

Understanding the Lived Experience of Patients by Mining Online Health Boards

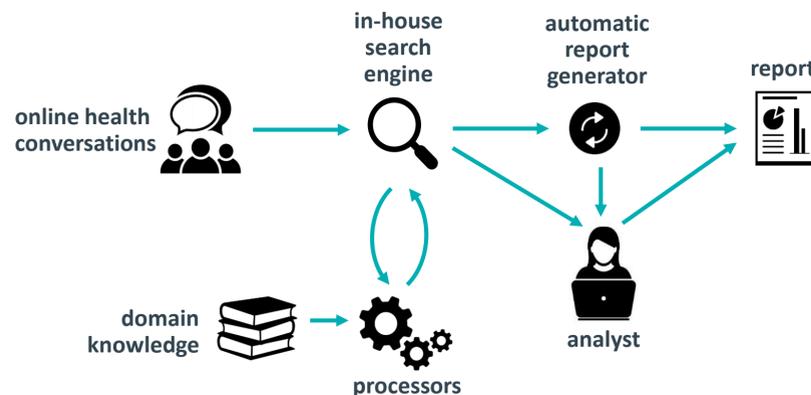
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Online health boards (OHBs) are web-based forums where patients post publicly about their conditions. We evaluated the extent to which OHB posts could be used to generate meaningful insights into the lived experience of patients. Specifically, we sought to (a) capture patient reactions to the Covid-19 pandemic, (b) determine pathways to diagnosis of the rare disease ANCA-associated vasculitis (AAV) and (c) develop clinical outcome assessments (COAs) for chronic heart failure (CHF).

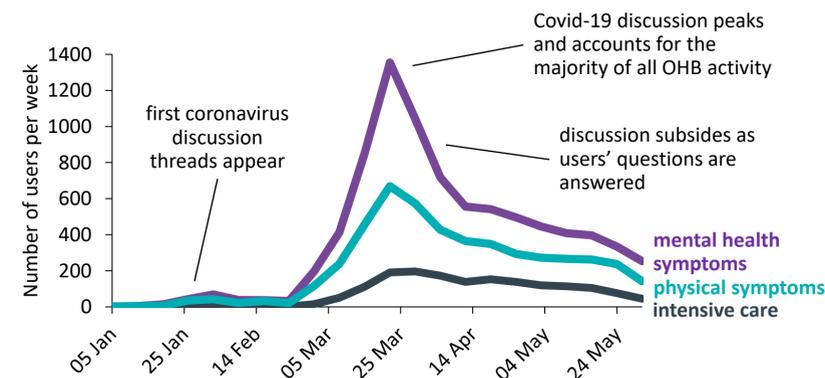
METHODS

For each use case, a keyword-based search was performed to retrieve relevant English language posts from multiple OHBs. A machine learning approach discarded all posts except those where a patient was writing about themselves or someone in their care. Computer-assisted coding was applied to these posts and numerical analysis used to extract insights from the coding. Where possible, our findings were compared to those obtained using traditional methods.

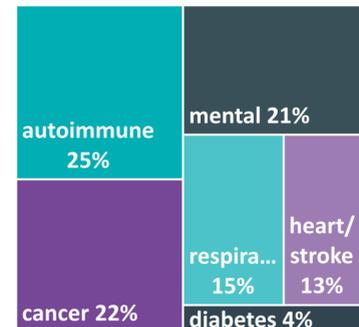


RESULTS: COVID-19

We monitored the number of users raising concerns about Covid-19 across three major OHBs in early 2020.

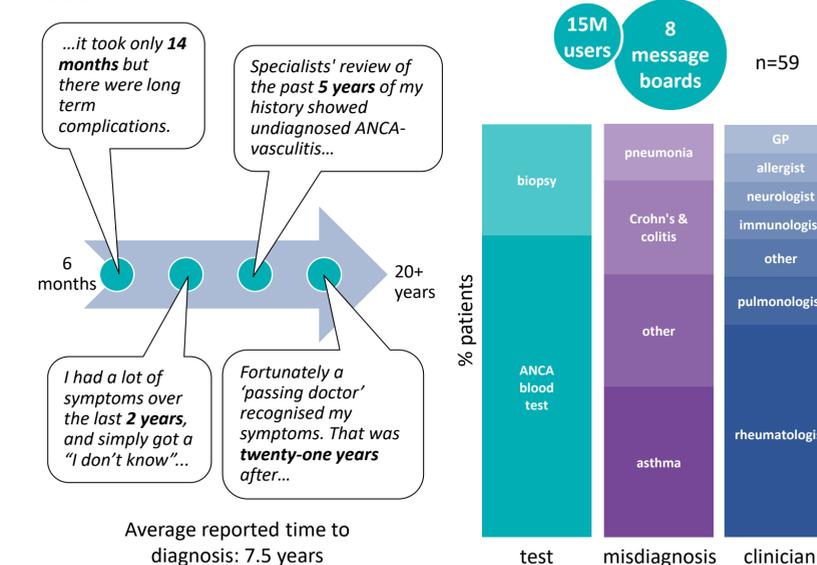


Individuals at risk of immuno-deficiency accounted for nearly half of users discussing Covid-19 concerns. People with existing mental health conditions also featured highly.



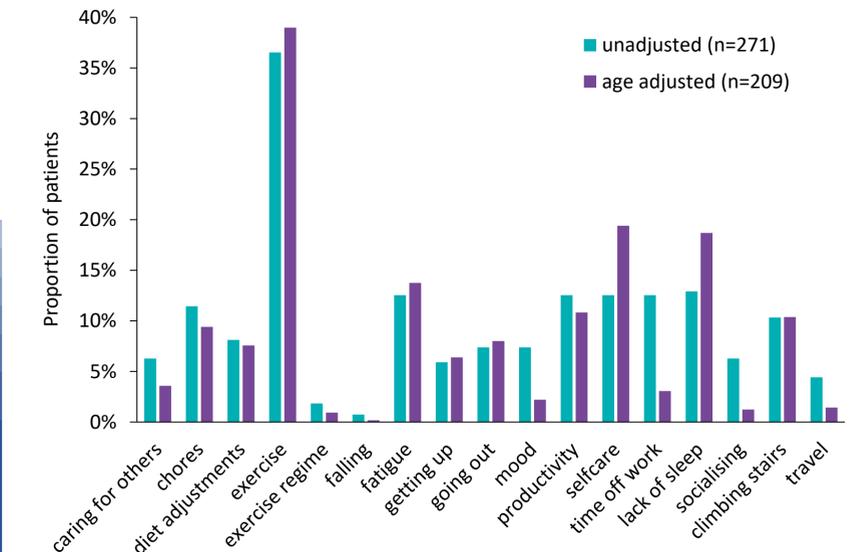
RESULTS: ANCA ASSOCIATED VASCULITIS

Misdiagnosis of rare diseases is common, as clinicians naturally gravitate to associating symptoms with more prevalent conditions. We were able to determine patient journeys to AAV diagnosis, including misdiagnoses, the clinical specialism of the individual who diagnosed them, and which diagnosis test was used.



RESULTS: CHRONIC HEART FAILURE

To assist in development of patient-centric COAs for CHF we identified 17 main patient-reported impacts, shown below according to how many patients reported them.



Subsequent analysis resolved the importance of specific types of exercise.

CONCLUSION

Mining OHBs offers an alternative methodology for capturing patient experience across a range of applications. Its strengths are the immediacy with which insights can be acquired, the size of cohorts that can be studied and the ability to retrospectively perform longitudinal studies. However, the approach is limited by the inability to probe beyond existing post content, the reliance on patients to proactively share their experience, and the inability to independently evidence their diagnosis.

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