Conflict-of-interest statement

- FT is a full-time employee of Sprout Health Solutions, providing Social Media Listening (SML) services to commercial clients.
- This work was funded in-house at Sprout Health Solutions with no client involvement or financial support.

Use of Social Media Listening (SML) Methods for Understanding the Patient Experience of Chronic Disease: A Scoping Review

Fernanda Trevisan, Vanessa Cooper and Sarah Clifford

Sprout Health Solutions

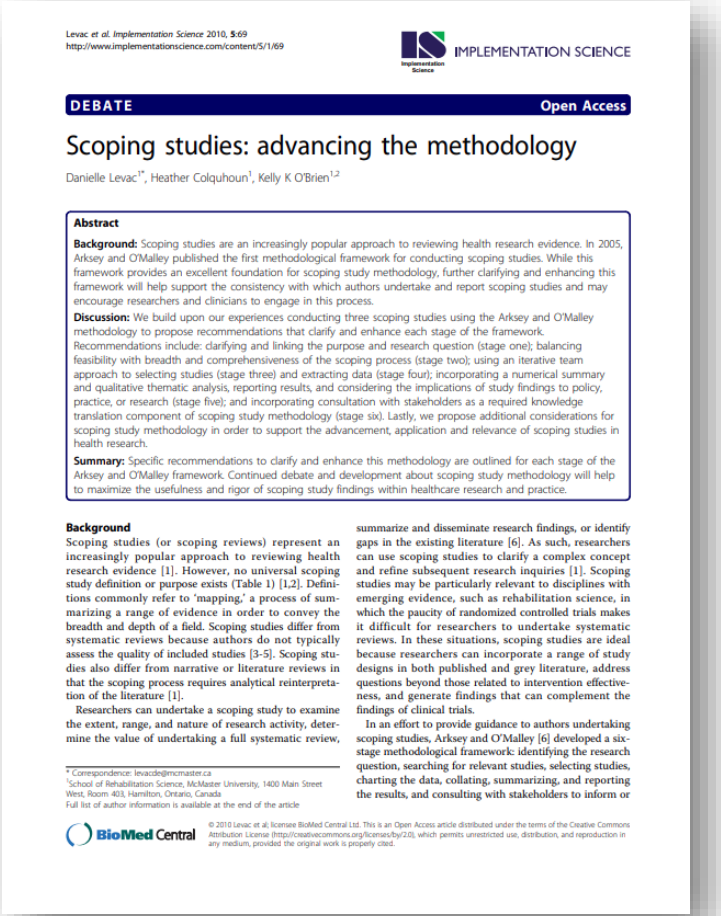
Background

- *Social media listening (SML) is an approach to harness information derived from social media platforms and generate insights into users' experiences as well as monitor and analyse discussions on health-related topics*
- Use of SML has increased rapidly in recent years
- No reviews of social media listening to understand the patient experience of chronic disease
- 'Patient experience' refers to the impact of the disease, condition or treatment on the lives of patients[1]

1 Upton F.H.R.. 6—21st Century Cures Act. 114th Congress (2015–2016) Jul 13. 2015; Available at:. www.congress.gov/bill/114thcongress/house-bill/6/text.

Methods

- ✓ Guidance for the conduct of scoping studies was followed[1,2]
- ✓ Six steps:
  1. Defining the research questions
  2. Identifying relevant studies
  3. Selecting studies
  4. Charting the data
  5. Collating, summarizing, and reporting the results
  6. Consulting with a second reviewer
- ✓ In line with this guidance, no quality assessment of the studies included in the review was conducted[1]



Levac *et al. Implementation Science* 2010, **5**:69
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IMPLEMENTATION SCIENCE

DEBATE **Open Access**

Scoping studies: advancing the methodology

Danielle Levac[1*], Heather Colquhoun[1], Kelly K O'Brien[1,2]

Abstract

Background: Scoping studies are an increasingly popular approach to reviewing health research evidence. In 2005, Arksey and O'Malley published the first methodological framework for conducting scoping studies. While this framework provides an excellent foundation for scoping study methodology, further clarifying and enhancing this framework will help support the consistency with which authors undertake and report scoping studies and may encourage researchers and clinicians to engage in this process.

Discussion: We build upon our experiences conducting three scoping studies using the Arksey and O'Malley methodology to propose recommendations that clarify and enhance each stage of the framework. Recommendations include: clarifying and linking the purpose and research question (stage one); balancing feasibility with breadth and comprehensiveness of the scoping process (stage two); using an iterative team approach to selecting studies (stage three) and extracting data (stage four); incorporating a numerical summary and qualitative thematic analysis, reporting results, and considering the implications of study findings to policy, practice, or research (stage five); and incorporating consultation with stakeholders as a required knowledge translation component of scoping study methodology (stage six). Lastly, we propose additional considerations for scoping study methodology in order to support the advancement, application and relevance of scoping studies in health research.

Summary: Specific recommendations to clarify and enhance this methodology are outlined for each stage of the Arksey and O'Malley framework. Continued debate and development about scoping study methodology will help to maximize the usefulness and rigor of scoping study findings within healthcare research and practice.

Background

Scoping studies (or scoping reviews) represent an increasingly popular approach to reviewing health research evidence [1]. However, no universal scoping study definition or purpose exists (Table 1) [1,2]. Definitions commonly refer to 'mapping,' a process of summarizing a range of evidence in order to convey the breadth and depth of a field. Scoping studies differ from systematic reviews because authors do not typically assess the quality of included studies [3-5]. Scoping studies also differ from narrative or literature reviews in that the scoping process requires analytical reinterpretation of the literature [1].

Researchers can undertake a scoping study to examine the extent, range, and nature of research activity, determine the value of undertaking a full systematic review, summarize and disseminate research findings, or identify gaps in the existing literature [6]. As such, researchers can use scoping studies to clarify a complex concept and refine subsequent research inquiries [1]. Scoping studies may be particularly relevant to disciplines with emerging evidence, such as rehabilitation science, in which the paucity of randomized controlled trials makes it difficult for researchers to undertake systematic reviews. In these situations, scoping studies are ideal because researchers can incorporate a range of study designs in both published and grey literature, address questions beyond those related to intervention effectiveness, and generate findings that can complement the findings of clinical trials.

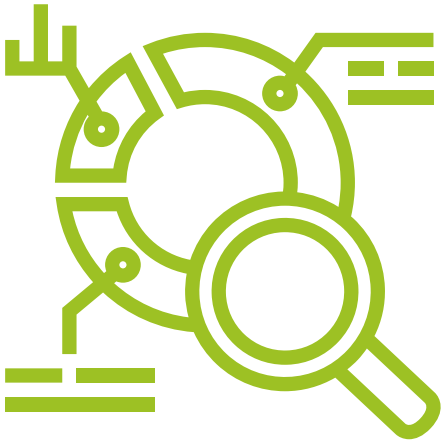
In an effort to provide guidance to authors undertaking scoping studies, Arksey and O'Malley [6] developed a six-stage methodological framework: identifying the research question, searching for relevant studies, selecting studies, charting the data, collating, summarizing, and reporting the results, and consulting with stakeholders to inform or

* Correspondence: levacdle@mcmaster.ca
[1]School of Rehabilitation Science, McMaster University, 1400 Main Street West, Room 403, Hamilton, Ontario, Canada
Full list of author information is available at the end of the article

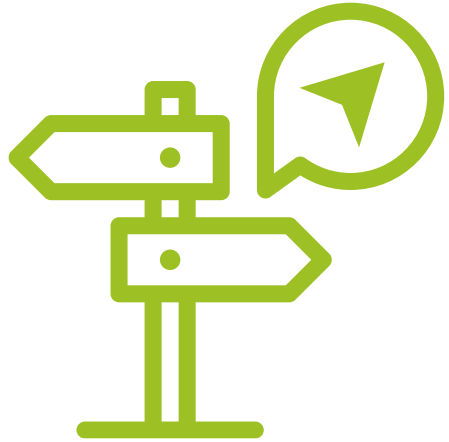
1. Levac, Colquhoun, and O'Brien. "Scoping studies: advancing the methodology." *Implementation science* 5.1 (2010): 1-9.
2. Arksey, Hilary, and O'Malley. "Scoping studies: towards a methodological framework." *International journal of social research methodology* 8.1 (2005): 19-32.

Research questions

RQ1: What social media listening methods have been used to understand patients' experiences with chronic diseases and treatments?



RQ2: What have social media listening studies revealed about patients' experiences of living with chronic diseases and treatments?



RQ3: What ethical issues and limitations have been identified in social media listening studies?

Identifying relevant studies

✓ Search conducted in PubMed

	Concept	Search terms
1	Patient	Patient
2	Social media listening	social media listening OR social listening OR social media content analysis OR retrospective keyword frequency analysis
3	Patient AND social media listening	1 AND 2
4	Experience	experience OR quality of life OR quality-of-life OR symptom OR impact OR concern OR belief OR perception
5	Combined search	3 AND 4

Selecting the studies

✓ **Inclusion criteria:**

1. Primary research
2. Study methods included social media listening
3. Subjects included patients with a chronic physical health condition
4. The focus was on patient experience of illness
5. Articles were published in the last 10 years (from 2011)

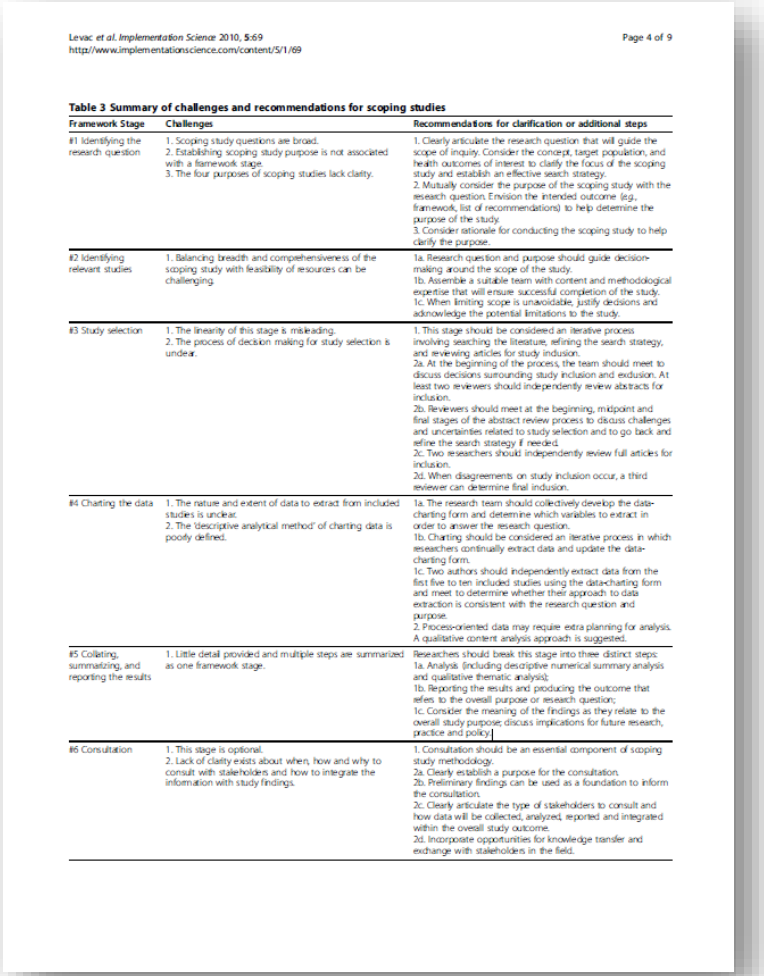
✓ **Exclusion criteria:**

1. Subjects are not patients with a chronic physical disease (e.g. orthodontics, mental health, drug or alcohol, healthy participants, infertility, surgery, vaccination)
2. Focus on the quality or usefulness of online tools, online/social media surveys or information
3. Related to quality assessment of hospitals

Charting, collating and summarizing the data

1. Data were extracted in MS Excel

2. Methods used to synthesise the data
   - Descriptive numerical summary analysis
   - Qualitative thematic analysis of study findings



Levac *et al. Implementation Science* 2010, 5:69
http://www.implementationscience.com/content/5/1/69

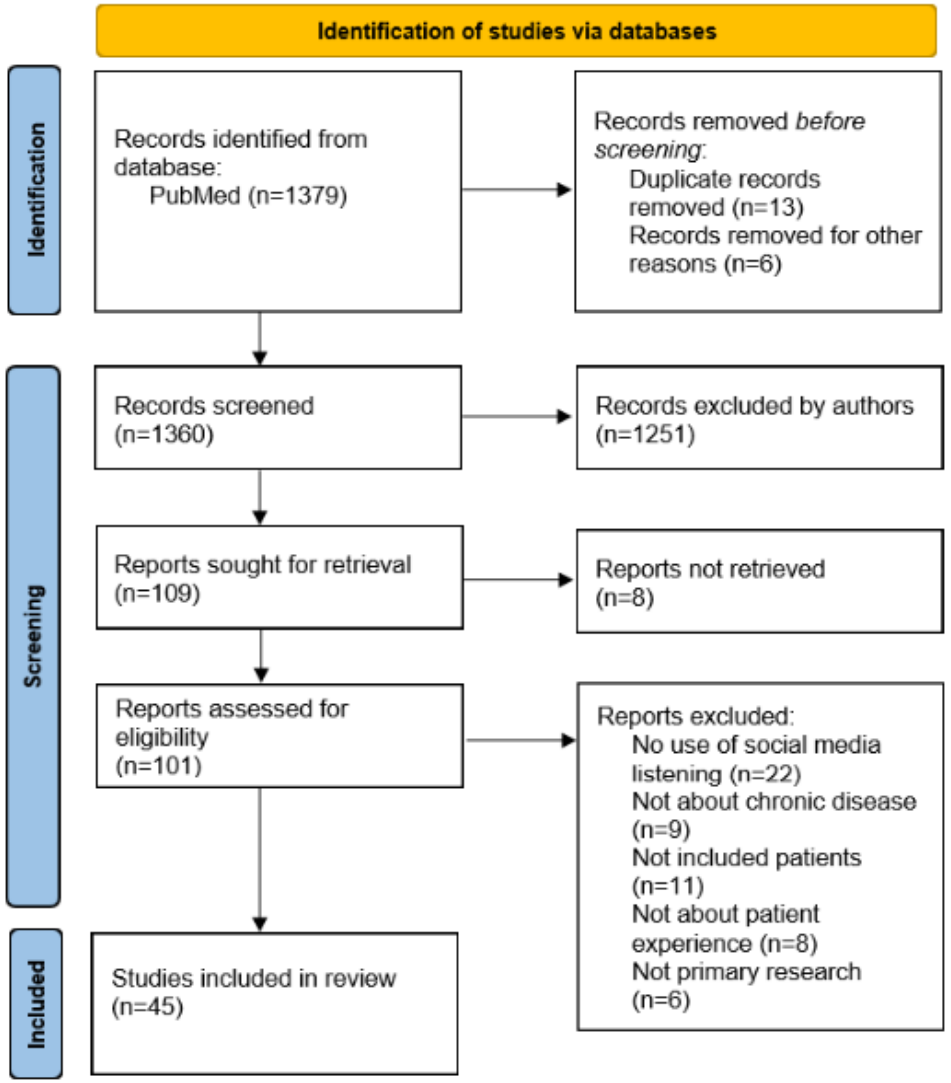
Table 3 Summary of challenges and recommendations for scoping studies

Framework Stage	Challenges	Recommendations for clarification or additional steps
#1 Identifying the research question	1. Scoping study questions are broad. 2. Establishing scoping study purpose is not associated with a framework stage. 3. The four purposes of scoping studies lack clarity.	1. Clearly articulate the research question that will guide the scope of inquiry. Consider the concept, target population, and health outcomes of interest to clarify the focus of the scoping study and establish an effective search strategy. 2. Mutually consider the purpose of the scoping study with the research question. Envision the intended outcome (e.g., framework, list of recommendations) to help determine the purpose of the study. 3. Consider rationale for conducting the scoping study to help clarify the purpose.
#2 Identifying relevant studies	1. Balancing breadth and comprehensiveness of the scoping study with feasibility of resources can be challenging.	1a. Research question and purpose should guide decision-making around the scope of the study. 1b. Assemble a suitable team with content and methodological expertise that will ensure successful completion of the study. 1c. When limiting scope is unavoidable, justify decisions and acknowledge the potential limitations to the study.
#3 Study selection	1. The linearity of this stage is misleading. 2. The process of decision making for study selection is unclear.	1. This stage should be considered an iterative process involving searching the literature, refining the search strategy, and reviewing articles for study inclusion. 2a. At the beginning of the process, the team should meet to discuss decisions surrounding study inclusion and exclusion. At least two reviewers should independently review abstracts for inclusion. 2b. Reviewers should meet at the beginning, midpoint and final stages of the abstract review process to discuss challenges and uncertainties related to study selection and to go back and refine the search strategy if needed. 2c. Two researchers should independently review full articles for inclusion. 2d. When disagreements on study inclusion occur, a third reviewer can determine final inclusion.
#4 Charting the data	1. The nature and extent of data to extract from included studies is unclear. 2. The 'descriptive analytical method' of charting data is poorly defined.	1a. The research team should collectively develop the data-charting form and determine which variables to extract in order to answer the research question. 1b. Charting should be considered an iterative process in which researchers continually extract data and update the data-charting form. 1c. Two authors should independently extract data from the first five to ten included studies using the data-charting form and meet to determine whether their approach to data extraction is consistent with the research question and purpose. 2. Process-oriented data may require extra planning for analysis. A qualitative content analysis approach is suggested.
#5 Collating, summarizing, and reporting the results	1. Little detail provided and multiple steps are summarized as one framework stage.	Researchers should break this stage into three distinct steps: 1a. Analysis (including descriptive numerical summary analysis and qualitative thematic analysis); 1b. Reporting the results and producing the outcome that refers to the overall purpose or research question; 1c. Consider the meaning of the findings as they relate to the overall study purpose; discuss implications for future research, practice and policy.
#6 Consultation	1. This stage is optional. 2. Lack of clarity exists about when, how and why to consult with stakeholders and how to integrate the information with study findings.	1. Consultation should be an essential component of scoping study methodology. 2a. Clearly establish a purpose for the consultation. 2b. Preliminary findings can be used as a foundation to inform the consultation. 2c. Clearly articulate the type of stakeholders to consult and how data will be collected, analyzed, reported and integrated within the overall study outcome. 2d. Incorporate opportunities for knowledge transfer and exchange with stakeholders in the field.

1. Levac, Colquhoun, and O'Brien. "Scoping studies: advancing the methodology." *Implementation science* 5.1 (2010): 1-9.

Results

Studies included: PRISMA flow diagram[1]



n= 45

1. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71

Study aim and design

69%

were **exploratory** aiming to understand patients' experiences of living with a chronic disease/treatment

31%

were **analytical,** looking to answer a specific question or test a hypothesis

100%

of the study designs were **cross-sectional**

9%

triangulated the data with other study outcomes (e.g., follow up patient interviews)

Location

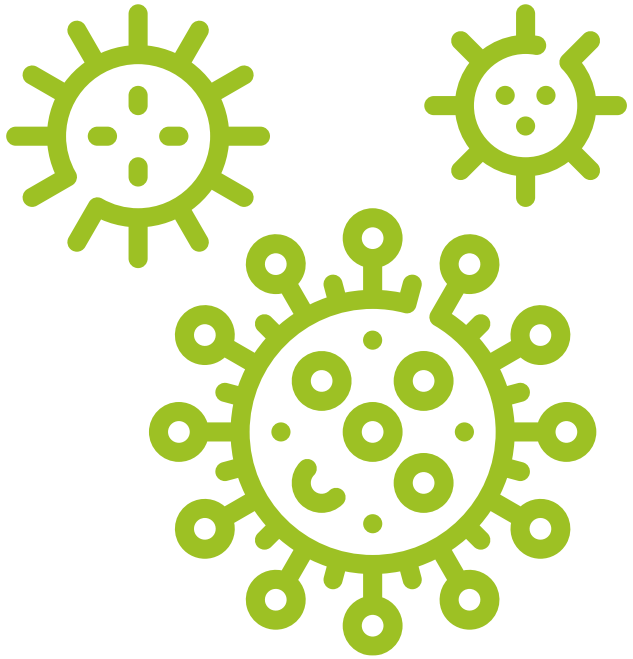
36% USA only

22% Global*
16% >1 English-speaking country**
11% UK only
7% Not declared
2% Australia only, 2% China only, 2% France only, 2% Sweden only

*Only 2 global studies declared searching for content beyond English language

**Australia, Canada, New Zealand, the United Kingdom, United States, South Africa, India

Types of diseases/treatments



37% Multiple types of cancer

20% Treatments
7% Rare diseases
7% Eye conditions
4% Hypertension
26% Other diseases (arthritis, bronchiectasis, cardiovascular diseases, COPD, CKD, epilepsy, IBD, Parkinson, status epilepticus, stress urinary incontinence and total joint arthroplasty)

Sample characteristics

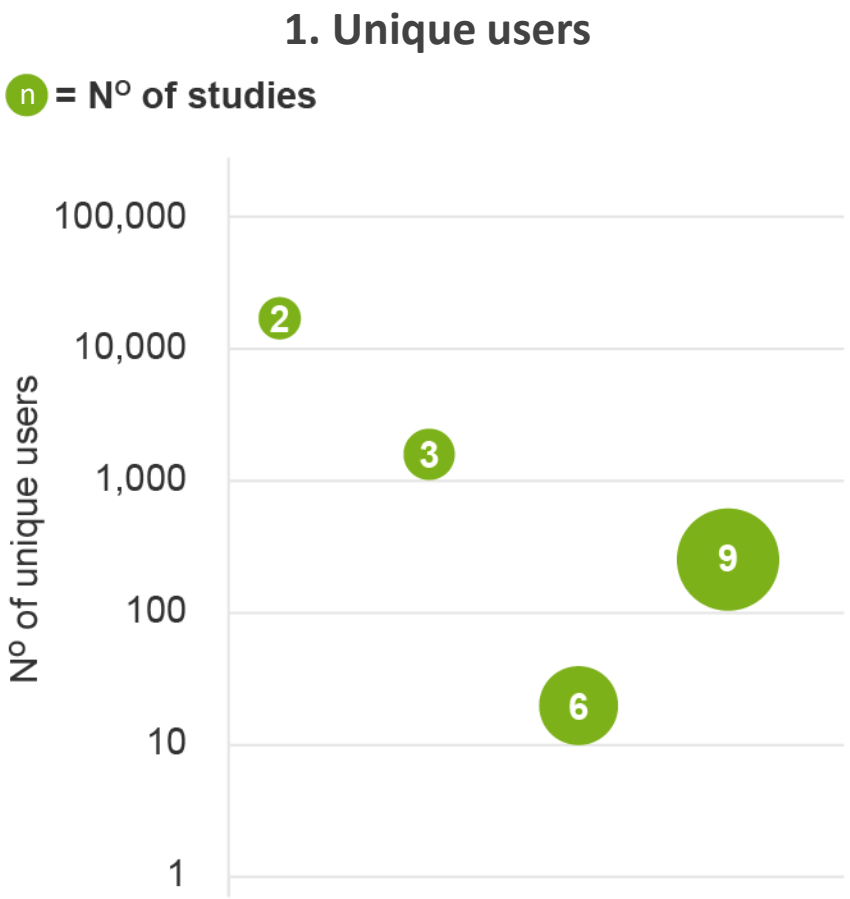
64% did **not** report any socio-economic or demographic data

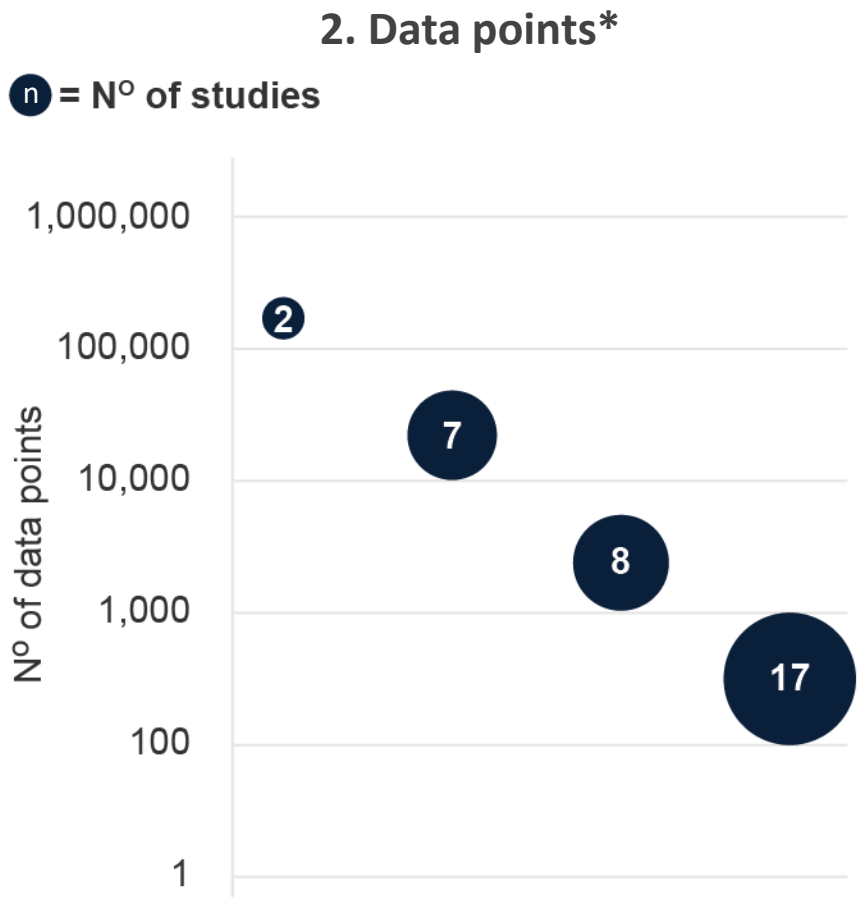
Reasons: no consent or not available

36% reported *some* type of data.

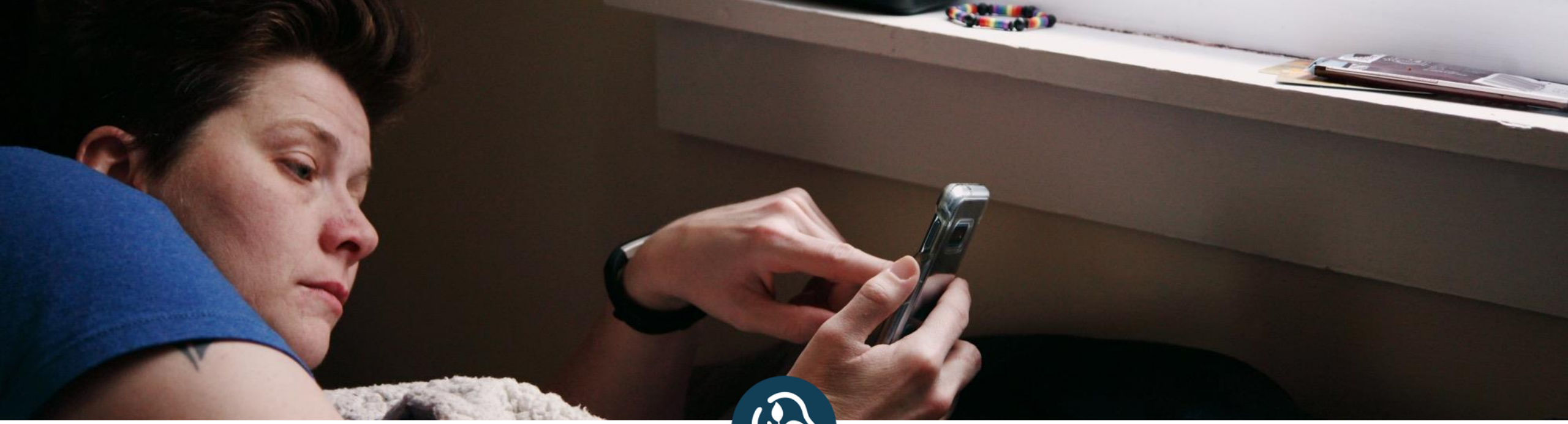
Of these:
Median age: ~40 years old (26-57)
Gender: 75% female 15% male
Interesting fact: 3 studies reported that age was ‘guessed’ by the researchers

Sample size



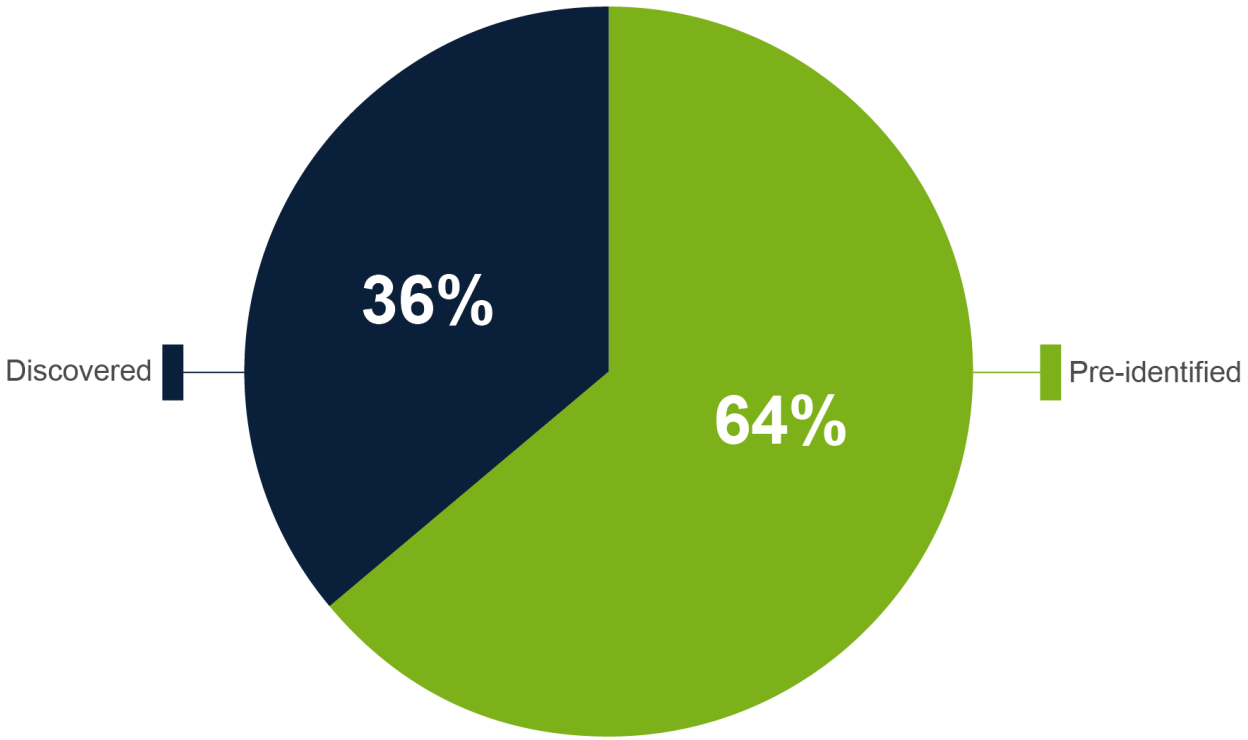


*Data grouped into measurable units. For example: 1 thread = ~ 5 comments = 1 data point



What social listening methods have been used to understand patients' experiences with chronic disease?

Platform identification method and types of platforms



49% Generic

Most popular platforms:
Twitter (14 studies) and *Facebook* (10 studies)

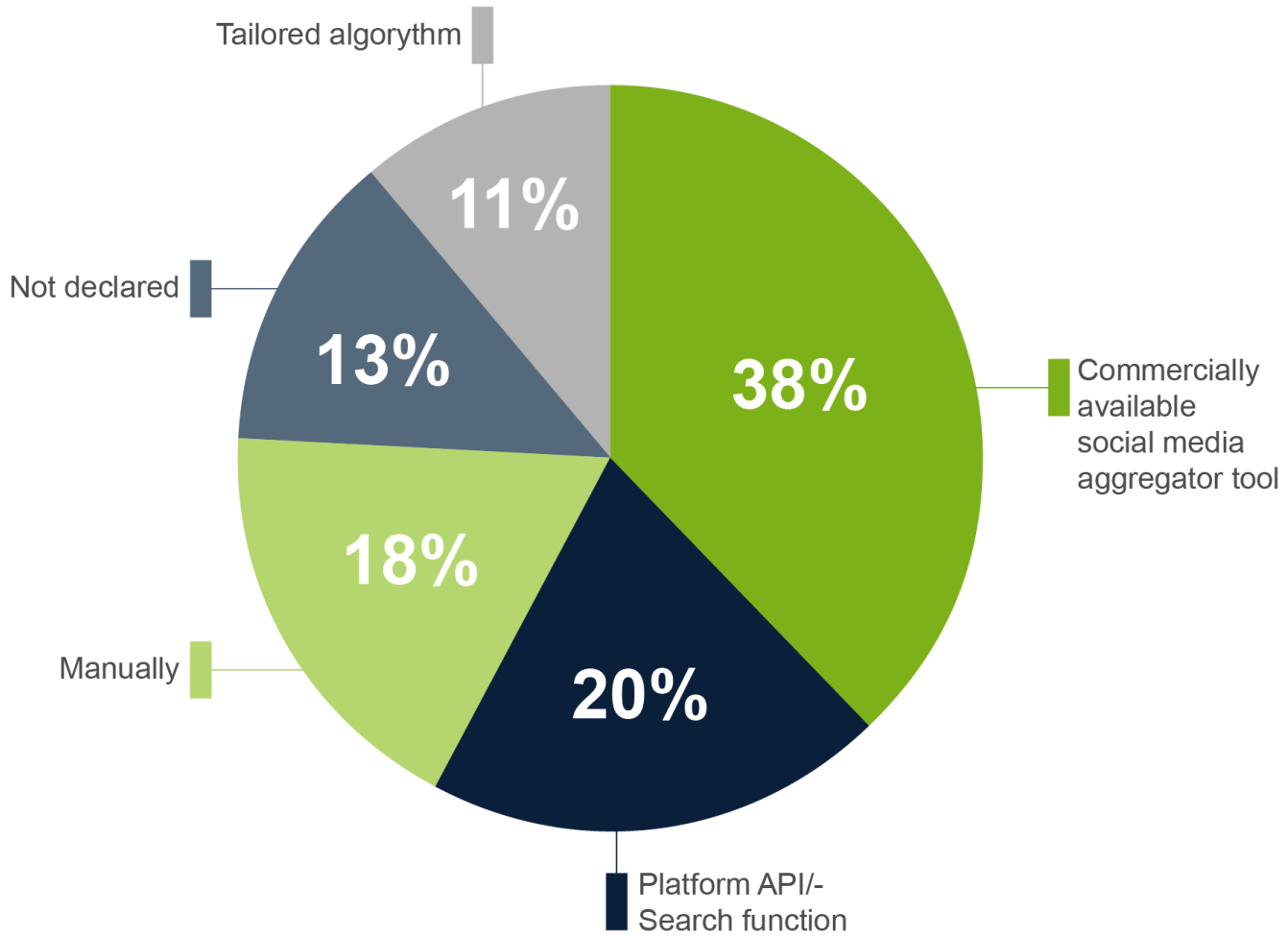
20% Disease-specific

18% Patient-oriented social media platform

patientslikeme®

13% mixed platforms

Data extraction method



Overall analysis methods

73% conducted thematic analysis

Only 13% applied a psychological theoretical model

Other types of popular analysis included:

Frequency analysis (incl. word cloud and conceptual model)

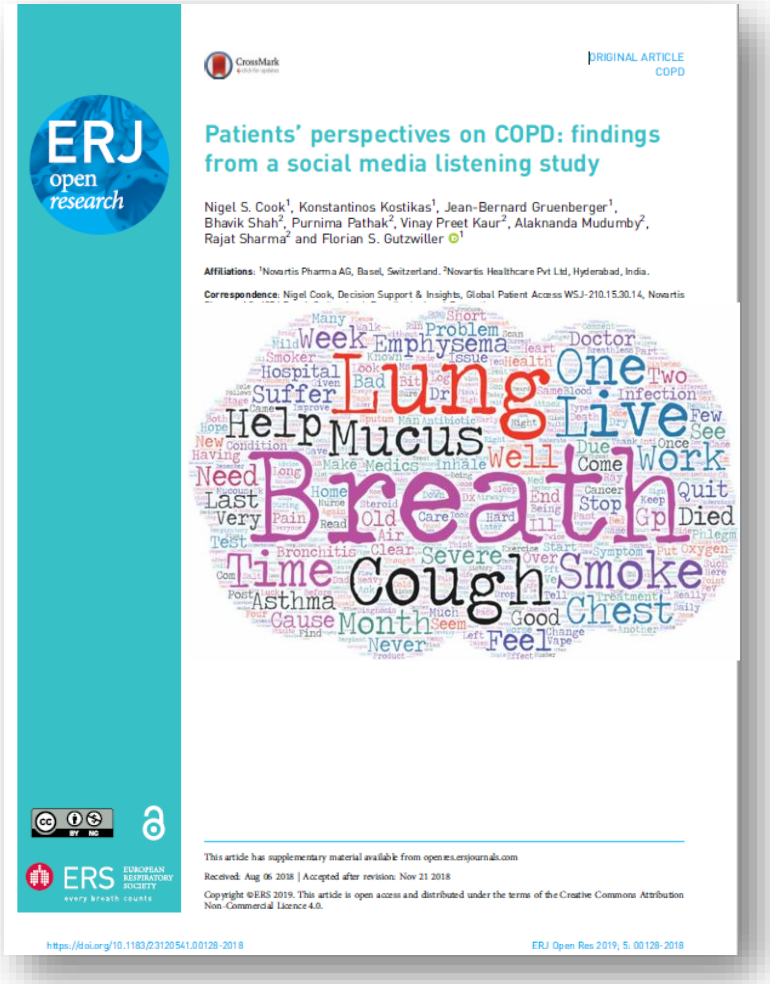
Descriptive statistics

Sentiment analysis

Lexical analysis

Semantic analysis

Popularity of hashtags



Example of a Wordcloud in Cook et al. (2019)[1]

1. Cook et al. "Patients' perspectives on COPD: findings from a social media listening study." *ERJ open research* 5.1 (2019).

Data analysis methods

27% Used data mining*

100% of studies with > than 1,000 unique users and >10,000 data sets used data-mining

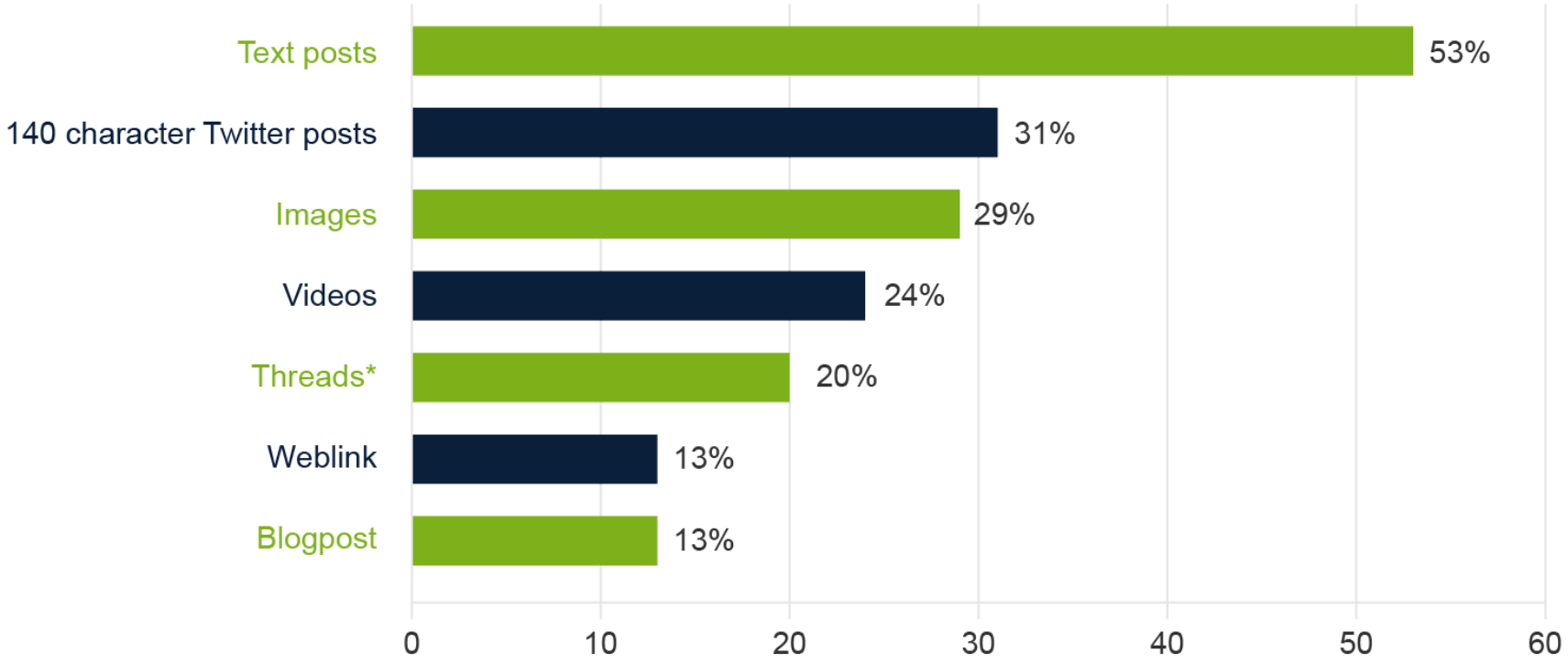
Advantages: find main content from large datasets quickly. Larger sample = less sample selection biases

Disadvantages: text mining can get some content lost and underrepresent low-frequency topics

~70% of the studies that did not used data mining (manually), selected a *sample* from the total dataset to conduct the analysis

*Data mining is an automated method that helps determine the main content from large amounts of text quickly.
For example: sentiment analysis, semantic analysis and lexical analysis.

Type of data



*groups of messages posted in response to a topic

Overlapping groups – sum is not 100%

Examples

A

TABLE II.
Thematic Analysis of Categories of Patient Posts Tagged #headandneckcancer.

Theme	No. of Occurrences (%)	Example of Post	Cohen's κ
Medical appointments and procedures	104 (81.3%)	"Day 5 radiation in the books. 25 more to go. Chemo/radiation tomorrow."	0.92
Managing treatment effects and symptoms	85 (66.4%)	"Today is the first day I've felt human in a long while! Eating is getting easier (would be even better if this…sore on the roof of my mouth would go away) and I haven't lost weight for the first time in like a month. Cut my fentanyl dose in half and only taking oxy at night now. Skin is dry but healed around my neck."	0.83
Social support	24 (18.8%)	"It's been a very long year and I've met many amazing people who were/are going through the same thing. I couldn't have done it without the support of my wife, family & amazing crazy…friends."	0.78
Cancer milestones	44 (34.4%)	"Second PET scan done, second NED results! Almost 6 months since my last treatment, and a little over 2 months from now will be my first Cancerversary. I can't believe it."	0.84
Cancer screening and prevention	29 (22.7%)	"I've now had my carcinoma removed from my nose now….I'm posting this as I really want to make people aware that if you don't protect your skin from the sun you may get skin cancer….I also used sun beds when I was younger…don't do it"	0.92

NED = no evidence of disease; PET = positron emission tomography.

Example of thematic analysis using **quotes** from posts on **Instagram** in Gao et al. (2012)[1]

B

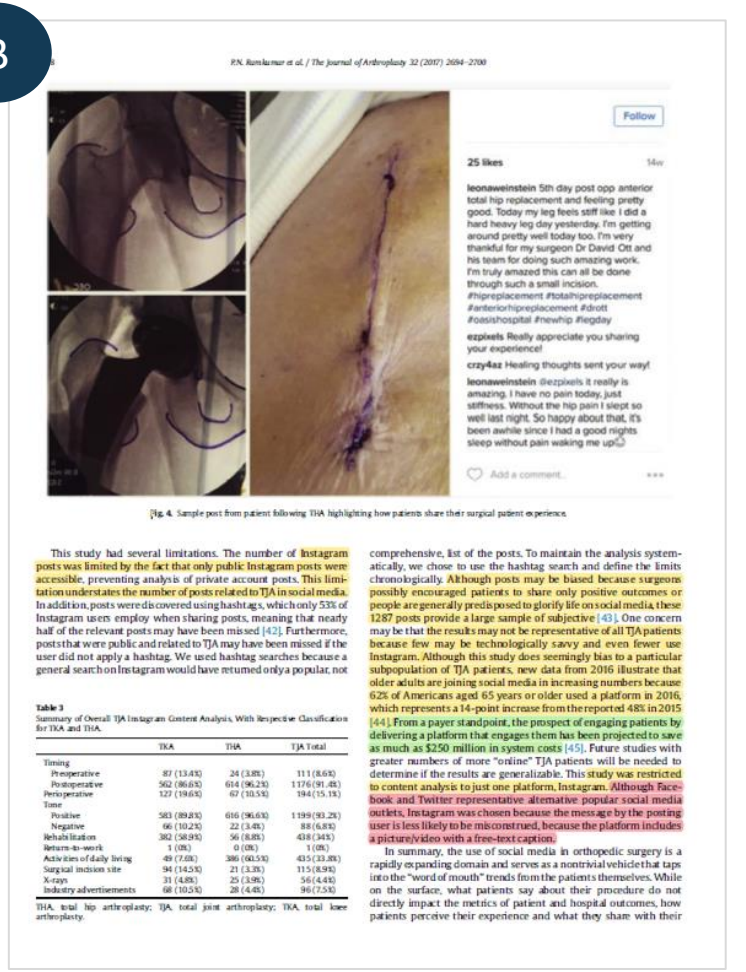


Fig. 4. Sample post from patient following THA highlighting how patients share their surgical patient experience.

This study had several limitations. The number of Instagram posts was limited by the fact that only public Instagram posts were accessible, preventing analysis of private account posts. This limitation understates the number of posts related to TJA in social media. In addition, posts were discovered using hashtags, which only 53% of Instagram users employ when sharing posts, meaning that nearly half of the relevant posts may have been missed [42]. Furthermore, posts that were public and related to TJA may have been missed if the user did not apply a hashtag. We used hashtag searches because a general search on Instagram would have returned only a popular, not comprehensive, list of the posts. To maintain the analysis systematically, we chose to use the hashtag search and define the limits chronologically. Although posts may be biased because surgeons possibly encouraged patients to share only positive outcomes or people are generally predisposed to glorify life on social media, these 1287 posts provide a large sample of subjective [43]. One concern may be that the results may not be representative of all TJA patients because few may be technologically savvy and even fewer use Instagram. Although this study does seemingly bias to a particular subpopulation of TJA patients, new data from 2016 illustrate that older adults are joining social media in increasing numbers because 62% of Americans aged 65 years or older used a platform in 2016, which represents a 14-point increase from the reported 48% in 2015 [44]. From a payer standpoint, the prospect of engaging patients by delivering a platform that engages them has been projected to save as much as $250 million in system costs [45]. Future studies with greater numbers of more "online" TJA patients will be needed to determine if the results are generalizable. This study was restricted to content analysis to just one platform, Instagram. Although Facebook and Twitter represent alternative popular social media outlets, Instagram was chosen because the message by the posting user is less likely to be misconstrued, because the platform includes a picture/video with a free-text caption.

In summary, the use of social media in orthopedic surgery is a rapidly expanding domain and serves as a nontrivial vehicle that taps into the "word of mouth" trends from the patients themselves. While on the surface, what patients say about their procedure do not directly impact the metrics of patient and hospital outcomes, how patients perceive their experience and what they share with their

Table 3
Summary of Overall TJA Instagram Content Analysis, With Respective Classification for TKA and THA.

	TKA	THA	TJA Total
Timing			
Preoperative	87 (13.4%)	24 (3.8%)	111 (8.6%)
Postoperative	562 (86.6%)	614 (96.2%)	1176 (91.4%)
Perioperative	127 (19.6%)	67 (10.5%)	194 (15.1%)
Tone			
Positive	583 (89.8%)	616 (96.6%)	1199 (93.2%)
Negative	66 (10.2%)	22 (3.4%)	88 (6.8%)
Rehabilitation	382 (58.9%)	56 (8.8%)	438 (34%)
Return-to-work	1 (0%)	0 (0%)	1 (0%)
Activities of daily living	49 (7.6%)	386 (60.5%)	435 (33.8%)
Surgical incision site	94 (14.5%)	21 (3.3%)	115 (8.9%)
X-rays	31 (4.8%)	25 (3.9%)	56 (4.4%)
Industry advertisements	68 (10.5%)	28 (4.4%)	96 (7.5%)

THA, total hip arthroplasty; TJA, total joint arthroplasty; TKA, total knee arthroplasty.

Example of a study that reported **images** in Ramkumar et al. (2017)[3]

C

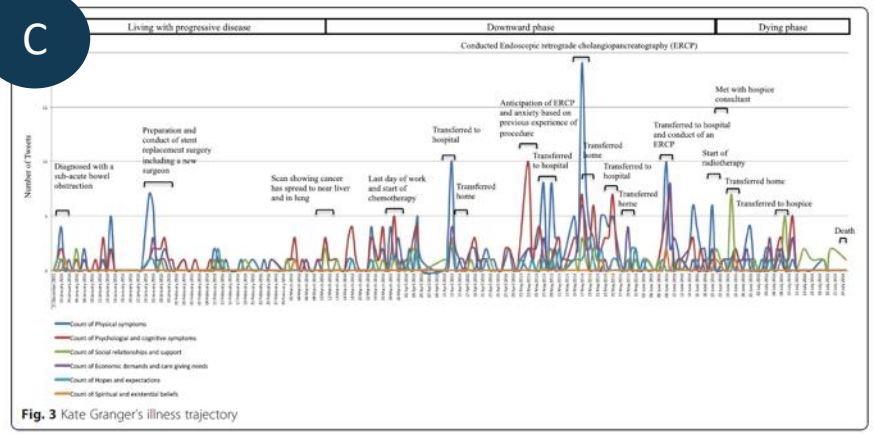


Fig. 3 Kate Granger's illness trajectory

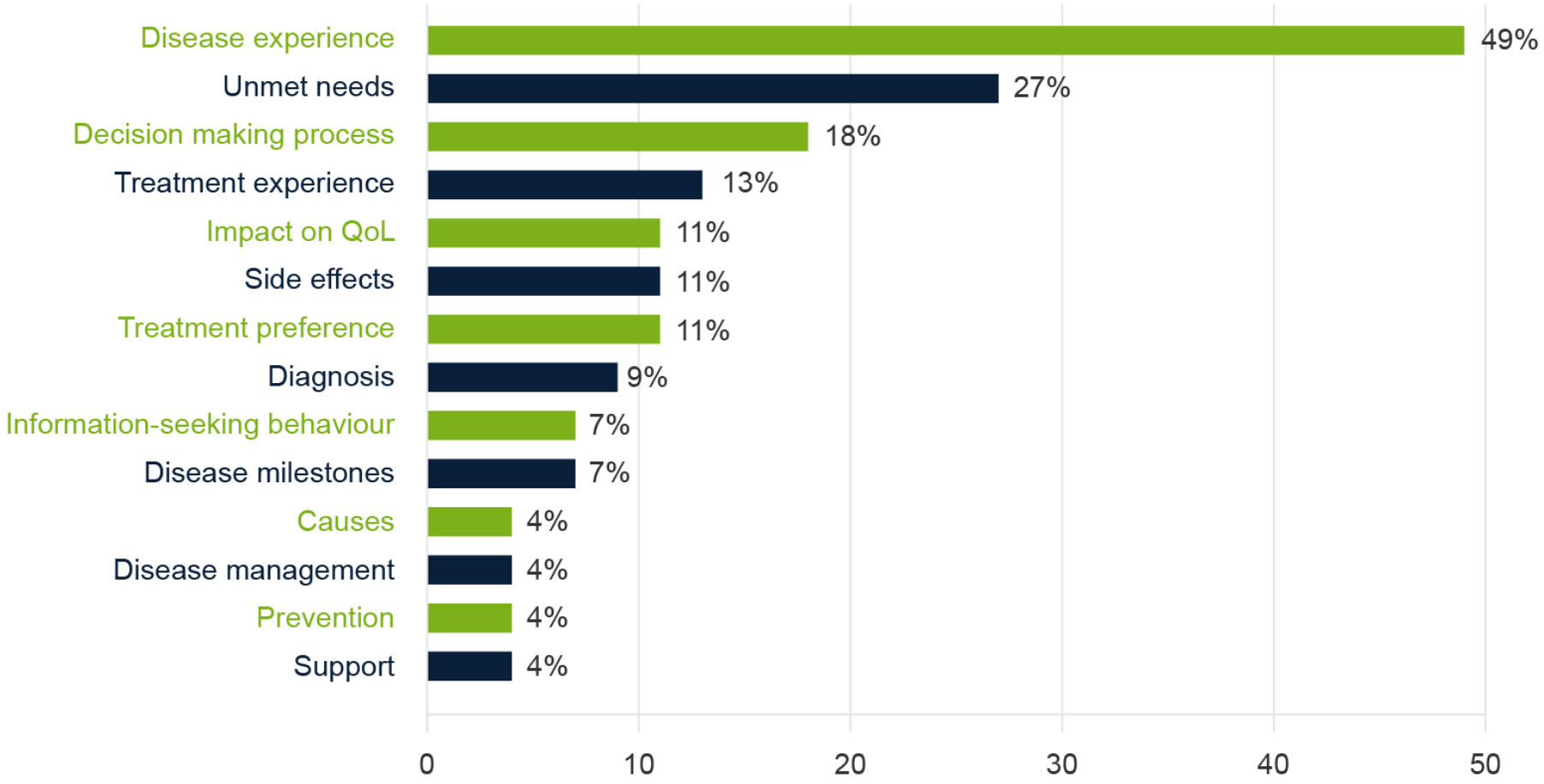
Example of **Tweets** mapped according to the illness trajectory in Taylor and Pagliari (2018)[2]

1. Gao, Smith, and Malloy. "Head and neck cancer and social media: the patient experience and cancer survivorship." *The Laryngoscope* 131.4 (2021): E1214-E1219.
2. Taylor and Pagliari. "# Deathbedlive: the end-of-life trajectory, reflected in a cancer patient's tweets." *BMC palliative care* 17.1 (2018): 1-10.
3. Ramkumar et al. "Social media and total joint arthroplasty: an analysis of patient utilization on Instagram." *The Journal of arthroplasty* 32.9 (2017): 2694-2700.

What have social media listening studies revealed about patients' experiences of living with chronic disease?

Outcomes

Disease experience, unmet needs and decision making process were the most reported outcomes



Overlapping groups – sum is not 100%

Thematic analysis of study findings

Findings of the studies reporting on patient experience were organised into six themes

Thematic analysis of study findings

Findings of the studies reporting on patient experience were organised into six themes

Impact of illness and symptoms

- **Physical, emotional, social and economic impact** of living with the illness
- **The types, frequencies, intensity and impacts of symptoms** associated with the chronic illness

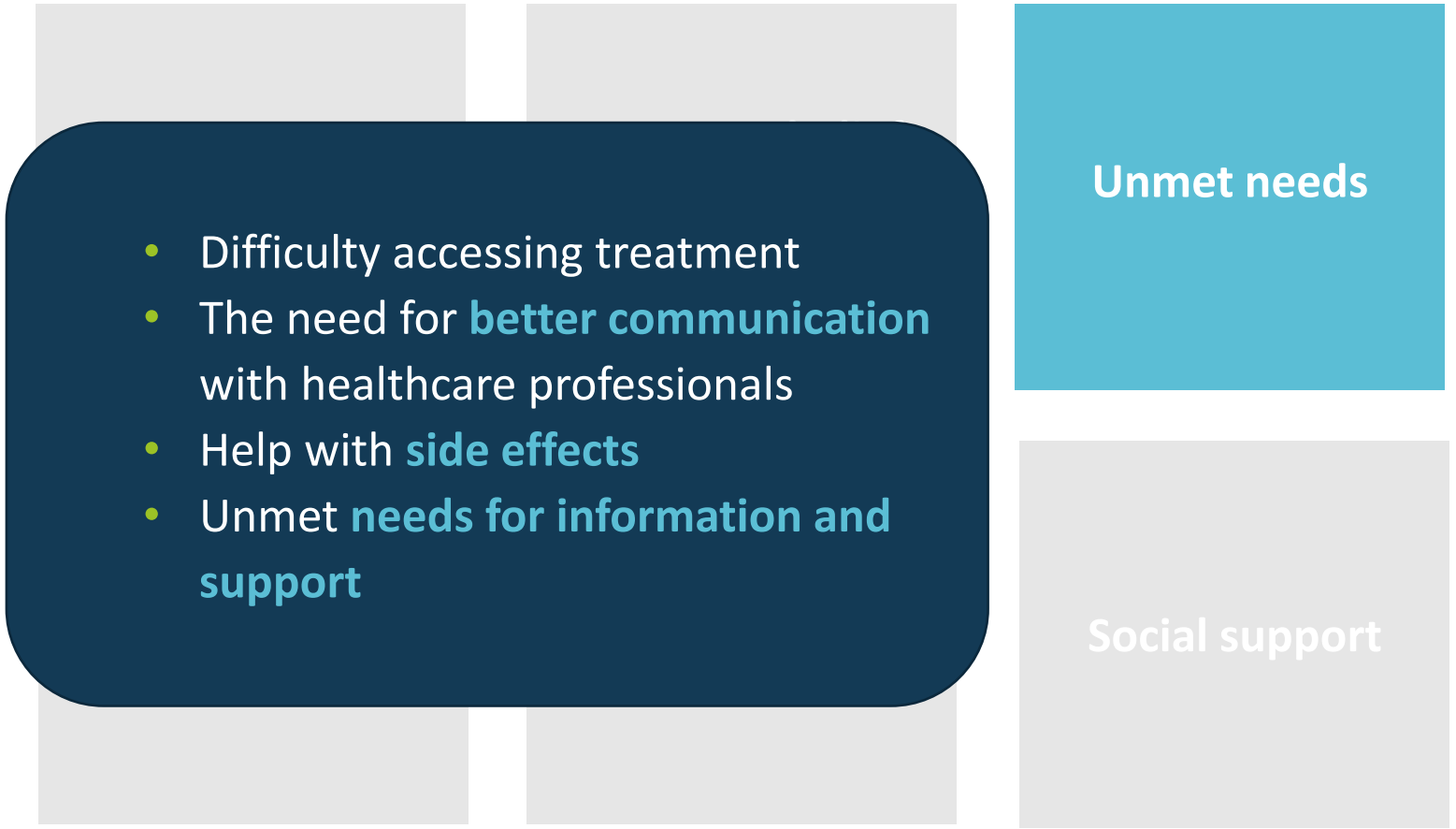
Experiences of healthcare

Thematic analysis of study findings

Findings of the studies reporting on patient experience were organised into six themes

Thematic analysis of study findings

Findings of the studies reporting on patient experience were organised into six themes



Thematic analysis of study findings

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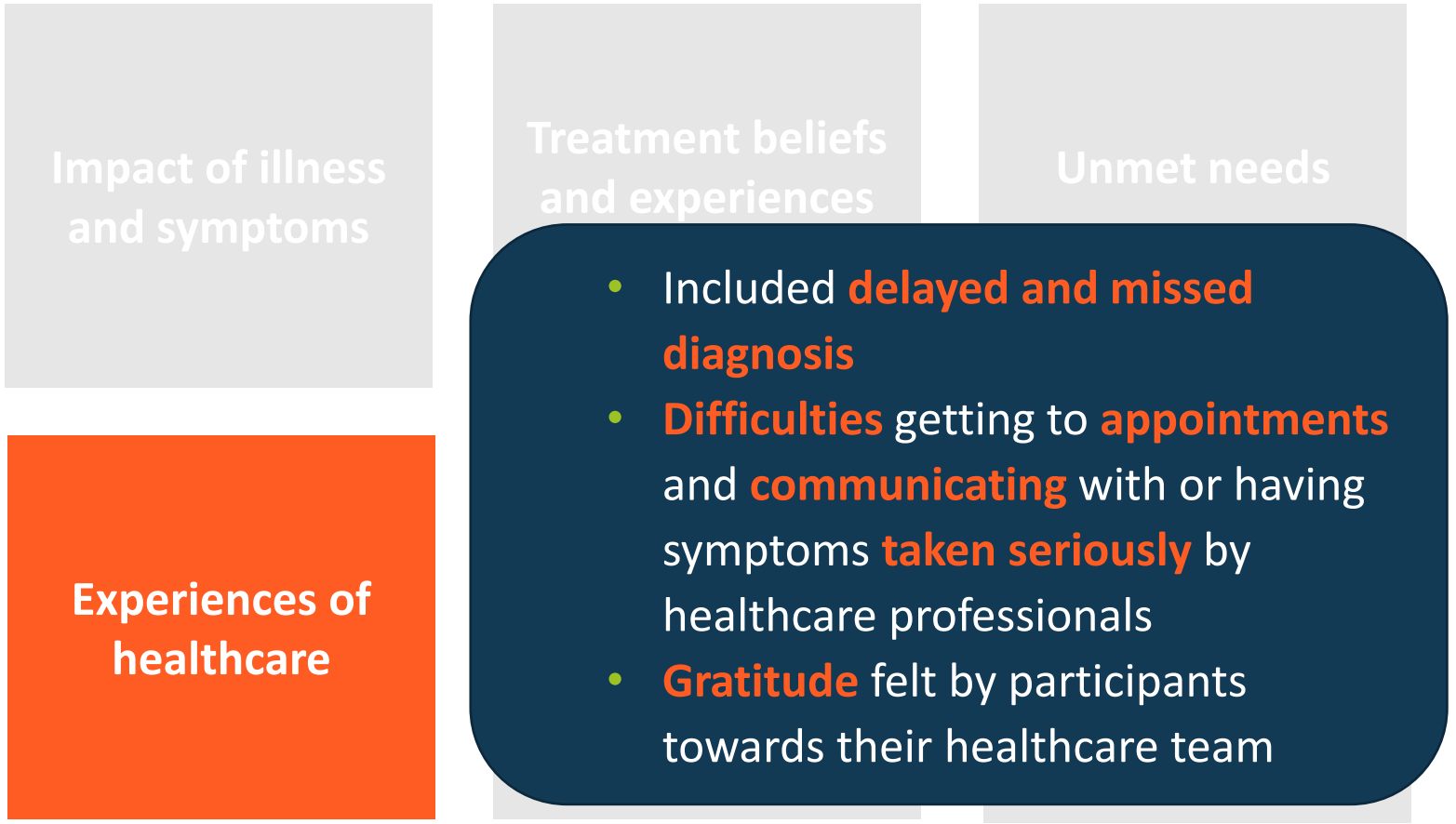


Thematic analysis of study findings

Findings of the studies reporting on patient experience were organised into six themes

Impact of illness and symptoms

Treatment beliefs and experiences

Unmet needs

Experiences of healthcare

Milestones

- Posts about **the importance to patients of disease milestones** including remission of disease, initiation and completion of treatment, and transitions between different phases of disease.
- **Living life to the fullest rather than survival of a disease**

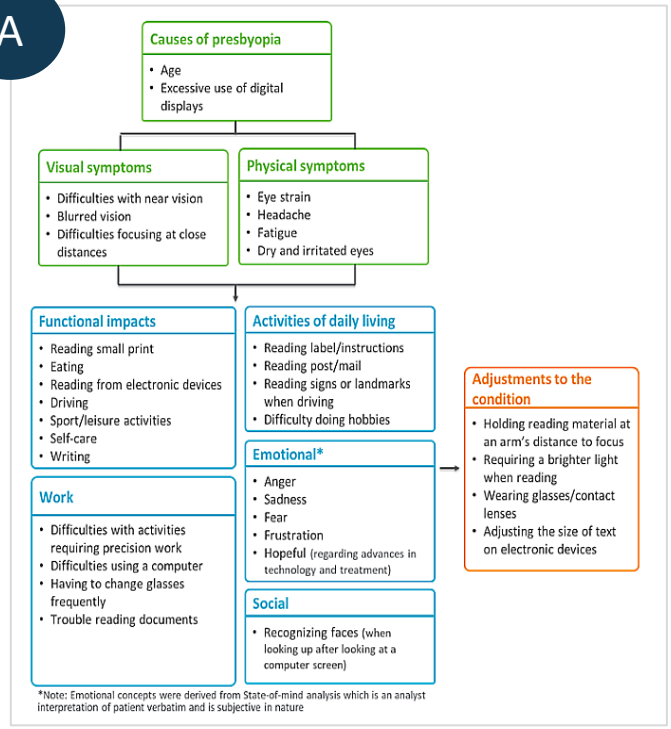
Thematic analysis of study findings

Findings of the studies reporting on patient experience were organised into six themes

Outcomes

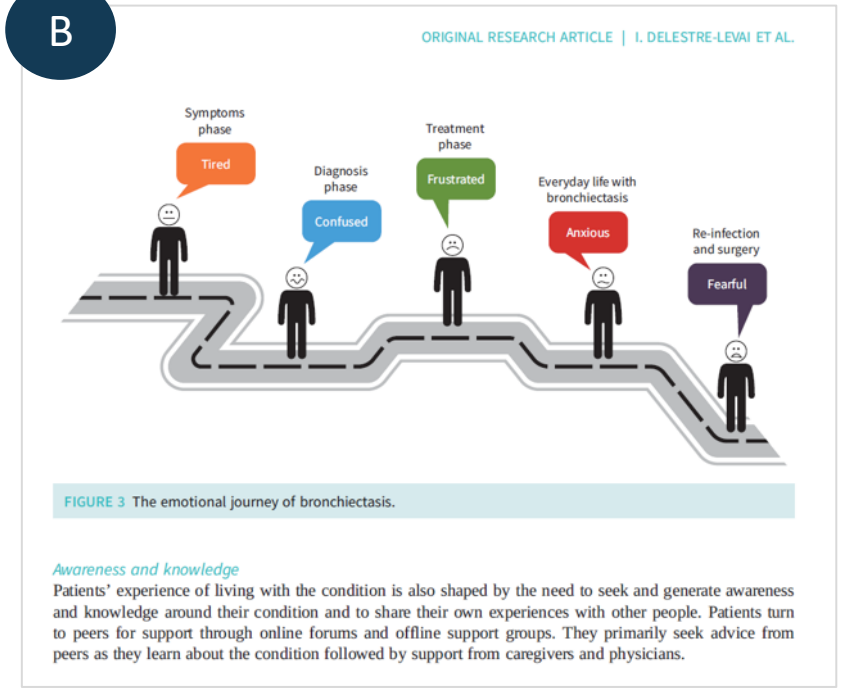
Examples in practice

A



Impact of illness and symptoms: Conceptual model in Wolffsohn et al. (2020)[1]

B



Treatment beliefs and experiences: Emotional journey in Delestre-Levai et al. (2021)[2]

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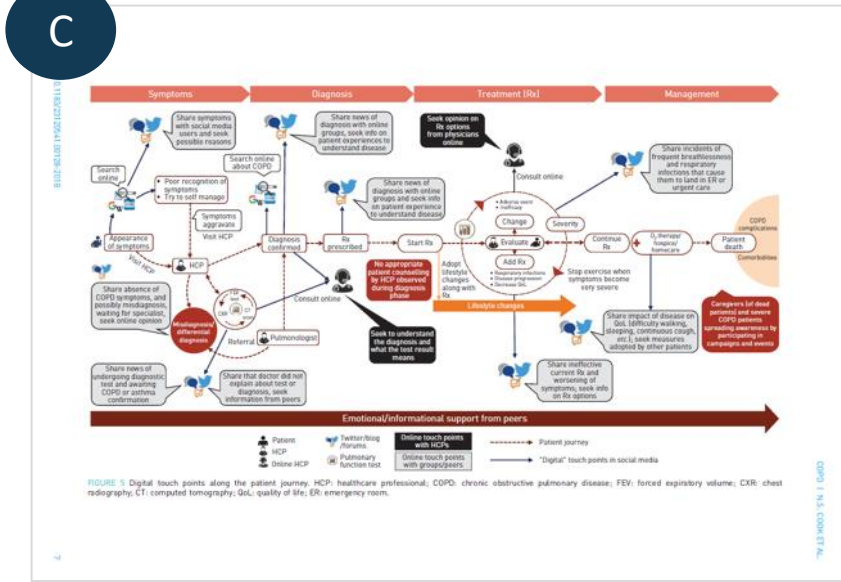


Experiences of healthcare & Milestones: Digital touch points along the patient journey Cook et al. (2019)[3]

1. Wolffsohn, et al. "Social Media Listening to Understand the Lived Experience of Presbyopia: Systematic Search and Content Analysis Study." *Journal of medical Internet research* 22.9 (2020): e18306.
2. Delestre-Levai et al. "Patients' perspectives on Bronchiectasis: findings from a social media listening (SML) study." *ERJ Open Research* (2021).
3. Cook et al. "Patients' perspectives on COPD: findings from a social media listening study." *ERJ open research* 5.1 (2019).

What ethical issues and limitations have been identified in social media listening studies?

Ethics

76%

Stated ethical factors in their study

22%

Asked for informed consent of the participants

80%

Used publicly available data

49%

Requested IRB approval

WMA

Declaration of Helsinki

33%

Complied with study guidance or organizational guidance

HIPAA COMPLIANCE

Limitations reported

User selection bias was the main reported limitation. Bias towards younger, more educated and high-income people should be considered despite the growing use of social media amongst the elderly

58% User selection bias

36% Content bias
31% Accuracy, quality and reliability issues
29% Lack of demographic information
27% Sample selected bias
22% Self-reported diagnosis
18% Lack of data-mining tools (automation)

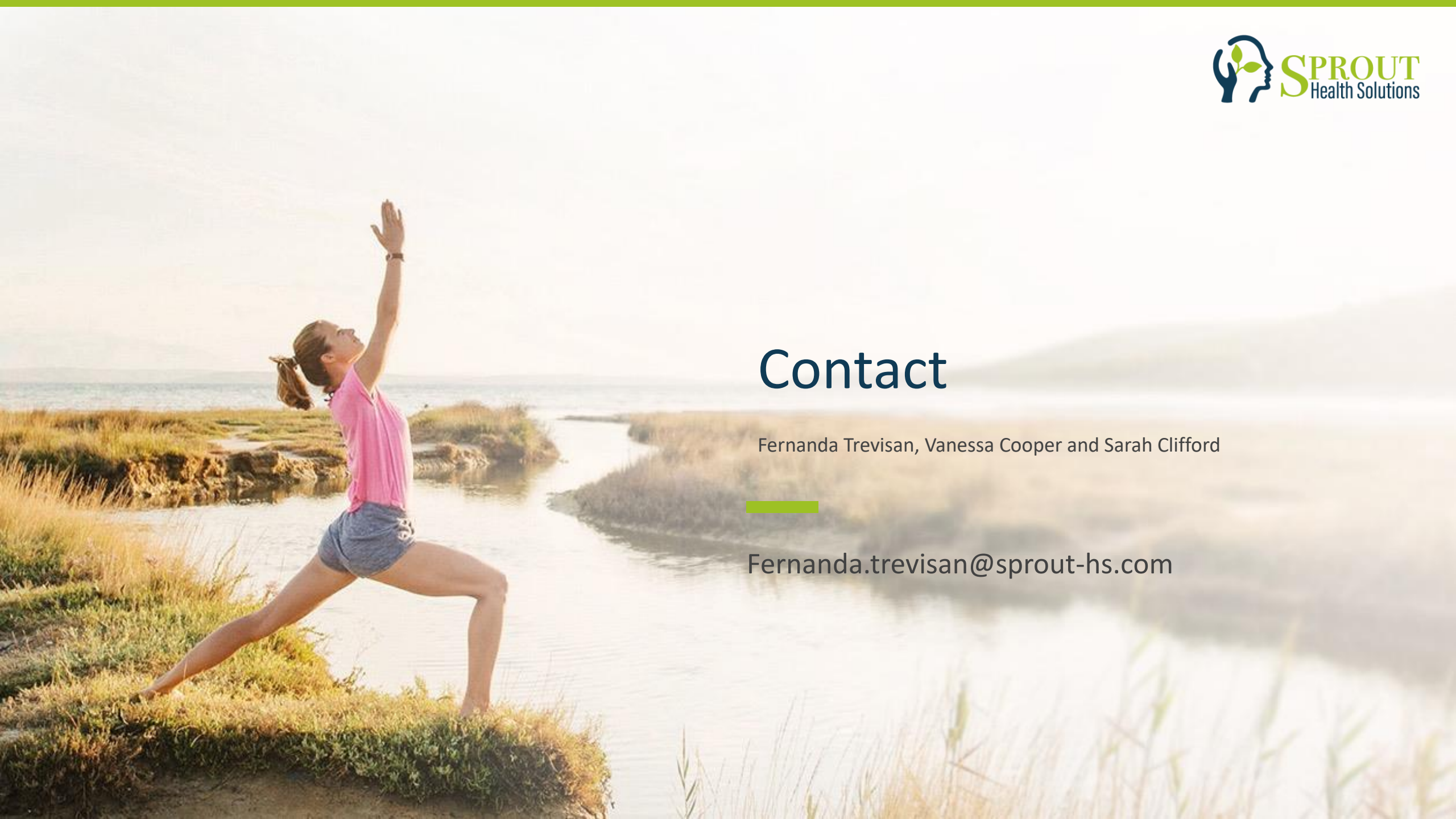
Overlapping groups – sum is not 100%

Limitations of this scoping review

- No guidelines on the conduct of social media listening studies that could be followed
- One author was responsible for the majority of screening and data extraction which may have introduced bias
- Single electronic database (PubMed) – including a search of more databases may increase the number of studies included
- Our search terms may not have been comprehensive enough to pick up studies in every chronic illness
- No contact was made with authors to verify methodological issues

Discussion and conclusions

- Range of methods used to conduct the SML exercises and for analysing the data
- SML can generate rich insights into the patient experience of chronic disease
- SML can be used as a key pillar of patient insights work:
    - Potential to tap in to a broader range of voices than we typically get from qualitative interview/focus group studies
    - It offers a broad range of data sources (e.g. images, videos and blogs in addition to text posts)
    - The experiences that patients share online have not been prompted by or limited to the questions asked by a researcher
- However, the generalisability of findings may be limited by selection bias and others
- Potential for SML to be used alongside traditional qualitative methods to triangulate findings
- Variation in use of ethics approval and methods suggests that clearer guidelines may be helpful to guide best practice in this field



Contact

Fernanda Trevisan, Vanessa Cooper and Sarah Clifford

Fernanda.trevisan@sprout-hs.com