The Twitter Adventure of #MyHealthRecord: An Analysis of Different User Groups During the Opt-Out Period

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Abstract. My Health Record (MHR), which is an online health summary for Australians, was changed from the opt-in to the opt-out model, and therefore sparked a vast discussion on Twitter. In order to understand the debate, the information dissemination and the levels of engagement, we have analysed tweets posted from July 2018 to February 2019. In this paper, we report on the findings of the patterns of discussion, the hashtags and the numbers of retweets and likes from different user categories. The results show that the discussion was highly political, and the tweets from the MHR official accounts had lower propagation and engagement than other user groups. This work highlights the implications of using social networking sites (SNSs) to promote large-scale mandatory electronic health record systems.

Keywords. My Health Record, electronic health record, personal health record, social networking sites, Twitter

Introduction

My Health Record (MHR) is an online information system for storing and accessing key health information summary of individuals in Australia. It is managed and maintained by the Australian Digital Health Agency (ADHA), which is an Australian Government agency to design and deliver the national digital health strategy and the relevant information systems and technologies. Originally designed as an opt-in system, people could choose to enrol into MHR if they need one. In order to increase the participation of MHR, the Government changed its enrolment model from opt-in to opt-out after trials of the new model in different parts of Australia. Under this opt-out model, eligible Australian people would have a record automatically created in MHR if they did not exclude themselves. The move from explicit consent (opt-in) to implicit consent (opt-out) triggered a huge amount of debates on Twitter, which is the largest social networking site (SNS) worldwide. After the opt-out period, approximately 2.5 million (10%) have chosen to opt-out [1], which is higher than the 1.9% opt-out rate in earlier trials [2,3].

Our aim is to understand the patterns of tweets amongst different user groups during the opt-out period. People's attitudes towards electronic health record systems are critical

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for their adoption [4], and understanding consumers' needs is an important factor in the success of health information systems [5–7]. As health consumers have been using SNSs as a platform for various health purposes [8–11], we assume that they use Twitter to learn and discuss with others about MHR. Meanwhile, clinicians, experts and social activists expressed their views and opinions in this event of significant changes. Such participation in online discussion created a unique opportunity to understand holistically how different groups think about MHR and similar electronic health record systems.

In this study, we collected tweets using the Twitter Search Application Programming Interface (API) for 8 months. We obtained 46,693 tweets from 14,178 users excluding the retweeted content. After data pre-processing, 28,894 tweets from 1,634 users with active participation were analysed, and this subset of data accounted for 62% of the raw dataset. We categorised these users into 11 groups and studied their activities. In this paper, we report on the tweeting patterns, the hashtags, and the numbers of retweets and likes among user categories.

1. Data and Method

We supplied 7 query strings to the Twitter Search API, namely "my health record", #myhealthrecord, #myhealthrecords, @MyHealthRec, #myhr, #MyHealthRecordFail, #mhr, for collecting data for our study. These queries covered the tweets posted from the official MHR Twitter accounts, the tweets with the words "my health record", as well as other relevant hashtags. A dedicated server was set up for downloading these tweets continuously over the data collection period.

The data collection started in one week before the initial opt-out period of MHR (8th July 2018) and ended in one week after the opt-out closed (9th Feb 2019). The data collection lasted for 213 days or 31 weeks. Initially there were 197,456 tweets downloaded. However, a vast amount was only retweeting other tweets which had the same content as the original ones. After removing the retweeted ones, 46,693 tweets posted by 14,178 users remained. We observed that the distribution of tweets was extremely skewed and long-tailed, i.e. only very few people posted lots of tweets, but a substantial number of users posted a very small number. (Figure 1(a)). In this case, we focused on active users who had 5 or more tweets posted about MHR. As a result, 28,894 tweets (62%) from 1,634 active users (12%) were kept for the next stage of analysis. Figure 1(b) shows the steps of data selection in our research.
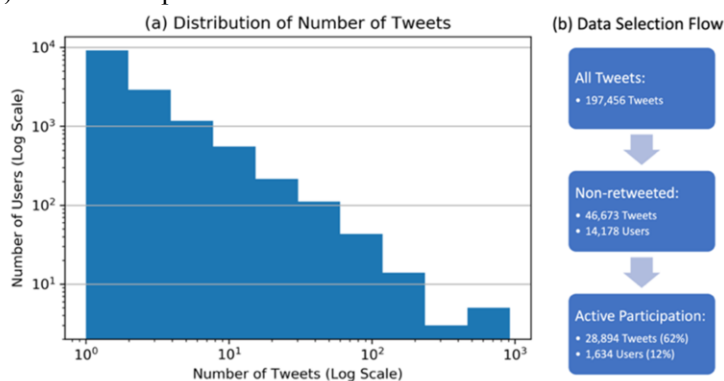

Figure 1. (a) The distribution of the tweets posted by individual users in log scale. Red area depicts the portion of tweets analysed in this paper. (b) The data selection process.

For the 1,634 users who actively participated, we grouped them into 11 categories. The list of categories was generated by a number of iterations of thematic coding [12] of the self-description in users' profiles. Two researchers separated coded the users and compare the results with each other. Table 1 lists the categories and their descriptions.

Table 1. User categories

Name	Description	Count	%
Academic	Academics or Researchers	82	5.0%
Clinician	Doctors, Nurses, Practitioners and Health Professionals	97	5.9%
IT	IT and Cybersecurity Professionals	205	12.5%
Law	Lawyers and Law Groups	27	1.7%
Media	Media, News, Writers and Reporters	274	16.8%
My Health Record	The MHR account, ADHA and the CEO of ADHA	5	0.3%
Patient Group	Patients and Consumer Groups	65	4.0%
PHN	Primary Health Networks (An Australian Government initiative to improve primary care access for patients)	27	1.7%
Politician	Politicians (both elected and not elected)	19	1.2%
Privacy Advocate	Groups or individuals that advance the awareness of privacy	40	2.4%
Public	Individuals who cannot be grouped in other categories	793	48.5%
Total		1,634	100%

2. Results

We studied the number of tweets post by different categories of users in each week and these are presented in Figure 2.
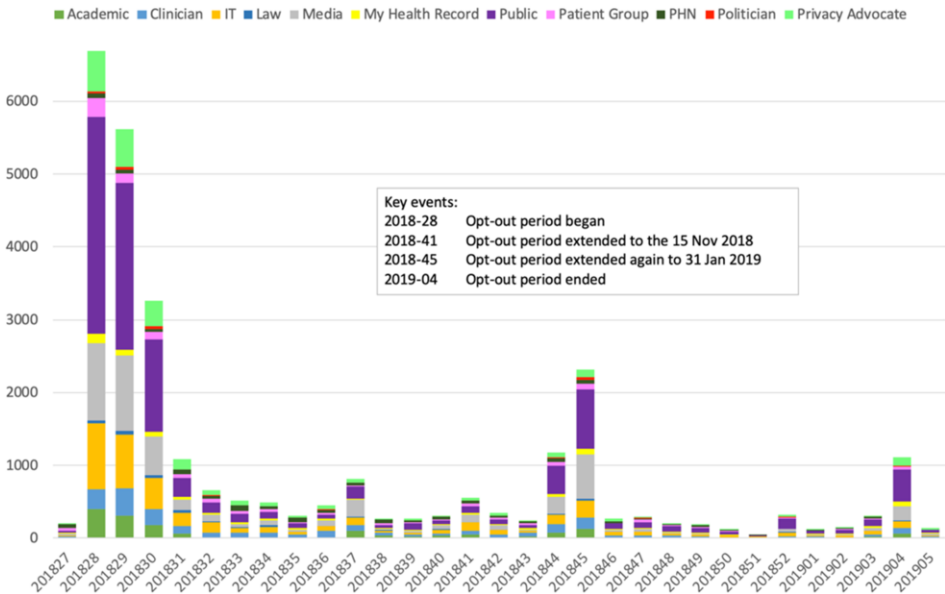

Figure 2. The numbers of tweets posted by users in different categories, organised in weeks.

As shown in Figure 2, the number of tweets demonstrated surges at the key changes about the opt-out, e.g. the start of the opt-out period and the deadline extensions. In the week of the beginning of the opt-out (week 2018-28), users published the greatest number of tweets topped at 6,688. The trend decreased rapidly after the first week and

then slightly increased a month before the original deadline (week 2018-37). The discussion went quiet and revived near the second extension of the deadline (week 2018-45). The last spike of conversations happened approximately when the opt-out stopped (week 2019-04). In general, the peaks during the opt-out period were not as high as the one at the start of the period.

Additionally, we counted the number of tweets in all hashtags and present the top 15 in Table 2. As listed in the table, we can identify some key topics from these hashtags: (1) politics; (2) opt-out; (3) digital health; (4) privacy; and (5) cybersecurity. Particularly, tweets about "auspol" (i.e. Australian politics), significantly outweighed the others.

Table 2. The top 15 hashtags

#	Hashtag	Count	#	Hashtag	Count	#	Hashtag	Count
1	auspol	4,785	6	health	538	11	cybersecurity	242
2	optout	1,845	7	optoutmhr	346	12	security	212
3	privacy	1,232	8	myhealthoptout	278	13	infosec	210
4	ehealth	665	9	healthcare	277	14	australia	198
5	digitalhealth	551	10	thedrum	242	15	data	165

Next, we present the counts of retweets and likes by different user categories. Since most of the Twitter users can only retrieve the retweet details and the likes of the tweets that they can read, such a global picture is hard to obtain without downloading and analysing the tweets from all users.

Figure 3 illustrates the numbers of tweets posted by certain user categories (the vertical axis) and the categories of corresponding retweeters (the horizontal axis). We have identified some interesting observations from this figure:

- Politician (79%), Privacy Advocate (56%), Media (54%), IT (50%), Academic (48%), Law (46%) and Clinician (42%) categories (yellow shaded) could expose their tweets to a wider audience, demonstrated by higher percentages of retweets from Public.
- The tweets from MHR were mainly retweeted by their own and PHN accounts, and Politician accounts even retweeted none of them (green shaded).
- The tweets posted by PHN were mainly retweeted by MHR, and not many by other PHN peers and none by Politicians (blue shaded).

Retweeted by → / Sent by ↓	Academic	Clinician	IT	Law	Media	My Health Record	PHN	Patient Group	Politician	Privacy Advocate	Public
Academic	248 (13%)	100 (5%)	155 (8%)	15 (1%)	173 (9%)	13 (1%)	2 (0%)	23 (1%)	1 (0%)	239 (13%)	885 (48%)
Clinician	76 (3%)	720 (31%)	189 (8%)	15 (1%)	91 (4%)	38 (2%)	5 (0%)	27 (1%)	1 (0%)	185 (8%)	964 (42%)
IT	159 (6%)	133 (5%)	467 (16%)	30 (1%)	254 (9%)	1 (0%)	0 (0%)	26 (1%)	1 (0%)	343 (12%)	1438 (50%)
Law	27 (10%)	16 (6%)	36 (13%)	6 (2%)	13 (5%)	1 (0%)	0 (0%)	4 (1%)	0 (0%)	46 (17%)	125 (46%)
Media	405 (7%)	247 (4%)	713 (12%)	45 (1%)	710 (12%)	8 (0%)	4 (0%)	70 (1%)	22 (0%)	555 (9%)	3293 (54%)
My Health Record	48 (4%)	141 (11%)	21 (2%)	1 (0%)	22 (2%)	457 (34%)	350 (26%)	74 (6%)	0 (0%)	5 (0%)	213 (16%)
PHN	49 (6%)	56 (7%)	1 (0%)	0 (0%)	3 (0%)	675 (80%)	17 (2%)	28 (3%)	0 (0%)	1 (0%)	12 (1%)
Patient Group	53 (6%)	52 (6%)	26 (3%)	3 (0%)	59 (7%)	105 (12%)	29 (3%)	0 (0%)	227 (26%)	50 (6%)	257 (30%)
Politician	10 (2%)	9 (2%)	10 (2%)	1 (0%)	25 (6%)	2 (0%)	0 (0%)	1 (0%)	9 (2%)	19 (5%)	324 (79%)
Privacy Advocate	369 (7%)	337 (7%)	431 (9%)	57 (1%)	385 (8%)	0 (0%)	0 (0%)	21 (0%)	7 (0%)	569 (11%)	2807 (56%)
Public	163 (3%)	201 (4%)	360 (6%)	40 (1%)	411 (7%)	1 (0%)	0 (0%)	42 (1%)	16 (0%)	550 (10%)	3843 (68%)

Figure 3. The numbers of retweets by users in different categories.

In addition, we analysed the likes among user categories, and the results are shown in Figure 4. Some insights include:

- Tweets from Politicians (81%), Privacy Advocate (64%), Media (57%), IT (56%), Academic (52%), Law (50%) and Clinician (41%) categories were liked by Public, which were higher than the percentages of retweets in general.
- 39% of the posts from Clinicians were liked by their peers; 38% of PHN's tweets were also liked by other PHN accounts (green shaded).
- Information from MHR accounts was liked mostly by PHN accounts (33%),

Public (21%), Clinician (17%) and themselves (12%), in order (blue shaded).

- Politician, Media and Privacy Advocate groups did not like any tweets from MHR and PHN categories (red shaded).

Liked by → Sent by ↓	Academic	Clinician	IT	Law	Media	My Health Record	PHN	Patient Group	Politician	Privacy Advocate	Public
Academic	231 (16%)	132 (9%)	144 (10%)	11 (1%)	89 (6%)	6 (0%)	3 (0%)	23 (2%)	3 (0%)	48 (3%)	743 (52%)
Clinician	88 (4%)	899 (39%)	206 (9%)	8 (0%)	82 (4%)	16 (1%)	16 (1%)	25 (1%)	2 (0%)	41 (2%)	943 (41%)
IT	178 (9%)	145 (7%)	353 (18%)	20 (1%)	86 (4%)	1 (0%)	5 (0%)	10 (0%)	6 (0%)	87 (4%)	1122 (56%)
Law	31 (15%)	17 (8%)	29 (14%)	4 (2%)	5 (2%)	0 (0%)	0 (0%)	1 (0%)	0 (0%)	13 (6%)	101 (50%)
Media	401 (9%)	281 (6%)	595 (13%)	24 (1%)	296 (7%)	1 (0%)	10 (0%)	33 (1%)	10 (0%)	240 (5%)	2521 (57%)
My Health Record	57 (5%)	194 (17%)	44 (4%)	7 (1%)	0 (0%)	131 (12%)	369 (33%)	74 (7%)	0 (0%)	0 (0%)	234 (21%)
PHN	88 (11%)	105 (13%)	19 (2%)	0 (0%)	3 (0%)	218 (27%)	307 (38%)	45 (6%)	0 (0%)	0 (0%)	28 (3%)
Patient Group	58 (9%)	64 (10%)	30 (5%)	2 (0%)	18 (3%)	51 (8%)	55 (9%)	179 (28%)	1 (0%)	7 (1%)	182 (28%)
Politician	6 (2%)	8 (3%)	17 (5%)	1 (0%)	11 (3%)	1 (0%)	1 (0%)	2 (1%)	5 (2%)	9 (3%)	258 (81%)
Privacy Advocate	265 (7%)	228 (6%)	396 (11%)	42 (1%)	184 (5%)	0 (0%)	2 (0%)	10 (0%)	12 (0%)	162 (4%)	2332 (64%)
Public	210 (4%)	150 (3%)	363 (8%)	35 (1%)	217 (5%)	4 (0%)	3 (0%)	32 (1%)	30 (1%)	205 (4%)	3524 (74%)

Figure 4. The numbers of likes by users in different categories.

3. Discussion

In this section, we discuss several insights including the overall trends, the political nature of the discussion, the observations of the MHR accounts and other types of users.

Firstly, the trend of the ongoing discussion about MHR was driven by the key events such as the start, the extensions, and the end of the opt-out arrangements. From Figure 3 we observe that the bursts were caused by the increased participation from people in IT, Media, Privacy Advocate and Public (uncategorised users) categories. The ratios of the messages posted were higher than other times. Generally speaking, this pattern follows the findings from other research which suggests that conversations about public health are often driven by key news events and media coverage [13].

Additionally, the results suggest that the discussion of MHR on Twitter were very political. This is demonstrated by the extreme high presence of the hashtag "auspol" and "thedrum" (which is a TV news commentary show), as well as the participation and the diffusion by politicians' accounts. The political nature attracted many media accounts to report on the MHR, which led to greater participation from individuals for discussing the issues. However, in such an atmosphere, it was hard to exchange views on the actual features, clinical benefits, design issues and potential improvement of the MHR system. As suggested by previous work, when political messages are the centre of the discussion, people tend not to talk about the actual health and medical issues [14].

A retweeted post is information propagation from one user to another [15,16]. The higher numbers of retweets indicate the messages can reach more audiences and propagate further. In terms of the information dissemination, our results show that the tweets from the official MHR accounts were less effective than other user groups. In fact, more than half of their tweets were retweeted by MHR and PHN accounts, and only a small portion was retweeted and liked by Public. If the ADHA and the MHR team would like to convey the messages to general users, they have to analyse why their tweets were not attractive and refine their strategies of using SNSs.

Likes (also known as favourites) are used to show appreciation or "thanks" on Twitter [17], thus the numbers of likes represent levels of engagement demonstrated by the readers. As tweets from the MHR user category were mostly liked by Clinician, PHN and MHR themselves, the messages appeared to be more engaged by health professionals, rather than general Twitter users who have a wide range of background from patients,

health consumers, to healthy people. Some research has shown that the content on MHR requires higher health literacy and is not targeted for the patient cohorts who need the system [18]. Our finding suggests that their campaigns on Twitter have similar shortcomings. There was a disparity between the content and the audience.

Another observation is that none of the politicians was interested in the tweets from the MHR group, including the Minister of Health who oversees the ADHA and the MHR system. Given that the tweets from politicians have a strong impact (e.g. 79% of their tweets were retweeted and 81% were liked), getting their support and leveraging their power on SNSs can be good strategies to disseminate information about the uptake of electronic health systems and to further improve the public's understanding.

In contrast, professional groups such as academics, medical/health practitioners, IT/cybersecurity experts and law professionals had higher engagement with other users. Therefore, their tweets were more powerful and reached further to disseminate information. Their participation also enriched the discussion over MHR by adding their expertise into the debate. On the other hand, the results imply that privacy advocates had a strong position against MHR as they retweeted and liked none of the posts from MHR.

4. Conclusion and Future Work

We present an analysis on Twitter posts about MHR in this paper. Our study reveals that the conversations are driven by key events of opt-out and highly political. In addition, some professional user groups are more effective to engage with users, while the propagation and engagement of the MHR official accounts have a high potential for improvements. Participation and engagement on SNSs are now parts of public debates. Although the aim of this paper is not to suggest that the debate on Twitter has a huge impact on the public's decision-making for the MHR opt-out, the Government and health agencies still need to be prepared for better use of new media to effectively educate and communicate with different stakeholders.

One limitation of our study is that we have not analysed whether the engagement is positive or negative. Additionally, the manual coding of user categories does not cover all users and may contain errors. For future work, we plan to perform sentiment analysis on the dataset and to generate themes from the text content. These will inform models for promoting the uptake of mandatory electronic health records to health consumers.

Acknowledgement

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