Social media promotion of health tests with potential for overdiagnosis and/or overuse: protocol for a content analysis

Brooke Nickel, Raffael Heiss, Patti Shih, Emma Gram, Tessa Copp, Melody Taba, Ray Moynihan, Joshua Zadro

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Brooke Nickel[1] BSc, MIPH, PhD; Raffael Heiss[2]; Patti Shih[3]; Emma Gram[4]; Tessa Copp[1]; Melody Taba[1]; Ray Moynihan[5]; Joshua Zadro[1]

[1]Sydney School of Public Health Faculty of Medicine and Health The University of Sydney Sydney AU
[2]Center for Social & Health Innovation The Entrepreneurial School Management Centre Innsbruk Innsbruk AT
[3]Australian Centre for Health Engagement Evidence & Values School of Health and Society University of Wollongong Wollongong AU
[4]Center for General Practice Department of Public Health University of Copenhagen Denmark AU
[5]Institute for Evidence-Based Healthcare Faculty of Health Sciences and Medicine Bond University Gold Coast AU

Corresponding Author:
Brooke Nickel BSc, MIPH, PhD
Sydney School of Public Health
Faculty of Medicine and Health
The University of Sydney
127A Edward Ford Building (A27)
Sydney
AU

Abstract

Background: In recent years social media have emerged as an important space for commercial marketing of health tests which can be used for the screening and diagnosis of otherwise asymptomatic healthy people. However, little is known about how health tests are promoted on social media and whether the information provided is accurate, balanced and there is transparency around conflicts of interest.

Objective: This study aims to understand and quantify how social media is being used to promote health tests with potential for overdiagnosis and/or overuse, to asymptomatic healthy people. Specifically, the study will explore whether the information being promoted is evidence-based, how the benefits and harms of the tests are discussed, what narratives are used, and examine transparency around potential conflicts of interest in promotion of the tests.

Methods: Content analysis of social media posts on the Anti-Mullerian Hormone (AMH) test, whole-body MRI scan, multi-cancer detection (MCED) test, testosterone test and gut microbe test from influential international social media accounts on Instagram and TikTok will be conducted. The five tests have been identified as having the following criteria: 1) there are evidence-based concerns about overdiagnosis and/or overuse, 2) there is evidence and/or concerns that the results of tests do not lead to improved health outcomes for asymptomatic healthy people and may cause harm or waste, and 3) the tests are being promoted on social media to asymptomatic healthy people. English language text-only posts, images, infographics, articles, recorded videos including reels and audio-only posts will be included. Posts from influencers and/or pages with <1,000 followers, stories, live videos and non-English posts will be excluded. Using keywords related to the test, the top posts will be searched and screened until there are 100 eligible posts from each platform for each test (1000 posts total). Data from the caption, video and on-screen text will be summarised and/or extracted into an Excel spreadsheet and included in the analysis. The analysis will take a deductive approach using a pre-specified framework. Quantitative data will be analysed in SPSS.

Results: Data on Instagram and TikTok has been searched and screened. Analysis has not yet commenced. The findings will be disseminated via publication/s in peer-review international medical journals and will also be presented at national and international conferences in late 2024 and 2025.

Conclusions: This study will contribute to the limited evidence base on how social media may be driving overdiagnosis and causing overuse of healthcare services. Understanding this is essential to develop strategies to mitigate potential harm and plan solutions, thus protecting members of the public from being marketed low-value tests, becoming patients unnecessarily and taking resources away from the health system.

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Authors: Brooke Nickel[1,2], Raffael Heiss[3], Patti Shih[4], Tessa Copp[1,2], Emma Gram[5], Melody Taba[1,2], Ray Moynihan[6], Joshua Zadro[7]

1. Sydney Health Literacy Lab, Sydney School of Public Health, Faculty of Medicine and Health, The University of Sydney, Australia
2. Wiser Healthcare, Sydney School of Public Health, Faculty of Medicine and Health, The University of Sydney, Australia
3. Center for Social & Health Innovation, Management Centre Innsbruk – The Entrepreneurial School, Austria
4. Australian Centre for Health Engagement Evidence & Values, School of Health and Society, University of Wollongong, Australia
5. Center for General Practice, Department of Public Health, University of Copenhagen, Denmark
6. Institute for Evidence-Based Healthcare, Faculty of Health Sciences and Medicine, Bond University, Australia
7. Sydney Musculoskeletal Health and Institute for Musculoskeletal Health, Sydney School of Public Health, Faculty of Medicine and Health, The University of Sydney and Sydney Local Health District, NSW, Australia

Corresponding author: Dr Brooke Nickel
127A Edward Ford Building (A27)
The University of Sydney
NSW 2006
Australia
brooke.nickel@sydney.edu.au

ABSTRACT

Background: In recent years social media have emerged as important spaces for commercial marketing of health tests which can be used for the screening and diagnosis of otherwise generally healthy people. However, little is known about how health tests are promoted on social media and whether the information provided is accurate, balanced and if there is transparency around conflicts of interest.

Objectives: This study aims to understand and quantify how social media is being used to discuss/promote health tests with potential for overdiagnosis and/or overuse, to generally healthy people. Specifically, the study will explore whether the information being featured relies on evidence, how the benefits and harms of the tests are discussed, what narratives are used, and examine transparency around potential conflicts of interest in promotion of the tests.

Methods: Content analysis of social media posts on the Anti-Mullerian Hormone (AMH) test, whole-body magnetic resonance imaging (MRI) scan, multi-cancer detection (MCED) test, testosterone test and gut microbe test from influential international social media accounts on Instagram and TikTok will be conducted. The five tests have been identified as having the following criteria: 1) there are evidence-based concerns about overdiagnosis and/or overuse, 2) there is evidence and/or concerns that the results of tests do not lead to improved health outcomes for generally healthy people and may cause harm or waste, and 3) the tests are being promoted on social media to generally healthy people. English language text-only posts, images, infographics, articles, recorded videos including reels and audio-only posts will be included. Posts from accounts with <1,000 followers, as well as stories, live videos and non-English posts are excluded. Using keywords related to the test, the top posts were searched and screened until there are 100 eligible posts from each platform for each test (1000 posts total). Data from the caption, video and on-screen text will be summarised and/or extracted into an Excel spreadsheet and included in the analysis. The analysis will take a combined inductive approach when generating key themes and deductive approach using a pre-specified framework. Quantitative data will be analysed in SPSS.

Results: Data on Instagram and TikTok has been searched and screened. Analysis has not yet commenced. The findings will be disseminated via publication/s in peer-review international medical journals and will also be presented at national and international conferences in late 2024 and 2025.

Conclusions: This study will contribute to the limited evidence base on the nature of the relationship between social media and the problems of overdiagnosis and overuse of healthcare services. Understanding this is essential to develop strategies to mitigate potential harm and plan solutions, with the aim of helping to protect members of the public from being marketed low-value tests, becoming patients unnecessarily and taking resources away from genuine need within the health system.

Keywords: social media; influencers; tests; overdiagnosis; overuse; evidence-based medicine; promotion

INTRODUCTION

The idea that early detection of health conditions and/or diseases is always better, as it offers the best chance of being cured, has been around for decades, and continues to grow in popularity [1]. However, evidence demonstrates that lay people often overestimate the benefits and underestimate the harms of tests

[2], and there is increasing evidence that inappropriate testing can harm healthy people and the quest for early detection can lead to overdiagnosis [3-9]. Overdiagnosis is now widely recognised and occurs when generally healthy people are diagnosed or labelled with a disease that would never cause them harm [10, 11]. This can occur as a result of undergoing screening tests (e.g. cancer screening[12]) and can lead to the overuse of further tests, and overtreatment. More recently there have been concerns direct-to-consumer (DTC) tests can lead to overdiagnosis of generally healthy people and overuse [13, 14]. The harmful consequences of overdiagnosis can include physical harm from unnecessary tests and treatments, psychological harm from being labelled with a condition and/or disease that won't cause harm, and receiving invasive treatments that also carry financial consequences [11]. It can also lead to an unsustainable burden on the healthcare system. A review of relevant literature has identified potential drivers of overdiagnosis across five domains: culture, the health system, industry, professionals, and patients and the public [15]. The review found many causes, including common beliefs that "more is better", systemic financial incentives to deliver more tests and treatments, technological changes enabling increasingly sensitive test, and patient expectations clinicians will "do something"[15]. While the use of more sensitive tests and the promotion of tests, advertising and traditional media have been identified as drivers, there are as yet few data on how social media might drive overdiagnosis and overuse.

In recent years social media have emerged as an important space for commercial marketing of health products [16], including various early detection tests [17], which can be used for the screening and diagnosis of otherwise healthy people. Companies themselves are very active on social media, promoting their products through traditional advertisements that appear in users' news feeds. Companies are also partnering with social media influencers [18] – individuals who amass large followings on social media and exert significant influence over their audience through engaging content [19]. While platforms themselves claim to regulate health information and misinformation, the current regulations around what can be promoted on social media are minimal [13]. Influencers may share health information to their audiences, even though they may not necessarily be qualified to give health information. The social media promotion of health products can often be based on personal anecdotes and opinion or, at worst, on pseudoscience or conspiracy theories. For example, studies now have identified the impact that influential social media has on health misinformation across various conditions [20-23], including most recently widespread COVID-19 misinformation[24, 25] which has negatively affected people's health behaviours [26, 27]. However, little is known about how health tests are promoted on social media and whether the information provided is accurate, balanced and there is transparency around conflicts of interest.

This study therefore aims to quantify and understand how social media is being used to discuss/promote health tests with potential for overdiagnosis and overuse to generally healthy people. The study will explore what themes are being used in the discussion/promotion of the tests, how the benefits and harms including overdiagnosis and overuse of the tests are discussed, whether evidence is being used in the promotion of tests, what is the overall tone, and transparency around potential conflicts of interest in promotion of the tests.

METHODS

Study design: Content analysis of information on tests from influential social media platforms Instagram and TikTok. Content analysis [28] is a widely used qualitative research technique, which also utilises quantitative methods to analyse written content, enabling themes, meanings, and concepts to be quantified and evaluated through coding. The study will be reported according to the Standards for Reporting Qualitative Research (SRQR) reporting guideline [29].

Inclusion and exclusion criteria: English-language social media posts on five specific tests (as outlined below) from influential international social media accounts. The five tests have been identified as meeting the following criteria: 1) there are evidence-based concerns about overdiagnosis and/or overuse, 2) there is

evidence and/or concerns that the results of tests do not lead to improved health outcomes for generally healthy people and may cause harm or waste, and 3) the tests are being promoted on social media to generally healthy people. The authors also have interest and expertise in several of the identified tests [14, 30, 31].

Influential accounts will be defined for the study as an individual or company account with >1,000 followers that discuss the specific test in question and categorised as nano (1,000-10,000 followers), micro (10,000-100,000 followers), macro (100,000-1 million followers) and mega (1 million + followers) [32] based on number of followers. Text-only posts, images, infographics, articles, recorded videos including reels and audio-only posts will be included. Posts from accounts with <1,000 followers, as well as stories, live videos and non-English posts are excluded.

Data collection: The tests include the Anti-Mullerian Hormone (AMH) test, whole-body magnetic resonance imaging (MRI) scan, multi-cancer detection (MCED) test, testosterone test and gut microbiome test. These tests are intended for individuals of varying sociodemographic characteristics including sex and age, and included a range of costs.

We chose to focus on the platforms Instagram and TikTok as they are two of the most fastest growing platforms across all age demographics relevant for the promotion of the five identified tests. These platforms are predominantly for short-form content (e.g. Infographics, Reels, TikToks), which has become more popular than longer-form content (e.g. long videos, long posts, blogs) in recent years. Shorter content may also be more impactful because it is accessible with shorter videos specifically more likely to receive more engagement [33]. Furthermore, these platforms have recent documented instances of influential celebrities promoting tests with significant evidence-based concerns about overdiagnosis (e.g. Kim Kardashian and the whole body MRI on Instagram [17]).

We created new Instagram and TikTok accounts and searched the two platforms using keywords related to each of the tests. Keywords for each test were included based on pilot testing. We searched and screened the top posts (as defined by the platform) until we had 100 eligible posts in each platform for each test. We included and assessed posts based on the platform they have been posted on (i.e. if a post was created on TikTok but posted in Instagram then will include it in the eligible Instagram posts) and any duplicate posts across the keywords and/or platforms were removed. This method was first piloted with one test (the AMH test). Searching and screening was conducted on the two platforms by one researcher using the newly created accounts. Eligibility of posts were confirmed by a second researcher. The eligible posts were saved in the account and will be returned to by the researchers to summarise, extract and analyse the data.

We will collect summarised data on publicly available demographics (e.g. date of the post), credentials of influencers and/or credibility of influential pages (e.g. expertise – medical doctor or not), paid partnership/disclosure (present/absence of the information), amount of followers (micro, macro, mid-tier, mega), and engagement metrics (e.g. views, likes, comments).

Included tests:

1. *Anti-Mullerian Hormone (AMH) test for fertility*

As the average age of mothers at first birth is increasing in high-income countries [34], there has been growing attention around the AMH test, often termed the ‘egg timer test’. AMH test is a blood test that is used to estimate ovarian reserve, in other words the number of eggs in a woman’s ovaries [35, 36]. While AMH testing has been shown to be useful in the context of a fertility treatment [37], there is no evidence to support the AMH test as a reliable measure of fertility for women in the general population as it cannot reliably predict likelihood of pregnancy, timing to pregnancy or specific age of menopause for individuals [38-40]. As a result of this evidence, the American College of Obstetricians and Gynaecologists strongly discourages AMH testing in women not undergoing IVF [41]. Yet despite clear evidence of its lack of benefit,

recent data suggests that some women are taking the test as they believe it can inform their chance of conceiving [42]. Furthermore, recent content analyses of both fertility clinics [30] and companies [31] websites found that these tests are being widely marketed to the general population online, and that many of the websites are making false and misleading claims to women about what the AMH test can tell them. Together this raises concerns about widespread overuse of the AMH test [43].

2. *Whole-body MRI scan for detection of a range of diseases in their earliest stages e.g. cancer(s)*

Whole-body MRIs use strong magnetic fields and radio waves to scan and generate detailed images of the entire body. Whole-body MRI scanning has been available for more than a decade, and is largely used for screening those with high genetic risk of cancer [44]. This procedure now typically takes an hour, and despite the claimed usefulness of whole-body MRI for cancer detection in high-risk individuals, its promotion to generally healthy people in the general population is raising concerns about overdiagnosis [45, 46]. There is currently no evidence that these highly sensitive tests provide net-benefit for people at average risk of disease [47, 48]. Alongside the potential for overdiagnosis across a number of conditions and potentially unnecessary invasive treatments, the associated anxiety and cost (ranging between approximately $2000-$4,000 USD) of whole-body MRIs are important to consider. Whole-body MRIs are not recommended by major international medical professional societies with people without symptoms.

3. *Multi-cancer early detection (MCED) tests*

MCED tests are a type of 'liquid biopsy' aim to detect cancers early before symptoms develop. They use genomic profiling to detect cancer DNA cells circulating in the blood [49]. In 2016 the FDA first approved the liquid biopsies for detection of gene mutations in circulating tumour DNA, designed for clinicians to monitor cancer patients [50]. At present the MCED test has not been fully approved by the FDA, yet it has granted 'breakthrough device designation' to at least three MCED tests. Companies are currently offering the tests to consumers and clinicians as laboratory developed tests (LDTs). While clinical and community interest continues to grow, with MCED tests being discussed as the 'holy grail' for cancer detection [51], it is still unclear whether the benefits outweigh the harms. Although MCED tests have shown in early small-scale studies to increase cancer detection and are designed to have high specificity i.e. reduce false-positive results [52-55], there are valid concerns surrounding overdiagnosis [56]. There are clinical trials [57, 58] underway internationally to assess the performance and utility of the tests. However, data from these trials could take over a decade and to date no evidence exists to robustly inform decisions about effectiveness, including reduction in late-stage cancer incidence and overall mortality. Furthermore, like the whole-body MRI scan the cost of these tests are extremely expensive (currently approximately $1,000 USD) raising additional health inequity issues for population screening.

4. *Testosterone test for low testosterone*

As men age, testosterone levels naturally begin to decline. While testosterone deficiency can be a serious medical condition in some men and require treatment, for many men low testosterone or "low T" is a prime example of disease mongering [59, 60]. Since early 2000, there has been an increase in testosterone testing and prescribing [61-63]. "Low T" awareness campaigns targeting middle-aged men in high-income countries with messages about checking testosterone levels if they had low libido, were experiencing mood changes or had gained weight has in part driven this increase [64, 65]. More recently, testing is being promoted amongst men in the fitness industry as a way to go on testosterone therapy and help build muscle. Testing for testosterone levels typically requires a blood sample to be taken in the morning by a medical professional, however direct-to-consumer tests that usually involves collecting a blood sample now exist and results can be provided within days. While there is variability in guidelines of what is considered low testosterone, there is currently no evidence that testosterone testing provides clinical benefit for asymptomatic healthy men [66]. Furthermore, as testosterone levels vary, a single measurement is unreliable and without a clear context of the person being tested, in the case of direct-to-consumer testosterone testing, it runs the risk of both false-positive and false-negatives results. It is also important to note that the long-term safety in

relation to adverse cardiovascular events and mortality of testosterone therapy has not yet been established, with an FDA-mandated study ongoing [67].

5. *Gut microbiome test*

The gut microbiome test measures the microorganisms in a person's gastrointestinal (GI) tract. A sample of stool is taken and sent to a lab and analysed for, in some cases hundreds of, different types of bacteria, viruses and fungi. Although the microbiome test has not been rigorously tested for accuracy or safety, with the FDA having yet to approve home microbiome tests, a growing number of companies are offering this 'wellness' test with the promise of identification of diseases and disorders (and precursors to diseases and disorders) such as bowel diseases/disorders, depression, diabetes and cancer. These tests also provide personalised reports that suggest dietary adjustments. Experts have noted that while the test looks promising, the evidence behind the claims of what the test can do is still in its infancy – with promises being made that are greater than what the current science can offer [68]. At this time the tests can only really satisfy a person's curiosity rather than add any value to clinical decision making [69], which in turn can lead to overdiagnosis and overtreatment of those taking the test [70].

Data analysis: Data from the caption, audio/video and on-screen text will be summarised and/or extracted into an Excel spreadsheet and included in the analysis. The analysis will take both an inductive approach when generating key themes arising from the posts and deductive approach using a pre-specified framework in line with our aims, to examine: 1) benefits, 2) harms including overdiagnosis and overuse, 3) evidence 4) overall tone, and 5) financial disclosures. Independent extraction and review of the data will then be undertaken by one researcher to develop an initial list of recurring themes. The coding tool will be informed by analysis of other coding tools used in similar previous work on media reporting of new tests [71, 72]. Two researchers will then independently apply this coding tool to 20% of posts to evaluate the reliability of the coding tool. Level of agreement between the two coders across the codes (e.g. benefits, harms, evidence, tone and disclosures), and by test, will be assessed using Cohen's kappa (k) and be interpreted as <0.00='poor', 0.00–0.20='slight', 0.21–0.40='fair', 0.41–0.60='moderate', 0.61–0.80='substantial' and ≥0.81='almost perfect' [73]. Agreement will be considered acceptable if k >0.6 for a sample of at least 20% of posts. In some cases, level of agreement might appear low using the k statistic due to high prevalence f a particular value for a variable. This is known as the kappa paradox [74-77]. Therefore, we will also consider the level of agreement acceptable if k is ≤0.6 but crude agreement is ≥85%. If k is ≤0.6 and crude agreement is <85%, data will be re-coded (using 20% blocks) until acceptable level of agreement is met. Once agreement is acceptable, one researcher with experience in public health and/or overdiagnosis research, will code the remaining posts.

Differences in outcomes by test and by platform, followers, and length of posts (across all 1000 posts) will be reported. Logistic regression analyses will be used to investigate whether posts by medical doctors, post with evidence and posts with clear financial disclosures are more or less likely to be balanced in their discussion/promotion of the test in terms of benefits, harms and overall tone. Our hypothesis is that posts by medical doctors and posts with evidence are more likely to be balanced, and posts with clear financial disclosures are less likely to be balanced. Quantitative data will be analysed in Excel and SPSS version 28 (IBM).

Ethical considerations: The data collected and analysed in this study is unequivocally public. Data will be largely reported in aggregate form, however in cases where specific excerpts (e.g. quotes) are reported as examples, as is typical with the content analysis method [28], these will be short (e.g. a few lines) and non-identifiable (e.g. no personal or professional information or reference will be given). A waiver of consent from The University of Sydney Human Research Ethics Committee has been granted (2023/913).

RESULTS

Progress to date: Data on each of the five tests has been searched and screened on Instagram and TikTok.

Analysis has not yet commenced.

Dissemination: The findings will be disseminated via publications in peer-review international medical journals and presentations at national and international conferences in late 2024 and 2025.

DISCUSSION

It is anticipated that this study will reveal fresh insights into how balanced the information and promotion of tests with potential for overdiagnosis and/or overuse is on social media. This study will therefore contribute to the limited evidence base on the nature of the relationship between social media and the problems of overdiagnosis and overuse of healthcare services. Analysing how these five popular tests are currently being promoted on two influential social media platforms will provide a snapshot of the wider issue. It is now acknowledged that the public and patients alike are turning to social media for health information [78]. Therefore, the concern driving this analysis is not that these tests exist or are being promoted on social media or used by those with serious symptoms, but that they may be being promoted to generally healthy individuals without good evidence of benefit, explicit information about their harms and potentially relevant information on conflicts of interest [15]. Future research using similar methods can also be conducted to investigate the promotion of drugs, treatments, and disease definitions, and potential ways to reduce the volume of misleading marketing, to further add to the much-needed evidence base as social media continues to disseminate health information and market health products.

This has both strengths and limitations. This is the first study to analyse the promotion of tests on social media that have concerns relating to overdiagnosis and/or overuse. The study will only include and analyse posts on Instagram and TikTok. However, as stated in the Methods these were chosen as they are two of the most widely used and fastest growing platforms across relevant age groups in which the tests relate to, are predominantly used for shorter more impactful content [33], and have been recently used to promote these tests by influential celebrities [17]. Posts on these platforms have been screened systematically using the methods described above and the top 100 eligible posts mentioning the tests were included. Comments and replies will not be analysed, nor will posts from influencers with <1000 followers, which may have provided additional information to the analysis although it is not anticipated that this will impact the overall findings. Lastly, the posts will be screened and returned to for analysis. In that time the content may be removed, or the number of followers may have changed. Again, it is not anticipated that this will impact the overall findings.

Conclusion: Understanding whether there is a problem in how tests with potential for overdiagnosis and/or overuse are being discussed and promoted on social media, and the extent of the promotion is essential to develop strategies to mitigate potential harm and plan solutions. This information will also potentially help to protect members of the public from being marketed low-value tests and becoming patients unnecessarily. It will also help to minimise overuse which takes resources from genuine need, threatening the sustainability of health systems.

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Data availability: The data sets generated during and/or analysed during this study are available from the corresponding author (BN) on reasonable request.

Author contributions: BN and JZ conceptualised the study. All authors were involved in the design. BN and JZ screened the data. BN, TC, EG, RM and JZ were involved in acquisition of the data. All authors were involved in drafting, critical revision, and approval of the final paper.

Conflicts of interest: BN and EG are members of the International Scientific Committee of Preventing

Overdiagnosis.

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