Consumer Engagement in a Virtual World

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Objectives

Learning Objectives-
After this session attendees will be able to:
1) Identify 3 ways to connect and outreach to underserved populations virtually, using technology.
2) Describe how to utilize video platforms (such as Facebook LIVE) to increase consumer engagement.
3) Identify 2 examples of ways to engage consumers in-person in creative ways.
What does Genetics Mean?
Genetics

https://www.ashg.org/education/everyone_1.shtml
The Burden of Genetic Disease on Inpatient Care in a Children’s Hospital


An underlying disorder with a significant genetic component was found in 71% of admitted children.

The vast majority (96%) of underlying chronic disorders in children in this study were either clearly genetic or had a genetic susceptibility.

Total charges for 1996 were >$62 million, of which $50 million (81%) was accounted for by disorders with a genetic determinant.
What are the Regional Genetics Networks?
What are the Regional Genetics Networks?

- Who knows what the RGN’s are?
- In 2017, the Maternal and Child Health Bureau of the Health Resources and Services Administration (MCHB/HRSA), Genetic Services Branch (GSB)
- Awarded grants to establish the seven Regional Genetics Networks (RGNs)
- 3 year cycle ends in May 2020
- On-going efforts to improve the health of medically underserved by promoting the translation of genetic medicine into public health and health care services.
- Who has worked with your local RGN?
7 Regional Genetics Networks
The National Genetics Education and Family Support Center is a three-year initiative (June 2017- May 2020) led by: Genetic Alliance in partnership with the Regional Genetics Networks, Family Voices, and Parent to Parent USA.

The focus of Family Center is to build a network of partners and develop accessible tools to improve access to and the quality of genetic services.
MSRG N- Mountain States Regional Genetics Networks

- 8 State Region

MSRG N’s mission is to ensure that individuals with genetic disorders and their families have access to quality care and appropriate genetic expertise and information through facilitating a professional network of:

- genetics clinics,
- key primary care practices,
- consumer advocates,
- and state health department resources.
MSRGN’s Infrastructure: UPP, State Teams & Genetic Ambassadors

- **State Teams**: 5-10 individuals - consumers, genetics professionals, primary care professionals, and public health staff with 2 co-leads.
- **Underserved Populations Project**: 3 Pilot sites in year #1 of grant with 3 underserved populations (more about this in 2 slides!)
- **Genetic Ambassadors**: Families, Consumers, and Individuals impacted by and living with genetic conditions

### MSRGN’s “Customers” or Members

- Genetic Professionals (Geneticist and GC)
- Consumers
- Families
- Patients
- Individuals with a Genetic Condition
- Family Leaders
- Primary Care Physicians
- Public Health Professionals
Who is Underserved?

- Medically Underserved Areas/Populations are areas or populations designated by HRSA as having:
  - too few primary care providers,
  - high infant mortality,
  - high poverty or
  - a high elderly population.

- Search your state: Google: MUA FIND
- [https://data.hrsa.gov/tools/shortage-area/mua-find](https://data.hrsa.gov/tools/shortage-area/mua-find)
Medically Underserved in MSRGN

- UPP project
- 3 Pilot sites: 3 Underserved Populations:
  - San Antonio Texas: Hispanic
  - Grand Junction/Durango Colorado: Rural
  - Tuba City Arizona: Native American

- Other Underserved Populations in our region:
  - The Undiagnosed
  - The Developmentally Delayed
  - Geographically isolated - frontier counties
  - Culturally isolated
Engagement

Live? In Person? Virtual? Remote? which is better?
A total of 291 individuals participated and were predominantly female (69.0%). Majority reported incomes less than $30,000 (72.9%) and identified as African American/Black/Caribbean (49.3%) or Mexican/Mexican American (34.3%). Most participants regularly used smartphones (63.2%) and the Internet (75.9%). Respondents frequently used Facebook (84.8%), and less commonly used Instagram (43.6%), and Twitter (20.0%).

Physical Activity in an Underserved Population: Identifying Technology Preferences

US Adults who use at least 1 social media site

% of U.S. adults who use at least one social media site

PEW RESEARCH CENTER

https://www.pewinternet.org/fact-sheet/social-media/
By Race

% of U.S. adults who use at least one social media site, by race

Source: Surveys conducted 2005–2018. Data for Hispanics includes only surveys that included Spanish-language interviews.

PEW RESEARCH CENTER

https://www.pewinternet.org/fact-sheet/social-media/
By Income

% of U.S. adults who use at least one social media site, by income

PEW RESEARCH CENTER

https://www.pewinternet.org/fact-sheet/social-media/
% of U.S. adults who use at least one social media site, by education level

PEW RESEARCH CENTER

https://www.pewinternet.org/fact-sheet/social-media/
% of U.S. adults who use at least one social media site, by community type

Source: Surveys conducted 2005-2016.
PEW RESEARCH CENTER

https://www.pewinternet.org/fact-sheet/social-media/
By Social Media Platform

Majority of Americans now use Facebook, YouTube

% of U.S. adults who say they use the following social media sites online or on their cellphone

<table>
<thead>
<tr>
<th>Platform</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facebook</td>
<td>73%</td>
</tr>
<tr>
<td>Instagram</td>
<td>35%</td>
</tr>
<tr>
<td>Pinterest</td>
<td>29%</td>
</tr>
<tr>
<td>Snapchat</td>
<td>27%</td>
</tr>
<tr>
<td>LinkedIn</td>
<td>25%</td>
</tr>
<tr>
<td>Twitter</td>
<td>24%</td>
</tr>
<tr>
<td>WhatsApp</td>
<td>22%</td>
</tr>
</tbody>
</table>

Note: Pre-2018 telephone poll data is not available for YouTube, Snapchat, or WhatsApp. Source: Survey conducted Jan. 3-10, 2018. Trend data from previous Pew Research Center surveys.

“Social Media Use in 2018”

PEW RESEARCH CENTER

https://www.pewinternet.org/fact-sheet/social-media/
UPP project revealed certain underserved populations that have access to social media through smartphones.

Statistics show 62% of smartphone owners have used their phone to get info about a health condition.

Question for MSRGN, can we contribute to being a SOURCE of that information for genetics in order to engage

https://www.pewinternet.org/2015/04/01/us-smartphone-use-in-2015/
Engagement - Virtual or In-person?

- New Website Development
- Consumer Scholarship for Summit
- Genetic Ambassador Program Begins +SOG training +FB Group
- Facebook Advertising Texas Team
- Genetic Summit 2019
- 2017 Family Voices Leadership Conference SOG Training
- Genetic Summit 2018
- Serving on Groups Consumer Training
- Facebook Live - Your Genetic Questions Answered
- Genetic Pop-Ups
Consumer Scholarships @ Genetics Summit

Giving new members an opportunity to engage with MSRGN at our 2018 Genetics Summit.
Genetic Ambassadors + Facebook Group

A place for our families and consumers to connect, network, get involved, learn and grow in MSRGN

- Launched in November 2018
- A place for Genetic Ambassadors to connect
- A place to share MSRGN news, scholarships, updates, between calls
- Quick Response: Tagging members
- A subset of active families
Genetic Ambassadors
Facebook Group
Engagement - Virtual or In-person?

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- Genetic Summit 2019

2017 Family Voices Leadership Conference SOG Training

Genetic Summit 2018

Facebook Live- Your Genetic Questions Answered

Genetic Pop-Ups
Facebook Live: Your Genetic Questions Answered

A way to increase consumer engagement through genetics education to families and answer some of their top questions

- Launched in January 2019
- Once a month on the Mountain States Regional Genetics Network Facebook Page
- Based on a consumer FB survey done in the fall of 2018
- Answers recorded using zoom with subject matter experts and then played through FB live.
- Think about what education you can deliver through FB LIVE
Facebook LIVE

Example:
Autism & Genetics

Join Us... April 24th
Autism Awareness Month
April 24th: 3 Questions and 5 Facebook Lives:
7/8/9pm ET, 6/7/8pm CT, 5/6/7pm MT, 4/5/6pm PT
on the Mountain States Genetics Facebook Page

Dr. Scott Answers
3 Common Questions about
#Genetics and #Autism
on Facebook Live

Your Questions Answered about...
GENETICS AND AUTISM

Dr. Daryl Scott
Associate Professor
Molecular and Human Genetics
Baylor College of Medicine

https://www.youtube.com/watch?v=sgFNCGFts-o
Facebook LIVE - A QI Project

Act

Plan

Study

Do
Facebook LIVE - DATA

Fourth Week of January 2018, Week Comparison
(Daily Page Engaged Users)
Facebook LIVE- DATA

Daily/Weekly/28Day REACH

- **Daily Total Reach Daily**: The number of people who saw any content from your Page or about your Page and are on Facebook. This includes posts, check-ins, ads, and social information from people who interact with your Page and more. (Unique Users)
- **Weekly Total Reach Weekly**: The number of people who saw any content from your Page or about your Page and are on Facebook. This includes posts, check-ins, ads, and social information from people who interact with your Page and more. (Unique Users)
- **28 Days Total Reach 28 Days**: The number of people who saw any content from your Page or about your Page and are on Facebook. This includes posts, check-ins, ads, and social information from people who interact with your Page and more. (Unique Users)
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2017 Family Voices Leadership Conference SOG Training

2018 Genetic Summit 2018 Serving on Groups Consumer Training

2019 Facebook Live- Your Genetic Questions Answered

2020 Genetic Pop-Ups
Facebook Advertising in order to reach a specific audience

An Example from our Texas Team, who wanted to reach parents in Texas with Genetic resources

- Led by our Texas team to outreach to parents in their state with resources
  - $5/day
  - $200 budget
  - 3 ads
  - Reach= 18,000
  - Impressions= almost 40,000
  - Link Clicks= approx. 200
  - $1/link click
Mountain States Regional Genetics Network

Raising a child with a genetic condition can be an amazing yet, sometimes challenging experience. To find genetic resources in #Texas to help make your journey a bit easier, click below!

www.mountainstatesgen... Genetics Resources in Texas
LEARN MORE

Mountain States Regional Genetics Network
Sponsored •

MountainsatesGenetics....
Genetic Resources in Texas
Resources for Families in Texas
LEARN MORE
Facebook Advertising

Custom Audiences
In-Person Engagement: Genetics Pop-Up

The “old fashion” way or the wave of the future?
Engagement- Virtual or In-person?

2017
- New Website Development
- 2017 Family Voices Leadership Conference
- SOG Training

2018
- Consumer Scholarship for Summit
- Genetic Summit 2018
- Serving on Groups Consumer Training

2019
- Genetic Ambassador Program Begins
  + SOG training
  + FB Group
- Facebook Advertising Texas Team
- Facebook Live- Your Genetic Questions Answered

2020
- Genetic Pop-Ups
- Genetic Summit 2019
Genetics Pop-Ups

A way to engage families at a community level
What is a Genetic Pop-Up?

- A Genetics Pop-up is a small (5-8 person) gathering, held in the local community, spearheaded by a genetic ambassador, to share genetic resources with families and those who work with families impacted by genetics.

- MSRGN sends a Gene-in-a-Box resource kit

- MSRGN provides a $300 budget to cover a $20 stipend/gift card per attendee, and the remainder of the budget may be used for food/drink (no alcohol!) at the pop-up!
Gene-in-a-Box
Our First Genetics Pop-Up: Texas Sickle Cell
Do you want to get involved: Genetics POP-UP?

- Houston, TX (date of popup 4/27/19)
- Edgewater, CO (date of popup: 5/4/19)
- Littleton, CO (date of popup 5/5/19)
- Yuma, AZ (date of popup: week of May 13)
- Dallas Area, TX (week of 5/20)
- Reno, NV (date of popup: 5/23/19)
- Austin, TX (date not set yet)
- Sheridan, WY (date not set yet)
Wrapping Up

- Consumer engagement cannot be ONE SIZE FITS ALL... a HYBRID approach has worked for our organization.
- Virtual and In-person engagement COMPLEMENT one another and can be used to ENHANCE one another.
- Using different modes of engagement- videos, pop-ups, scholarships, Facebook lives, online groups, and even advertising can help you reach your audience.
Questions and a Challenges

- Questions?
- Challenge: Connect with your Regional Genetics Network
- Challenge: Try a Facebook Live for your organization
- Challenge: Are you near a genetic pop-up site?
Questions?

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