

Preferences and interests of diabetes social media users regarding a health-promotion intervention

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Background: Nowadays, rapid and accessible participatory research on diabetes can be carried out using social media platforms. The objective of this study was to identify preferences and interests of diabetic social media users regarding a health-promotion intervention targeting them.

Methods: Social media followers of the Norwegian Diabetes Association were invited to participate in the creation of a health-promotion intervention on diabetes by expressing their opinions through an online questionnaire posted on Facebook, Twitter, and Instagram. The questionnaire asked participants about their demographics and preferences regarding type of health content: format, frequency, and channels to deliver content. Questions regarding the perceived quality of diabetes-related information and satisfaction with content on social media were also included.

Results: The questionnaire was answered by 346 participants: 332 (96%) of those were reached via Facebook, 66.5% of respondents (n=230) identified themselves as women, 54% (n=187) as individuals diagnosed with type 1 diabetes, and 71% (n=235) were aged 30–64 years. The preferred type of content was “research and innovation on diabetes”, selected by 78.0% of the respondents. “Text format” was the choice for 93.4%, and 97.3% would prefer to find health-promotion content on Facebook. There was heterogeneity in the desired frequency of this content. In a scale ranging from 0 to 100, the perceived quality of diabetes-related information on social media was 62.0±1.2 and satisfaction with such content 61.9±1.3.

Conclusion: The approach used in this study was successful in reaching and involving participants quickly, and could also potentially increase diabetes patients’ engagement and satisfaction with health-promotion interventions, enhance their sense of community, and thus help people attain healthier lifestyles. It is a limitation that our sample might not have been fully representative, as the most interested social media users might have chosen to participate.

Keywords: community-based participatory research, diabetes, health promotion, health education, social media

Introduction

Evidence of the benefits of community-based participatory research in health care is growing.^{1–6} “Participatory” refers to the involvement of representatives of those who would be the primary beneficiaries of that research.^{7,8} This kind of research could also offer a series of additional advantages to participants in the public health sector compared to traditional top-down approaches. One of these advantages is the potential to increase the interest of participants (ie, people affected by a health condition) in a project in which they have participated. Participatory health research can enhance participants’ psychological sense of community^{9,10} and raise their awareness about their chronic condition, which may enable them to have greater autonomy and better health.^{7,11} In addition, participatory approaches could improve researchers’ and public

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health promoters' understanding of what people affected with chronic diseases consider important, and prompt them to tailor intervention programs according to the target audience's preferences and interests.^{7,8,11-14}

However, researchers using participatory approaches have repeatedly reported challenges in engaging representatives.¹⁵⁻¹⁸ Nowadays, the use of online social media could bring new possibilities to attract the attention of these populations and engage them in health-promotion interventions.¹⁹⁻²⁴ Meta-analyses and reviews have reported positive effects of social media use for promoting healthy lifestyles and improving self-management among people affected with chronic diseases.^{20,22,25-32} Social media allow researchers to reach target audiences rapidly. Using social media as platforms for community-based participatory research could also increase the interest and engagement of targeted audiences and thus be a valuable method for the design and delivery of health-promotion programs targeting people with chronic diseases.^{7,8,11,12}

Social media have been used in health-promotion planning and intervention design. Balatsoukas et al³³ conducted a narrative review of theoretical and empirical factors influencing the effectiveness of social network-enabled interventions. The authors included 42 studies, with 20 showing the use of a theory/model in the design of those interventions. Those 20 interventions were based on a mix of theories, including behavioral change theories, social networking theories, and others. Many of the atheoretical interventions were based on the expected emergent properties of social networks. As an example, AURORA³⁴ was focused on the expected positive effects on emotional health if positive experiences are shared. The objectives of the use of social networks in those health interventions were social support, sharing personal experiences and emotions, and education. Social network analysis was performed in several interventions to identify usage patterns that may be used to design future interventions. In other interventions, social networks had a motivational role, including peer pressure, peer-to-peer challenges, games, and competitions.

We are carrying out a community-based participatory research project involving researchers, health care professionals, staff from the Norwegian Diabetes Association, and social media users among members of the Norwegian Diabetes Association. Within this project, social media health-promotion content regarding diabetes is to be created according to the preferences of the social media users of the Diabetes Association. This is one of the first studies to combine a participatory approach and social media to

involve participants in the creation of a health-promotion intervention for diabetes that will be delivered through online channels. Gabarron et al³⁵ found that most posts published on open social media channels from a diabetes association concerned diabetes awareness, such as recipes, celebrations, or group gatherings. These represented 65% of the Facebook posts, 88% of the Instagram posts, and 48% of the Twitter posts.³⁵ Scientific content posts represented 17% of the messages published on Facebook, 38% on Twitter, and 8% on Instagram.³⁵

In this study, we are presenting the results to the questionnaires used to identify the interests and preferences of the diabetes association's social media users regarding a health promotion intervention.

Aims

The objective of this study was to identify preferences and interests of diabetes social media users regarding a health-promotion intervention targeting them.

Methods

Members of the Norwegian Diabetes Association³⁶ participated, together with researchers and health care professionals, in the design of a project aimed at creating a health-promotion intervention for diabetes, with the goal of promoting a healthy lifestyle using a participatory approach and social media. They actively participated in several stages of the project design, including creation of the questionnaire to collect information required to create content for the intervention. They also participated in distribution of the questionnaire through their social media channels, and are actively involved in the creation of the health-promotion intervention's content, as well as the analysis, interpretation, and dissemination of results of this project. Further details of this research project have been published elsewhere.³⁷

The opinion of diabetes social media users is relevant to identify how this health-promotion intervention should be designed, delivered, and maintained. Therefore, all social media followers of the Norwegian Diabetes Association were potentially invited to participate in the definition of content by expressing their opinions through an ad hoc, voluntary, and anonymous online questionnaire. The responses to that questionnaire will be used to design a health-promotion intervention for diabetes to be delivered through social media.

The questionnaire was provided via LimeSurvey,³⁸ and hyperlinks to it were posted on the three social media channels of the Diabetes Association (Facebook, Twitter, and Instagram) in November 2017, potentially reaching

35,000 followers.³⁶ We expected to get the questionnaire answered by about 350 social media users (ie, approximately 1% of the social media users on the Norwegian Diabetes Association's channels). The questionnaire asked participants to identify themselves by sex, type of respondent (diagnosed with type 1 or type 2 diabetes, family member of a diabetes patient, health care professional, or other), and age group (<18, 18–29, 30–44, 45–64, and ≥65 years). The questionnaire asked them to indicate their preferences regarding a health-promotion intervention on diabetes (respondents were able to choose more than one of the four options, and also to express any preferences that were not specifically mentioned) as per the following categories.

- Preferred type of content: personal aspects of self-management (eg, how to be motivated to follow-up with diabetes), technical aspects of self-management (eg, how to use blood-glucose sensors), research and innovation on diabetes, health care services, and/or interviews or personal stories from other people with diabetes. These types of content categories were chosen following a previous study.³⁵
- Content format: text, images, and/or video.
- Content frequency: several times per day, daily, every second or third day, weekly, or more seldom.
- Preferred platform to find this content: Facebook, Twitter, Instagram, and/or others.

Additionally, they were asked to rate on a scale of 0–100 (where 0 meant “very unsatisfied” and 100 “totally satisfied”) the quality of diabetes-related information on social media and their satisfaction with the diabetes-related information they found on social media. Descriptive statistics were used to summarize questionnaire answers, and χ^2 tests were performed to examine relationships among categorical variables. Data were analyzed using SPSS version 25 for Mac.

This study was assessed by the Norwegian Regional Ethics Committee (REK Sør-Øst) and declared exempt, falling outside the Norwegian Health Research Act³⁹ (2017/764C). As the questionnaire was classified as non-medical, voluntary, and anonymous, obtaining further consent was not deemed necessary. The treatment of personal information was approved by a data-protection officer (personvernombudet) at the University Hospital of North Norway (0720).

Results

In only 1 week, we received 346 responses from social media users: 332 of these questionnaires were from Facebook (96%), 14 from Instagram (4%), and 0 from Twitter. A total of 230 identified themselves as women (66.5%) and 101 (29.2%) as men. Fifteen respondents (4.3%) did not specify their sex. Table 1 summarizes the reported demographics of the respondents.

A summary of the social media users' preferences for a health-promotion intervention on diabetes (type, format, frequency, and platform) according to type of respondent and by age group can be found in Tables 2 and 3, respectively.

Regarding the preferred type of content, no significant differences were found between sexes. “Research and innovation” was the most commonly cited by all participants, specifically selected by 100% of those under the age of 18 years ($n=7$, $\chi^2_{4,304}=12.882$; $P=0.12$). Content on “technical aspects of self-management” was more frequently chosen by those aged 18–29 ($n=28$, 59.6%), 30–44 ($n=62$, 68.9%), and 45–64 ($n=83$, 63.8%) years ($\chi^2_{4,304}=9.856$, $P=0.043$). “Interviews or personal stories” were more frequently preferred by women ($n=93$, 43.9%) vs men ($n=24$, 26.4%; $P=0.004$).

Text format was preferred by almost all adults, and 57.1% of those aged 18 years and under ($\chi^2_{4,304}=15.382$, $P=0.004$). Image format was mostly preferred by social media users

Table 1 Demographics of social media-user respondents to the questionnaire (n=346)

	Men n (%)	Women n (%)	Total n (%)
Type of respondent^a			
Diagnosed with type 1 diabetes	54 (15.6)	133 (38.4)	187 (54.0)
Diagnosed with type 2 diabetes	34 (9.8)	39 (11.3)	73 (21.1)
Family member of diabetes patient	13 (3.8)	58 (16.8)	71 (20.5)
Health care professional	3 (0.9)	19 (5.5)	22 (6.4)
Age group, years			
<18	4 (1.2)	6 (1.7)	10 (2.9)
18–29	14 (4.0)	38 (10.9)	52 (15.0)
30–44	24 (6.9)	72 (20.8)	96 (27.7)
45–64	46 (13.3)	93 (26.9)	139 (40.2)
≥65	13 (3.8)	21 (6.1)	34 (9.8)

Note: ^aMultiple choice available for this category.

Table 2 Social media users' preferences regarding a health-promotion intervention on diabetes according to type of respondent

	Diagnosed with type 1 diabetes, n (%)	Diagnosed with type 2 diabetes, n (%)	Family member of diabetes patient, n (%)	Health care professional, n (%)	Total, n (%)
Type of content^a					
Research and innovation on diabetes	135 (78.5)	40 (61.5)	62 (91.2)	20 (95.2)	237 (78.0)
Technical aspects of self-management	123 (71.5)	21 (32.3)	50 (73.5)	14 (66.7)	188 (61.6)
Personal aspects of self-management	94 (54.7)	36 (55.4)	35 (51.5)	8 (38.1)	161 (52.8)
Interviews/personal stories from other people with diabetes	60 (34.9)	16 (24.6)	32 (47.1)	9 (42.9)	117 (38.5)
Content on health care services	70 (40.7)	23 (35.4)	29 (42.6)	11 (52.4)	114 (37.5)
Format of content^a					
Text	158 (92.4)	60 (95.2)	64 (94.1)	21 (100)	281 (93.4)
Images	91 (53.2)	14 (22.2)	42 (61.8)	13 (61.9)	150 (49.8)
Videos	47 (27.5)	10 (15.9)	21 (30.9)	7 (33.3)	79 (26.2)
Frequency of content					
Daily or several times per day	72 (42.9)	15 (24.2)	24 (36.4)	7 (33.3)	110 (37.3)
Every second or third day	31 (18.5)	12 (19.4)	20 (30.3)	5 (23.8)	60 (20.3)
More seldom	65 (38.7)	35 (56.5)	22 (33.3)	9 (42.9)	125 (42.4)
Platform^a					
Facebook	165 (97.1)	60 (96.8)	67 (98.5)	21 (100)	291 (97.3)
Instagram	36 (21.2)	3 (4.8)	11 (16.2)	7 (33.3)	52 (17.4)
Twitter	7 (4.1)	1 (1.6)	5 (7.4)	1 (4.8)	14 (4.7)

Note: ^aMultiple choice available for each type of preferred content (except frequency) and by type of respondent.

aged 18–29 years ($\chi^2_{4,304}=43.731, P<0.001$). Video format was the more frequently chosen format by respondents <18 years old ($\chi^2_{4,304}=12.485, P=0.014$). No significant differences between sexes regarding content format were found.

Nearly all the questionnaires were answered following a link from Facebook, and none from Twitter. Of the respondents from Facebook, 272 (90.4%) indicated being interested

in text format, 143 (49.3%) in images, and 73 (25.2%) in video. Of the respondents from Instagram, nine (81.8%) indicated being interested in text format, seven (63.6%) in images, and six (54.5%) in video.

Regarding content frequency, no significant differences were found between sexes or age groups. Regarding which of the platforms on which they would like to find

Table 3 Social media users' preferences regarding a health-promotion intervention on diabetes according to age group

	<18 years, n (%)	18–29 years, n (%)	30–44 years, n (%)	45–64 years, n (%)	≥65 years, n (%)	Total, n (%)
Type of content^a						
Research and innovation on diabetes	7 (100)	37 (78.7)	79 (87.8)	90 (69.2)	24 (80.0)	237 (78.0)
Technical aspects of self-management	2 (28.6)	28 (59.6)	62 (68.9)	83 (63.8)	13 (43.3)	188 (61.8)
Personal aspects of self-management	5 (71.4)	30 (63.8)	42 (46.7)	71 (54.6)	13 (43.3)	161 (53.0)
Interviews/personal stories from other people with diabetes	4 (57.1)	22 (46.8)	39 (43.3)	44 (33.8)	8 (26.7)	117 (38.5)
Content on health care services	3 (42.9)	18 (38.3)	31 (34.4)	49 (37.7)	13 (43.3)	114 (37.5)
Format of content^a						
Text	4 (57.1)	44 (95.7)	84 (94.4)	121 (93.8)	28 (93.3)	281 (93.4)
Images	4 (57.1)	37 (80.4)	53 (59.6)	53 (41.1)	3 (10.0)	150 (49.8)
Videos	4 (57.1)	17 (37.0)	28 (31.5)	26 (20.2)	4 (13.3)	79 (26.2)
Frequency of content						
Daily or several times per day	3 (42.9)	13 (28.3)	34 (39.1)	50 (40.0)	10 (33.3)	110 (37.3)
Every second or third day	1 (14.3)	13 (28.3)	16 (18.4)	25 (20.0)	5 (16.7)	60 (20.3)
More seldom	3 (42.9)	20 (43.4)	37 (42.5)	50 (40.0)	15 (50.0)	125 (42.4)
Platform^a						
Facebook	6 (87.5)	43 (95.6)	88 (98.9)	126 (98.4)	28 (93.3)	291 (97.3)
Instagram	4 (57.1)	16 (35.6)	18 (20.2)	13 (10.2)	1 (3.3)	52 (17.4)
Twitter	1 (14.3)	1 (2.2)	6 (6.7)	6 (4.7)	0	14 (4.7)

Note: ^aIt was possible to choose several options for each type of preferred content (except frequency).

health-promotion content, no significant differences between sexes were found, except for Twitter: although very uncommonly chosen, it was more frequently preferred by men ($n=8$, 9.0%) than women ($n=6$, 2.9%; $P=0.022$). Instagram was the media more frequently chosen by participants <18 years old ($\chi^2_{4,99}=27.322$, $P<0.001$).

Regarding the perceived quality of diabetes-related information on social media (on a scale of 0–100), the respondent's average rating was 62.0 ± 1.2 (median 60). The average satisfaction rate with the diabetes-related content on social media was 61.9 ± 1.3 (median 60). No differences were found in average ratings on perceived quality of information or satisfaction with content between men and women, the different age groups, or types of respondents.

Discussion

Summary of main findings

In only 1 week, the online questionnaire posted on the three social media channels from the Norwegian Diabetes Association was answered by 346 participants, almost all from Facebook. Two-thirds of respondents identified themselves as women, 71% as aged 30–64 years, and 54% as individuals diagnosed with type 1 diabetes.

The participants, social media users from the Norwegian Diabetes Association who accessed the study mainly from Facebook, expressed much interest in finding health-promotion content on Facebook, focusing on diabetes research and innovation, and for content presented in text format. The average perceived quality of diabetes-related information on social media was rated 62.0, and satisfaction with such content was rated 61.9.

Social media users' interests and perceived quality and satisfaction of diabetes-related information

Correct and appropriate information is the basis for optimal self-management. Several studies have found that in the last couple of decades, Norwegians in general have become increasingly reliant on the Internet for information about health and illness.^{35–37} Our present study finds that users of diabetes social media groups are interested in receiving diabetes-related information through social media channels, such as Facebook, Instagram, and Twitter. In addition, the youngest might prefer online video-based information, a format offered earlier by YouTube, Vimeo, and other online video-sharing platforms, and now also available on almost every social media channel. Patients are familiar with these online services, increasingly through mobile platforms, and most use one or more of the social media services every day

for obtaining information and communicating, both professionally and privately.^{38–42}

It is interesting to note that while the main interest in closed diabetes social media groups seems to be related to self-management,^{33,43} the responses from mainly diabetes patients through their patient organization found in this study reflect most interest in diabetes research and innovation. This discrepancy might be related to the fact that users feel freer to discuss personal issues and self-management in a closed group on social media, as reported in a previous study, where it was found that mainly diabetes self-management messages were posted in closed groups.³⁵

The questionnaire respondents rated the quality of diabetes-related information on social media an average of 62.0 points and their satisfaction with such content 61.9 (scale 0–100). With the launch of the health-promotion intervention based on social media users' preferences and interest, we expect to improve their satisfaction and views regarding the quality of content.

Participation and engagement with creation of a health-promotion intervention

This study showed that a group of people affected with diabetes had an interest in participating in the development of a health-promotion intervention that will target them. Those who responded to the questionnaire were able to identify contents, formats, frequencies, and channels that were meaningful for them, but the community-based participatory approach in this project was broader. Our research project was planned and designed from an early stage in close collaboration with staff at the Norwegian Diabetes Association. By involving social media users of the Diabetes Association in the creation of the health-promotion intervention, this project might also have a positive effect on the four elements mentioned in the sense-of-community theory:⁹ by being asked about their preferences and interests, participants' feeling of belonging to the group could be enhanced; by being able to choose content and formats for the health-promotion intervention, participants' feeling of having influence on the group could increase, which additionally could intensify their interest in the group; participants might feel they will be reinforced, because group members' interests and preferences regarding the health-promotion intervention will be met (in this case, the health-promotion intervention will provide them with more content on diabetes research and innovation in text format on the association's Facebook channel); and a shared emotional connection, consisting in sharing the history of having

developed together the health-promotion intervention that will benefit all group members.

However, using social media for health promotion is not exempt from disadvantages. Due to differences in access to technology, cultural differences, and preferences, the use of social media strategies for public health promotion may in some circumstances increase health inequities.^{44–50} Misinformation occurs very frequently in social media and is rapidly spread. Social media postings containing misinformation may have significant negative effects on people's health.^{51,52} Another issue is that social media groups may be used for malicious behavior. Studies have shown greater incidence and severity of bullying online compared to offline networks, and online bullying may contribute to the development of depression and other problems.^{53,54}

Limitations and further research

Although we received a good amount of completed questionnaires, it is not possible to generalize our findings to all social media users from the Norwegian Diabetes Association, since we can assume we mainly got answers from the most engaged users and we do not have access to personal details of the members for privacy reasons. We asked the respondents which social media channels they preferred for receiving information about diabetes and how often they would like such information. One might assume this information would correspond to their actual social media use (ie, platform and frequency of use), but we did not ask specifically about actual use. Further research should explore social media users' interests, engagement, and satisfaction with a health-promotion intervention in which they have participated. In future research, collecting data for a longer period might result in a higher number of respondents and thereby the possibility of an even more detailed analysis according to further subcategorization of the respondents.

It has been reported in the scientific literature that people affected with type 2 diabetes and belonging to lower socioeconomic groups have more diabetes-related complications and higher diabetes-related mortality compared to those in higher socioeconomic groups.^{55–57} Future research could consider collecting socioeconomic data of participants to analyze the differences among groups. The results of such an analysis would allow adaptation of interventions to participants' preferences, while also taking socioeconomic status and associated health-related consequences into consideration. As part of this project, we will investigate how the use of a community-based participatory research approach listening to the users' preferences can potentially

increase diabetes patients' engagement and satisfaction with the health-promotion intervention and help people attain healthier lifestyles. The findings from this project will be communicated to the scientific community who and shared with the social media users of the Diabetes Association.

Conclusion

Users of diabetes social media groups are interested in participating in the creation of a health-promotion intervention on diabetes. They are especially interested in knowing more about research and innovations in diabetes, receiving contents in text format, and in finding the contents on Facebook. The use of community-based participatory research to acknowledge users' preferences helped to reach and involve the participants rapidly and could potentially increase diabetes patients' engagement and satisfaction with the health-promotion intervention, enhance their sense of community, and thus help them to attain healthier lifestyles.

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Author contributions

All authors contributed toward data analysis, drafting and critically revising the paper and agree to be accountable for all aspects of the work. EG and ED additionally contributed to the creation of the on-line questionnaire, and data acquisition. All the authors have reviewed and approved the final version.

Disclosure

The authors report no conflicts of interest in this work.

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