

Community-Sourced Itinerary for HPV Vaccine: A Case Study of the Use of WeChat Group to Reconstruct Healthcare Solution

Xiaojuan Ma

mxj@cse.ust.hk

Hong Kong University of Science and Technology

ABSTRACT

In this case study, we investigate how women members of two selected WeChat groups apply a community-sourcing method to compile their HPV vaccine itinerary.

ACM Reference Format:

Xiaojuan Ma. 2019. Community-Sourced Itinerary for HPV Vaccine: A Case Study of the Use of WeChat Group to Reconstruct Healthcare Solution. In *Proceedings of CHI Workshop on Unpacking the Infrastructuring Work of Patients and Caregivers around the World (CHI 2019)*. ACM, New York, NY, USA, 3 pages. <https://doi.org/10.1145/nmnnnnn.nnnnnnn>

1 INTRODUCTION

Cervical cancer is the fourth most common cancer among women, with an estimated 530,000 new cases worldwide in the year 2018 [10]. Human papillomavirus (HPV) vaccines are the best approach that exists for prevention and control of cervical cancer as well as reducing the risk of other HPV-related cancers or diseases [5]. Over 160 countries have approved the use of HPV vaccines since 2006, but many low- and middle-income countries still have no or limited access to the medicine.

In China, cervical cancer is the most common cancer of female genital system with an increasing incidence rate and high mortality rate [8]. It is only until the year 2016 that the China Food and Drug Administration (CFDA) approved HPV vaccine for the first time. This move has evoked public awareness about the risk of HPV and raised the demand for immunization as a result. However, delayed and limited medicine supply as well as the high price and various restrictions (e.g., age) entailed hinders the widespread use of HPV vaccines across China. As an alternative, many female mainland China residents who are at considerably high risk of cervical cancer seek to get HPV vaccination in other regions or countries (e.g., Hainan province, Hong Kong SAR, Singapore, Korea, New Zealand, etc.). This phenomenon creates a profitable vaccine tourism business, which, however, may impose unintended pressure on the medical service system at the destination and ultimately hurt local healthcare consumers as well as those from China [3, 11].

To ensure successful completion of a full regime of HPV vaccination (e.g., the Gardasil 9 vaccine requires three injections over 12 months), one needs to plan multiple trips carefully and stay tuned

for the most up-to-date information on drug supply, price, and policy during the entire course. In this case study, we investigate how women (in mainland China and Hong Kong) exploit community intelligence in social media – through WeChat group in particular – to chart their HPV vaccine itinerary.

2 CRISIS OF HPV VACCINE TOURISM

Hong Kong SAR, one of the closest neighboring regions of mainland China with the most recent HPV vaccine available for sale, is a popular destination of HPV vaccine tourism. Taking a vaccine tour is not cheap. As an estimation [9], a client is generally charged for the vaccine itself (HK\$1,200 ~ HK\$1,700 per dose × 3) + a possible private sector consultation fee (HK\$800+ per visit and/or a possible jabbing fee of HK\$100, varying per clinic and doctor). The total cost is around HK\$6500 ~ HK\$8000 (about \$800 ~ \$1000) plus fees paid to the agency and other travel expenses [6]. Since Merck & Co.'s Gardasil 9 became available in Hong Kong, it is reported that over two million women from mainland China have taken the vaccine trip [6]. In 2017 alone, it is estimated that 90 percent of the 800,000 doses of Gardasil 9 administered in Hong Kong were sold to mainlanders [3], creating a huge business.

Accordingly to the Department of Health of Hong Kong SAR, the three types of HPV vaccines (namely 2-valent, 4-valent, and 9-valent vaccine¹) currently available in Hong Kong are all prescription-only drugs that can only be applied after clinical assessment by locally registered doctors [5]. In other words, one can only receive HPV vaccination from a registered doctor at his/her practicing address which could be a hospital, a medical center, or a clinic. Take the 9-valent (Gardasil 9) vaccine as an example. A client has to visit the doctor three times at least to administer the three shots required for the full course (if aged 15 and above) within a year at specific intervals. One critical issue is that the doctors usually only prescribe one shot at a time. The clients are thus vulnerable to fluctuations in the supply and price of the medicine. Even though many vaccine tourists sign a contract with privately-run clinics² and put down a full payment upfront with the help of some travel agencies or insurance agencies, there is still no guarantee that they can complete the full course as planned [11].

Many of such unfortunate incidents happened in Hong Kong in the year 2018. It started with Merck & Co.'s temporary shut down of drug production due to a cyber attack in mid 2017 [7]. The imbalance between disrupted production and pressing demand quickly drained Hong Kong's HPV vaccine supply. Thousands of clients, many of whom had already finished one or two shots, were informed that they could not take the injection(s) as scheduled

Permission to make digital or hard copies of all or part of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for components of this work owned by others than ACM must be honored. Abstracting with credit is permitted. To copy otherwise, or republish, to post on servers or to redistribute to lists, requires prior specific permission and/or a fee. Request permissions from permissions@acm.org.

CHI 2019, May 4–9, 2019, Glasgow, Scotland UK

© 2019 Association for Computing Machinery.

ACM ISBN 978-x-xxxx-xxxx-x/YY/MM...\$15.00

<https://doi.org/10.1145/nmnnnnn.nnnnnnn>

¹The number indicating how many HPV genotypes the medicine can cover [5].

²HPV vaccination program of the public sector and charity sector mainly serve age-appropriate girls and young women of low-income background [9].

because of a shortage of the jabs and that the contract had to be terminated on a short notice [3]. Even if these clients got a refund for the remaining course, the time and money they had already spent would have gone to waste. If they wanted to purchase a single shot separately, the price was around HK\$3500 per dose during that critical period, double the normal price.

Both mainland and Hong Kong local healthcare consumers were hit by the vaccine crisis. It is reported that, by the first week of June 2018, the Hong Kong government’s Customs and Excise Department had received 3,423 complaints involving HPV injections, and its Consumer Council had recorded over 1,000 complaints about HPV vaccine delays [3]. Many of the medical tourists who failed to receive HPV vaccination as intended formed several chatting groups (400 to 500 members each) on WeChat, the most popular multi-purpose messaging service in China, to complain about their cases and discuss about possible (legal) actions to take over the issue [11]. In the meantime, more and more women in both mainland China and Hong Kong who still demand immunization against HPV turn to various WeChat groups for information and advice before they commit to the course of vaccination. In this case study, we use the conversations around HPV vaccination in two selected WeChat groups as a lens to explore how people use this platform to construct their vaccine itinerary collectively.

3 COLLECTIVE CONSTRUCTION OF VACCINE ITINERARY

WeChat group is a feature provided by WeChat that allows multiple users (up to 500) to communicate in the same channel. Every message posted in the group chat is visible to all group members. A WeChat user can join multiple groups, which may vary in size, community composition, and purpose. We choose two representative WeChat groups (denoted as **CN** and **HK** in the rest of the paper) to investigate how members use this platform to plan for HPV vaccination in the year 2018 – a period during which Hong Kong experienced vaccine supply scramble and recovery. CN is the female alumni network of an organization based in mainland China. Most of its members are women who were born and raised in China, but may now work and live in different regions and countries after leaving the organization. HK is a community for (female) employees and (female) family members of a local organization in Hong Kong. A considerable number of these women came to work in Hong Kong from mainland China, and many of them live in the same neighborhood close to the organization. Both WeChat groups had over 200 members by the end of 2018 (Table 1). Women in these two communities are generally health-conscious and are likely to be interested in measures that can protect them against cervical cancer.

For each group, we first extract all messages related to HPV vaccine by searching for questions containing the keyword and all the subsequent replies, and then transcribe and paraphrase the messages for privacy protection. We obtain over 500 HPV-related messages (questions and replies) from CN and more than 150 messages from HK during the entire year of 2018. We further conduct thematic analysis on the processed data to identify the most popular topics under the theme. Table 2 summarizes the frequency of questions under each topic with examples. In general, through the

Table 1: Basic information of the two Wechat groups .

Data as in the year 2018	CN	HK
Size	283	228
Composition	alumni	(family) member
Gender	female only	female mainly
No. HPV-related messages	538	156

Table 2: Distribution of questions in the two WeChat groups.

Topic of Question and Example	CN (73)	HK (25)
General question about HPV vaccine “What is the difference between 4-valent and 9-valent?”	7	-
Applicable condition “It is true that the vaccine is ineffective after certain age?”	15	7
Availability in certain region/country “I only have one shot left. Which country in Asia offers 9-valent?”	26	3
Trusted source of supply “Does AliHealth provide HPV [vaccination program]?”	9	10
Price (and insurance plan) “What’s the total cost of getting the vaccine in Hong Kong?”	7	3
Process “How can I get into the waiting list?”	4	2
Side effect “What’s the probability of having allergic reaction to the vaccine?”	5	-

conversations people can get a better sense of the importance of the vaccine, whether they should administrate it, where the vaccine is approved for sale, place to get a prescription (with good service), as well as the cost, process, and potential side effects.

4 COMMUNITY-SOURCING AS A LOW-COST SOCIOTECHNICAL SOLUTION

Wechat group provides a channel for collectively infrastructuring healthcare solutions at a low *transaction* cost – “the cost of ensuring that the information actually is true” [2] given the nature the communities, and at a lower *information* cost – “the cost of gathering information on the assumption that it is true” [2] given the relatively high media synchronicity of the platform.

4.1 Building Trust to Reduce Transaction Cost

There are several possible reasons why people trust these particular WeChat groups and turn to them for help on health-related matters. First, unlike many existing question-and-answer sites and online forums on which users are often anonymous and/or have no offline connections, the two WeChat groups we study are online extension of actual physical communities. People join the groups by invitation of existing members with identify verified and relevance justified. This to a large extent brings down the chance of some random person spamming or self-advertising for profit. Any pieces of information circulated in the group chat would have been filtered

by their posters – a kind of gatekeeping through social ties [1], and thus may be deemed more trustworthy than those published by some unknown or unreliable parties on the Internet. Take the CN group as an example. When members post news or tips about HPV vaccine, they often acknowledge the source to show the credibility of the information, such as attaching a photo at the scene, referring to a post of an authorized government agency or news media, quoting the physicians they have consulted personally, etc.

Second, members in these two groups are mainly (if not all) women amongst high-risk age group for cervical cancer and other HPV-related diseases. They tend to have similar education background (university or higher) and similar socioeconomic status. These women are likely to be aware of the risk of cervical cancer and thus are interested in ways that can protect them against HPV. Given their relatively high sensitivity to the subject, it is possible that some members have already looked into solutions that are applicable to other people in the group. In other words, they are capable of eliciting useful information about cervical cancer prevention and control. For instance, a member complained in the HK group chat that parallel imports were flooding the Hong Kong vaccine market and she had a hard time finding a reliable private sector. Another member soon posted a few photos of the dealer-imported vaccine that she purchased from an authorized medical center to teach people how to read the labels. In another case, someone asked about the quality of service of a private clinic in the HK group, and another person replied that, “*My friend is going there for vaccination tomorrow. I will update you [on its service] once she returns.*”

Third, as HPV infection and cervical cancer happen in the female genital system and the effectiveness of the vaccine is related to history of sexual activities [5], many people may feel uncomfortable talking about related issues in public, especially in Chinese culture. The WeChat group – CN in particular, creates a close community in which members are less concerned about face management. They are willing to share personal experiences, provide first-hand information, and discuss sensitive matters (“*bold*” or “*politically incorrect*” topics in people’s own words) with an open mind, which makes the solutions constructed more credible and valuable. For example, a girl in the CN group described the severe side effect (“*short of breath, intense stomachache, and cold sweat*”) she experienced after taking the first HPV injection and advised others to try to avoid taking the shot during menstruation.

4.2 Cultivating Community to Minimize Information Cost

Another benefit of using the selected WeChat groups as a source of collective knowledge is the ease of getting the most up-to-date, relevant information. Compared to many ad-hoc chatting groups that are lack of maintenance, the two online communities we studied are rather stable and active. Group members have foster a culture of caring for and helping one another. Whenever a question is posted, responses often arrive within minutes. This is close to synchronous communication in a single conversational thread, while in many forums or Q&A sites requests from people in need of immediate feedback may be left unattended for days if not weeks. Also, knowing that many women in the community are interested in HPV vaccine, whenever they come across some related information

people will voluntarily broadcast it in the group chat. For example, members reported in the HK WeChat group that “*Many clinics have stopped booking HPV reservations. Some cannot deliver the drugs to those with contract in the past two days.*” in May 2018 and that “*Vaccine shortage is less severe now.*” in October 2018.

In addition, people can direct their questions to a specific member using the @ function in WeChat, to further boost the efficiency of information gathering. For example, a girl in the CN group directly consulted an alumnus who went to worked in Hong Kong for five years after leaving the organization about her vaccine experience there. In the HK group, a member who received vaccination at a clinic near the neighborhood got many direct messages about its price and service. In these cases, member familiarity within the group lowers the cost of grounding [4], compared to the situations in conventional online health communities.

In summary, community-sourcing is particularly good in situations where individuals only have access to partial information or they demand trustworthy (second) opinions.

5 CONCLUSION

Though a case study on HPV vaccine and WeChat group, we explore the benefits of community-sourcing as a low-cost sociotechnical solution to planning a path to intended healthcare service.

ACKNOWLEDGMENTS

To Fang, for the support and discussion.

REFERENCES

- [1] Karine Barzilai-Nahon. 2009. Gatekeeping: A critical review. *Annual Review of Information Science and Technology* 43, 1 (2009), 1–79.
- [2] Mark Casson et al. 1995. The organization of international business. *Books* (1995).
- [3] Elizabeth Cheung and Karen Zhang. 2018. Hong Kong medical centres under fire after selling HPV cervical cancer vaccine Gardasil 9 when they couldn’t get it. Retrieved February 14, 2019 from <https://www.scmp.com/news/hong-kong/health-environment/article/2151174/hong-kong-medical-centres-under-fire-after-selling>
- [4] Herbert H Clark, Susan E Brennan, et al. 1991. Grounding in communication. *Perspectives on socially shared cognition* 13, 1991 (1991), 127–149.
- [5] the Government of the Hong Kong Special Administrative Region Department of Health. 2018. Human Papillomavirus and Vaccine. Retrieved February 14, 2019 from https://www.cervicalscreening.gov.hk/english/hum/hum_ccv.html
- [6] Bruce Einhorn and Daniela Wei. 2018. China’s Vaccine Tourists Drain Hong Kong’s Supply of Cancer Drug. Retrieved February 14, 2019 from <https://www.bloomberg.com/news/articles/2018-06-13/china-s-vaccine-tourists-drain-hong-kong-s-supply-of-cancer-drug>
- [7] Michael Erman and Jim Finkle. 2017. Merck says cyber attack halted production, will hurt profits. Retrieved February 14, 2019 from <https://www.reuters.com/article/us-merck-co-results/merck-says-cyber-attack-halted-production-will-hurt-profits-idUSKBN1AD1A0>
- [8] Xiyi Jiang, Huijuan Tang, and Tianhui Chen. 2017. Epidemiology of gynecologic cancers in China. *Journal of gynecologic oncology* 29, 1 (2017).
- [9] Health Matters. 2018. Big News! After Shortage, The HPV Gardasil 9 Vaccine is Back in Hong Kong. Retrieved February 14, 2019 from <https://www.healthymatters.com.hk/hpv-vaccine-is-now-back-in-hong-kong/>
- [10] World Health Organization. 2018. Cervical cancer. Retrieved February 14, 2019 from <https://www.who.int/cancer/prevention/diagnosis-screening/cervical-cancer/en/>
- [11] Alice Yan. 2018. Hundreds of mainland women threaten legal action over HPV vaccine shortage in Hong Kong. Retrieved February 14, 2019 from <https://www.scmp.com/news/china/society/article/2147127/hundreds-mainland-women-threaten-legal-action-over-hong-kong>