REVEALING PATIENT-REPORTED EXPERIENCES IN HEALTHCARE FROM SOCIAL MEDIA USING THE DAPMAV FRAMEWORK

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ABSTRACT

Understanding patient experience in healthcare is increasingly important and desired by medical professionals in a patient-centred care approach. Healthcare discourse on social media presents an opportunity to gain a unique perspective on patient-reported experiences, complementing traditional survey data. These social media reports often appear as first-hand accounts of patients’ journeys through the healthcare system, whose details extend beyond the confines of structured surveys and at a far larger scale than focus groups. However, in contrast with the vast presence of patient-experience data on social media and the potential benefits the data offers, it attracts comparatively little research attention due to the technical proficiency required for text analysis. In this paper, we introduce the Design-Acquire-Process-Model-Analyse-Visualise (DAPMAV) framework to equip non-technical domain experts with a structured approach that will enable them to capture patient-reported experiences from social media data. We apply this framework in a case study on prostate cancer data from /r/ProstateCancer, demonstrate the framework’s value in capturing specific aspects of patient concern (such as sexual dysfunction), provide an overview of the discourse, and show narrative and emotional progression through these stories. We anticipate this framework to apply to a wide variety of areas in healthcare, including capturing and differentiating experiences across minority groups, geographic boundaries, and types of illnesses.

Keywords  Patient Experience · Social Media · Natural Language Processing · Topic Modelling · Sentiment Analysis · Prostate Cancer

1 Introduction

Health systems in countries like Australia represent a significant investment of public resources [1]. There has been increasing interest in not only the activity that such systems generate, but also in better understanding and measuring patient experience and patient outcome [2, 3, 4, 5]. Historically, there has been a focus on using mortality as a measure of outcome [6]. If greater or fewer people die while in the care of a facility, the facility can estimate that it is performing worse or better respectively. Alone, however, this outcome provides an insufficient view of healthcare for complete performance monitoring, as it overlooks many other aspects of healthcare, and potentially capturing ill performance once lives have already been lost [7, 8]. To attain a more holistic approach to performance monitoring, the Australian Health
Performance Framework (AHPF) identifies indicators of health system performance as accessibility, appropriateness, continuity of care, effectiveness, efficiency and sustainability, and safety [9]. As such, these indicators are incorporated into health systems performance monitoring and are effectively measured by hospitals. However, the perspective of a hospital alone is incomplete for a comprehensive assessment of the health system’s performance; there are some aspects of care where patients are the best judges of their health-related outcomes [10].

1.1 Patient-reported experiences are useful

Areas of healthcare where patients may be the best judge include health-related quality of life, physical function, psychological well-being, subjective symptoms such as pain, social function, and cognitive function [10]. The World Health Organisation has identified the importance of patient engagement in benefiting healthcare systems, processes, and policies [11]. Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) have been developed to capture patient feedback and address the gap in healthcare performance monitoring by harnessing the patient’s perspective [12]. This feedback is vital in providing quality healthcare that matches the public’s expectations. It facilitates the alignment of resources with patient priorities and can act as an accountability structure [13]. Due to its importance, patient-reported feedback is used in performance indicators for many institutions [14].

1.2 Traditional methods of capturing patient-reported experience overlook insightful information

Surveys have been the traditional tools of choice for capturing patient-reported experiences. For example, the Australian Commission on Safety and Quality in healthcare released the Australian Hospital Patient Experience Question Set (AHPEQS) – a core set of satisfaction questions – as a tool that hospitals can use to capture patient-reported experiences [15]. This survey captures aspects of patient feedback related to general satisfaction in a multiple-choice format. For example, Question 1 states ‘My views and concerns were listened to’, with the prescribed responses ‘Always’, ‘Mostly’, ‘Sometimes’, ‘Rarely’, ‘Never’, and ‘Didn’t apply’. Other questions relate to needs being met, feeling cared for, feeling involved, feeling informed about care, communication, pain management, confidence in safety and care, unexpected harm, and overall quality of care, all with similar programmed answers. The full set of questions is provided in Appendix A in Table 4.

While surveys such as the AHPEQS capture specific areas of patient feedback, they are often restricted by their predefined scope and generality. These rigid surveys can result in blind spots in understanding the patient journey. For example, the AHPEQS asks whether ‘individual needs were met’, but there is no scope to capture the patient’s specific needs. The AHPEQS also asks how often the patient ‘felt confident in the safety of their treatment and care’, yet does not facilitate the patient to outline when or where they felt unsafe. Deployment of these surveys is time-consuming, involving research and approval to ensure that the survey meets specific needs. While this is to the benefit of a survey in its ability to capture necessary information, it leads to a delayed deployment. Hence the survey may miss critical, time-dependent data. To ensure that patient-reported experiences are captured more thoroughly through survey, sufficiently long surveys are necessary. Survey length, however, is negatively associated with respondent rate [16]; balance must be struck between respondent rate and survey length. Another tool that plays a role in capturing patient-reported experience is the focus group. Focus groups have more freedom in their scope than surveys and hence have may have fewer blind spots. However, they are time-consuming, difficult to scale to get a population-level understanding of patient experience, and lack generalisability to the broader population [17]. The primary purpose of the focus group in this setting is to be an exploratory tool that can direct survey questions to align with areas of patient concern [18]. In order to effectively capture patient experience, patients need freedom to discuss relevant issues that allow for unconstrained reports of patient experience and patient outcome at an appropriate scale that neither surveys nor focus groups offer.

1.3 Social media is a rich source of information

Social media hosts vibrant forums featuring the discussion of topics related to social issues [19, 20]. These discussions are information-rich and may provide meaningful insights into how complex issues are perceived at individual and community levels. As users determine discussion topics and their details, the discussion often corresponds to social issues relevant to their respective communities [21]. The broad coverage of issues is directly aligned with areas of social concern. As many of these insights have the potential to be highly valuable, there is a growing demand for their capture [22, 23, 24]. Social media, therefore, rapidly being adopted by researchers as a tool to explore these social issues to uncover valuable insights into public opinion [25, 26, 27]. However, social media data is unstructured. This lack of structure introduces a challenge, as structured data is far easier to analyse at scale. Technological improvements in natural language processing aid in revealing latent structure in otherwise unstructured data. While this means researchers have pathways to analyse social media and other unstructured data at scale, this pathway is often inaccessible to those
Table 1: Number of daily active users [36, 37, 38] and Google Scholar search results for Facebook, Reddit, and Twitter using search terms patient experience and or Natural Language Processing. Retrieved 29 June, 2022. Table 3 shows the exact Google Scholar search terms, corresponding to the column Search Key

| Search Key (See Table 3) | Facebook       | Reddit         | Twitter        |
|--------------------------|----------------|----------------|----------------|
| Daily Active Users       | 1,920,000,000  | 50,000,000     | 229,000,000    |
| -                        | 6,790,000      | 2,150,000      | 7,580,000      |
| Patient Experience       | 17,400         | 15,200         | 17,700         |
| Natural Language Processing | 82,300    | 20,900         | 119,000        |
| Patient Experience + Natural Language Processing | 1,050    | 260            | 1,130          |

without a technical background. There is a need for guidance in analysing unstructured data for researchers with a non-technical background.

1.4 Social media hosts patient-reported experiences

Discussion around healthcare is widespread on social media platforms such as Twitter, Facebook, and Reddit [28, 24]. Here, patients have the scope to discuss what is important to them in as much detail as they want. Due to its anonymity and lack of direct face-to-face interactions, social media has been evidenced to elicit high levels of self-disclosure in people, who tend to reveal themselves more intimately than in face-to-face interactions [29]. This level of self-disclosure may make social media a rich source of information for revealing personal patient-reported experiences to researchers. Healthcare systems may utilise this information to improve their facilities and procedures. Researchers have called for mining social media data as a complementary tool to improve healthcare systems [24]. To aid future researchers in deciding which platform to gather patient experience data from, we summarise the research use of Twitter, Facebook, and Reddit and assess their appropriateness in the context of patient-reported experiences.

1.5 Social media research in patient-reported experiences

Table 1 shows that there are over 15,000 Google Scholar search results for articles related to patient experience. Examples of these can be seen for Facebook [30], Reddit [31, 32, 27], and Twitter [33, 34, 35]. There is a rapid growth of social media research related to patient-reported experiences. Figure 1 shows exponential growth in the number of Google Scholar search results for a combined search of Natural Language Processing and patient experience. These Google Scholar searches were made using the following search terms under conditions that will be subsequently described.

\[[social media platform] AND 'natural language processing' OR 'NLP' AND 'patient experience' OR 'patient experiences' OR 'patient reported experience' OR 'patient reported experiences'\]

The text [social media platform] was replaced with ‘Facebook’, ‘Reddit’, and ‘Twitter’. The search was filtered by date to find the cumulative number of articles that had been published by each successive year.

1.6 Social media research overview

Twitter, a popular social media platform, is often the subject of research [39]. On Twitter, users post online in the form of tweets. Prior to October 2018, these tweets were limited to 140 characters and now are limited to 280 characters. Tweets may contain hashtags that allow users to tag keyword phrases that correspond to specific topics or issues. Reddit, colloquially known as the ‘front page of the internet’, is another social media platform that receives attention from researchers [40]. Discussion on Reddit occurs in a different form to that on Twitter. On Reddit, users post to communities that cover specific topics, known as subreddits. A user may create a new post to a subreddit or may post a reply to another user’s post or reply. Facebook is another social media platform that attracts attention from researchers. On Facebook, discussion often occurs in the form of posts and replies made to users’ walls, groups, businesses’ walls, and other pages.

Twitter is the most frequent subject of research, with approximately 1.1 times and 3.5 times more Google Scholar search results than Facebook and Reddit respectively, seen in Table 1. One possible mechanism for Twitter’s research
Figure 1: Cumulative Google Scholar search results for articles related to Natural Language Processing and patient experience for social media platforms; Facebook, Reddit, and Twitter. A binary logarithm transformation has been applied to the y-axis.

popularity over Reddit’s could be Twitter’s greater popularity, having 4.49 times more daily users than Reddit, also seen in Table 1. With almost ten times more users than Twitter, Facebook is underrepresented in research articles per daily active user. This underrepresentation may be explained by restrictions imposed on Facebook’s data accessibility in response to the 2018 Cambridge Analytica data scandal [41, 42]. The widespread use and data policies of Twitter and Reddit make them suitable platforms for research over other platforms such as Facebook, whose data policies are more prohibitive for research [43].

Twitter has no prescribed community structure for the discussion of specific topics. Topics on Twitter are optionally discussed through the use of hashtags. This approach allows posts to be identified as belonging to multiple topics simultaneously. Reddit, contrastingly, has no obvious method for cross-topic discussion. Reddit’s structure instead necessitates posting to exactly one subreddit. This subreddit usually hosts most of the discussion around that topic, creating a sense of community. One study noticed that in the context of the ‘Me too’ movement, discussion on Twitter was less personal than on Reddit and instead focused on encouraging others to speak up [44]. Reddit’s lack of post character limit that Twitter enforces may make it a more suitable platform for deeper discussion surrounding healthcare, as users do not need to restrict the content they share to fall under the character limit.

1.7 Challenges of using social media data

Surveys offer a highly structured medium to collect public opinion data. This structure results from targeted questioning in conjunction with predefined multiple-choice answers. The structured format allows responses to be tallied into a
format that lends itself to analysis. Free-text data, however, lacks the structure possessed by surveys and imposes a significant obstacle in eliciting patient-reported experiences from social media data [45]. Natural Language Processing (NLP) models aim to address this lack of structure by using statistical and machine learning models to uncover latent structure [46]. This structure reveals patterns or trends across corpora that allow for an at-a-glance understanding of the content of the documents that close reading is not needed to obtain. Once this latent structure has been uncovered, we can enjoy data ripe for analysis.

1.8 The need for a guiding framework

Natural language processing tools are usually applied by researchers with a technical background. Many of these tools are left inaccessible to a non-technical person. Many healthcare researchers and practitioners without the background necessary to know how these tools should be applied, yet the domain knowledge to make the most of them, are unable to mine\textsuperscript{1} social media text to uncover patient-reported experiences. This dichotomy motivates the need for a generalised reproducible framework that facilitates healthcare researchers to exploit free-text narratives. We introduce the Design-Acquire-Preprocess-Model-Analyse-Visualise (DAPMA V) framework to meet this need. The DAPMA V framework outlines the complete process from the design of the problem to the visualisation of results for text analysis from social media discourse.

This framework will be explored through the lens of prostate cancer discussion. Aside from non-melanoma skin cancers, prostate cancer is Australia’s most commonly diagnosed cancer (21,808 diagnoses in 2009). It is also the fourth leading cause of death amongst Australian men (3,294 deaths in 2011) [47].

| DAPMA V Framework for Social Media Analysis |
|-----------------------------------------------|
| **Design** | **Aquire** | **Preprocess** | **Model** | **Analyse** | **Visualise** |
| Find relevant subreddit | Web scrape subreddit | Tokenize | Topic modeling | Construct topic wordclouds | Input word |
| Specify subreddit | Sample if necessary | Remove stopwords | Topic output | Construct topic densities | Topic visualized & density |
| Yes | | Remove small docs | | | |
| Data | | Remove uncommon words | Sentiment-Topic Correlations | | |
| Sampled Data | | | Sentiment analysis | | |
| | | | | | |

Figure 2: Design-Acquire-Process-Model-Analyse-Visualise (DAPMA V) framework for analysis of social media discussion relating to patient-reported experiences.

2 DAPMA V Framework

2.1 D - Design

The design stage is the first stage in the DAPMA V process, summarised in the first column of Figure 2. In the design stage, we choose a relevant social media data source. In this example, we will walk through the steps to find relevant data on Reddit. Following this choice, we select the time frame to collect the posts in.

\textsuperscript{1}To analyse and draw insights from data at scale.
One way to select the subreddit would be to use the Reddit search bar to search for the overall theme of the discussion and select a relevant community from the communities tab. Consider for this example that we are interested in observing prostate cancer discussion. We type ‘Prostate Cancer’ into the search bar. This is seen in Figure 3a. The results of this search are seen in Figure 3b, where we have navigated to the communities tab. We notice a specific prostate cancer community called ‘/r/ProstateCancer’. We can click on this community to be taken to the subreddit (Figure 3c). We see posts made by Reddit users, an About Community, as well as flairs, and post tags entered by users that can be filtered. We can explore the posts to ensure they are relevant to the conversation we want to capture. If so, we move on to specifying our timeline.

The About Community box on the right-hand side of Figure 3c shows that the subreddit was created on August 19, 2010. This date may be important as some subreddits may be too new for their intended research purposes.

2.2 A - Acquire

Data acquisition is the second stage of the DAPMA V process, summarised in the second column of Figure 2. In the data acquisition process, we retrieve the Reddit posts in the subreddit that we wish to analyse from the period specified in the design phase. We obtain the Reddit posts using the Pushshift Application Protocol Interface (API), an interface to the Pushshift archiving platform that provides researchers access to Reddit data [48]. The choice of the Pushshift API may be favourable to Reddit’s API as it offers a greater rate of post-acquisition [48].

Social-media datasets are vast and may have entries in the order of millions or billions. Computationally demanding algorithms inhibit the rapid exploration of large text datasets. To avoid lengthy processing, we can thin out our text data to reduce the size of the dataset, if necessary. As a means of thinning out our dataset, we can sample the documents in our corpus without replacement. The number of samples we take will determine the speed of our analysis. The amount that is thinned out, if thinning is necessary at all, will be determined by the researcher’s intent. If, in the later analysis, we find results lack specificity, we may want to thin the dataset out less.

Reddit posts also may be tagged in certain ways. As an example, the subreddit ‘/r/COVID19Positive’ can have posts tagged with the flairs ‘Question-for medical research’, ‘Tested Positive - Family’, ‘Presumed Positive - From Doctor’, ‘Tested Positive - Me’, ‘Question-to those who tested positive’, and finally ‘Tested Positive’. These flairs give us additional data about posts we may want to consider. In particular, if we are only interested in posts relating to a particular flair, we can filter out the other flairs to reduce the run time of the models and potentially improve the specificity of the results. However, in cases with limited data, including additional yet largely relevant flairs may improve the model’s performance.

2.3 P - Preprocess

Preprocessing is a preliminary form of data processing prior to the principal analysis that prepares the data to be in a form that is suitable, effective, and efficient for the required analysis [49]. Efficiency is primarily centred around finding a representation of the data that reduces the feature space while maintaining as much relevant information as possible. In this section, we outline basic procedures typically used for text analysis [50, 51].

2.3.1 Tokenize

Tokenization is the process of deconstructing text into a list of distinct units, called tokens [50]. A token may be a unigram (a single word), a bi-gram (two consecutive words), more generally, an n-gram (n consecutive words), a sentence, and many other things.

2.3.2 Remove Stopwords

When conducting text analysis, we may wish to remove a list of words, denoted stopwords, from the corpus [46]. Words that are often considered stopwords are common words that add little contextual information. Examples of stopwords include ‘the’, ‘and’, ‘of’, and ‘in’. Removal of these words decreases the dimensionality of the data, thereby reducing the computational complexity and hence the time taken to model.

2.3.3 Remove Small Documents

Excessively small documents may be removed in text preprocessing [52]. Small documents may not contain sufficient information to be valuable, depending on the context of the data and the research question. Including small documents may dilute the effectiveness of the results while also increasing the computational complexity. Researchers will benefit
(a) Using the Reddit search bar to search for Prostate Cancer. Once the search term is entered, we can click **Search for ‘Prostate Cancer’** to perform the search. Results are seen in Figure 3b.

(b) Reddit search results for **Prostate Cancer**, performed in 3a. The first result is a community titled /r/ProstateCancer. We click on this entry to navigate to the /r/ProstateCancer subreddit, seen in Figure 3c.

(c) Prostate Cancer subreddit resulting from the searches made in Figures 3a-3b. Posts can be seen in the left column (blurred for anonymity), and details about the community can be seen in the right column.

Figure 3: Process of finding a relevant subreddit.
from assessing their needs based on the context of their problem and the size of their dataset when deciding whether or not to set a minimum document length threshold.

2.3.4 Remove Uncommon Words

Removal of uncommon words is another common preprocessing technique to reduce the feature space [53]. Word frequencies typically follow a Zipfian distribution, and are heavily tailed, with a large number of rare words [54]. As a result, removing only exceedingly rare words (for example, those with less than three occurrences) can significantly reduce the feature space without compromising critical information.

2.4 Model

2.4.1 Topic Modelling

Large amounts of unstructured text data pose a challenge to researchers as their high complexity masks information. Tools in natural language processing (NLP) allow information to be uncovered and presented in a structured format that we can then analyse. Topic modelling is one such NLP tool that uncovers information in unstructured text data. Topic modelling can be viewed as a dimension reduction tool that projects high-dimensional text data onto low-dimensional spaces, peeling back complexity to reveal interpretable structure [46]. This dimension reduction occurs through the summarisation of text into topics or conversational themes. Documents (which can be social media posts) are reduced to mixtures of topics, providing an overview of their contents. Topics are represented by collections of words that are used in similar contexts. Figure 4 shows the topic modelling process, taking documents, finding appropriate topics, and then representing the documents as mixtures of these topics.

Figure 4: Topic Modelling Overview
2.4.2 Sentiment Analysis

Sentiment analysis is another natural language processing tool that, similar to topic modelling, reduces the complexity of documents. However, instead of deconstructing documents into topics, sentiment analysis identifies emotions conveyed in the text.

2.5 Analyse

In a grounded theory approach, where we let the data drive the research, analysis and visualisation are heavily intertwined. Observations made from the data through visualisation often evoke further questions. These questions can be used to cultivate hypotheses that may be answered through analysis. Results from the analysis may be explored through further visualisation. This further visualisation may lead to more questions, hypotheses, and further analysis to complete the cycle.

Topic modelling allows us to take our social media posts and uncover the topics that people discuss. The levels of discussion for each topic tell us how often particular themes are discussed. Profiling documents in this way yields an overview of the overall themes being discussed, themes in individual documents, themes in documents belonging to specific groups, longitudinal trends, and more, depending on the questions we want to ask. Similarly, sentiment analysis results can be analysed to see overall sentiment, sentiment in specific posts or groups of posts, and temporal changes.

2.6 Visualise

To produce a topic word cloud, we make use of the topic distributions found from topic modelling. These tell us the probability that a word is in a topic, $P(\text{word|topic})$. Visualisation of these probabilities through word clouds illustrates words contained in the topic. The size of a word in a word cloud relates to the probability that the word is selected from the topic.

2.6.1 Dimension Reduction

Visualising topic interactions allows for the exploration of related themes. Topic interactions may be found in multiple ways. The network’s approach to topic modelling uses a hierarchical stochastic block model (hSBM), and inherently captures topic interactions through a matrix of community-to-community interactions [51, 55, 56]. This matrix tells the probability of edges between and within communities. Topic interactions may alternatively be found through their correlations. An effective way to quickly visualise these interactions is to convert the interactions into a measure of dissimilarity and produce a topic map by performing a dimension reduction of the high-dimensional topic interaction data down to two dimensions. Traditional approaches such as principal components analysis (PCA) and multidimensional scaling (MDS) attempt to preserve the pairwise distance structure of the high-dimensional data in a lower-dimensional projection. Modern approaches such as t-distributed stochastic neighbour embedding (t-SNE) and uniform manifold approximation (UMAP), which focus on preserving local distances, not global distances, typically perform well, especially when viewing local structures. These approaches may not be as appropriate as MDS when the importance is on considering the global structure [57, 58, 59].

3 /r/ProstateCancer Data

We follow the DAPMAV process to acquire 4074 posts and replies from the Reddit community /r/ProstateCancer between 2019 and 2021. These consist of 631 posts and their 3443 replies. The mean number of non stopwords in the posts is 50.6, and 31.2 for their replies (34.2 combined mean). The longest post consists of 738 non stopwords. We restricted posts and replies to consist of at minimum ten non stopwords to remove documents with few words, as inspection showed documents with fewer than 10 non stopwods to have largely uninformative discussion. The prostate cancer stories posted to Reddit often feature mentions of the subject’s age. String detection using REGEX was used to estimate subjects’ ages (in decade brackets). Figure 5 illustrates the results of this. In addition to age, subjects of the narrative are identified by male family member names, seen in Figure 6 REGEX was used to estimate the identity of the male family members: brother, father, grandfather, husband, son, and uncle.
4 Results

4.1 Topic Modelling

Global word frequencies from a discussion give a broad overview of the discourse. While there is something to be gained from these word frequencies alone, they often struggle to capture the full context of the discussion they are involved in. Topic modelling captures this context by forming communities of words that are frequently used in the same context. We identify topics from the prostate cancer discourse that illustrate several revealing aspects of the discussion. These topics are manually summarised into a one- to two-word summary of what the topic appears to represent. Table 2 shows this summary, the corresponding figure reference number, and the density of the topic.

Network topic modelling reveals the hierarchical structure of topics discussed in the prostate cancer data. In the supplementary materials, an interactive application displays this structure in a radial tree, where each root node is a word whose size is given by its empirical use, and hierarchical topic membership is defined by connections to parent nodes [60]. This topic structure allows for a detailed view of the discussion by breaking down the conversation into distinct topics which cover a particular aspect of the conversation. The following subsections will contain results relating to select topics found through the discourse and relate them to aspects of healthcare.

Our topic model reveals a hierarchical structure with four layers. The first (most general) layer is a single topic further divided into two highly general topics in the second layer. The third layer contains twenty relatively general topics and the fourth layer 107 highly specific topics. We show six select topics of the twenty from the third layer in Figure 7.

4.1.1 Prognostic Staging

Prostate screening is often encouraged for men with an increased risk for prostate cancer. Digital rectal examinations (DRE) and prostate-specific antigen (PSA) tests are the most common screening tests. Abnormalities in these screenings, such as an enlarged prostate or elevated levels of PSA, indicate a potential risk for prostate cancer. If abnormalities are present, further diagnostic procedures are often referred. These include imaging procedures such as magnetic resonance imaging (MRI) and ultrasound, as well as prostate biopsy, wherein a tissue sample is removed from the prostate and analysed to determine if cancerous cells are present. These tests are often conducted by a urologist. We see that this specific aspect of the diagnostic pathway (except PSA testing) is captured in the ‘prognostic staging’ topic, shown as a word cloud in Figure 7a, with a density of 0.051, indicating the topic corresponds to 5.1% of the discourse.

4.1.2 Prognostic Scoring

Prostate biopsy detects the presence of cancerous cells. If cancerous cells are detected, the biopsy tissue samples (cores) are analysed and given a Gleason score to determine how far the tissue deviates from healthy prostate tissue. If abnormalities are present, further diagnostic procedures are often referred. These include imaging procedures such as magnetic resonance imaging (MRI) and ultrasound, as well as prostate biopsy, wherein a tissue sample is removed from the prostate and analysed to determine if cancerous cells are present. These tests are often conducted by a urologist. We see that this specific aspect of the diagnostic pathway (except PSA testing) is captured in the ‘prognostic scoring’ topic, shown as a word cloud in Figure 7b, with a density of 0.028.
Figure 7: Six topics found through topic modelling of the /r/ProstateCancer discourse.
4.1.3 Diagnosis

Discussion on the diagnosis of prostate cancer forms a topic, represented by the word cloud in Figure 7c. It has a density of 0.042, indicating that 4.2% of the informative words in the discussion are drawn from this topic. The diagnosis discussion is characterised by the notable words ‘diagnosed’ and ‘diagnosis’. This discussion appears to be often framed from the perspective of a child of the patient, with the paternal words ‘dad’, and ‘father’ being prominent words in the topic. Associated words ‘spread’, ‘aggressive’, and ‘stage’ indicate this topic corresponds to discussion of the stage that the cancer has reached. Words such as ‘bones’, ‘lungs’, and ‘metastasised’ may indicate late-term cancer that has begun to spread to other sites in the body. As part of the diagnosis topic, we see some discussion related to the outlook and treatment methods available, noted by the words ‘prognosis’, ‘curable’, ‘treatable’, ‘opinions’, ‘decisions’, and ‘decision’.

4.1.4 Prostate Function

Figure 7d evidences discussion on /r/ProstateCancer evolving into conversation related to sensitive topics, such as incontinence and erectile dysfunction (ED), two major side effects of the removal of the prostate in a procedure known as a radical prostatectomy (RP). This topic appears with a density of 0.050, indicating that it corresponds to 5% of the discourse. The use of the words ‘nerve’, ‘erectile’, ‘dysfunction’, ‘ed’, ‘impotence’, and ‘ability’ can all be interpreted in the context of erectile dysfunction. There is a presence of the words ‘lost’, ‘loss’, and ‘shrunk’, which appear to indicate that there is a worsening in the condition, and conversely, ‘returned’, ‘return’, ‘remission’, ‘improvement’, ‘increasing’, ‘amazing’, and ‘wonderful’. We see that discussion around penile shrinkage, a result of a loss of blood flow after prostatectomy, is captured in this topic through the former words, as well as ‘length’.

4.1.5 Sexual Intercourse

Figure 7e shows discussion related to sexual intercourse with a density of 0.051 and appears highly related to the topic in Figure 7d. Whereas the topic in Figure 7d appears to show discussion on sexual function and the lack thereof, the topic in Figure 7e appears to go into more detail about the sexual experience of people with prostate cancer.

4.1.6 Prostatitis

Figure 7f illustrates discussion related to prostatitis symptoms, inflammation of the prostate, commonly due to bacterial infection. These symptoms may include urinary pain and burning, difficulty passing urine, ‘dribbling’ (leaking urine), increased frequency of urination, blood in urine, generalised pain in the abdomen and genitals, and fever [61]. This discussion is observed through the use of the topic words ‘prostatitis’, ‘urine’, ‘urinating’, ‘urination’, ‘peeing’, ‘flow’, ‘stream’, ‘difficulty’, ‘weak’, ‘dribble’, ‘frequent’, ‘pain’, ‘painful’, ‘discomfort’, ‘hurt’, ‘burning’, and ‘fever’.

4.1.7 Other Topics

Many other topics are included in the online supplementary materials as word-clouds [62]. We found the topics primarily corresponded to five main categories, which we manually labelled as; ‘diagnosis’, ‘treatment’, ‘symptoms’, ‘experience’, and ‘general’.

4.2 Topic Landscape

The topic-topic interactions tell us the likelihood of topic co-occurrence, giving insights into the relationships between topics. As the network approach to topic modelling is built on a bipartite document-word network, within and between topic interactions are of probability zero. Edges in the network occur between words and documents, and hence the communities of words that form topics are connected only through their connections to communities of documents. We therefore use the two-step interaction matrix to retrieve topic-topic interactions, propagating edges from topics to documents, and back to topics. This interaction matrix gives a matrix of probabilities for topic co-occurrence, considering interactions within and between topics. We convert this to a dissimilarity measure by taking the negative co-occurrence rates. Using UMAP, we perform a dimension reduction from the topic-space to a two-dimensional space that seeks to preserve local distances between topics. This two-dimensional topic representation produces a map of the topics, seen in Figure 8. We note that here we are considering topics at the lowest (most specific) level in the topic hierarchy. We show the three most common words for each topic, scale the words’ sizes to correspond to their relative frequencies, and colour according to the classifications made.
Figure 8: Topic landscape founds using UMAP with dissimilarity based on the negative co-occurrence rate between topics. The top three words from each topic at the lowest level in the topic hierarchy are shown and classified.
Table 2: Table showing the most prevalent word in the topic (topic identifier) and the overall usage of the topic in the /r/ProstateCancer discourse.

| Topic                  | Figure | Usage density |
|------------------------|--------|---------------|
| Sexual function        | 7e     | 0.051         |
| Prognostic staging     | 7a     | 0.051         |
| Prostate functioning   | 7d     | 0.050         |
| Diagnosis              | 7c     | 0.042         |
| Prostatitis            | 7f     | 0.031         |
| Prognostic scoring     | 7b     | 0.028         |

4.3 Topic Progressions and Emotional Arc

The average positional structure of topics may reveal the general trends that /r/ProstateCancer posts follow. We may gain insight into how these stories are told by capturing these trends. To find this positional structure, we find density estimates for the positions of topics throughout documents. First, we find normalised word positions in documents as the window of the document that the word occupies. For example, in a document consisting of two words: ‘Hello world.’, the word ‘Hello’ occupies the range $[0, 0.5)$ and the word ‘word’ occupies the range $[0.5, 1]$. The words can be replaced with their topics, and the positional densities taken as the relative frequency of the positional occupancy of the topic (relative to the topic’s total use), say $t$, 

$$p(x|\hat{t}) = \frac{\sum_d 1_{\hat{t} = t^d_x}}{\sum_d \int_0^1 1_{\hat{t} = t^d_x} dx},$$

where $t^d_x$ is the topic of document $d$ at position $x$, and $1_{\hat{t} = t^d_x}$ is the indicator function,

$$1_{\hat{t} = t^d_x} = \begin{cases} 
1, & \text{if } \hat{t} = t^d_x, \\
0, & \text{otherwise.}
\end{cases}$$

Figure 9 shows stacked topic-position densities for each topic found at the second-lowest level of the topic hierarchy. The density stacks are arranged in ascending order of median position, i.e. topics discussed more frequently early (on average) are at the top of the stack. The lower half of Figure 9 shows the average emotional arc of the prostate cancer discourse by plotting the average sentiment against the normalised position through document [63]. The most dominant-topic progression throughout the collective narrative is highlighted by segmenting the arc into the topics with the highest density at the respective positions.

5 Discussion

5.1 DAPMAV Framework

The DAPMAV framework introduced in this paper provides a structured approach for analysing patient-reported experiences found on social media. We follow the principles of this framework to elicit patient-reported experiences from prostate cancer discourse on the Reddit community /r/ProstateCancer.

The inductive reasoning underpinning this discussion – in which real-world data is explored to generate ideas – is established in grounded theory. Uncovering structure in vast qualitative data sources reduces complexity. The uncovered structure reveals themes in the data. These themes can be codified to identify core concepts. Storylines can be built from the core concepts, which form the basis for model and hypothesis development. Tools in NLP allow us to uncover structure in online collections of patient-reported experience narratives. We demonstrate the utility of the DAPMAV framework to find and qualitatively analyse patient-reported experience discourse from social media discussions on prostate cancer.
Figure 9: Distribution of topic discussion throughout the text.
5.2 Topic Modelling

Topic modelling distills the Reddit prostate cancer discourse into many themes. We codify these themes into five classifications. Two of the five classifications of discussion are related to clinical care. In particular, topics can be classified as ‘diagnosis’, representing topics corresponding to discussion surrounding diagnosis and healthcare processes in the typical diagnostic pathway for prostate cancer, such as family history, screening, exams, biopsy, and diagnosis. The second of the clinical care topic classifications is the ‘treatment’ classification for topics related to treatment pathways. The treatment pathway discourse is characterised by topics around active surveillance, prostatectomy, radiation therapy, androgen deprivation therapy, and others. The presence of these clinical care topics is important as it offers a new perspective on patient experience across diagnostic and disease treatment pathways. Two other classifications capture a more patient-centric arm of discussion, with communication of symptoms being one classification and patient experience being the other. Some examples of the symptom-related topics are erectile dysfunction, sexual function, incontinence, pain, and anxiety. These are topics of a highly sensitive nature and reveal an intimate level of detail in their discussion that may be difficult to obtain in a survey. The patient experience classification encompasses topics such as quality of life, support, and questions. The final classification, ‘general’, captures the remaining discussion and pertains to topics that may occur in many contexts, such as the mention of prostate cancer.

One area of prostate cancer symptom discussion that was identified relates to sexual dysfunction, an unfortunate reality for many people who suffer from prostate cancer. Those who experience sexual dysfunction due to prostate cancer often indicate that the dysfunction negatively affects their quality of life. However, this suffering is frequently made in silence, as sexual dysfunction may be viewed as embarrassing, emasculating illness with a high degree of perceived stigma [64, 65]. The intimate and unconstrained discussion related to sexual dysfunction that can be found online offers a rare window into the covert experiences faced by those who suffer from it. Topics seen in Figure 7d and Figure 7e capture the rich essence of these stories with expressive language and contribute to over 10% of the total /r/ProstateCancer discourse.

Topic modelling allows batch processing of the prostate cancer corpus and reveals insightful characteristics of the nature of the corpus. We gain an overview of each element of discussion and, importantly, draw comparisons between these elements and the real world. We qualitatively summarise the discourse by identifying topics with tangible aspects of healthcare. This identification allows for a qualitative exploration of patient views on these areas of healthcare and the ability to challenge our current views on them by comparing and contrasting our prior understanding with observations made.

5.3 Topic Landscape

Analysis of specific topics provides specific insights related to the topics but does not capture the general theme of conversation. To summarise the entire discourse, we show a landscape of topics in Figure 8. This landscape forms a map of topics whose geographical regions correspond to clusters of topics that frequently occur together. These topics are represented with their three most prevalent words. Topics relating to patient experience are central to the map and shown in green. General topics are most prevalent in the top right of the figure and are coloured black. Topics relating to symptoms are shown in red and form a region on the left side of the figure that extends towards the top middle. The relative closeness of symptom and experience topics illustrates the frequent interactions between these types of topics. The treatment topic in purple is dispersed throughout the right half of the landscape and heavily interwoven with the diagnosis topic. This diagnosis topic is coloured yellow and extends from the bottom middle to the middle right. As UMAP produces this dimension reduction, global structure insights are traded off for greater visualisation of local structures.

5.4 Topic Progressions and Emotional Arc

The average sentiment of the prostate cancer discourse (Figure 9) exhibits a fall-rise pattern. This pattern is one of six basic story arcs, commonly known as the ‘man-in-a-hole’ plot. This plot follows a typical trajectory of tragedy, followed by resolution. The fall, or tragedy, is characterised by the diagnosis topic, leaving the sentiment to bottom out and stay negative for most of the discourse. This bottoming-out corresponds to peaks in general discussion of prostate cancer, followed by a peak in the discussion of symptoms. During the rise, we see a peak in the use of topics related to patient experience, such as quality of life. This characterisation of the collective discourse into diagnosis, general discussion, and discussion of symptoms, followed by discussion of experience, is not entirely surprising. It follows a likely trajectory through healthcare. First, being diagnosed, then learning about the condition, experiencing symptoms as a result of the condition worsening or as side effects of treatment, and finally closing with some discussion on their experience. However, this pathway is somewhat incomplete, as discussion on treatment does not feature in this timeline. Note that this is due to the discussion on treatment being relatively evenly dispersed throughout the timeline. There are
no strong peaks in the discussion of treatment across the timeline; hence, the peaks for other topic classifications are more prominent in comparison.

6 Conclusion

6.1 DAPMAV Framework

In this paper, we motivated the need for a generalised reproducible framework for conducting social media analysis of healthcare discourse. To meet this need, we propose the Design-Acquire-Process-Model-Analyse-Visualise (DAPMAV) framework. A case study is conducted to demonstrate the utility of the framework, where social media discussion on prostate cancer on /r/ProstateCancer is explored. We follow a grounded theory approach to qualitatively analyse our data in this case study. The findings of this case study outlined demonstrate the effectiveness of the DAPMAV framework and motivate its use for uncovering patient-reported experiences in other areas of health. In general, grounded theory justifies the use of these tools to explore data. Qualitative explorations such as these uncover patient reported experiences, allowing for freedom that would be difficult to achieve in a survey. Wider patient perspectives can be considered; there are no constraints determining which aspects of patient experiences we find. In this approach, we let the patients tell us what is important. It is not the ideas of the domain expert that drive the research; it is the patient’s discussion about what is important that drives this research. This research perspective is receptive to forming new ideas based on what we observe and can lead to developing new research questions that are aligned with public interest.

6.2 Case Study: /r/ProstateCancer

We use a network approach to topic modelling to show detailed discussion topics in prostate cancer narratives. These topics are identified with aspects of health and healthcare at macro and micro levels, and codified. In doing so, we observe that /r/ProstateCancer is a rich data source for intimate discussion of sexual dysfunction and sexual experience. This finding demonstrates that social media discussions of prostate cancer, in particular /r/ProstateCancer, may be useful in future research that considers sexual dysfunction and sexual experience through the eyes of the patient.

A summary of the discourse is presented in a graphic overview that links related topics together in space and shows which classifications of discussion these topics belong to. This graphical overview provides an explication of the themes of discussion. It can be considered a map of the concepts at the core of the patients’ concerns. For this reason, this map may be of value to healthcare practitioners – allowing them to better understand patient concerns through patient eyes – as well as healthcare researchers, who may find that this map generates research questions.

Emotional understanding of the narratives is found through sentiment analysis. On a global level, the /r/ProstateCancer discourse follows a fall-rise emotional arc. We show that the fall is characterised by discussion related to diagnosis. In general, we find that the narratives follow a path that corresponds with a typical clinical path; the initial discussion is focused on the diagnostic pathway, the discussion on symptoms and treatment is more concentrated towards the middle, and the end is characterised mainly by the discussion on experience.

6.3 Limitations

While the framework does not remove the need for technical proficiency in undertaking the analysis, it provides a structure that anyone can adopt. Methods such as network-based topic modelling can be computationally demanding when dealing with vast quantities of data. We propose that to overcome computational concerns, data can be sampled. Yet, with advances in computational power, these may become issues of the past. While social media gives everyone a voice, socioeconomic factors influence different demographics’ presences online. This introduces biases into the results we find, and as such, it is important to keep these biases when drawing conclusions from these results. However, the DAPMAV framework enables us to serve minority demographics if they participate in specific online communities, as applying this framework to those communities would allow for a greater understanding of their unique issues. Geographic health system boundaries are drawn where social media boundaries are not. We have analysed prostate cancer data from a global source, finding a global view of prostate cancer experience. Local health systems will face a variety of challenges. Some of these challenges will be unique; however, many will be reflective of what we find across the globe. By analysing data from various countries, the DAPMAV framework would allow us to consider the differences across countries. Topics capture a theme of discussion using a family of words; however, the use of a word from a topic does not necessarily guarantee that the word is being used in the context of the topic. For example, the word ‘dad’ appears in the diagnosis topic and hence has a strong association with the discussion surrounding diagnosis. However, the word ‘dad’ may be freely used in another context. This potential misassociation does not mean that topics are not useful or informative; on the contrary, they are. Topics arrive from an optimal compression of information and hence provide a useful simplifying representation of discussion that assists in forming an overview of the themes in a
discussion and the words used in the themes. For an overview to be useful, it must simplify a concept. No simplification comes without some loss of information, for there is no such thing as a free lunch. Instead, a balance must be struck between retaining enough information for insights to be drawn and reducing cumbersome complexity that detracts from understanding.

### 6.4 Future Research

Several areas of future research have been outlined in this paper. We reinstate those and identify some potential other areas for future research: apply the DAPMAV framework more broadly to other cancers or health issues to harness patient-reported experiences, apply the DAPMAV framework to geographically identified data to compare patient experience similarities and differences across borders, apply the DAPMAV framework to minority groups’ data to gather insights about relevant issues. /r/ProstateCancer is home to intimate discussion on sexual dysfunction and sexual experience, which may be a valuable resource to other researchers working on prostate cancer or patient experience.

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Table 4 shows the Australian Hospital Patient Experience Question Set. Table 3 shows the Google Scholar search terms from search keys seen in Table 1.

| Search Key | Google Scholar Search Term |
|------------|----------------------------|
| -          | [social media platform]    |
| Patient Experience | [social media platform] AND ‘patient experience’ OR ‘patient experiences’ OR ‘patient reported experience’ OR ‘patient reported experiences’ |
| Natural Language Processing | [social media platform] AND ‘natural language processing’ OR ‘nlp’ |
| Patient Experience + Natural Language Processing | [social media platform] AND ‘patient experience’ OR ‘patient experiences’ OR ‘patient reported experience’ OR ‘patient reported experiences’ AND ‘natural language processing’ OR ‘nlp’ |
Table 4: Australian Hospital Patient Experience Question Set (AHPEQS), a core set of satisfaction questions that hospitals can use to capture patient-reported experiences [15].

| Survey Questions                                                                 | Response options                  |
|----------------------------------------------------------------------------------|-----------------------------------|
| My views and concerns were listened to                                           | Always                            |
|                                                                                  | Mostly                            |
|                                                                                  | Sometimes                         |
|                                                                                  | Rarely                            |
|                                                                                  | Never                             |
|                                                                                  | Didn’t apply                       |
| My individual needs were met (if answer always/mostly, skip to Q4)               | Always                            |
|                                                                                  | Mostly                            |
|                                                                                  | Sometimes                         |
|                                                                                  | Rarely                            |
|                                                                                  | Never                             |
| When a need could not be met, staff explained why                                | Always                            |
|                                                                                  | Mostly                            |
|                                                                                  | Sometimes                         |
|                                                                                  | Rarely                            |
|                                                                                  | Never                             |
| I felt cared for                                                                 | Always                            |
|                                                                                  | Mostly                            |
|                                                                                  | Sometimes                         |
|                                                                                  | Rarely                            |
|                                                                                  | Never                             |
| I was involved as much as I wanted in making decisions about my treatment and care| Always                            |
|                                                                                  | Mostly                            |
|                                                                                  | Sometimes                         |
|                                                                                  | Rarely                            |
|                                                                                  | Never                             |
| I was kept informed as much as I wanted about my treatment and care              | Always                            |
|                                                                                  | Mostly                            |
|                                                                                  | Sometimes                         |
|                                                                                  | Rarely                            |
|                                                                                  | Never                             |
| As far as I could tell, the staff involved in my care communicated with each other about my treatment | Always                            |
|                                                                                  | Mostly                            |
|                                                                                  | Sometimes                         |
|                                                                                  | Rarely                            |
|                                                                                  | Never                             |
|                                                                                  | Didn’t apply                       |
| I received pain relief that met my needs                                         | Always                            |
|                                                                                  | Mostly                            |
|                                                                                  | Sometimes                         |
|                                                                                  | Rarely                            |
|                                                                                  | Never                             |
|                                                                                  | Didn’t apply                       |
| When I was in the hospital, I felt confident in the safety of my treatment and care| Always                            |
|                                                                                  | Mostly                            |
|                                                                                  | Sometimes                         |
|                                                                                  | Rarely                            |
|                                                                                  | Never                             |
| I experienced unexpected harm or distress as a result of my treatment or care (if answer is no, skip to Q12) | Yes, physical harm               |
|                                                                                  | Yes, emotional distress           |
|                                                                                  | Yes, both                         |
|                                                                                  | No                                |
| My harm or distress was discussed with me by staff                              | Yes                               |
|                                                                                  | No                                |
|                                                                                  | Not sure                          |
|                                                                                  | Didn’t want to discuss it          |
| Overall, the quality of the treatment and care I received was:                   | Very good                         |
|                                                                                  | Good                              |
|                                                                                  | Average                           |
|                                                                                  | Poor                              |
|                                                                                  | Very poor                         |