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Use of Twitter to Promote Awareness of Familial Hypercholesterolemia

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Awareness of familial hypercholesterolemia (FH), a prevalent genetic disorder that greatly increases risk of early-onset myocardial infarction, is low¹. It is estimated that of the ~1.3 million people with FH in the US, <10% have been diagnosed¹. Twitter is being increasingly used in academic cardiovascular settings²; however, its potential for promoting awareness of cardiovascular genetic disorders such as FH is unknown. September is designated as the National Cholesterol Education Month (NCEM) to promote awareness of hypercholesterolemia as a risk factor, including through social media. Additionally, the International FH Awareness Day established by the FH Foundation as part of NCEM, includes a 'Tweet-a-thon'³. We investigated whether there was an increase in FH-related Twitter activity during NCEM in September 2018, using this as a surrogate for FH awareness.

This study was deemed exempt by the institutional review board as it did not involve human or animal subjects. Publicly available Twitter data were used to support the findings of this report and are available from the corresponding author upon request

We quantified FH-related Twitter activity from August-October 2018 using Sprinklr Listening Explorer software to extract tweets and engagement metrics, including reach (the potential audience size of tweets, measured by total follower counts of users who shared content). As a control, we examined the reach of colorectal cancer (CRC) related tweets during the same period.

FH-related tweets were classified as true positive or false positive based on a keyword list derived from manual review of tweets. This preprocessing step was performed by keyword

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matching using Python (script is publicly available and can be accessed at <https://github.com/bastia1989/FHtweet>). All true positive tweets were then categorized via name entity recognition of profile descriptions, to identify users as ‘organizations’ or ‘individuals’. Tweets were also classified based on their message format as updates (mentions + original tweets + retweets with comments), retweets (without comments) and replies.

A qualitative content analysis of a random sample of 600 tweets was performed and topic-keyword tables were created to define six thematic categories: awareness/prevention, diagnosis, treatment, lifestyle, knowledge dissemination, and conferences/fundraisers. Tweets were then binned into these categories based on presence of relevant keywords.

During NCEM in September, FH-related tweets increased by 152.9% compared to August and then declined by 58.8% in October. The topic reach for FH was 11.1 M in August and increased by 250.6% in September to 37.7 M. The reach declined by 71.9% in October to 10.6 M. In comparison, the reach for CRC declined from 453.1 M in August to 300.5 M in September and then increased by 120.9% to 677.0 M in October which happens to be Breast Cancer Awareness Month.

The highest number of FH-related tweets (n=2240) was on International FH Awareness Day (Figure A). The top discussion themes unique to September were FH Awareness Day and NCEM, while Genetic Testing and Race 4 FH were unique to August and The FH Foundation and FH Summit 18 were unique to October. In each month, organizations posted a higher proportion of updates, while individuals retweeted more. Across all three months, the vast majority of tweets by both organizations and individuals were categorized as awareness/prevention, followed by diagnosis (Figure B).

To the best of our knowledge this report is the first to examine the potential role of Twitter to promote awareness of FH. We demonstrated a >250% increase in FH-related topic reach on Twitter during NCEM, relative to the prior month. To confirm that this increased activity was not due to an increase in overall Twitter usage, the reach for CRC, a condition with a high lifetime risk, was examined and found to be lower in September than in August⁴. This finding was in contrast to the reach for FH in September and supported the conclusion that FH-related Twitter activity peaked due to NCEM.

FH-related tweet content analysis revealed that during the study period, majority of tweets posted by both organizations and individuals were in the awareness/prevention category. This finding was in contrast to a previous study that reported Twitter users were more likely to tweet on social aspects of awareness campaigns rather than health aspects⁵. The highest number of daily tweets recorded in each month were associated with singular events, similar to a prior report that found tweets related to cardiology increased in response to news and events². This study had several limitations: First, FH-related tweets were extracted on an earlier date compared to CRC-related tweets; second, additional work is needed to establish that increase in Twitter activity leads to increase in objective measures of awareness, quantified by surveys; lastly we did not examine the trend in FH-related Twitter activity over time.

The significant increase in FH-related Twitter metrics during NCEM suggests that Twitter has the potential to promote FH awareness. Our report motivates future research on the use of social media to improve FH detection and thereby reduce morbidity and mortality. Health systems, hospitals and providers should consider increasing their Twitter presence and engage in real-time discussions with the global community to promote disease awareness and disseminate knowledge.

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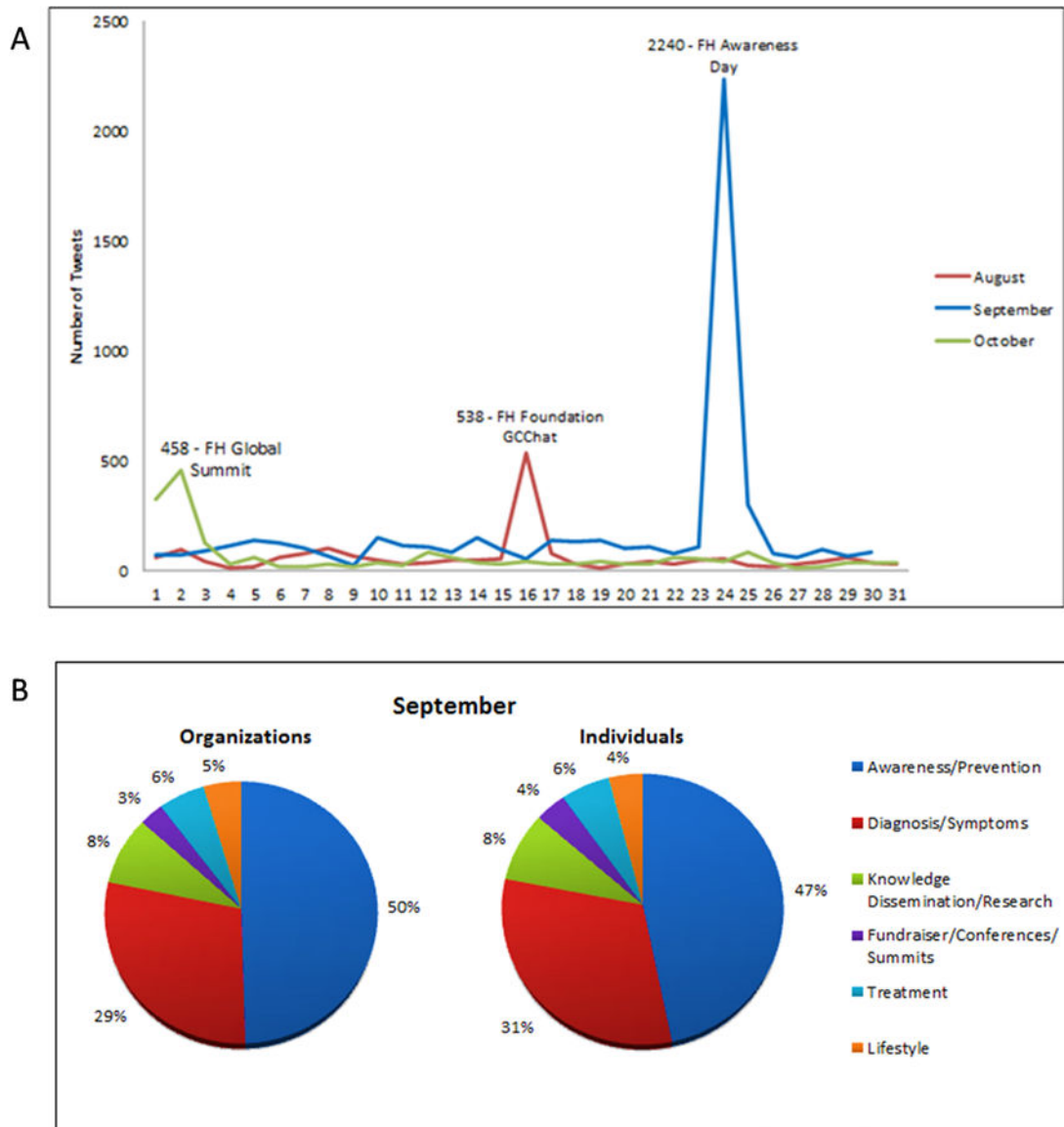


Figure. Twitter Data from August – October 2018. **(A)** FH-related Twitter activity across three months with peak tweet days in each month and associated events. **(B)** Categorization of tweets from organizations and individuals during NCEM in September 2018.