lending has been on hold and we extended the due date out several months. We are following best practices for quarantining returned items from the Medical Library Association.

Susan Chandler: We only provide new wigs; infection control standards prohibit re-use. Knitted caps have been accepted before COVID-19 but are no longer accepting donations and not sure if or when we'll resume.

Janet Papadakos: Thank you Kathy Jinkins

Susan Chandler: We provided space initially for screening but have the space back, however we are closed indefinitely.

Lisa Scheib: we are looking into an eLibrary

Janet Papadakos: Can Kathy J tell us about guidance from MLA?

Carol Nottingham: has anyone had experiences with sending web links to materials verses handing them out in person since COVID?

Lisa Scheib: we have been quarantining books that patients are returning

Kathy Jinkins: The MLA website has the quarantine recommendations on their website

Kathy Jinkins: Books returned should be wiped down with disinfectant wipes and quarantined for 14 days

Lisa Scheib: that is what we do at SCCA

Julie Bulger: We are also self-service Resource Center without a door. I have been physically working there as much as possible and allow limited numbers in and also manage what literature I give to people. Wiping down constantly. Itâ€™s been appreciated to have a human presence, especially for our new patients. Absorbing a lot of emotion from both patients and staff.

Kathy Jinkins: mlanet.org is the website

Lisa Scheib: we have a form patients can fill out about the information they need, and then a health educator gathers the info and either emails them or mails them the resources.

Anne Bidelman: Our patient and family advisors are in the clinics to provide that human connection.

Janet Papadakos: Here is a lib guide to some good cancer & COVID consumer health site: https://guides.hsict.library.utoronto.ca/c.php?g=696870&p=5115391. Courtesy of Michelle Snow and Rouhi Fazelzad, Princess Margaret Cancer Centre
Pat Stahl: I think it's important to think about ways to recreate the social aspects of all that goes on in the resource centers. So in that regard, the one to one connection is even more important.

Martha Hickey: Lisa, that's a great idea. Would you be able to share that list with the group?

Lisa Scheib: We have a form patients can fill out about the information they need, and then a health educator gathers the info and either emails them or mails them the resources.

Jila Tanha: At MD Anderson, our Learning Center’s Recommended Resources Online guides, guides to information on cancers and health-related topics, are available online: http://mdandersontlc.libguides.com/home

Kimberley Aslett: The Australian Library Association has a checklist for reopening libraries

Annalise Sansouci: This was great! Thank you! I'm so glad I found this group!

Susan Chandler: This has been most helpful! Would you considering repeating in a few weeks as we all gain experience with re-opening??

Martha Hickey: This meeting was so helpful! Would you all agree? Would we be able to have another meeting like this?

Ruth Barker: Thank you for the session and information. Stay well everyone.


Lisa Scheib: thank you!!

Rania Abdulla: thank you

Carmen Alcalde: Thank you so much.

Jennifer Garcia: Thank you! This was very informative

Julie Bulger: Thank you - very helpful!

Nina Galpern: thank you. would love to hear more.

Jeff Yancey: Thanks everyone!

Annalise Sansouci: Yes please!

Jila Tanha: Great discussion! Thank you.

Donna Branson: Thanks, great discussion!

Lori Santoro: Thank you!!

Carol Nottingham: thanks for the thoughtful conversation

Wendy Hanson: Thank you, this was very informative.

Janet Papadakos: Thank you

Lisa Horton: Great conversation! Thank you

Ben Umakanthan: thank you everyone

Daniella Lock: Thank you. Great discussion!