Thank you to our sponsors!
Day 2: Thursday, October 19, 2023

12:00-12:10 pm ET
Welcome & Welcome Back

12:10-1:30 pm ET
Translating data into stories: How to make research understandable for nonscientific (lay) audiences
Facilitator: Kathleen Gallagher, MPH, VP of Health Services, Data Management, Patient Advocate Foundation

1:30-1:45 pm ET
Patient Insight Congress 2024 Preview

1:45-2:00 pm ET
Closing Remarks
As a result of today’s session we hope you will...

- Understand the purpose of data storytelling
- Identify ways to translate scientific concepts into consumable information
- Learn how to design research posters for non-scientific audiences
PATIENT INSIGHT Congress

October 19, 2023

Translating Data into Research Stories
COMMUNITY AGREEMENT

1. Keep it confidential
2. Be present as fully as possible
3. Balance between listening and talking
4. Respect differences, be open to new concepts and ideas
5. Take a break if you need one
6. **For this session you may want a pen and paper**
Data storytelling couples data visualization with compelling narratives that help audiences better comprehend and take action based on data analysis. While effective data visualization helps people grasp and remember key takeaways, data storytelling is essential for helping them understand why those takeaways matter.

Lydia Hooper, Data Visualization Expert and Information Design Writer
Key Elements

NARRATIVE

VISUALS

CHANGE

DATA

EXPLAIN

ENLIGHTEN

ENGAGE
Audience & Intent

- Scientific research community
- Individuals with differing levels of research exposure
- Nonscientific or lay community

- Publications/journal articles
- Oral presentations
- Poster presentations
Audience & Intent

- Scientific research community
- Individuals with differing levels of research exposure
- Nonscientific or lay community
- Publications/journal articles
- Oral presentations
- Poster presentations
FUN EXERCISE: Recipe Challenge

I love a good recipe exchange.

My best friend shared the following simple baking recipe with me to kick off the fall baking season...
- 430 grams Triticum aestivum
- 6 grams Saccharomyces cerevisiae
- 6 grams sodium chloride
- 360ml dihydrogen monoxide (21°C)
- 3 and ¼ cups bread flour
- 2 teaspoons instant yeast
- 2 teaspoons salt
- 1 and ½ cups water at room temperature
Narrative/Language

- Introduction/Background
- Objective
- Methods
- Results (Data)
- Discussion/Conclusion
- Why is this problem important to them/their community
- What is the problem my research is trying to solve
- How did I collect the information to answer my research question
- What did the information I collected tell me about this problem
- Why is this information important to the population I am trying to reach
Data

- Narrative
- Visuals
- Change
- Explain
- Enlighten
- Engage

PATIENT INSIGHT Congress

patientinsightinstitute.org  patientadvocate.org
FUN EXERCISE: Bad vs. Good Data

Every day we consume information (data) with our eyes — signs, billboards, magazines or brochures.

When data is communicated in a clear way visually, we can adsorb and understand the message being shared.
Imagine you are a driver along a road on a Tuesday morning at 9 a.m.
Imagine you are a driver along a road on a Tuesday morning at 9 a.m.

Can you park in this spot?
Can you park in this spot?

Imagine you are a driver along a road on a Tuesday morning at 9 a.m.
Information overload vs.
## Data

<table>
<thead>
<tr>
<th>Purebred?</th>
<th>Spay/Neutered?</th>
<th>Beta Estimate</th>
<th>Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
<td>1.2488</td>
<td>3.486</td>
</tr>
<tr>
<td>Yes</td>
<td>Yes</td>
<td>-2.6044</td>
<td>0.258</td>
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</tr>
<tr>
<td>Yes</td>
<td>Yes</td>
<td>-2.6044</td>
<td>0.258</td>
</tr>
</tbody>
</table>
Data

Purebred/Not spayed or neutered

VS.

Not purebred/Not spayed or neutered
Visuals/Design
What makes a good research poster?
**Background**

- Gastric and gastroesophageal junction (GEJ) cancer patients and their caregivers can be at high risk for financial hardship.
- We conducted a pilot randomized study testing a 3-month proactive financial navigation program vs usual care among gastric and GEJ patients and their informal caregivers (Fig 1).
- Proactive navigation was provided by two partnering organizations, Consumer Education and Training Services (CENTS) and Patient Advocate Foundation (PAF).

**Methods**

- Eligibility criteria is outlined in Table 1.
- Caregiver participation was optional for this study.
- Proactive financial navigation included:
  - Financial and legal planning from CENTS counselors.
  - Access to financial resources from PAF case managers.
- All participants were asked to complete surveys at baseline, 3-months, and 6-months.
- Baseline and 3-month survey data and CENTS/PAF documentation were analyzed for this abstract.
- Financial hardship is defined as one of the following: accrual of debt, taking out loans, or decline in household income by ≥ 20%.

**Results**

- 19 patients (10 intervention, 9 usual care) and 13 caregivers (8 intervention, 4 usual care) were enrolled in the study.
- Patient and caregiver characteristics and intervention services provided are detailed in Table 2 and figure 2, respectively.
- Engagement with CENTS and PAF was more likely to happen if a caregiver was present, with 65% of interactions including a caregiver.
- 3-month follow up data shows that patients and caregivers in the usual care arm had slightly more instances of financial hardship (N=4, 44%) than patients and caregivers in the intervention arm (N=2, 20%).
- There were no significant differences in financial well-being or quality of life between arms.

**Conclusions**

- Early data from our study suggests benefits from delivery of a proactive financial navigation intervention.
- Patients were more likely to engage with CENTS and PAF if a caregiver was involved, showing the importance of having caregiver involvement for cancer patients through diagnosis and treatment to help mitigate financial hardship.

**Acknowledgments:**

Funding for this work is provided by the NCI/NEI Lilly and Company Quality of Care in Gastric Cancer.
What makes a poster consumable?

- Color is Key
- White Space is Important
- Infographics vs. Data Charts
- Consider an Impact Statement
- Include a Recommendation Section
- Design is Significant
- Make Data Impactful
- Incorporate Clear and Concise Text
FUN EXERCISE: I spy

Now that we have shared what is helpful to nonscientific audiences when viewing a research data story can you tell me what about the following poster examples reflect these design enhancements?

Remember we are looking for things that make the data story accessible to nonscientific audiences.
Background

- Financial toxicity (FT) is the cumulative financial burden due to medical care
- PT is well-established in breast and gynecologic malignancies
- BRCA mutation carriers have significant risk factors for PT:
  - Increased cancer risk
  - Frequent screening
  - Need for prophylactic surgery

Objectives

1. Describe and quantify rates of financial toxicity among BRCA1/2 carriers
2. Identify factors associated with financial toxicity

Methods

- 265 Unaffected BRCA+ Female Patients Eligible and Contacted
- 119 patients with email addresses available
- 146 patients with phone numbers only
- 76 patients consented to, and completed, the survey (28.7%)

- Comprehensive Score for financial Toxicity (COST) tool to assess FT
- Demographics, Health Related Quality of Life, and Medical Information collected via RedCap and EMR

Results

<table>
<thead>
<tr>
<th>Table 1: Demographics</th>
<th>All Respondents (n = 76)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital Status</td>
<td></td>
</tr>
<tr>
<td>Married/Partnered</td>
<td>64.5%</td>
</tr>
<tr>
<td>Single</td>
<td>22.4%</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>10.5%</td>
</tr>
<tr>
<td>Widowed</td>
<td>2.5%</td>
</tr>
<tr>
<td>Insurance</td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>82.3%</td>
</tr>
<tr>
<td>Medicare w/supplement</td>
<td>9.2%</td>
</tr>
<tr>
<td>Medicare, no supplement</td>
<td>2.5%</td>
</tr>
<tr>
<td>Medicaid</td>
<td>2.6%</td>
</tr>
<tr>
<td>Other</td>
<td>2.6%</td>
</tr>
<tr>
<td>Annual Income</td>
<td></td>
</tr>
<tr>
<td>&lt;$50,000</td>
<td>18.7%</td>
</tr>
<tr>
<td>$50,000-$99,999</td>
<td>40.8%</td>
</tr>
<tr>
<td>&gt;$100,000</td>
<td>28.9%</td>
</tr>
<tr>
<td>Prefer Not to Answer</td>
<td>10.5%</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
</tr>
<tr>
<td>White, Non-Hispanic</td>
<td>98.5%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 2: Prophylactic Surgery</th>
<th>n = 76</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any Prophylactic Surgery</td>
<td>Mastectomy</td>
</tr>
<tr>
<td></td>
<td>Bilateral Salpingo- Oophorectomy</td>
</tr>
<tr>
<td></td>
<td>77.6%</td>
</tr>
<tr>
<td></td>
<td>34.2%</td>
</tr>
<tr>
<td></td>
<td>57.9%</td>
</tr>
</tbody>
</table>

Conclusions

1. Financial toxicity is an existing problem in BRCA carriers.
2. There are no obvious predictors of high FT in BRCA carriers
3. Patients with high FT have increased cost-avoidant behaviors, which can lead to compromised or disrupted healthcare

Mean COST Score 27, Range 3-44
Patients were divided into tertiles with COST score < 24 representing high FT
No significant associations between the high FT and low/medium FT groups re: income, insurance type, marital status, or race

Strengths

- Novel study
- Focused on patient quality-of-life
- Widespread implications for BRCA+ patients

Limitations

- Single-center study with limited sample size, racial homogeneity
- Patient-reported outcome
- Lacks a contemporary control
**Background**
- Under-resourced patients with cancer often face financial burdens.
- Financial burden may be related to:
  - Cancer treatments
  - Inability to work due to treatment side effects
  - Employment loss may affect insurance coverage
  - Safety net programs provide material support and financial counseling for patients facing financial burdens during cancer treatment

**Objectives**
- Understand impact of cancer on employment and insurance in patients seeking safety net services

**Methods**
- Study Design: Cross-sectional, 35-question survey focusing on job loss, insurance coverage, and safety net services
- Participants: Patients with cancer who received services from Patient Advocate Foundation from July 2016 to June 2017
- Outcomes: Patient-reported financial needs, utilization of safety net services and programs in prior year
- Statistical analysis: means and standard deviations or frequencies and percentages

**Table 2. Participant characteristics (N=121)**

<table>
<thead>
<tr>
<th>Age (means, SD)</th>
<th>Gender</th>
<th>Race</th>
<th>Common types of cancer</th>
<th>Cancer types</th>
</tr>
</thead>
<tbody>
<tr>
<td>60 (18)</td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td>Female: 294 (56.7)</td>
<td>Male: 128 (24.4)</td>
<td>Other/missing: 74 (43.7)</td>
<td>Breast: 293 (6.4)</td>
<td>Kidney: 61 (13.6)</td>
</tr>
<tr>
<td>Black or African American: 42 (21.8)</td>
<td>White or Caucasian: 314 (8.6)</td>
<td>Other: 155 (7.5)</td>
<td>Prostate: 42 (6.4)</td>
<td>Small-intestinal: 458 (8.5)</td>
</tr>
</tbody>
</table>

**Cancer negatively impacts employment and insurance status. Many patients utilize safety net services, yet some patients still need assistance covering out-of-pocket costs.**

**Results**
- **60% of patients reported their employment was affected by their cancer**
- **65% of patients sought assistance from safety net, social support, or copayments programs**
- **30% of patients reported the insurance coverage was also affected**

**Figure 3. Employment impact due to the effects of cancer proposals (N=121)**

**Figure 4. Safety net programs utilized (n=121)**

**Figure 5. Medical program**

**Figure 6. Financial support or charity programs utilized (n=121)**

**Figure 7. Copayment assistance programs utilized (n=121)**

**Figure 8. Out-of-pocket costs covered by charitable copayment assistance (n=189)**

**Out-of-pocket costs remained after charitable copayment assistance**
- **Employment status is affected for more than half of patients with cancer**
- **Third of patients whose employment is affected also have breaks or losses in insurance coverage**
- **Financial burden comes in patients with cancer due to losses in employment and insurance, resulting in need for safety net programs**
- **Safety net programs are commonly utilized, but do not cover all needs of patients with cancer**

**Conclusions**

**Future Directions**
- Further research is needed to identify approaches to reducing the adverse financial impact of cancer care.
Scaling up vaccination is central to public health strategies to manage the COVID-19 pandemic. Despite vaccine approval, public concerns over safety/efficacy and general distrust have heightened vaccine hesitancy. This is concerning among people with HIV who are vulnerable to more severe COVID-19 disease.

**PROJECT DESIGN**

We conducted a cross-sectional online survey of 271 HIV/AIDS patients in July 2021 to explore vaccine acceptance, barriers, trust and vaccine information sources in patients served by Patient Advocate Foundation.

**DEMOGRAPHICS (N = 271)**

- 90% Male
- 81% Caucasian
- 83% Aged 56 years or older
- 86% Household income <$48,000
- 96% Household size 1 or 2
- 44% Urban residence

**KEY FINDINGS**

**Vaccine Acceptance**

History of Flu Vaccination 93%

Vaccine acceptance was measured by history of prior influenza vaccination and COVID vaccine status. Overall, 96% (n = 259) of HIV patients indicated that they intended to vaccinate for COVID-19.

Receipt of COVID-19 Vaccine 93%

**Vaccine Hesitancy**

4%

Only a small number of respondents (n = 12; 4%) indicated that they had concerns about vaccination against COVID-19. Main reasons for not vaccinating (multi-select):

67% Unable or unwilling to vaccinate

75% Safety of the vaccine

**Vaccine Information & Trust**

- Patients report receiving or seeking COVID-19 vaccine information from multiple sources
- 64% Doctor most trusted source (17%)
- 41% Television
- 41% Online

**Vaccine Barriers**

Regardless of vaccination status, barriers to vaccination included the following concerns:

- 66% No available appointments
- 13% Fear
- 12% Knowing someone who had an adverse reaction

**RECOMMENDATIONS**

Messaging about COVID-19 vaccination must come from sources trusted by patients.

Providers are best positioned to mitigate the effect of the fear of adverse events and safety concerns about vaccine hesitancy.

HIV-specific COVID-19 vaccination communication strategies need to be developed that stress the importance of accurate, easily accessible and understandable information, as well as balance risk and benefit information, positively framing adverse side effects, and dismantling related misinformation.

**REFERENCES**


Thinking about today’s conversation regarding data story telling are there any questions you want to ask or are their elements of a good nonscientific research poster design that we missed?

Patients/advocates/caregivers – are their questions you would like to ask the researchers attending today?

Researchers – do you have questions you want to ask the patients/advocates/caregivers attending today?
What’s Next?

• We will send all participants links to slide decks and meeting recordings
• Please complete evaluation (link in chat)
• Registration will open for our in-person Patient Insight Congress next week. Scholarship applications will open January 2024.