

Interdisciplinary Learning Health System Response to Public Vaccine Concerns

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Abstract. In Victoria, Australia, jurisdictional vaccine safety service is conducted by SAEFVIC (Surveillance of Adverse Events Following Vaccination in the Community). SAEFVIC developed a public Vaccine Safety Report (saefvic.online/vaccinesafety) to present key surveillance information. This study applies an interdisciplinary learning health system approach to evaluate the report, taking into consideration public expressions of concern on social media.

Keywords. Vaccine safety, vaccine hesitancy, learning health systems, public health report, heuristic evaluation

1. Introduction

Adverse Events Following Immunisation (AEFI) is broadly defined as any possible unwanted medical side effects after vaccination [1]. AEFI may be causally, temporally, or coincidentally linked to vaccine exposure and its administration [2]. Vaccine safety surveillance of AEFI is a critical component of national immunisation programs [1,3]. In Victoria, Australia, jurisdictional vaccine safety services are provided by SAEFVIC through enhanced AEFI surveillance integrated with clinical services for all types of vaccines [4]. Vaccines have reduced the prevalence and incidence of vaccine-preventable diseases. However, as vaccine preventable diseases become less common, some people start to view the risks of AEFI as more serious than the risk of disease [1]. Concerns about COVID-19 vaccine safety and AEFI have been found to be associated with vaccine hesitancy and decreased intention to vaccinate [5]. The impact of these concerns can be amplified when expressed and shared through online social networks and media [6]. SAEFVIC staff experienced first-hand the increased community anxiety on COVID-19 vaccines through phone calls and other correspondence with the public [4]. Transparent communication of vaccine AEFI is associated with improved long-term trust [7]. To provide a medium to communicate vaccine safety data and provide clinicians with an online resource, a public-facing web-based report ('Vaccine Safety Report') was

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developed by an interdisciplinary team of immunisation specialists and epidemiologists (<https://saefvic.online/vaccinesafety>) [4]. Moving forward, SAEFVIC aims to adapt the report to be more accessible to the general public, and directly responsive to their concerns. As part of a larger project called VaxPulse, this study applies an iterative learning health system (LHS) framework that systematically integrates social media data, SAEFVIC data, and interdisciplinary expertise to generate insights towards adapting the Vaccine Safety Report for a general public audience.

2. Methods

An LHS operationalises data collected routinely as part of a digital health intervention into actionable insights to support improved quality and outcomes of health services. The value of LHS is highlighted by a national priority setting process, where establishing it across all Australian National Health and Medical Research Council-accredited research translation centres was identified as top priority [8]. The LHS implemented in this study follows a cyclical, 3-stage process [9], illustrated in Figure 1. In the first LHS stage, Practice generates Data. We used Machine Learning (ML) models to identify personally experienced COVID-19 vaccine reactions [10]. We then applied our ML models on 352,218 Reddit posts collected from January 2021 to June 2022 to identify associated safety concerns expressed by people on social media, where we found myocarditis (inflammation of the heart muscle) and pericarditis (inflammation of the saclike tissue surrounding the heart) as the most discussed COVID-19 AEFI. People expressed concerns, e.g., about higher risks of developing myocarditis and pericarditis from vaccines than from COVID (risk-benefit ratio); the increased risk on younger age groups; and the compound risk from multiple vaccine doses (Table 1). SAEFVIC collects and analyses vaccine surveillance data, presenting, among others, latest information on myocarditis and pericarditis in the Vaccine Safety Report including total number of cases reported in Victoria, rates per dose, and the rates per age group and vaccine brand.

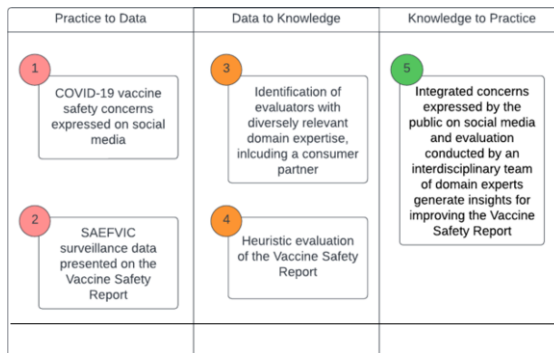


Figure 1. Learning health system towards adapting the Vaccine Safety Report.

Table 1. Example social media posts identified that expressed concern about COVID-19 vaccines.

Myocarditis and Pericarditis Concerns
“if you are young and healthy you are more likely to develop heart issues from the vaccine than COVID”
“are we talking about the myocarditis caused by the shot that we’re expected to have 3x by now how many booster until your heart stops?”

“there are reports of young people getting myocarditis after their second covid shots in the news recently...should I start worrying?”

In the second LHS stage, we transformed the Data generated into Knowledge. We applied a heuristic evaluation process to analyse the Vaccine Safety Report on myocarditis and pericarditis. Heuristic evaluation is a cost-effective usability design method enabling experts to systematically evaluate interfaces such as personal health record systems, and recommend suggestions. The set of heuristics we used was selected based on its systematic development as a tool for evaluation of dashboard visualisations [11], and have been used to evaluate a patient health data portal [12]. Heuristic evaluation benefits from involvement of end users and domain experts, thus the following evaluators were invited to conduct the evaluation: DP is a consumer partner and represents vaccinees; GLD with background in human-computer interaction; JH in consumer engagement; JK in communication and social science; and FM in clinical education and public engagement. The evaluators were first asked to read through the sample social media posts that express concern about the risks of myocarditis and pericarditis associated with COVID-19 vaccines (examples in Table 1). They were encouraged to consider these expressed concerns of the public and note down any comments and suggestions they may have to improve the way information is presented. The evaluators were also encouraged to consider elements of the set of heuristics used that may not be a good fit for evaluating immunisation, vaccine safety, or public health data; or any crucial elements that may be lacking, and offer any recommendations.

In the third LHS stage, the Knowledge gained as lessons and insights will inform Practice. By integrating concerns expressed by the public on social media and a usability design evaluation method conducted by an interdisciplinary team of domain experts, initial insights will be generated for adapting the Vaccine Safety Report.

3. Results

The heuristic evaluation identified design aspects with most areas for improvement, based on proportion of ‘No’ that indicate the Report did not meet usability factor criteria: orientation (‘No’=44%), flexibility and efficiency of use (‘No’=40%), aesthetic and minimalist design (‘No’=38%), information coding (‘No’=33%), & match between system and the real world (‘No’=32%), shown in Figure 2. The evaluators were also asked to give an overall score for each design aspect that rates how severe the identified issues were: 0 for no usability problem; 1 for cosmetic problem; 2 for minor usability problem; 3 for major usability problem, and 4 for usability catastrophe. Table 2 depicts the mean of these ratings, & show that in general there are minor usability issues.

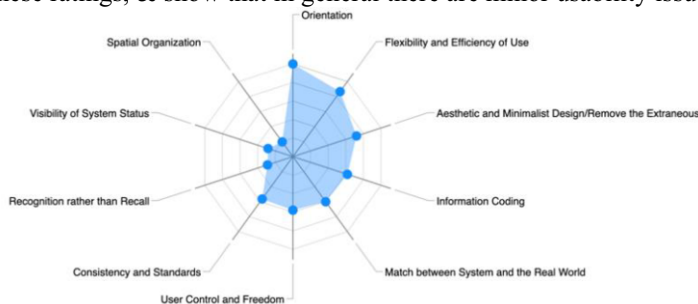


Figure 2. Design aspects with most areas for improvement.

Table 2. Severity scores on each of the heuristic design aspect.

Heuristic	Mean	Heuristic	Mean
Visibility of System Status	2.0	Flexibility and Efficiency of Use	1.0
Spatial Organization	1.8	Information Coding Orientation	1.0
Aesthetic and Minimalist Design	1.4	User Control and Freedom	1.0
Recognition rather than Recall	1.4	Consistency and Standards	0.8
Match between System and the Real World	1.2		

Thematic analysis of heuristic evaluators' comments and suggestions on data presentation provided a number of key recommendations to improve the usability of the visualisations on myocarditis and pericarditis. Table 3 shows the four themes: Audience, relevance of information; User Goals, ease of finding information based on goal; Interactivity, appropriate interactivity and visual cues to aid in understanding data; and Navigation, ease of navigating the web page.

Table 3. Themes, recommendations to improve the Vaccine Safety Report to better respond to public concerns.

Theme	Sample Recommendations
Audience	"There is a huge amount of data available, much more than would be necessary for the average consumer coming here for info on a concern"; "this could be very difficult for a social media user to interpret"
User Goals	"lay readability of the text could be improved, in particular for people who would like to understand the risk-benefit ratio of myo-peri"; "could be interpreted in a negative light as it lacks context"
Interactivity	"good to have different colours to help differentiate between Myo and Peri"
Navigation	"Suggest implementing breadcrumb navigation"

4. Discussion

This study is a learning health system response to the concerns people expressed on social media, particularly on myocarditis & pericarditis. It conducts a heuristic evaluation of Victoria's Vaccine Safety Report towards making it more accessible to the general public, and responsive to their concerns. The social media data guided evaluators where improvements should be focused, highlighted by discovered themes on 'Audience' and 'User Goals'. The evaluation identified design areas that present opportunities for adaptation such as revising text readability based on health literacy of consumers, and decreasing the level of detail in the visualisations. An evaluator suggested developing a 'deck of graphs' that could be presented when public concerns are identified, which could also be useful to refer to media such as news networks. Interestingly, the overall severity scores contrasted with the evaluators' comments. This indicates the utility of the set of heuristics to evaluate dashboard visualisations, but not its utility for evaluating vaccine safety information presented to a concerned public. The use of heuristics is part of a user experience and web designer's evaluation tool kit, & we recommend using additional patient education and health literacy evaluation tools, such as PEMAT [13]. The interdisciplinary LHS approach used in this study identified the strengths & limitations of different domain expertise, & provided valuable insights in our effort to solve the complex challenges of responding to vaccine safety concerns.

5. Conclusions

This study applies a LHS framework with an interdisciplinary team of domain experts, to conduct an initial evaluation of the Vaccine Safety Report. This process could be broadened in the future to include regular, timely analysis of other top social media concerns, matched with cost-effective evaluation of vaccine safety information.

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