The Use of Social Media Listening to Collect Oncology-Specific Patient Experience Data: a Scoping Review

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Background

- Social Media Listening (SML) is a passive method for collecting and analysing patient experience data (PED) from online sources, particularly social media.[1]
- SML captures first-hand, spontaneous, and unfiltered patient experiences related to disease and treatment without direct patient interaction.[1,2]
- The Food and Drug Administration (FDA) recognises SML as a valid method for collecting PED for patient-focused drug development; it is also used by the pharmaceutical industry in drug development.[1-3]
- There is a significant and growing worldwide global burden of cancer.[4]
- PED (including SML) is underutilised in regulatory benefit-risk assessments for oncology drugs by both the European Medicines Agency (EMA) and FDA (c. 10%).[5]
- The usage and full potential of PED, especially gathered via SML, to inform regulatory decisions and drug development remain uncertain and underexplored despite policy targets.[1,5]

Objective

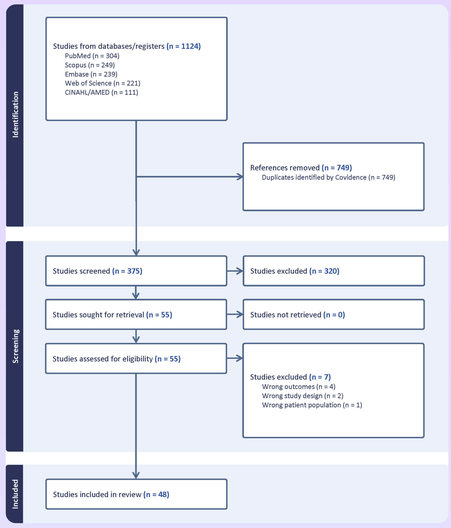
We aimed to map the research landscape of oncology-specific PED captured using SML, including who conducts research, why, and the types and volume of data gathered.

Methodology

- We conducted a scoping review[6] of six databases (CINAHL (Cumulative Index to Nursing and Allied Health Literature), AMED (Allied and Complementary Medicine Database), Embase, PubMed, Scopus, and Web of Science), searching for studies published from inception until October 2024.
- Abstract and full-text screening and data extraction were completed by one investigator; at each stage a second investigator assessed 20% of studies. Conflicts were resolved by a third investigator.
- The inclusion criteria were:
  - The study population are patients with a diagnosis of cancer.
  - The study is in English.
  - The study includes and reports on the primary analysis of secondary data obtained via social media listening about oncology-specific PED.
- We synthesised the characteristics of the studies and summarised the types of data collected by mapping them to five a priori categories. These categories were informed by the FDA's definition of PED,[7] as well guidance from IMI-Prefer.[8]

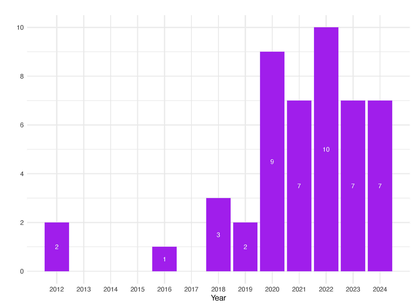
Results: PRISMA

- We retrieved 1124 studies, of which 749 were identified as duplicates by Covidence.
- 375 study abstracts were screened, and 320 studies were excluded at this stage.
- Of 55 full-text studies read, **48 were included in the synthesis.**



Results

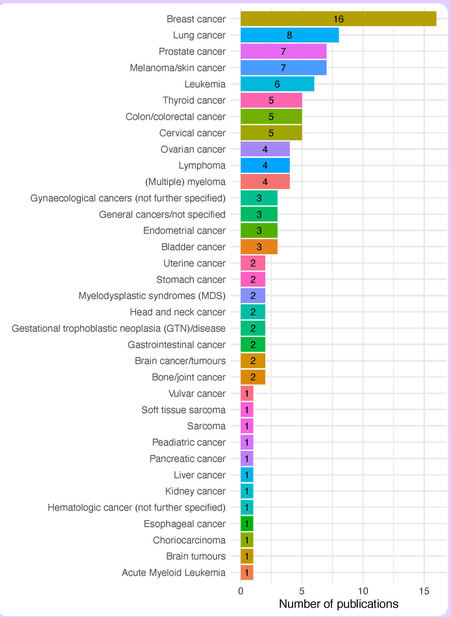
Year published



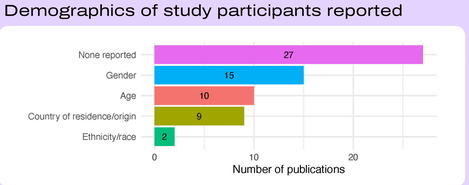
Funder:
- No funding received/not reported: 24
- Industry: 15
- Governmental: 5
- Other: 2
- Academic: 2

Analysis methods used:
- Manual: 23
- Mix of manual and computational: 19
- Computational: 6

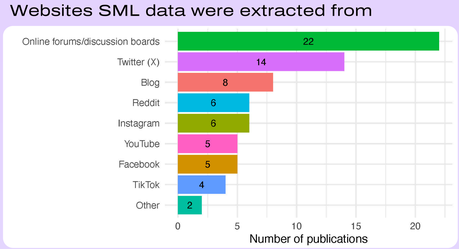
Types of cancers included in analysis



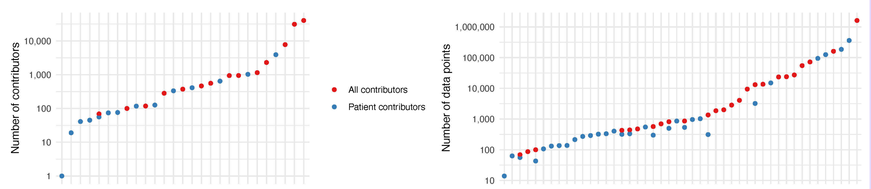
Demographics of study participants reported



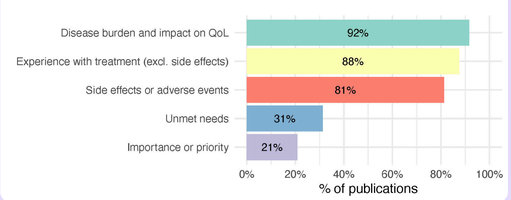
Websites SML data were extracted from



Sample Sizes (where reported:)



Types of SML Patient Experience Data Collected



Summary of results

- **40/48 studies (83%) were published from 2020 onwards,** reflecting the novelty of SML.
- The **most common cancer types** in the included studies were breast cancer, lung cancer, prostate cancer, melanoma/skin cancer, and leukaemia.
- Researchers used a **wide range of analysis methods**, ranging from more conventional manual, thematic analysis to computational methods such as natural language processing and machine learning.
- The data gathered often related to **general disease impacts and burden** (92% of studies), treatment experiences (88%) and information on side effects and adverse events (81% of studies).
- Most studies (27/48, 56%) **did not report any demographic data**.
- SML data was most gathered from **online forums/discussion boards** (22/48 studies, 46%), following by Twitter (X) (14/48, 29%), and blogs (8/48, 17%).

Conclusions

- Using SML to gather oncology-specific PED is employed by researchers in heterogenous ways. Data on side effects and adverse events may be of particular interest to regulators.
- SML-specific reporting standards could improve consistency and thoroughness of published studies and their usability.

References

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