OUKA
Osaka University Knowledge Archive

Title	Promoting Public Awareness in Genetic Disorder through Social Media
Author(s)	Nur Adilah Kamarrudin; Noorshahida Abu Tholib; Sulaini Mat ll; Suliana Shamsuddin Alias; Teguh Haryo Sasongko; Johari Yap Abdullah; Ahmad Yusdirman Yusoff
Citation	医療・生命と倫理・社会. 13 P.32-P.42
Issue Date	2016-03-30
Text Version	publisher
URL	https://doi.org/10.18910/57391
DOI	10.18910/57391
rights	
Note	

Osaka University Knowledge Archive : OUKA

https://ir.library.osaka-u.ac.jp/

Osaka University

Promoting Public Awareness in Genetic Disorder through Social Media

Nur Adilah Kamarrudin[1,2], Noorshahida Abu Tholib[1,2], Sulaini Mat Il[2], Johari Yap Abdullah[2,3], Ahmad Yusdirman Yusoff[4], Suliana Shamsuddin Alias[2], Teguh Haryo Sasongko[1]

[1]Human Genome Center, School of Medical Sciences, USM Health Campus, Kubang Kerian, Kelantan; [2]Yayasan Orang Kurang Upaya Kelantan, Kota Bharu, Kelantan; [3]School of Dental Sciences, Universiti Sains Malaysia; [4]Centre for Knowledge, Communication & Technology, USM Health Campus, 16150 Kubang Kerian, Kelantan

Abstract

Social media has changed the way we communicate. The technology is developing rapidly and changed the way we share information and experiences with friends and acquaintances such as the use of Facebook, Twitter, YouTube, and others. Internet users, especially youngsters, are quick to adopt with this technology. Social media is changing the way people respond to information and engage with each other. The objective of this project is to engage the social media especially Facebook and YouTube to promote community awareness on genetic disorder. In order to share knowledge on genetic with the community, the Facebook Page has been created and it is called "Kenali Genetik Fahami Pewarisan DNA". The YouTube account has also been created to store videos on genetic, and would be linked to Facebook Page. Among the contents to be included in the Facebook Page and YouTube are genetic knowledge and home visit experiences with families living with more than one disabled children. The analysis on Facebook Page offers some insights such as the "likes" and "post reach" in the Page. Both Facebook Page and YouTube is handled by an admin who is responsible to update contents to be shared with the communities. The Facebook Page can help us reach large groups of people frequently, with messages tailored to their needs and interests, especially in genetic issues. The ability to share news and stories through social media will further increase the coverage which helps in increasing awareness. However, it is challenging to promote this Facebook Page as compared to other "fun" Page. The possibilities of using other social media such as Twitter and Instagram could be explored to reach greater coverage of the community.

Keywords

Social Media, Knowledge, Awareness, Facebook, Youtube

1. Introduction

Social media can be very useful tools to promote knowledge in health care among community. Now, people are using social network to find information especially in healthcare. Therefore, we used social media to share information on genetic disorder. This study intended to spread the awareness regarding genetic disorder among Malaysian citizen through Facebook Page and Youtube. Social media websites, representing various forms of consumer-generated content (CGC) such as blogs, virtual communities, wikis, social networks, collaborative tagging, and media files shared on sites like YouTube and Flickr, have gained substantial popularity in online travelers' use of the Internet (Gretzel, 2006;Pan, MacLaurin, & Crotts, 2007).

According to Journal of Computer-Mediated Communication (Danah. M, 2008) social network site is defined as web-based services that allow individuals to construct a public or semi-public profile within a bounded system and articulate a list of other users with whom they share a connection. Social network sites (SNSs) such as MySpace, Facebook, Youtube, Twitter and others attracted millions of users every year (Xiang & Gretzel, 2010). The term ''social media'' can be generally understood as Internet-based applications that carry consumer-generated content which encompasses ''media impressions created by consumers, typically informed by relevant experience, and archived or shared online for easy access by other impressionable consumers'' (Blackshaw, 2006).

Social media refers to activities among consumers who communicated online and shared information using interactive media to facilitate the creation and sharing of content in the form of words, pictures, video and audio (Safko & Brake, 2009). Stern (2009) categorized social media as follows: message rooms and forums, the spotlight and the opinion space, a series of social, blogs and micro blogs, virtual bookmark and media partnerships.

1.1 Introduction to Facebook and Youtube

Facebook is an expanding social network that has exceeding previously existing social network sites. It was created by Mark Zuckerberg in 2004 and by 2007, Facebook was reported to have more than 21 million registered members generating 1.6 billion Page views each day (Needham & Company, 2007). Besides that, Facebook provides daily, weekly, monthly and yearly report and analysis for users.

YouTube is media sharing sites, such as video, photos and podcasting. The Internet domain name "youtube.com" was activated on 2005. YouTube has created a platform for these participants to present their personal videos, which normally filmed using hand held point and shoot cameras. In addition, Youtube allowed users to upload, share, and view videos.

1.2 Health communication through social media

Social media phenomenon as a new media is very popular nowadays. According to Thomas (2006), health communication refers to the use of science communication strategies to inform and influence the knowledge, attitudes and practices of individuals and communities in matters of health and health care. Facebook is capable in providing health information contributed to further awareness on healthcare, nutrition, diet, diseases and remedy information (Azura & Norazmie, 2014).

Facebook Pages and Youtube with health education information will be explained to show how they can be beneficial to new media users. This is very useful medium to the patients, families, organizations, industry, clinicians, and research. Facebook and Youtube can be an interactive medium to create awareness in health communication via internet. Besides that, Facebook and Youtube are beneficial to all age groups as an inexpensive medium because they are free to use with no registration fee.

2. Literature Review

Facebook is the biggest social media site in terms of monthly active users, compared to other social media platforms, Facebook has achieved even more remarkable percentage of mindshare. Facebook has challenged and countered the established method on how people connect and converse (Mohamed et.al (2005). This makes Facebook as the largest social networking site recorded in term of number of registered users in Malaysia (Mahmud & Omar2013). One survey on the social networking site in Malaysia by Malaysian Digital Association (MDA) found that the number of registered users for Facebook is 8 million people (Mahmud, Z.M & Omar, A, 2013). Table 1 below shown the examples of social network sites that related to human genetics.

Table 1. Social Network sites in Malaysia that are related to human genetics

Case	Description
A- Facebook Page: Malaysian Society Of Human Genetic	Provides platform for the human geneticists.
B- Facebook Page: Malaysian Rare Disorders Society	The voluntary organization that represents the voices of patients and families affected by rare disorders.

Below are examples of social network sites usages by society organizations in Malaysia that are related to human genetics.

Case A: Malaysian Society of Human Genetic (MSHG)

The Malaysian Society of Human Genetics was established in April 2012. It is a professional body that provides a platform for the human geneticists and those interested in the field of human genetics throughout Malaysia to meet and exchange ideas. MSHG have 126 fans by 14 September 2015. MSHG use Facebook Page to share knowledge of human genetics. Their methods are posting articles, sharing links and photos.

Case B: Malaysian Rare Disorders Society (MRDS)

Malaysian Rare Disorders Society (MRDS) was formed in 2004, with the help and guidance of the Genetic Unit, Department of Paediatrics, University Malaya Medical Centre. MRDS missions are to support and provide resources to members affected with rare disorders. In addition to increase awareness on rare disorders through education, training and public awareness programs. Besides that, MRDS wants to establish network between individuals and families with rare disorders with relevant support organizations, genetic and allied health professionals. MRDS Facebook Page was created on 2004 and has been liked by 705 people by 14 September 2015. MRDS also promotes their organization via websites.

3. Methodology

The Facebook Page has been created in December 2014 in order to promote awareness to public on genetic disorder. This approach is important to help people understand on genetic and other valuable information.

3.1 Kenali Genetik Fahami Pewarisan DNA

The Facebook Page has been created 2014 and it is called “Kenali Genetik Fahami Pewarisan DNA” or KGFP. By 14 September 2015, the total Page was liked by 202 people. The purpose of this research using Facebook is to promote public awareness on genetic disorder and to share information about the rare disease. Besides that, other approach of KGFP Page is the information was provided in Bahasa Malaysia version, which was collected from trusted source.

The Facebook structure consist of basic functions such as news feed, wall, like, friend, timeline, message, notifications, network and groups. For the application, Facebook provides functions to create events, places, post photos, videos and links. For information collected in English version, they would be translated into Bahasa Malaysia. In addition, other social network media such as Youtube (Community Genetic USM) has also been linked to KGFPD. The user interface of Facebook Page is shown in Figure 1.

Figure 1. The interface of Facebook Page 'Kenali Genetik, Fahami Pewarisan DNA' (KGFP)

There are many ways to get a group of friends in the Facebook especially for personal, groups and Pages. Firstly, for Facebook Page, the best approach to promote the Page was to "Invite Friends" to follow the Page. "Invite Friends" tool sends notifications to friends suggesting them to "Like" that particular Page. This can help in increasing growth for new Pages or facilitate further viral growth for established Pages. The 'Share' button lets people add a personalized message before sharing them on their timeline, groups, or to their friends via a Facebook Message.

Based on Figure 2 below, it shows how the flow Facebook process. The flow is begins from Page that was liked and the Page was reviewed by non-friends. It can gain the number of members in community Page using that method.

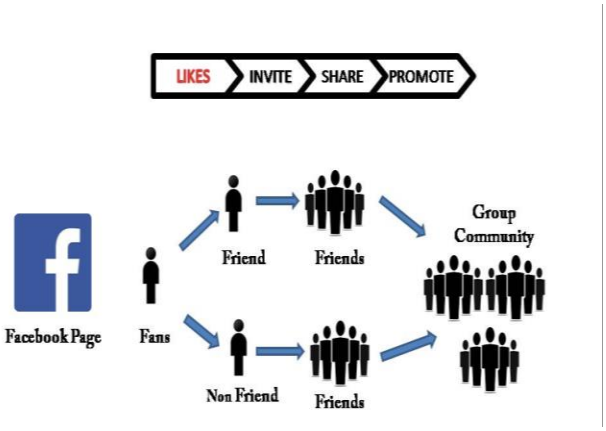

Figure 2. The process of the Facebook

3.2 Community Genetic USM (CGUSM) Youtube

The Community Genetic USM (CGUSM) Youtube channel has been created November 2014. By 28 September 2015, the total View on CGUSM by 729 views. Overall, since November 2014 until September 2015, about 34 videos have been uploaded in CGUSM Youtube channel. The purpose

of this research using Youtube is to share video about awareness on genetic disorder and other education healthcare. Besides that, the CGUSM containing lectures on genetic disorders and other contemporary issues in human genetics. The user interface of Youtube channel is shown in Figure 3.

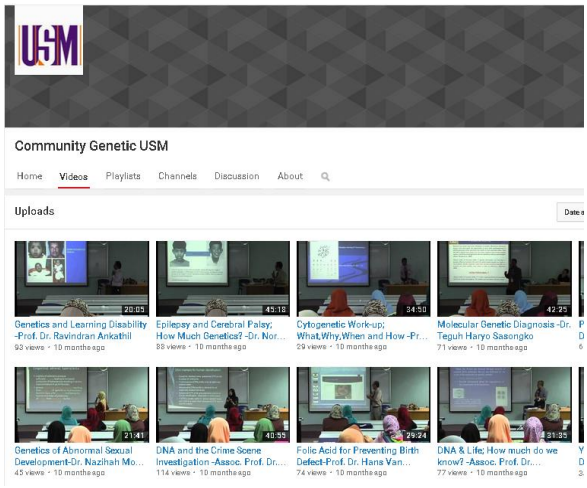

Figure 3. The interface of Youtube channel 'Community Genetic USM'

4. Result and Discussion

The summary of results to measure the usages of Facebook in order to promote genetic disorder are collected and analyze by Facebook report. These measurements are self-reported and only the admin of Facebook Page could view the report. The collected information are: total fans, people reaches on Page, demographic descriptive variables, including places, gender and age. Between January 1st and 28 September 2015, the total number of people following the Facebook Page is 207 people.

Table 2 below shows the percentage of fans Page and people reached by gender. Total observation conducted in this research is 207 comprising 113 women and 94 men. It was found that women fan percentage is slightly higher than men, where it was 55 % and 45 % for women and men respectively. For people reached, women are slightly higher than men.

Table 2. The percentage of fans and people reached by gender

Gender	Fans Percentage (%)	People Reached Percentage (%)
Women	55%	60%
Men	45%	39%

Table 3 show the total number of Page fan gender and age that were divided into 5 groups, between 13 -54 years old. It was found that both group of women and men between 25 - 34 shows the highest percentage of fan. The lowest percentage of fan for women and men is demonstrated by age group between 13-17 and 45-54 years old. It can be concluded that all age group for women

have slightly higher fan percentage than for men. This finding clearly shows that young people tend to be frequent Facebook followers.

Table 3. The total Page fans gender percentage based on age group

Gender	Age Group (years old)				
	13-17	18-24	25-34	35-44	45-54
Women	2%	16%	25%	8%	2%
Men	0.98%	13%	18%	8%	1%

From the Table 4 below, the analysis shows the different language people used to communicate based on self-select default languages. The Page had been reviewed by fans in English (US, 110 people), English (UK, 48 people), and the usage Page in Malay language was only by 34 people. It was found that users use the English (US) as a standard language in their Facebook usage.

Table 4. The languages usage by fans and people reached

Language	Fans	People Reached
English (US)	110	594
English (UK)	48	248
Malay	34	83
Indo	7	81
Thai	3	-
France	1	1
Traditional Chinese	1	1
English (India)	-	1
German	-	2
Korean	-	2
Japanese	-	3

Figure 4 shows the number of people who liked the Page based on monthly time range. The results show that starting from January until April, no increased number of like. In the middle of April, the ranking of Page likes increasing slightly every month followed by May, June, July, August and the highest number of fans on September.

Figure 4. The likes ranking Page on January till September 2015

Based on the observation, these Pages have been viewed by people in all 14 states in Malaysia as shown in Table 5. The highest number of fans was from Kelantan. (72 people), followed by Kuala Lumpur (29 people) and Pulau Pinang (10 people). The least fan was from Johor (1).

Table 5. Total Page reached by user state in Malaysia

State	People Reached
Kota Bharu	72
Kuala Lumpur	29
Pulau Pinang	10
Kedah	10
Pahang	8
Sabah	4
Sarawak	4
Melaka	3
Perlis	3
Terengganu	3
Negeri Sembilan	3
Selangor	2
Perak	2
Johor	1

Table 6 shows the results of the Page fan and people reached by country; this Page has been viewed by people over the world such as Yemen, United Kingdom and Japan. From 1026 people reached post, 771 viewers were from Malaysia. Otherwise from the total number Page fan, 207 people was from Malaysia and the rest 1 fan from Taiwan, Canada, Yemen, Algeria, Ethiopia, Tajikistan and United Kingdom.

Table 6. The Page Fan and People Reached Impressions by Country

Country	Fans (n=207)	People Reached Post (n=1026)
Malaysia	189	771
Indonesia	8	201
Thailand	3	11
Taiwan	1	-
Canada	1	-
Yemen	1	-
Algeria	1	-
Ethiopia	1	-
Tajikistan	1	
United Kingdom	1	5
Japan	-	11
United States of America	-	8
Netherlands	-	1
Singapore	-	3
Italy	-	2
Australia	-	2
South Korea	-	2
Saudi Arabia	-	2
Germany	-	2

Table 7 shown the different post types based on average reach and engagement, types of engagement includes reach, post clicks and likes, comment and shares. The results on link post had a higher reaches by people compared to photo post.

Table 7. The total of type's engagement based on types of post

Types of Engagement	Type of Post	
	Link	**Photo**
Reach	491	38
Post Clicks	10	14
Likes, Comment & Shares	1	2

The summary of results to measure the usages of Youtube channel in order to give the knowledge to community on genetic disorder. The data are collected and analyze by Youtube analytics report. The collected information are: demographic, subscribers, likes and dislikes, video in playlist, comment and sharing.

Figure 5 shows the results of the viewers of Youtube channel by country. From total of 729 viewers, 260 viewers were from Malaysia.

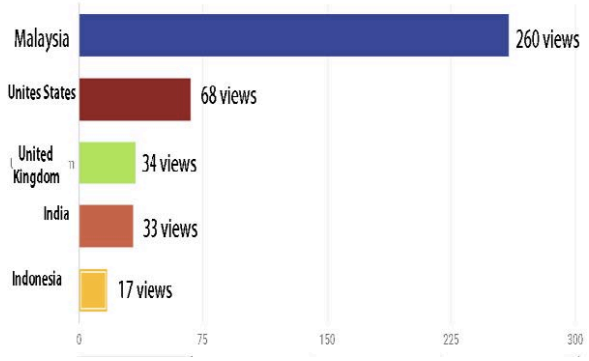

Figure 5. The viewers of CGUSM channel by country

According to Figure 6 shown the percentage of people viewer the CGUSM YouTube channel by gender. It was found that men percentage is slightly higher than female, where it was 51 % and 49 %.

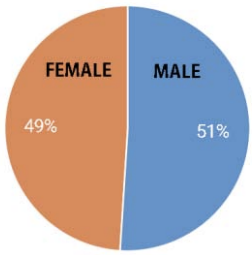

Figure 6. The percentage of people viewer the CGUSM YouTube channel by gender

5. Summary

The aim of this project is to promote community awareness on genetic disorder through social network. Online social network sites such as Facebook and Youtube played a role to educate community for knowledge in health especially in genetic disorder. It was challenging to promote this Facebook Page. In addition, Facebook can help to reach groups of people frequently with messages to their needs and interests, especially in genetic issues. As a conclusion, social media has helped us in transfer the knowledge to the public, especially to the rural community.

6. Acknowledgements

We would like to acknowledge with gratitude and the support from Knowledge Transfer Program Grant No. 203/PPSP/6750051 and thank all staffs of Human Genome Center and Department of Pediatrics Universiti Sains Malaysia as well as Yayasan Orang Kurang Upaya Kelantan for their contributions to this project.

7. References

Adzharuddin,A.N, & Ramly, M.N. (2014). Nourishing healthcare information over Facebook. *Procedia - Social and Behavioral Sciences* 172 (2015), 383-389.

Danah. M. (2008). Social network sites: Definition, history, and Scholarship. *Journal of Computer-mediated Communication* 13 (2008), 210-230.

Eszter, H. (2008). Whose Space? Differences among users and non-users of social network sites. *Journal of Computer-mediated Communication* 13 (2008), 276-297.

Gretzel, U. (2006). Consumer generated content – trends and implications for branding. *e- Review of Tourism Research*, 4(3), 9–11.

Mahmud, Z.M & Omar, A. (2013). Motif and frequency of students use facebook in university. *Malaysian Journal of Communication*, 29(1), 35-54

May, M. & Kwong, K. H. (2007). YHOO: Yahoo! may regret not paying up for Facebook.

Mohamed , A.A, Ibrahim, O. & Nilashi, M. (2005). The Security Awareness Framework for Social Network Sites Facebook: Case Study in Universiti Teknologi Malaysia. *Journal of Soft Computing and Decision Support Systems* 2(3), 1-8.

Nicholas. A.C. & Fowler, J.H. (2007). The Spread of obesity in a large social network over 32 years. *The New England Journal of Medicine* 357 (2007), 370-379.

Nicole .B., Charles. S. & Cliff. L. (2007). The benefits of Facebook "Friends" Social Capital and College Students' use of online social network sites. *Journal of Computer-Mediated Communication* 12 (2007), 1143-1168.

Pan, B., MacLaurin, T., & Crotts, J. C. (2007). Travel blogs and their implications for destination marketing. *Journal of Travel Research*, 46(1), 35–45.

Safko, L., & Brake, D. K. (2009). *The social media bible: Tactics, tools and strategies for business success*. New Jersey: John Wiley.

Thomas, R. K. (2006). *Health Communication*. New York: Springer Science+Business Media, Inc.

Xiang, Z. & Gretzel, U. (2010). Role of social media in online travel information search. *Tourism Management* 31(2), 179-188.