
Social Media in Hematology/Oncology

Udhayvir Singh Grewal, MD

*Fellow, Division of Hematology, Oncology, Blood and Marrow
Transplantation*

University of Iowa Hospitals and Clinics, Iowa City, IA

IOWA

Division of Hematology,
Oncology, Blood and Marrow
Transplantation

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None**

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Why should we care about social media?

The evolving role of social media in cancer care

- Social media platforms have emerged as tools for patients to access general health-related information and stay up-to-date with the latest therapeutic advancements.
- SM allows sharing information on cancer screening, prevention, treatment, and survivorship.
- Apart from patients with cancer and their caregivers, cancer centers and patient advocacy groups also use social media to disseminate content for patient education and fundraising activities.
- There is a growing interest in the pattern and nature of the consumption of information by the general public through these platforms.

Commonly Used Social Media Platforms

- Microblogging websites: Twitter
- Multimedia/picture-based: Facebook, Instagram
- Search engines: Google
- Purely video-based: YouTube
- Chat/message-based: WhatsApp

Twitter

- Twitter is a micro-blogging website that can be used for sharing content with users around the world in real time.
- Tweets (short messages that are limited to a maximum of 280 characters) serve as a **quick** and **efficient** source of information that can then be liked, shared (retweeted) or commented on by other users to amplify and to maximize outreach on a common platform.

Pancreatic Cancer Conversations on Twitter

- Pancreatic cancer is an intractable malignancy that is associated with a heavy burden of symptoms and poor overall survival.
- Patients, caregivers, care teams, and researchers use Twitter as a platform to connect and share information related to pancreatic cancer treatments.
- It has also been used as a platform for advocating for needs and concerns that are unique to patients with pancreatic cancer.

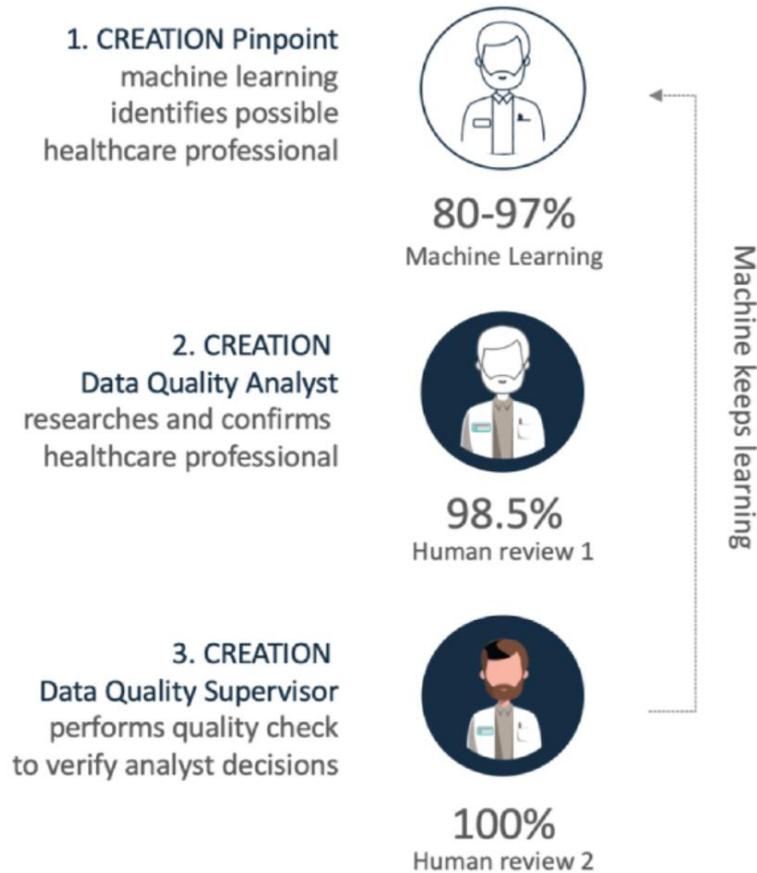
Grewal US, Gupta A, Doggett J, et al. Twitter Conversations About Pancreatic Cancer by Health Care Providers and the General Public: Thematic Analysis. JMIR Cancer. 2022;8(1):e31388.

Pancreatic Cancer Conversations on Twitter

- We used an online analytical tool (Creation Pinpoint) to quantify Twitter mentions (tweets and retweets) related to pancreatic cancer made between January 2018 and December 2019.
- Keywords, hashtags, word combinations, and phrases were used to search for Twitter mentions related to pancreatic cancer.
- Perspectives from Twitter users were then distilled based on their online behaviors.

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Creation PinPoint



The analytical tool used in this study, Creation Pinpoint, uses machine learning algorithms to identify possible health care provider profiles on Twitter that are later confirmed and verified by data analysts.

Healthcare Providers vs General Public

- Out of 1,258,028 mentions, we identified a total of 313,668 unique mentions (27,031 by health care providers and 307,449 by the general public) that were classified into the 5 domains of prevention, treatment, research, survivorship, and policy.
- Health care providers most often discussed pancreatic cancer research (10,640/27,031 mentions, 39.4%) while the general public most often discussed treatment (154,484/307,449 mentions, 50.2%).
- Health care providers focused the least on policy (28/27,031 mentions, 0.1%); the general public also focused the least on policy (93/27,031 mentions, 3.3%).

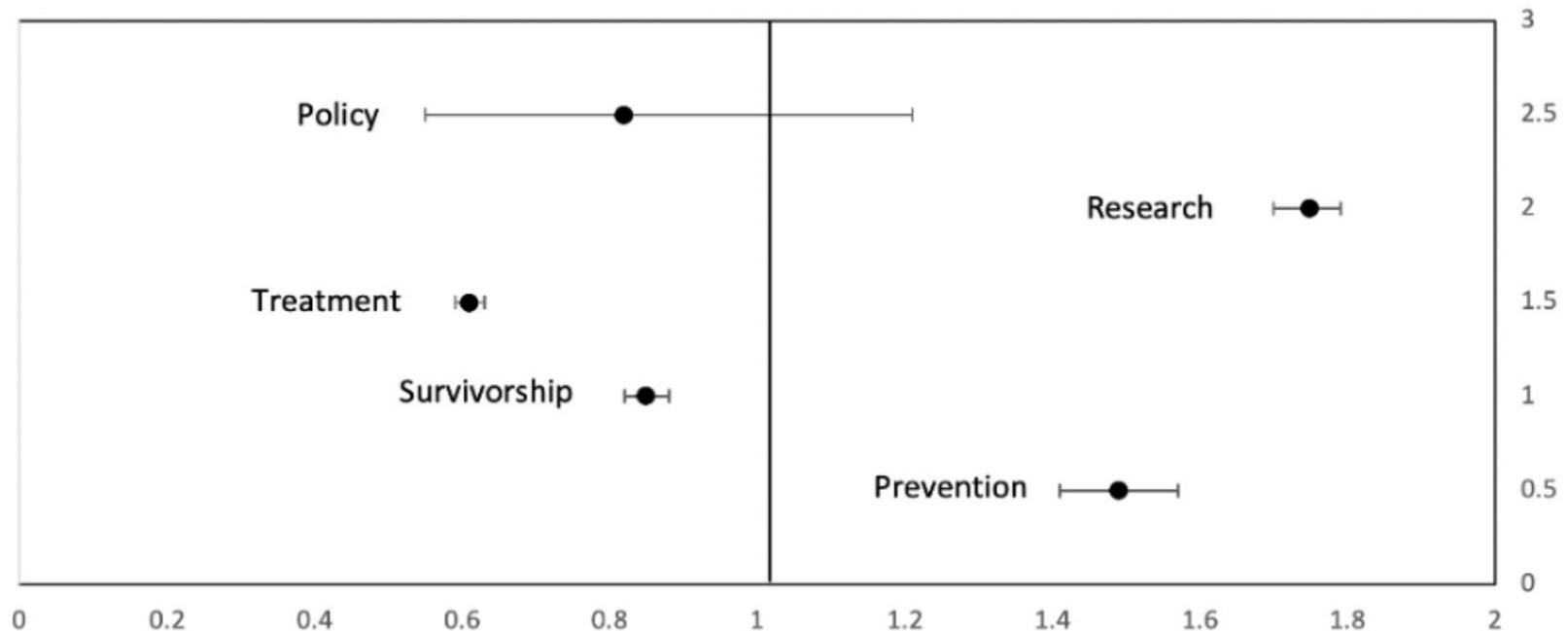
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Healthcare Providers vs General Public

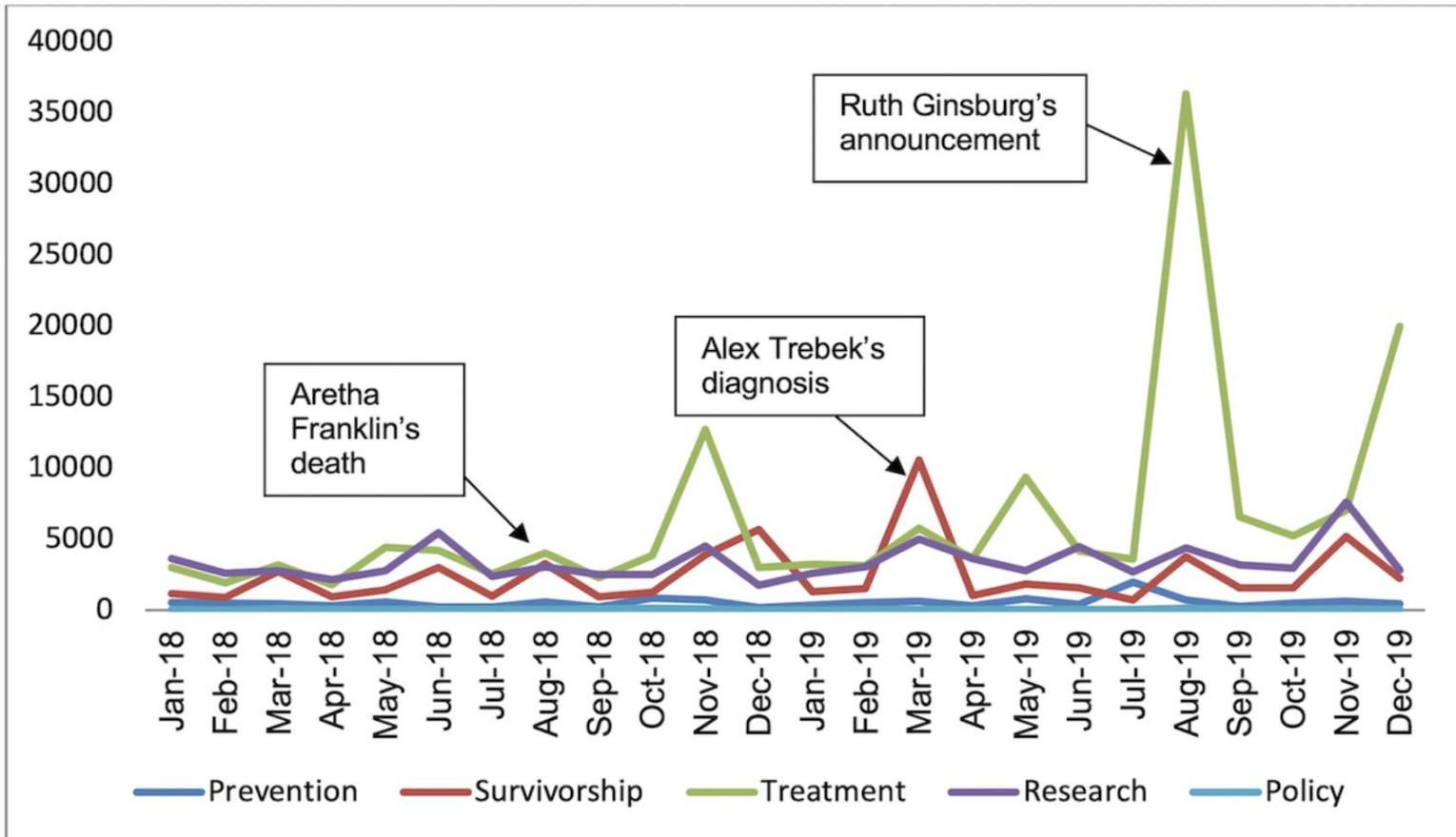
- A comparative analysis showed that health care providers were more likely to initiate conversations related to research (odds ratio [OR] 1.75, 95% CI 1.70-1.79, $P < .001$) and prevention (OR 1.49, 95% CI 1.41-1.57, $P < .001$) whereas the general public took the lead in the domains of treatment (OR 1.63, 95% CI 1.58-1.69, $P < .001$) and survivorship (OR 1.17, 95% CI 1.13-1.21, $P < .001$).

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Healthcare Providers vs General Public



Impact of celebrity diagnoses



Pancreatic Cancer Awareness Month

- Pancreatic Cancer Awareness Month did not increase pancreatic cancer mentions by health care providers in any of the 5 domains. However, over the study period of 2 years, mentions by the general public increased for treatment, survivorship, and research. Mentions of the topics of **prevention** and **policy** did not increase during Pancreatic Cancer Awareness Month.

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Google Trends

- Google Trends (GT) uses algorithms to normalize data for the overall searches for a given search term on a scale of 0 to 100, which is known as the search volume index (SVI).
- Although GT cannot supplement, infodemiological data generated using the platform can complement traditional data collection and analysis related to public awareness regarding cancer and cancer screening.

Google Trends- Colorectal cancer

- We analyzed GT SVI for ‘colon cancer” from January, 2004 to December, 2018. Temporal trends were analyzed using Mann Kendall Test and average SVI for colon cancer awareness month (March of every year) versus remaining months was also analyzed.
- State-level SVI for all 50 American states from 2012-2016 was compared with state-level incidence (IR) and mortality rates (MR) of pancreatic cancer obtained from the Center for Disease Control (CDC) cancer statistics data (2012-16).

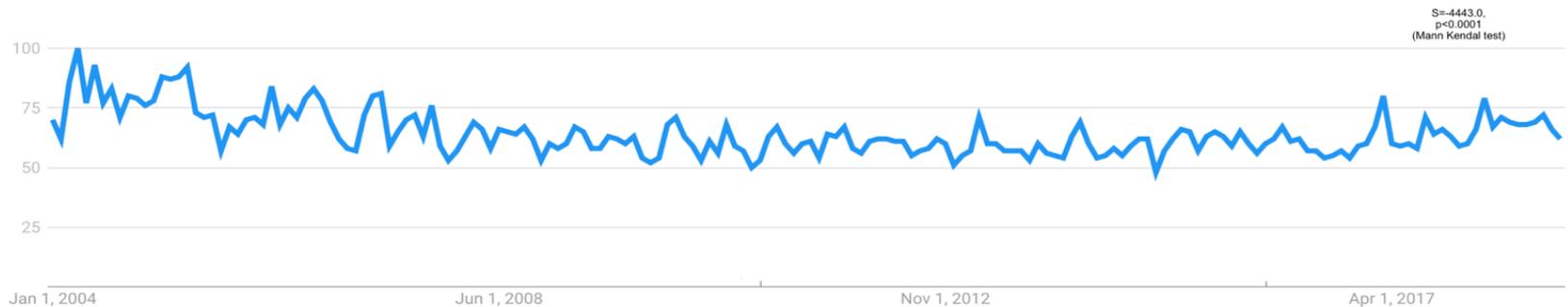
Grewal US, Searcy K, Mehta A. Can infodemiological data be used to assess public awareness and predict outcomes in colon cancer? Eur J Gastroenterol Hepatol. 2022 Sep 1;34(9):975.

Google Trends

- Average relative SVI throughout the study period (180 months) for CRC was found to be 64.33 ± 9.06 (Figure 1). Mann Kendall test indicated a temporal decrease in SVI for CRC from 2004 to 2018 ($S = -4443.0$, $p < 0.0001$). During colon cancer awareness months, a significant increase in median SVI for CRC was noted (78.1 vs 74.1, $p < 0.001$).
- From 2012-2016, state-level SVI was found to be significantly associated with state-level incidence ($R = 0.69$, $p < 0.001$) and mortality rates ($R = 0.61$, $p < 0.001$) of CRC.

Grewal US, Searcy K, Mehta A. Can infodemiological data be used to assess public awareness and predict outcomes in colon cancer? Eur J Gastroenterol Hepatol. 2022 Sep 1;34(9):975.

Google Trends: CRC



We noted a significant decline in the interest of the US population for CRC from 2004-2018.

However, a significant increase in public interest with colon cancer awareness months was noted.

States with higher SVI had higher incidence and mortality rates of CRC, indicating a positive correlation between public interest and overall outcomes.

Grewal US, Searcy K, Mehta A. Can infodemiological data be used to assess public awareness and predict outcomes in colon cancer? Eur J Gastroenterol Hepatol. 2022 Sep 1;34(9):975.

Assessing the Educational Value of Pancreatic Cancer Videos on YouTube®

- The top 100 most viewed videos on pancreatic cancer on YouTube® were assessed and data was collected on various variables such as views, likes, dislikes, comments, and more.
- Videos that were characterized into the patient education category, were further evaluated by a scoring rubric to evaluate their effectiveness at providing accurate and comprehensive information for patients.
- We created a rubric where videos would receive various points for including specific information in their videos such as definition, etiology, symptoms/signs, diagnostic methods, staging, complications, and treatments.

Garikipati S, Grewal US, Gaddam SJ, Sheth AR, Samant H. Assessing the Educational Value of Pancreatic Cancer Videos on YouTube. J Cancer Educ. 2022 (In Press)

Assessing the Educational Value of Pancreatic Cancer Videos on YouTube®

Patient Education Scoring Rubric

1. **Definition (Max 1 point):**
 - a. Describes pancreatic carcinoma as the malignant neoplasm of the pancreas.
2. **Etiology: (Max 2 points, 1 per category)**
 - a. Environmental: Smoking, alcohol, diet (high saturated fats, meat), obesity, and physical inactivity
 - b. Hereditary: Family history, genetic predisposition (cystic fibrosis), chronic pancreatitis
3. **Symptoms/signs: (Max 3 points, 1 for 1-3, 2 for 4-6, 3 for 7+)**
 - a. Weight loss
 - b. Fatigue
 - c. Anorexia
 - d. Jaundice
 - e. Abdominal pain
 - f. Dark urine
 - g. Nausea
 - h. Back pain
 - i. Vomiting
 - j. Diarrhea/Steatorrhea
 - k. Abdominal mass/distension
4. **Diagnosis: (Max 3 points, 1 for each category)**
 - a. Symptoms + Labs
 - b. Imaging: Ultrasound, CT, MRCP, ERCP
 - c. Biopsy: Percutaneous biopsy, EUS
5. **Staging/Prognosis (1 point)**
 - a. Mention staging and prognosis of pancreatic cancer
6. **Disease related Complications (Max 3 points, 1 for 1-3, 2 for 4-6, 3 for 7+)**
 - a. Pain
 - b. Jaundice
 - c. Gastric outlet obstruction
 - d. Depression/anxiety
 - e. Venous thromboembolism
 - f. Cachexia/Malnutrition
 - g. Ascites
 - h. Diabetes
 - i. Metastatic complications
7. **Treatment (Max 3 points, 1 for each)**
 - a. Chemotherapy
 - b. Radiation therapy
 - c. Surgery
8. **New treatments and alternative therapies (Max 2 points, 1 for 1-2, 2 for 3)**
 - a. EUS Fine needle injection/~~cytoreductive~~ ~~INF~~ ~~Erada~~
 - b. Monoclonal antibodies/immunotherapy (Keytruda)
 - c. New chemotherapeutic agents
9. **Surveillance after treatment (Max 2 points, 1 for each)**
 - a. Follow up visits with LFTs, RFT, CA 19-9
 - b. Follow up CT scans

Total: 20 points

The max score a video could achieve is 20 and the minimum score is 0 based on how comprehensive the videos were in terms of education.

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Assessing the Educational Value of Pancreatic Cancer Videos on YouTube®

- Videos uploaded by patients were the most discussed ($p = 0.014$) and liked ($p = 0.0028$) videos on YouTube®.
- The content of the videos (personal experience, advertisement, patient education, medical professional education, alternative treatments, and increased pancreatic cancer awareness) varied depending on the uploader (patients, healthcare providers, professional societies, media) of the videos ($p = 0.007$).
- Patient education videos were poor in being comprehensive on their education of pancreatic cancer based on our rubric (mean score of 7.67 ± 2.63 of 20 possible points).

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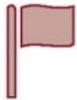
Social Media and HIPAA

- At the level of the individual's workplace, most universities, cancer centers, and large health systems often issue guidelines for employee social media use.
- These guidelines affirm that the same policies governing in-person interactions are applicable to social media, be it codes of conduct, copyright laws, HIPAA compliance, etc.
- However, existing data suggest that many health care professionals may have limited awareness of their institutional policies.

Social Media and HIPAA



Pearl 1: Deidentify health information.



Pearl 2: Recognize an error immediately.



Pearl 3: When in doubt, obtain patient consent.



Pearl 4: Engage your communications and legal offices.



Pearl 5: View regulations as protections, not barriers.



Pearl 6: Use restraint—EQ over IQ.

Subbiah IM, Grewal US. Development of a Regulatory Framework Governing Health Care Interactions on Social Media Platforms. JCO Oncol Pract. 2022 Aug;18(8):529-532.

Takeaway points...

- Social media allows oncology professionals to directly interact with patients and identify unmet needs/things that matter the most to patients.
- SM also provides a platform to disseminate latest developments in oncology practice and research.
- Infodemiological data from SM can be used to offer real-time insights into local cancer-related incidence and mortality data.
- Interventions from oncology professionals and healthcare systems are needed to enhance the educational value of content and information available on SM.
- Conscientious social media use to enhance clinical care calls for adherence with laws, regulations, and guidelines that govern its use in a professional setting.

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Thank you

→ udhayvir-grewal@uiowa.edu

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