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Breast cancer on social media: a quali-quantitative analysis of the content that generates more public engagement and how to improve its reliability

Ph.D. Thesis

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Table of contents

List of abbreviations	4
1. Introduction.....	5
1.1. Highlights in the history of cancer.....	5
1.2. Cancer epidemiology, incidence and mortality worldwide	7
1.2.1. Increase in cancer cases worldwide	8
1.3. Incidence of all types of cancer in Europe.....	8
1.4. Breast cancer definition, risk factors and epidemiology.....	9
1.4.1. Female breast cancer worldwide.....	9
1.4.1. Female breast cancer in Europe	9
1.5. Importance of prevention and early detection of breast cancer	10
1.6. Brief history of the Internet and social media.....	11
1.6.1. The start and development of the Internet	11
1.6.2. Four phases of the Internet.....	12
1.6.3. Rise and growth of social media.....	15
1.7. Health and cancer communication in the social media.....	17
1.8. Breast cancer on social media and Breast Cancer Awareness Month	19
1.9. Misinformation on health and breast cancer	20
1.10. Importance of health professionals' presence on social media.....	22
1.11. Significance, aims of this research and research questions	23
2. Methodology	25
2.1. Social media analysis.....	25
2.1.1. Content analysis	26
2.1.2. Credibility analysis	27
2.1.3. Type of rumours.....	28
2.1.4. Source of news stories	28
2.1.5. Content type analysis	29

2.1.6. ‘Yes’ or ‘no’ questions.....	29
2.1.7. Sentiment analysis	30
2.1.8. Celebrity presence.....	30
2.1.9. Pink October – Breast Cancer Awareness Month.....	31
2.2. Questionnaire - Hungarian doctors, health professionals and cancer researchers’ attitudes towards online health communication on breast cancer.....	31
2.2.1. Ethics approval.....	31
2.2.2. Development of the questionnaire	32
2.2.3. Participants and recruitment process	33
2.2.4. Open-ended responses analysis.....	33
2.2.5. Statistical analysis.....	33
3. Results.....	35
3.1. Social media content analysis	35
3.1.1. Source of news stories	35
3.1.2. Credibility analysis	36
3.1.3. Type of rumour	37
3.1.4. Content type.....	37
3.1.5. Mentions of breast cancer prevention and early detection/screening exams.....	39
3.1.6. Sentiment analysis	41
3.1.7. Mentions of symptoms.....	42
3.1.8. Mentions of risk factors	43
3.1.9. Mentions of scientific papers or specialist quotes	44
3.1.10. Celebrity presence.....	44
3.1.11. Breast Cancer Awareness Month.....	47
3.2. Questionnaire results.....	50
3.2.1. Basic demographics	50

3.2.2. How respondents search, consume and appraise information about breast cancer on the Internet	51
3.2.3. Do health professionals who work in Hungary disseminate science on social media?	53
3.2.4. Doctor-patient communication: How to deal with misinformation brought by breast cancer patients.....	54
4. Discussion.....	58
4.1. Credibility analysis, type of rumour and source of news stories	58
4.2. Content type	61
4.3. Mentions of breast cancer prevention and early detection/screening exams	62
4.4. Sentiment analysis	63
4.5. Mentions of prevention, early detection, symptoms, risk factors, scientific paper or specialist quotes	64
4.6. Celebrity presence.....	66
4.7. Pink October – Breast Cancer Awareness Month.....	68
4.8. Questionnaire discussion	69
5. Conclusions.....	73
6. Limitations	75
7. Further perspectives	76
Acknowledgements.....	77
List of Publications	78
Appendix.....	80
List of tables.....	80
List of figures.....	82
Ethical approval	83
Questionnaire - Hungarian doctors, health professionals and cancer researchers’ attitudes towards online health communication on breast cancer	86
Submission of the doctoral dissertation and declaration of the originality of the dissertation	91
Data availability statement.....	92
References.....	93

List of abbreviations

ARPANET - Advanced Research Projects Agency Network

BCAM – Breast Cancer Awareness Month

BRCA1 and BRCA2 – Breast cancer gene 1; breast cancer gene 2

CAM – Complementary and Alternative Medicine

CERN - European Organization for Nuclear Research

CINAHL - Cumulative Index to Nursing and Allied Health Literature

CNN – Cable News Network

COVID-19 - Coronavirus disease 2019

ESMO - European Society for Medical Oncology

EU – European Union

FDA – U.S. Food and Drug Administration

HIV - Human Immunodeficiency Virus

HPV - Human papillomavirus

HTML - HyperText Markup Language

ISI – Internet Search Interest

MOT - Magyar Onkológusok Társasága (Hungarian Society of Oncologists)

NBC – National Broadcasting Company

NEJM – The New England Journal of Medicine

NGO - Non-Governmental Organisation

NLP – Natural Language Processing

PubMed - Public/Publisher MEDLINE

U.S. – The United States of America

UK – The United Kingdom

WHO – World Health Organization

1. Introduction

Cancer is a group of over 100 diseases that can start in almost any organ or tissue of the body when cells grow uncontrollably, go beyond their usual boundaries (in a process called metastasis) and spread to other organs (World Health Organization, 2018). Tumors or neoplasms are classified as malignant or benign; the former are called cancer, the latter are not (Patel, 2020). There are two main categories of cancers: hematologic cancers, which affects blood cells, such as lymphoma, multiple myeloma and leukemia, and solid tumor cancers, which affects any other part of the body; most frequent types are breast, lung, prostate and colorectal cancers (American Cancer Society, 2020b).

1.1. Highlights in the history of cancer

The earliest records of cancer date back to about 30 centuries BC. The Egyptians, Persians and Indians already referred to malignant tumors. The oldest description of cancer was made in Egypt in the Edwin Smith Papyrus, and is a copy of part of an ancient Egyptian textbook on trauma surgery; it describes eight cases of tumors or ulcers of the breast and the writing says that there is no treatment for such disease (American Cancer Society, 2018). It was the studies of the Greek Hippocratic school, dating from the 4th century BC, which defined the disease better, characterizing it as a hard tumor that often reappeared after being excised, or that it spread to different parts of the body leading to death (Teixeira et al., 2007). The Hippocratic Corpus dealt with diseases that formed masses (also called *onkos*), and uses the term *karkinos* to describe ulcerating and non-healing lumps that included both benign or malignant tumors (Faguet, 2015).

The Renaissance period, when Galileo and Newton began using the scientific method, laid the foundation for the modern scientific study of disease; “In 1761, Giovanni Morgagni of Padua was the first to do something which has become routine today – he did autopsies to relate the patient’s illness to pathologic findings after death. This laid the foundation for scientific oncology, the study of cancer.” (American Cancer Society, 2018). The 18th century saw the birth of cancer epidemiology; “in 1773, the Academy of Lyon, France offered a prize for the best scientific report on ‘Qu'est-ce que le cancer’ (What is cancer?). It was won by Bernard Peyrilhe's (1735–1804) doctoral thesis; the first investigation to systematically explore the causes, nature, patterns of growth, and treatment of cancer.” (Faguet, 2015)

The 19th century witnessed another important advance in terms of cancer research. “The development of the cell theory, based on the works of Virchow (1821-1902), finally made it

possible to link the disease to cells and their division process” (Teixeira et al., 2007). In the 20th century, one of the main advances in the oncology field was the development of chemotherapy; it started with attempts to narrow the amount of chemicals that might treat or cure the disease by developing methods to monitor chemicals using transplantable tumors in rodents (DeVita & Chu, 2008).

Another highlight of the first half of the 20th century is the development of the hormonal therapy. In 1939, after observation of the effect of estrogens on breast cancer, Charles Huggins treated men with prostate cancer with hormones and got positive results to treat the disease – and he was awarded a Nobel Prize after that (DeVita & Chu, 2008).

On 2 December 1943, during the Second World War, German forces attacked the Italian port town of Bari with mustard gas; Stewart Alexander, a North American scientist and expert on chemical weapons, realized that the mustard-oil mixture destroyed the white blood cells of his patients (Ledford, 2020). His observations convinced other scientists about the value of this approach, and conducted more research on the topic, which helped in the development of the first chemotherapy treatments (Wilke, 2019).

“After promising animal research, physician researchers connected with Yale University and the University of Chicago tried injecting sulfur mustard and its somewhat milder relatives, the nitrogen mustards, into the veins of cancer patients in the early 1940s. This was the first time a systemic treatment was given for cancer. That proved to be valuable when you deal with certain kinds of leukemia or lymphoma.” (Wilke, 2019)

In the last decades of the 20th century and the first of the 21st century, the expansion of knowledge in the area of cancer biology led to remarkable progress in the early detection of the disease, treatment and prevention (Sudhakar, 2009). Advances in treatments have improved the quality of life of cancer patients and increased the chances of cure of various types of the cancer. According to data from the (United States) National Cancer Institute (2015), some of the most relevant milestones on cancer treatment are: the first complete cure of a human solid tumor, in 1953; the approval of the drug tamoxifen for the treatment of breast cancer, in 1978; the possibility of breast-conserving surgery for women with early-stage breast cancer, in 1985; the approval of tamoxifen to reduce the incidence of breast cancer in women at increased risk, in 1998; the development of the vaccine Gardasil which protects against HPV virus types 16 and 18, that cause nearly 70% of all cases of cervical cancer; the approval by FDA of pembrolizumab for the treatment of advanced melanoma, in 2014; and the Pan-Cancer Analysis

of Whole Genomes study in 2020, which unearths the complex role that changes throughout the genome play in cancer development, growth, and spread. Moreover, in 2021, two immunotherapy drugs — atezolizumab and pembrolizumab — were approved by the FDA for patients with metastatic triple-negative breast cancer (Latif et al., 2021).

Despite substantial advances in cancer research, literature indicates that cancer is in current times still one of the most dreaded illnesses in the view of lay people, in several countries (INCA, 2007; Ramers-Verhoeven et al., 2013; Robb et al., 2014). However, awareness and perception about cancer has considerable variations according to socioeconomic status, gender and education levels (Elangovan et al., 2016), with greater awareness levels among those who are more literate.

1.2. Cancer epidemiology, incidence and mortality worldwide

Cancer is one of the most frequent causes of death worldwide; in 2020, an estimated 19.3 million new cancer cases and nearly 10 million deaths from the disease have been recorded (Sung et al., 2021). **Table 1** shows the 10 most diagnosed cancers and its death rates in 2020.

Table 1. Ten most incident cancers and number of deaths worldwide in 2020 (the percentage refers to all 36 measured cancer sites)

Cancer site	Number of new cases (% of all sites)		Number of new deaths (% of all sites)	
Female breast	2,261,419	(11.7)	684,996	(6.9)
Lung	2,206,771	(11.4)	1,796,144	(18.0)
Prostate	1,414,259	(7.3)	375,304	(3.8)
Nonmelanoma of skin*	1,198,073	(6.2)	63,731	(0.6)
Colon	1,148,515	(6.0)	576,858	(5.8)
Stomach	1,089,103	(5.6)	768,793	(7.7)
Liver	905,677	(4.7)	830,180	(8.3)
Rectum	732,210	(3.8)	339,022	(3.4)
Cervix uteri	604,127	(3.1)	341,831	(3.4)
Esophagus	604,100	(3.1)	544,076	(5.5)

* New cases exclude basal cell carcinoma, whereas deaths include all types of nonmelanoma skin cancer. Source: Sung et al., 2021.

When we look at countries with the highest cancer mortality rates, we see a different picture compared to incidence rates (**Table 2**). In other words, although many of the new cancer cases have occurred in rich countries, deaths are concentrated in less economically developed nations.

Table 2. List of the five countries with the highest cancer incidence and highest mortality rates in 2020 (number of cases per 100,000 people)

Cancer incidence rates		Cancer mortality rates	
Australia	452.4	Australia	83.3
New Zealand	422.9	Malaysia	87.3
Ireland	372.8	Democratic Republic of Congo	74.9
United States	362.2	Guinea-Bissau	83.3
Denmark	351.1	Guyana	67.7

Source: IARC, 2020.

1.2.1. Increase in cancer cases worldwide

For 2040, the number of new cancer cases is estimated at 28.4 million cases, an increase of 47% over 2020 and which will affect developing countries above all - 64% to 95% of all cases will be concentrated in these areas (Sung et al., 2021). Worldwide, the estimated number of cancer-related deaths stands at 16.3 million for 2040, and “the future burden will probably be even larger due to increasing prevalence of factors that increase risk, such as smoking, unhealthy diet, physical inactivity, and fewer childbirths, in economically transitioning countries.” (American Cancer Society, 2020a). However, the main factor for the projected increase in cases is simply the aging of the population around the world (Pilleron et al., 2019).

1.3. Incidence of all types of cancer in Europe

Cancer is the second most important cause of death and morbidity in Europe; the first are circulatory diseases (OECD & European Union, 2020). The estimated age-standardized incidence rates of cancer in Europe in 2020 reveals that Ireland is the country with the highest number of new cases this year (372.8 cases per 100,000 people), followed by Denmark (351.1), The Netherlands (349.6), Belgium (349.2), France (341.9) and Hungary (338.2) (IARC, 2020). When we consider the estimated age-standardized mortality rates in the continent, we see that Serbia is in first place (151.7 per 100,000 people), followed by Hungary (149.0), Montenegro (145.2), Slovakia (141.3), Poland (137.5) and Croatia (133.3) (IARC, 2020). The total number of cancer cases is estimated to be around 2.7 million (all types, excluding non-melanoma skin cancer) and 1.3 million deaths in 2020 (Cattaneo, 2020). We can observe a difference between the incidence and mortality of cancer in Europe in relation to the region. Although many of the countries with the highest incidence are in the west of the continent, the highest mortality rates are concentrated in Central and Eastern Europe.

Female breast cancer is the most commonly diagnosed cancer in Europe in 2020 (with an estimation of 13.3% of all cancer diagnoses, or 355,000 women), followed by colorectal (341,000, 12.7%), prostate (336,000, 12.5%) and lung cancer (318,000, 11.9%); the cancers that cause the highest mortality rates in the continent are lung (20.4% of all cancer deaths), followed by colorectal (12.4%), female breast cancer (7.3%) and pancreatic cancer (7.1%) (Cattaneo, 2020). The vast majority of these deaths occur among people aged over 65 (OECD & European Union, 2020). Tobacco consumption and excessive alcohol consumption cause about 40% of the total cancer burden (World Health Organization, 2020).

1.4. Breast cancer definition, risk factors and epidemiology

Breast cancer disease can be defined as a disordered growth of breast cells. The most common types of breast cancer are: Invasive ductal carcinoma, when the cancer cells begin to grow in the breast ducts and then spread into other parts of the breast tissue; and invasive lobular carcinoma, when cancer starts to grow in the lobules of the breast and can also spread into other parts of the breast tissue; both of these types of breast cancer can metastasize to other parts of the body (CDC, 2021).

1.4.1. Female breast cancer worldwide

In 2020, female breast cancer is the most diagnosed type of cancer among women in 158 countries worldwide (IARC, 2020). In 2020, there were 2.3 million women diagnosed with breast cancer and 685,000 deaths globally and by the end of 2020 there were 7.8 million women who received a breast cancer diagnosis in the past 5 years, making it the world's most frequent type of cancer (World Health Organization, 2021).

Nearly 50% of breast cancers develop in women over 40 years old with no other identifiable risk factors; however, some behaviours or characteristics may increase the risk of breast cancer, such as obesity, family history of the disease, use of alcohol, exposure to radiation, post menopause hormonal therapy and tobacco use (World Health Organization, 2021).

1.4.1. Female breast cancer in Europe

As of 2018, Belgium had the highest incidence of breast cancer worldwide, with an age-standardized rate of 113.2 per 100,000 people, followed by Luxembourg (109.3), The Netherlands (105.9), France (metropolitan) (99.1), and New Caledonia (France) (98.0) (WCRF, 2019). All these countries and territories are officially located in Europe. Breast cancer is the most frequent type of cancer in women in all European countries (IARC, 2020).

1.5. Importance of prevention and early detection of breast cancer

Despite the expectation of an increase in cancer cases in the coming decades, it is important to reiterate that changes in the population's lifestyle and habits can reduce the likelihood of the disease onset.

Breast cancer often shows no symptoms in its early phases, and for this reason many cases are detected at more advanced stages, when the chances of cure are lower (Milosevic et al., 2018). Early-stage cancers are easier to treat than later-stage cancers, and this is why routine screening lowers the risk of death by breast cancer (Jin, 2014). More than 90% of women diagnosed with breast cancer at the earliest stages (stages 0 and I) survive for at least five years compared to around 15% for women diagnosed with the most advanced, metastatic stage of disease (stage IV) (Cancer Research UK, 2018).

In several countries, mammograms are part of the standard annual examinations women need to undergo after the age of 40, and women who are at higher risk should start this routine even earlier (Behring, 2021).

Moreover, approximately 23% of breast cancer cases are preventable (Cancer Research UK, 2015a). Some habits can help prevent breast cancer (and other types of cancer) such as (CDC, 2021):

- Keeping a healthy weight;
- Exercising regularly;
- Avoiding smoking;
- Eating fruits and vegetables daily;
- Limiting the intake of alcoholic drinks;
- Breastfeeding your children.

Despite the importance of screening tests and prevention measures, the rate of adherence to examinations to detect breast cancer in several European countries is low. For instance, in countries such as Hungary, Cyprus, Slovakia and Bulgaria, the proportion of women aged 50-69 years who had undergone a mammogram examination was below 40% in 2016 and 2017; and seven European Union member states had screening rates below 50% (Gaál, 2020). Fear of screening is also a factor that can affect attendance to screening exams; there are different

types of fear: concern if the cancer diagnosis is positive, fear of pain and fear of having to think about cancer (Vrinten et al., 2015).

One step to change this scenario is correctly informing the population about the importance of early diagnosis, prevention, risk factors and screening exams. The literature shows there is an urgent need for awareness, which includes and engages some marginalized groups in society (Akram et al., 2017; Islam et al., 2016; Újhelyi et al., 2018). Education and awareness need to be in schools, in the media, in health centers and also on the Internet, which includes social media.

1.6. Brief history of the Internet and social media

The Internet has transformed the way people communicate and get access to information. A message that used to take weeks to reach the other side of the planet now travels the world in just a few seconds. The Internet is a powerful mechanism for information dissemination and collaboration between individuals, regardless of geographical location.

1.6.1. The start and development of the Internet

The first prototype of the Internet emerged in the late 1960s with the creation of ARPANET, which stands for the Advanced Research Projects Agency Network (Andrews, 2013). This was funded by the United States Department of Defense and allowed multiple computers to communicate. Another important milestone happened in the end of the 1980s. “Tim Berners-Lee, a British scientist, invented the World Wide Web (WWW) in 1989, while working at CERN. The web was originally conceived and developed to meet the demand for automated information-sharing between scientists in universities and institutes around the world” (CERN, 2020). In 1993, CERN puts the World Wide Web in public domain, and in 1995 the consumer web starts to develop, with the emergence of websites such as Amazon, eBay and Yahoo (McGlynn, 2020). In 1998 Google is founded as a web data search and indexing service. In 2007, Apples creates its mobile phone, named iPhone, which becomes a dominant platform of mobile web; since then, a growing number of people use mobile phones to access the Internet and “by 2020, mobile web traffic accounts for approximately half of all web activity worldwide” (McGlynn, 2020). In January 2021 there were 4.66 billion active Internet users worldwide, which represents 59.5% of the total global population; 92.6% of them (4.32 billion people) access the Internet via mobile devices (Statista, 2021b).

1.6.2. Four phases of the Internet

The Internet as we know it in the 2020s is quite different from that of the 1990s, when it was still limited to a few users and services. The Internet itself is a revolutionary technological advance, but the developments that have arisen within it are equally groundbreaking. To better understand this evolution, the history of the Internet has been separated into four phases.

1.6.2.1. Web 1.0

The term Web 1.0 began to gain popularity in 2004, and it was created by the American programmer Tim O'Reilly. In fact, his goal was to show that a new Internet age was emerging, the so-called Web 2.0, which was opposed to the "old Internet" in several aspects.

The first phase of the Internet is mainly characterized by having static content, which is not always updated quickly. The manipulation and updating of websites required technical knowledge to be performed, that is, it was necessary to master codes such as HTML. For this reason, the number of people able to update the content of the pages, the so-called Webmasters, was limited. Information was produced and transmitted vertically. There was almost no interactivity between users and producers of contents; the information was received passively. The user was unable to reply, comment or send content (Cormode & Krishnamurthy, 2008). However, personal webpages were common, consisting of static pages hosted mainly on ISP-run web services or free web hosting services (Sharma, 2021).

The fact that this term refers to an Internet from the past does not mean that there are no more remnants of it on the current world wide web. In this context, non-interactive pages of encyclopedias are highlighted, such as Britannica (<https://www.britannica.com/>) and pages that propose the dissemination of content without opening space for interaction, such as the website MP3 (<https://www.mp3.com/>).

1.6.2.2. Web 2.0

The concept of Web 2.0 became known in October 2004 during the first conference of the same name, held in San Francisco, U.S., by O'Reilly Media and Media Live. However, this term was first used by Darcy DiNucci (1999). DiNucci said that the Web would become a dynamic environment, and that it would be present on TVs, in cars, phones, electronic games and even in household items such as the microwave (DiNucci, 1999). If we compare the Internet in 1999 and today, we can see that, in 2022, it is possible to connect through a much wider range of devices, whereas, in the late 20th century, the connection was made almost exclusively through

computers and laptops. For the next few years, the trend is that the variety of connectable devices and devices will be even greater than nowadays.

One of the principles discussed in the conference in 2004 was that the web would become a platform, meaning that users control their own data (O'Reilly, 2005). The web 2.0 has some user interface improvements and communications dynamism that encourages users to interact and share what they learn, making the Internet a more horizontal space, with more dialogue and interaction between content creator and consumer (Prandini & Ramilli, 2012).

This greater ease of interaction between users made social networks appear and become popular in the first years of the 21st century. Some of the famous Web 2.0 applications are Facebook, YouTube, Flickr, and Twitter (Madurai, 2018). Facebook was founded by Mark Zuckerberg in 2004 and is a North American social networking service; it allows users to share pictures, text, videos, articles, and connect with people. YouTube was founded in 2005 by Steve Chen, Chad Hurley, and Jawed Karim and is a video sharing platform, meaning that anyone can upload their home videos (or more professional ones) and share it worldwide (Hosch, 2021). Flickr was created by Ludicorp in 2004 and is a platform that allows users to upload and organize photos and video online, as well as share it with other users. Finally, Twitter was launched in 2006 and is a microblogging and social networking service, where users can share short text messages called "tweets", as well as videos, articles and pictures.

1.6.2.3. *Web 3.0*

Ten years after the term Web 2.0 became known and the Internet was revolutionized, with greater interaction and participation of users, it is possible to observe the emergence of what can be considered a new phase of the network, which is Web 3.0. While the previous generation witnessed the birth of interactive platforms, such as social media, this new phase, which extends from 2010 to 2019 (Almeida, 2017), takes a step forward.

This new phase is known as *semantic web*, is an attempt to describe and link web content in a manner that's meaningful to machines, transforming the web from a "web of documents" into a "web of data" (Heath, 2009). In other words, computers can understand and interpret data just like humans, through machine learning and artificial intelligence (Sharma, 2021).

While in Web 2.0 users gain power, in Web 3.0 it is time for machines (computers, tablets and smartphones) to have the capacity to produce and consume information. With its great

processing capacity, Web 3.0 can offer services and products to people and companies with high added value due to its assertiveness and high customization (Hoppen & Santos, 2015).

Some machine learning examples include ranking posts on social media, creating smart recommendation engines, sorting, tagging, categorizing photos, customer lifetime value assessments, face and voice recognition technologies. An example of technology that fits the parameters of Web 3.0 is Siri, which uses machine learning and artificial intelligence to act as a secretary to its users. According to its creators, Siri can make calls or send texts when users are driving, have their hands full, or are simply on the go. It also offers proactive suggestions — like texting someone that they're running late for a meeting (Apple, 2021).

1.6.2.4. Web 4.0

Despite not being a consensus in the literature, the concept of Web 4.0 is already widely discussed, and its possible consequences are analysed.

The concept of Web 4.0 is quite irregular and mutable. Since 2009, several definitions of the Web 4.0 have been suggested by numerous authors. However, there isn't a totally consensus regarding a solid definition of Web 4.0, contrarily to previous wide-accepted definitions of Web 1.0, Web 2.0 and Web 3.0. In this sense, it can be stated that Web 4.0 covers a set of multiples dimensions. Each of these dimensions offers a distinct, but simultaneously comprehensive, view of the Web 4.0 paradigm. It stands out that applications such as social networks, and technologies such as Internet of Things, Big Data, artificial intelligence and M2M play a key role in the adoption and implementation of Web 4.0 (Almeida, 2017, conclusion section).

Among the terms used to describe Web 4.0 are symbiotic web and ubiquitous web (Almeida, 2017). That is because the idea behind this phase is a symbiosis, an even greater integration between humans and machines. The Internet becomes even more pervasive across platforms and locations, existing not just on mobile devices such as tablets and smartphones, but literally everywhere. The boundaries between human and machines will blur. For instance, this encompasses full virtual-reality (VR) environments for web meetings and artificial systems communicating with humans as if they were humans too, using natural language (Pacelt, 2021).

Some technologies that make this evolution possible are **a) The Metaverse**, which is “a completely virtual world where people can socialize, work, and play” (Ghaffary, 2021). For example, individuals will be able to have meetings with family/friends who are thousands of miles away, not only from a screen, but they will be "present" in the environment, in 3D, almost like a physical presence; **b) Artificial intelligence**, which will be even more sophisticated, allowing, for example, cars to circulate without drivers and smart homes, where everything can be controlled with just voice commands (Menor, 2021).

1.6.3. Rise and growth of social media

Regardless of the Internet eras, its evolutions and paradigm shifts, the number of users of social media does not stop growing worldwide. In 2017, more than 2.8 billion people were using social media all around the globe, a number projected to increase to almost 4.41 billion in 2025, approximately half of the world population (Statista, 2020). “Social media global penetration reached nearly 54% in 2020. Northern and Western Europe had the largest penetration rate, followed by Northern and Southern America” (Statista, 2021e).

As of 2021, Facebook is the social media with the biggest number of active users worldwide, followed by YouTube and WhatsApp (see **Table 3**).

Table 3. Social media with the largest number of active users worldwide in October 2021

Social media name	Number of active users (in millions)
Facebook	2,895
YouTube	2,291
WhatsApp	2,000
Instagram	1,393
Facebook Messenger	1,300
Weixin/WeChat	1,251
TikTok	1,000
Douyin	600
QQ	591
Sina Weibo	566
Telegram	550
Snapchat	538
Kuaishou	506
Pinterest	454
Twitter	463

Reddit	430
Quora	300

Source: (Statista, 2021g)

Worldwide, the region with the highest active social media penetration is Western Europe, where 79% of the population are users of at least one of those platforms; however, the country with the highest active social networking penetration is the United Arab Emirates, with 99% of its population having access to at least one type of social media; the daily time spent on social networking by Internet users worldwide is 145 minutes, and 98% of Facebook users worldwide access this platform via any type of mobile phone (Statista, 2021g). In Hungary, there are 7.09 million social media users as of January 2021, which represents 73.5% of the total population; the number of social media users in Hungary increased by 550 thousand (+8.3%) between 2020 and 2021 (Kemp, 2021).

A growing number of individuals use social media as a source of information. In an extensive survey conducted in 2020, nearly 65% of respondents from populous countries such as Mexico, Argentina, Kenya, South Africa, Philippines and Brazil, declared they rely on social media as a source of news (Biancovilli, Makszin, & Csongor, 2021).

Nevertheless, when we see the pages or people with the highest number of followers on the biggest social networks, we note that the majority are related with the entertainment or sports sector. For instance, on Facebook, the fan pages with the largest number of followers (**Table 4**) are:

Table 4. Facebook fan pages with the largest number of followers as of June 2021

Facebook page	Number of fans (in millions)
Facebook	214.62
Samsung (electronic devices producer)	159.82
Cristiano Ronaldo (football player)	122.28
Real Madrid CF (football team)	111.33
Coca-Cola (beverage corporation)	106.96
FC Barcelona (football team)	103.35
Shakira (pop singer)	100.03
Tasty (recipes in video)	97.91
Vin Diesel (actor)	96.71
Leo Messi (football player)	90.16

Source: (Statista, 2021h)

On Instagram, a similar pattern can be found (**Table 5**). Furthermore, some celebrities are among the ones with the biggest number of fans/followers on both social networks.

Table 5. Instagram accounts with the highest number of followers as of July 2021

Instagram page	Number of followers (in millions)
@cristiano (football player)	315.75
@therock (actor)	254.76
@arianagrande (singer)	252.84
@kyliejenner (model)	249.65
@selenagomez (actress and singer)	245.5
@kimkardashian (model)	236.91
@leomessi (football player)	233.79
@beyonce (singer)	194.16
@justinbieber (singer)	183.79
@kendalljenner (model)	175.77

Source: (Statista, 2021i)

1.7. Health and cancer communication in the social media

Although they are not among the most followed in the world, there are several pages and groups in social media that address health promotion. They exist in different parts of the world and in a wide variety of languages. According to Moorhead et al. (2013), the main benefits of using social media for health communication include:

- (1) increased interactions with others, (2) more available, shared, and tailored information, (3) increased accessibility and widening access to health information, (4) peer/social/emotional support, (5) public health surveillance, and (6) potential to influence health policy. (Moorhead et al., 2013, results section)

It is known that the Internet is considered an important tool for the information search and decision-making in the health area (Moorhead et al., 2013; Strekalova & Krieger, 2017). According to data from 2021, 55% of EU citizens aged 16-74 declared they search for health information online in topics such as nutrition, disease, and health improvement, among others; in 2010, the number was 34% (Eurostat, 2021). The highest shares were recorded in Finland (77%), The Netherlands (76%), Denmark (72%) and Germany (70%); on the other hand, the lowest rates in the EU are in Romania (28%), Bulgaria (29%), Italy (35%; 2019 data) and Poland (43%); Hungary is above the EU average (62%) (Eurostat, 2021). In a large-scale study

conducted in France, it was found that the individuals who most seek health information online are younger women with higher than average educational level, higher than average household income, and having a chronic disease (Ducrot et al., 2021).

Another study conducted with a sample of the U.S. population shows slightly different results (Huo et al., 2019). They compared answers collected in 2013 and 2017, and noted that the use of social media for sharing health information had dropped significantly (from 24.7% to 15.7%). The authors believe that this drop may have to do with concerns about online privacy, after some security breaches in social media sites have occurred. Moreover, people aged 49 or less tend to share more health information on social media than other age groups. “The other factors associated with higher use of social media for sharing health information included female gender, a college education or higher, not being divorced/windowed/separated, being employed, or having a family history of any cancer.” (Huo et al., 2019). Another interesting finding of this study is the fact that people who seek information about cancer on social networks tend to be more optimistic, believing more in the possibility of cancer prevention and having less fear of the disease.

A systematic review that analysed peer-reviewed journal articles about social media for health purposes published between 2006 and 2020 shows that several new usages have emerged over time (J. Chen & Wang, 2021). There have identified 10 main current uses of social media for health purposes, which are: 1) Infoveillance: analysis of the unstructured information to inform public health and policies; 2) Disseminate health information and combat misinformation; 3) Health intervention: social media can be used to motivate behaviour change, for instance when they are motivated to publish everyday a picture of a healthy meal; 4) Social mobilization: for example, NGOs can mobilize social resources and use the social media to address health-related issues that may not be very widespread; 5) Facilitate health related research: social media can offer additional data to learn about patients’ disease experience and recruit research participants; 6) Professional development: health professionals can use social media to connect with each other, collaborate, learn about other experiences and follow medical conferences remotely, just to mention some examples; 7) Facilitate doctor-patient communication and offline health services: doctors can use social media to answer patients’ questions and encourage compliance with medication, for example; 8) Seek and share health-related information: this is the most common use by the public, as people would like to know, for instance, how to cook healthy and cheap meals, or they may want to get informed about the

risks of the seasonal flu; 9) Exchange social support in online communities: this encompasses informational support, emotional support, esteem support, network support, and tangible support; 10) Track and share health statuses or activities: the public can share their experiences throughout a breast cancer treatment, or record and share with peers their fitness activities, such as yoga and running.

All these uses can also be applied to cancer communication in social media. A systematic review dedicated to analysing social media interventions for cancer prevention shows that the main topics were cancer prevention education and social support, such as using chatting rooms and sharing videos/photos of their personal experiences with cancer (Han et al., 2018). Nevertheless, in most cases there was no scientific quality verification of the shared content, which can make room for misinformation sharing. The most frequently used social media platforms for the interventions were Facebook, blogs, YouTube, and Twitter.

Another research was devoted to understanding how parents of children with acute lymphoblastic leukaemia use their personal Facebook pages for cancer-related communication (Gage-Bouchard et al., 2017). Their results show that six main themes emerged, which are:

- (1) documenting the cancer journey,
- (2) sharing emotional strain associated with caregiving,
- (3) promoting awareness and advocacy about pediatric cancer,
- (4) fundraising,
- (5) mobilizing support, and
- (6) expressing gratitude for support. (Gage-Bouchard et al., 2017, results section).

That is, in addition to documenting their personal experiences, these platforms are also used to share knowledge about paediatric cancers and promote advocacy, which is positive.

1.8. Breast cancer on social media and Breast Cancer Awareness Month

As it is one of the most frequent types of cancer worldwide, several studies are dedicated to analysing the discourse related to breast cancer on social media. One systematic review investigated the breast cancer screening discourse on those media (Döbrössy et al., 2020). They observed that most of the discourses are produced by lay individuals, and there is a scarcity in the healthcare professionals' participation on these discussions. Regarding the most shared content, the prevailing sentiment towards screening ranges from neutral to favourable, and some of the main topics discussed include the changing of screening age recommendations in the U.S. and mammographic efficacy.

A scoping review about general breast cancer communication on social media (Shetty et al., 2021) concluded that there are four main themes among the online discussions: (a) Raising awareness, for instance with information sharing about screening and treatment options (b) social support, by providing cancer patients with guidance and emotional sustenance (c) reliability, which refers to trust and concerns about the quality of the information received and (d) others, which includes prevention, access to cancer centres and online privacy, for example.

There is also a considerable number of studies on how social media can be used as an informational tool for breast cancer patients. One literature review (Falisi et al., 2017) organized findings from articles published within this theme. Most were observational articles, followed by intervention articles and reviews/commentaries. The most measured outcomes on intervention articles were related to the participants' psychosocial well-being. Regarding the studies on social media content, most articles were exploratory descriptive analyses and "none of the content analysis articles attempted to link the content of the users' posts to physical health outcomes" (Falisi et al., 2017, findings section). Moreover, most of the identified support groups were self-driven, that is, without an expert presence.

October is in numerous countries worldwide the Breast Cancer Awareness Month (BCAM), an international health campaign launched in 1985 by the American Cancer Society and Imperial Chemical Industries in the United States (Moss, 2021), which aims to increase awareness of the disease, informing the population about the importance of mammography, self-examination, symptoms and encouraging donations and emotional support for breast cancer patients (Glynn et al., 2011). One study examined the Internet Search Interest (ISI), that is, Google Internet searches, for the terms "breast cancer" and "mammogram" in the United States. They found out that ISI was 2.34 times higher during BCAM in comparison with other months. This is a good indication that, at least in this geographic region, the awareness campaign has positive results in increasing public interest in relation to the disease and screening tests.

1.9. Misinformation on health and breast cancer

Over the years, the volume of information shared on the Internet has increased exponentially, and for this reason, one of the new uses of social media by institutions and by science/health journalists is to combat misinformation. In March 2020, the World Health Organization (WHO) declared COVID-19 a pandemic, less than three months after some cases of pneumonia caused by an unknown vector were identified in Wuhan, China (AJMC, 2021). The disease's

rapid spread around the globe was accompanied by a burst of news on the topic, on social media and beyond - a phenomenon called *infodemic* (Biancovilli, Makszin, & Jurberg, 2021). This is one of the reasons why concerns on misinformation about health in social media increased from 2020 onwards, and many studies proposed approaches to fight against this problem:

According to a systematic review on COVID-19 and misinformation (J. Chen & Wang, 2021), health institutions must increase efforts to monitor and enforce fact-checking of dubious information on social media, promote strategic and timely refutation to misinformation online, share personal experiences on social media to refute rumors, and use search optimization strategies within the social media platforms to redirect users who ask health-related questions to reliable information sources. Moreover, still according to them, “in addition to combating misinformation through social media, health institutions may also encourage health professionals to establish interpersonal relationships with patients and invite patients to conversations about misinformation that they may encounter online.” (J. Chen & Wang, 2021, results section)

Current debates point to the need for greater concern with the health content that is shared on social media, as this can have direct consequences on the health status of populations (Reidy et al., 2019). Individuals who are in the habit of using social networks or mobile phone applications to search for health information, as a rule, do not confirm the accuracy of the data they find with health professionals; among those who do, health professionals disagree with information on social networks in 36.7% of cases (Crilly et al., 2019). Vaccine misinformation, to mention an example, is a common concern. Vaccine deniers’ arguments against child vaccination are widespread on social media (Klimiuk et al., 2021). Therefore, it is important that health professionals and science communicators have a stronger presence on social networks with evidence-based and reliable content that is attractive to the lay population.

The same logic applies when it comes to online communication about breast cancer, despite the fact that COVID-19 is a much more recent disease with a shorter medical history. Most participants in breast cancer related online conversations are lay people, and they are responsible for the majority of shared misinformation (Döbrössy et al., 2020). On Pinterest, a social network dedicated to sharing images and texts, more than half of the content published about breast cancer (51.1%) contained some kind of misinformation, mostly about foods that allegedly prevent or treat cancer, or that hypothetically cause cancer (Wilner & Holton, 2020).

A study that analysed breast cancer and cervical cancer-related content on one of the most popular social media in China (Weibo) found that 30% of the content contains misinformation, and erroneous content relating to cancer prevention is shared in greater numbers than scientifically correct information (L. Chen et al., 2018).

1.10. Importance of health professionals' presence on social media

After the onset of the COVID-19 pandemic in 2020 and the need for physical distancing to break the spread of the disease, many studies began to address the importance of e-health and telemedicine, as well as online conversations between health professionals and patients (Ferrer et al., 2021; Holtz, 2021; Tebeje & Klein, 2021). However, not many studies address the importance of health professionals and science & health communicators dialoguing not only with people who are undergoing treatments, but also with the general population, avoiding the dissemination of false and misleading content. In addition, we believe it is important for these professionals to use online platforms to establish direct communication with the lay public, educating them in relation to health topics with reliable resources.

Some of the advantages of social media usage mentioned by physicians is the possibility of better understanding the needs of their patients, as well as broadcasting relevant and scientifically correct content to a wider audience (Campbell et al., 2016). Doctors know what patients do choose to talk about in their consultations, and this is frequently just 'tip of the iceberg'; this is why monitoring social media groups can help them comprehend what patients choose not to disclose, whether it is due to time constraints or a lack of trust and rapport (Sultan et al., 2021).

A qualitative study on social media use by health professionals from the U.S. (Bautista et al., 2021) shows that they do have an online presence (especially Twitter, for professional purposes and Facebook, for both private and professional reasons); and they use social media to correct health misinformation through acts of authentication (verification of the content) followed by acts of correction (priming and rebuttal).

Despite the advantages of the use of social networks by health professionals, we must comment on the potential challenges that this activity can generate. Possible pitfalls include privacy violations and discriminatory statements, for instance (Sultan et al., 2021). Even unintentionally, a text, video or any other multimedia format may reveal, directly or indirectly, the identity of a patient, or may contain expressions considered xenophobic and racist, just to name a few examples. In addition, if health professionals want to maintain contact with their

patients through social media, the ideal would be to have a separate professional account reserved for these types of interactions; using the private account is not a practice considered appropriate (General Medical Council, 2013). In another study, doctors showed uncertainty about the best way to use social media to communicate with a wider audience, expressing apprehension about backlash from the media or an employer based on a statement another physician had published (Campbell et al., 2016). A possible solution to this could be offering classes in medical schools on how students should conduct themselves if they are creating online content (Manfredini, 2021).

1.11. Significance, aims of this research and research questions

Most of the academic literature in the area of online health communication is focused on analysing the impact of the use of online tools between doctors and patients, or among patients, their families and support groups. Regarding research focused on breast cancer, a similar pattern is observed. Some studies address online discourses related to the early detection of breast cancer, including mammography, but investigations focused on disease prevention narratives were not found.

Therefore, the first aim of this study is to comprehensively analyse news stories about breast cancer shared on social media. The goal is to identify the main characteristics regarding the narratives in the sample of this study, including the scientific credibility of the content with more public engagement. Despite the substantial number of studies about online health and cancer misinformation, this is the first investigation dedicated exclusively towards effectively analysing breast cancer content across the most used social media worldwide. The research questions of this investigation are:

RQ1. What is the credibility of the content and the characteristics of the breast cancer news stories on social media that generates more engagement (in the form of total shares)?

RQ2. Are there any differences between the content shared in October (Breast Cancer Awareness Month) and other months of the year?

The second part of this thesis is dedicated to the analysis of a questionnaire applied to healthcare professionals across Hungary. Since it is believed that the presence of health professionals producing reliable content about health and breast cancer in social media is extremely important, some of these professionals were interviewed to understand if they work with it, what topics they address and how they dialogue with patients who present them with

misleading content. Again, there are no other studies in Hungary that analyse online medical content in this light. The research questions related to this part of the study are:

RQ3. Do Hungarian physicians, health professionals and researchers on cancer use social media to search, consume and produce information on health and breast cancer? If so, how?

RQ4. What do these professionals think of the available content on breast cancer, and what are their suggestions on how this content can be improved?

RQ5. How do health professionals assess the health literacy of their patients, and how this can be improved?

2. Methodology

2.1. Social media analysis

This is an exploratory quali-quantitative study, without prior hypotheses. News stories in English which addressed breast cancer were investigated. Data collection was conducted between 17 June 2019 and 17 June 2020.

An online tool called BuzzSumo was used (BuzzSumo, 2021) to compile the news stories from the studied sample. This tool has a large index of social media engagement data, comprising more than 5 billion articles. Users are able to discover the most popular content in any niche, by typing the topic of interest in the search tool. With this, it is possible to find meaningful insights based on what content is shared out on social media the most. For instance, users can discover what content format is more popular (if text, video, photos, etc), if there is a specific period of time when this content gets more public attention, or what types of subtopics under this content generates more social media engagement.

The keyword "breast cancer" was searched, in quotation marks, so that we only have results displaying this exact term, and not the words separately. The search was made within the "Web Content" tab, which lists and displays metrics of the most engaging articles, videos, and blog posts among the following social media sites: Facebook, Twitter, Pinterest and Reddit. These social networks are among those with the largest number of users in the world. As of 2021, Facebook had more than 2.9 billion monthly active users worldwide, and is the largest social network to date (Statista, 2021a). Twitter had 206 million daily active users worldwide (Statista, 2021f); Pinterest had 454 million monthly active users worldwide (Statista, 2021c); and Reddit mobile application had 50 million monthly active users worldwide on Android and iOS operating systems (Statista, 2021d).

The search was limited to pages in English, with no country restrictions. Statistical and content analysis of the stories which had at least 1,000 total shares were performed. This number was decided according to the following factors:

- The most shared news stories were exactly those which had greater visibility throughout the studied social networks, and therefore these stories are more relevant to this investigation.
- A cut for this sample should be established, which makes content analysis possible.

- This cut is sufficient to allow a broad overview of the conversations regarding breast cancer in the chosen period.

The news stories filtered by BuzzSumo were exported to an Excel table containing the following information: total shares (sum of shares, that is, when users share content on their personal pages, across all analysed social networks); total Facebook shares; Twitter shares; Pinterest shares; total Reddit engagements; and published date. Moreover, there is another metric related to Facebook only, and is the number of reactions given to each news story. On Facebook platform, reactions are buttons that allow users to share how they feel about a publication in an easy and specific way; the collection of reactions include: like, love, care, haha, wow, sad, and angry (Facebook, 2021). BuzzSumo lists the count of every reaction for every publication in the list.

2.1.1. Content analysis

The content analysis follows the methodology developed by Bardin (Bardin, 2013), which is an inductive analysis comprising of the steps listed:

1. Pre-analysis: In this step, the research objectives are defined, and the universe of the study is demarcated. This universe, called *corpus*, is the set of documents considered to be submitted to analytical procedures (Bardin, 2013). After the *corpus* definition, we implement a wide and careful reading of all the material.

2. Coding: This phase consists of a transformation - carried out according to precise rules - of the raw data of the text, transforming this by aggregation and enumeration, which allows the analysts to reach a representation of the content (Bardin, 2013). In this step, we created the coding schedule for this research, which is the form in which all the data relative to the news stories being coded will be entered (see **Table 6**).

3. Categorization: At this stage, every unit of the corpus is classified in groups that present similarities. Each news story was considered by us as a unit of the *corpus*. In this way, we used different dimensions to categorize each column of the coding schedule (**Table 6**). Two researchers performed the analysis of the material and its classification. The coding schedule and its dimensions were previously determined by both. Afterwards, the analysis of a sample of one hundred news stories was carried out separately by each of the researchers. Percent agreement was used to calculate inter-rater reliability, and the result is 83%. After analysing

this initial sample, one of the researchers concluded the categorization of the entire *corpus* (Biancovilli, Makszin, & Csongor, 2021).

4. Interpretation: This stage is when the analysts can make inferences from the *corpus* and evaluate its results. The focal point of the analysis can be the sender (or producer of the message); the receiver; the message and the medium. In this study, we chose to analyse the content through the message, which encompasses the code (in this case, the words) and the meanings that the message provides.

Table 6. Coding manual, comprising the coding schedule (the column headings indicate the dimensions to be coded) and its categories

Credibility	Type of rumour	Source of news stories	Content type	Mentions breast cancer prevention?	Mentions early detection or screening exams?	Sentiment	Mentions symptoms?	Mentions risk factors?	Mentions a scientific paper or quotes a specialist?	Celebrity presence?
Verified	Misleading	Traditional media	Real-life story	Yes	Yes	Positive	Yes	Yes	Yes	Yes
Rumour	False connection/context	Digital media	Risk factors	No	No	Negative	No	No	No	No
	Fabricated content		Treatment			Neutral				
	Satire		New technology							
			Solidarity							
			Educational							
			Complaint							
			Opinion							

2.1.2. Credibility analysis

The content analysis was commenced by classifying news stories according to its credibility. First, the stories were split them into the following categories: "Verified" (scientifically accurate) and "Rumours" (scientifically inaccurate, uncertain or false) (Sommariva et al., 2018). To ascertain accuracy, the researchers examined if the content of the news stories could be found in peer-reviewed journals indexed in the main health-related databases, such as Web of Science, PubMed, PsycINFO, Embase, Cochrane Library, CINAHL (D. Chapman, 2009). In cases where it was not possible to verify the information in scientific journals, an oncology

specialist and a journalist from a cancer foundation were consulted to assess the credibility of the news in question.

2.1.3. Type of rumours

For this analysis, the nomenclature developed by Wardle (2017) was utilized on the different types of misinformation, with certain adjustments. This author developed more specific terms to replace the use of the expression ‘fake news’, which is not the most precise. Extensive literature makes use of the term ‘misinformation’ when referring to false content that is unintentionally or unknowingly disseminated, whereas ‘disinformation’ refers to false content that is intentionally disseminated (Biancovilli, Makszin, & Csongor, 2021; Cuan-Baltazar et al., 2020; Fetzer, 2004; Wang et al., 2019; Wardle, 2017). Based on it, the following definitions were created:

- 1. Misleading content:** describes stories which are not entirely false yet lead the reader to misinterpret the data.
- 2. False connection/context:** We classified a rumour in this category when the headline does not support the content of the news story, or when genuine images, videos, photos, and audios were used outside their original context, or were manipulated.
- 3. Fabricated content:** Encompasses news stories without any indication of legitimate information (both in the textual and non-textual parts).

Here, once more, there was the support of an oncology specialist and a journalist from a cancer foundation for clarification in case of irresolution.

2.1.4. Source of news stories

The news stories were also classified according to its origin. The following categories were developed:

- 1. Traditional media:** these are the types of media that existed before the rise of the Internet, such is TV channels, radio networks, newspapers and book publishers (Yoon & Kim, 2001), just to name a few examples (they are still regarded as traditional media even though they have an online presence in the current days).
- 2. Digital media:** there are news sources launched online and exclusively published using this medium, such as blogs, social media pages and YouTube videos (Sommariva et al., 2018).

2.1.5. Content type analysis

The categories identified by the researchers for "content type" are the following:

- 1. Real life story:** testimonials from persons who have or had cancer, or family members of patients, or any other narratives from real life.
- 2. Risk factors:** stories whose emphasis is on a risk factor for breast cancer, such as sedentary lifestyle, unhealthy eating habits, family history, smoking, among others.
- 3. Treatment:** stories which publish or explain some type of treatment for breast cancer, be it well-known or ground-breaking; it can be both conventional medicine or related to complementary and alternative medicine (CAM).
- 4. New technology:** stories that announce or describe new technologies in the detection or prevention of breast cancer.
- 5. Solidarity:** stories that mention solidarity actions, for instance blood/hair donation for a sick person, or when parties become involved in breast cancer awareness actions.
- 6. Educational:** news stories that dedicate to explain what kind of food/behaviours can help prevent cancer in the long run, or what are the symptoms of breast cancer, for instance.
- 7. Complaint:** reports of problems that breast cancer patients experience, such as the lack of medication in hospitals or problems with health insurance providers.
- 8. Opinion:** when authors express their personal opinions on topics related to breast cancer, such as awareness campaigns.

2.1.6. 'Yes' or 'no' questions

In this content analysis there are some questions whose answer is only 'yes' or 'no' (Table 1). The objective of those questions is to assess from different angles the content of news stories. The goal is to investigate if those stories mention screening and early detection as this can have a significant beneficial impact in lowering the mortality and morbidity due to breast cancer (Dey, 2014), and it is of fundamental importance that the population gets informed about it. Numerous studies indicate that the knowledge of women clearly influence their acceptance of screening exams and treatment, across different cultural backgrounds (Ceber et al., 2010; Choudhry, 1998; Sim et al., 2009)

The same can be said about symptoms. Women need information about what are the breast cancer symptoms, so they can seek medical assistance in a timely manner (Sim et al., 2009). In addition, it is also important to inform the population that early-stage breast cancer, which are the most curable stage, does not always produce symptoms, so a mammogram should be done regularly to detect the disease (American Cancer Society, 2021a).

In addition to having knowledge about the tests, symptoms, and the importance of early detection, preventing the onset of breast cancer is also part of a good strategy to reduce the incidence of this disease in the population. Around 5% to 10% of all cases are due to inherited mutations of BRCA1 and BRCA2 genes; however, obesity, lack of physical activities and use of alcohol are also considerable risk factors that the population need to be informed about (Majeed et al., 2014).

The number of times a news story mentions a scientific paper or quotes a specialist was also measured. The availability of health professionals who dialogue with the media or who produce content on social networks is of paramount importance to reduce the spread of misinformation (Biancovilli, Makszin, & Jurberg, 2021). Moreover, science journalists also need to be able to translate the content of scientific and academic journals for the lay audience in an accessible way, solidifying the bridge between the technical knowledge produced in laboratories/universities and the non-specialized population.

2.1.7. Sentiment analysis

Another part of the study dedicated to analysing the prevailing sentiments in news stories. Sentiment analysis and opinion mining is the field of study that analyses people's opinions, sentiments, evaluations, attitudes, and emotions from written language (Liu, 2012). It consists of the use of natural language processing (NLP), machine learning, and other data analysis techniques to analyse text and deliver quantitative metrics. The goal is to understand what is the prevailing sentiment on breast cancer news stories on social media, and if this proportion changes according to the content type. To perform this analysis, a tool called MonkeyLearn (MonkeyLearn, 2021) was used, which provides free sentiment analysis using NLP.

2.1.8. Celebrity presence

The last measure in the coding schedule (Table 1) is the celebrity presence. The term celebrity signifies that someone possesses the quality of attracting attention, and a person can become a celebrity in virtually any profession (Furedi, 2010). It is well-known that celebrities can influence the mass public, helping to shape behaviours and attitudes. It can also support the

uptake of prevention programs (Biancovilli et al., 2015; Metcalfe et al., 2011). Celebrity involvement is a key strategy to engage a larger number of users on social networking platforms (Veale et al., 2015). In this study, the proportion of celebrities in the sample's news stories is analysed, and what types of feelings and content types are most prevalent.

2.1.9. Pink October – Breast Cancer Awareness Month

Another dimension analysed in this sample is the content produced during the month of October compared to the other months of the year. Every October marks the Breast Cancer Awareness Month, a worldwide campaign that has the aim to celebrate new research into prevention, diagnosis, and treatment, as well as to make everyone aware of the importance of knowing the symptoms, performing the screening exams and knowing the importance of early diagnosis (Karabay et al., 2018).

2.2. Questionnaire - Hungarian doctors, health professionals and cancer researchers' attitudes towards online health communication on breast cancer

The current standards of professional communication in medicine were developed with traditional face-to-face consultations as the template; while young doctors can be more comfortable with online communication, some senior professionals may struggle with a lack of skills to use social media tools, for instance (Brown et al., 2014). Some studies have already pointed out the importance of the use of social networks by medical professionals, either to better communicate with patients (Brown et al., 2014), or to share findings published in scientific articles to a wider audience (Fox et al., 2016). The presence of healthcare professionals and communicators in the online sphere goes beyond the traditional doctor-patient relationship. The COVID-19 pandemic showed us that quality and evidence-based content about the disease needs to be available to as many people as possible, in a clear and accessible language, thus avoiding as much as possible the dissemination of misinformation that can indirectly lead to deaths (Biancovilli, Makszin, & Jurberg, 2021; Li et al., 2020). High quality open access educational material should contain key information in a transparent, actionable format, alongside with content produced for social media and traditional communication methods (Chan et al., 2020). This is meant not only for patients, but also to inform the population and support prevention or early detection efforts.

2.2.1. Ethics approval

The study has an ETT TUKEB (Hungarian Medical Research Council - Tudományos és Kutatásetikai Bizottság) professional-ethical license: IV/9147-2/2020/EKU. This research is

authorized for the entire territory of Hungary. The investigation conforms to the principles outlined in the Declaration of Helsinki.

2.2.2. Development of the questionnaire

The semi-structured questionnaire was developed based on another validated survey (with some modifications) which aimed to provide a national profile of Australian doctors' attitudes towards the use of online social media. (Brown et al., 2014). The research questionnaire comprises of 27 questions in total, 17 closed-ended and 10 open-ended questions, all in English language. A first version of the questionnaire was used as a pilot, in a sample of 10 participants. Subsequently, this draft questionnaire was revised by three scientists from different backgrounds before we reached our final version: one sociologist, one anthropologist and one linguist.

Sociodemographic characteristics were obtained by using questions regarding age, nationality, gender, highest academic degree, medical specialty (if any), marital status, county where they work, and years of experience in the medical field. Subsequently, the next section of the questionnaire aimed at investigating if and how health professionals consume breast cancer information on the Internet, what exactly this content is about and what type of media they use (i.e., online newspapers, academic journals, social media). Then, the next section of the questionnaire focused on understanding doctors and researcher's science outreach activities on social media. Finally, the last section was answered only by physicians or other professionals who work directly with breast cancer patients, and they should express their opinions on the health literacy of the patients regarding breast cancer (if their patients have ever reported believing in misinformation related to breast cancer and what are the professionals' attitudes when this happens).

When discussing a topic that has different layers and nuances, using a number of open-ended questions is ideal. An anonymous questionnaire with some open-ended questions is believed to enable doctors and health professionals to explain their own opinions in a more detailed way, without the limitations of structured questions. Answers can also be used to substantiate closed questions, helping the researcher to be sure that an investigation tool is valid (O'Cathain & J Thomas, 2004).

The development and description of results of this questionnaire take into account the guidelines established by the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) (Eysenbach, 2004). Before answering the questionnaire, participants were

provided an informed consent, containing the objective of the research, the contact of the responsible researchers, the information that all data collected is anonymous and confidential, as well as the estimated time to answer the survey, which is 10 minutes. The participation was voluntary and there were no incentives offered.

2.2.3. Participants and recruitment process

This is a cross-sectional study with a convenience sample. The survey is online based, and Google Forms tool was used to make it available for the users. Due to the fact that this research was produced during the COVID-19 pandemic, focus groups or face-to-face interviews in hospitals or medical laboratories could not be organized, as this would pose a health risk. This is why a web-based survey was ideal in this context.

Potential participants were contacted via e-mail. Data collection took place from June 2021 to November 2021. Firstly, an invitation to fill the questionnaire was submitted by the president of the Hungarian Society of Oncologists (*Magyar Onkológusok Társasága* or MOT) to all its 1,100 members who have a registered e-mail. The first invitation was submitted in June 2021, the second in September 2021 and the third in November 2021.

The invitation to complete the questionnaire was also emailed to PhD students at the Doctoral School of Health Sciences in Pécs (October 2021) and to members of the Oncology Department at the University of Pécs (October 2021) and at Semmelweis University (September 2021). Snowball sampling technique was used to collect more answers from these institutions.

2.2.4. Open-ended responses analysis

All answers to open-ended questions were organized and scrutinised using the content analysis software Atlas.ti 7 Scientific Software Development GmbH. Codes that could represent the complexity and nuances of the written responses were developed, also using Bardin's methodology (Bardin, 2013) previously mentioned. The responses to each question were analysed separately, and codes corresponding to each group of answers were developed. For each part of an answer only one code was assigned. However, it is possible that a single answer addresses different topics, and therefore has more than one code (relating to the different parts of the answer).

2.2.5. Statistical analysis

Data were analysed using IBM SPSS Statistics V20, Minitab 16 and Microsoft Excel 2010. To characterize the distribution of the relative frequency (percentages or prevalence) of the

qualitative questions, the test for equality of two proportions was used. For bivariate analyses between quantitative and qualitative factors, the ANOVA test was used, and for comparisons among qualitative questions, the chi-square test was performed.

3. Results

3.1. Social media content analysis

Screening the media for breast cancer news stories published between June 2019 and June 2020 resulted in 9,811 hits. Of these, 1,594 news stories had at least 1,000 total shares.

3.1.1. Source of news stories

Regarding RQ1, most of the stories in the sample were published in digital media (76.73%), whereas 23.27% originated from traditional media. However, the most shared news story (**Table 7**) was published in Fox News, a 24-hour traditional media outlet from the United States, dedicated to delivering breaking news, political and business news, launched in 1996 (Fox News, 2021). Among the twenty stories with the most shares, thirteen were published by traditional media outlets: four times by Fox News and once by nine other media entities, such as The Epoch Times, Metro, CNN and NBC News. All of those are originated from the United States, except for Metro, which is a news tabloid from the United Kingdom, created in 1999 (Metro UK, 2021). The most shared story in a digital media is authored by the blog The Breast Cancer Site, which is developed by the Greater Good Charities, a charitable organization from the United States that works to improve the health and well-being of people, pets, and the planet (The Breast Cancer Site, 2021).

Table 7. Top 20 most popular news stories related to breast cancer (measured by total shares in social networking sites), its credibility and content type, between June 2019 and June 2020

Rank	News story title and webpage	Total shares	Verified or rumour	Content type
1	Trial vaccine wipes out breast cancer in Florida patient (Fox News Orlando)	1,822,993	Rumour	Treatment
2	Loyal boyfriend who stuck with girlfriend during breast cancer proposes on her last day of chemo (The Epoch Times)	734,482	n/a	Real-life story
3	Breast Cancer Vaccine Has Eliminated Cancer in Its First Human Patient (The Breast Cancer Site)	729,185	Rumour	Treatment
4	Dad with breast cancer 'rejected from support groups because he's a man' (Metro)	640,106	n/a	Real-life story
5	Albuquerque Police Department paints a patrol car pink for Breast Cancer Awareness Month (CNN)	635,438	n/a	Real-life story
6	Shannen Doherty reveals breast cancer is back, now stage 4 (NBC News)	356,393	n/a	Real-life story
7	Scientists Successfully Turn Breast Cancer Cells Into Fat to Stop Them From Spreading (Science Alert)	352,749	Verified	Treatment

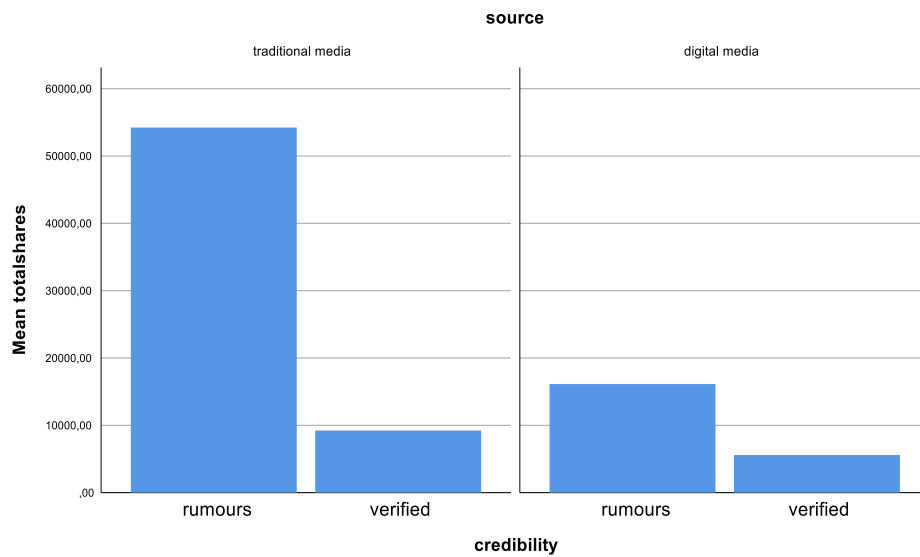
8	Mom of 6 who survived breast cancer dies from COVID-19 (WGXA)	279,729	n/a	Real-life story
9	Trial vaccine wipes out breast cancer in Florida patient (Fox News Phoenix)	267,336	Rumour	Treatment
10	New blood test can detect breast cancer 5 years before lumps appear (NY Post)	188,567	Rumour	Treatment
11	Mom of 6 who survived breast cancer dies from COVID-19 in Snohomish Co. (KOMO-TV)	167,651	n/a	Real-life story
12	Olivia Newton-John winning breast cancer battle as tumours shrunk thanks to marijuana (Express)	164,526	Rumour	Treatment
13	Mom of 6 who survived breast cancer dies from COVID-19 (Local 12)	161,878	n/a	Real-life story
14	Trial vaccine wipes out breast cancer in Florida patient (Fox News DC)	161,035	Rumour	Treatment
15	19-year-old Ghanaian creates system to predict and diagnose breast cancer (Ghana Web)	149,237	Rumour	New technology
16	Black women are over 6 times more likely to get breast cancer from hair dye and relaxers- New study finds (Pulse)	145,238	Rumour	Risk factors
17	Mayo Breast Cancer Vaccine Could Be Available In Less Than A Decade (Forbes)	141,629	Verified	Treatment
18	Shannen Doherty shares she has stage 4 breast cancer: 'I'd rather people hear it from me' (Good Morning America)	138,195	n/a	Real-life story
19	Sad News, Robin Roberts Painfully Reveals She Had Breast Cancer. (YouTube)	134,769	n/a	Real-life story
20	Mom of 6 who survived breast cancer dies from COVID-19 (Fox News Nashville)	130,886	n/a	Real-life story

3.1.2. Credibility analysis

Among the news stories selected for coding, 69.7% have not been classified according to credibility. This is because these news items do not address science, risk factors, prevention, treatment or other aspects, which can be assessed for scientific accuracy. Considering only the news classified according to credibility (n=483), 17.25% are 'verified' and 13.05% are 'rumours'.

When investigating the amount of shares in relation to the credibility of the content (Fig. 1), it is possible to note that the content classified as "rumours" tends to be more shared than scientifically correct content, both in digital and traditional media. "Rumours" is less frequent in the sample but totalled 5,755,192 shares. Meanwhile, the "verified" stories had 1,747,352 total shares (3.29 times less).

Figure 1. Mean of total shares of content classified as ‘verified’ and ‘rumours’ both in traditional and digital media.



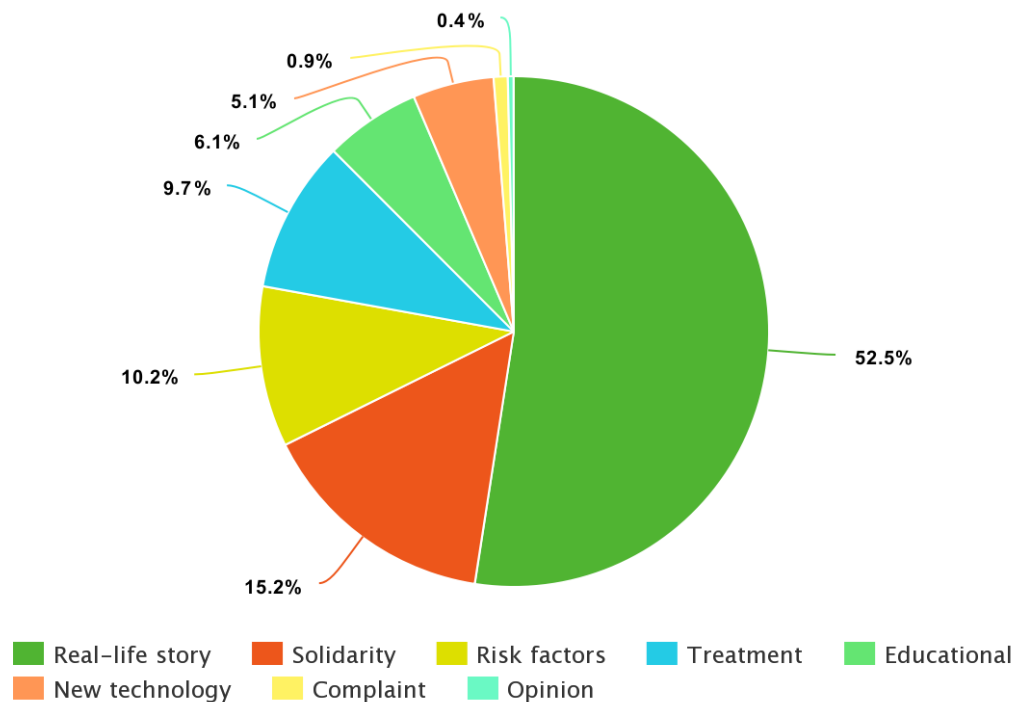
3.1.3. Type of rumour

When examining the most common types of rumours, ‘false connection/context’ represent 62.7% of the total, ‘misleading content’ are 34.9% of the total, and totally false content, that is, ‘fabricated content’ category, represents 2.4% of the total.

3.1.4. Content type

When examining the distribution of content type categories in the studied sample (**Fig. 2**), most stories are classified as ‘real-life story’ or ‘solidarity’ (67.69%). These stories have no scientific content, since they are focused on narrating the life of an individual or family members with cancer, publicizing actions to raise money for cancer hospitals or requesting donations of any kind for patients in need, to mention a few examples.

Figure 2. Percentage of news stories per content type

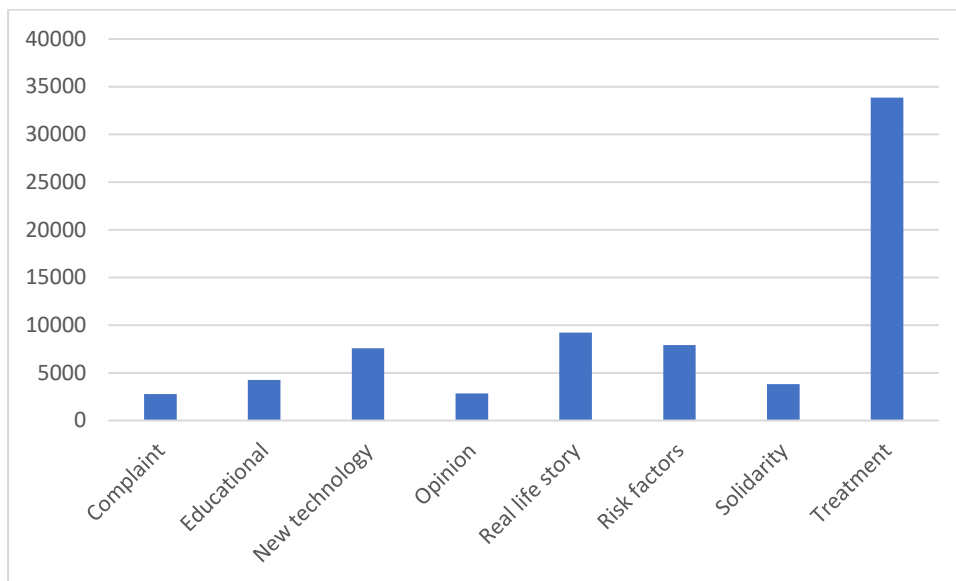


In this sample, a repetition of the same news among the stories with the most total shares was noted (**Table 7**). These stories are reproduced on different web pages, often with the same (or very similar) titles and texts.

For instance, it is possible to see how the trial vaccination against breast cancer of a patient in Florida was highlighted (the story was repeated four times in the Top 20, and 13 times in the Top 50). The death from COVID-19 of a mom of 6 who survived breast cancer was also noteworthy, being repeated four times in the Top 20, and eight times in the Top 50.

When analysing the average number of shares according to the type of content (**Fig. 3**), it is observable that "treatment" tend to generate a considerably greater engagement than other themes (33,854 average shares in the sample). In second place there are news about "real-life stories" (9,205 average shares) and in third place, "risk factors" (7,922 average shares).

Figure 3. Average shares according to content type in the sample.



3.1.5. Mentions of breast cancer prevention and early detection/screening exams

Most analysed news stories do not address ways of preventing or early detecting breast cancer (Table 8). In the studied sample, 5.08% of the stories comment on prevention and 19.7% mention early detection. There is an extraordinarily strong statistical connection (Cramer's value = 0.435; Fisher's exact test, $p < 0.001$) between content type and prevention; and between content type and early detection (Cramer's value = 0.355; Chi-square test: $p < 0.001$).

Table 8. Percentage of news stories that mention prevention and early detection, according to the content type

	Prevention			Early detection		
	Yes	No	Total	Yes	No	Total
Treatment	0.6	99.4	100	17.5	82.5	100
Real-life story	0.7	99.3	100	16.6	83.4	100
Risk factors	25.3	74.7	100	5.6	94.4	100
New technology	1.2	98.8	100	73.2	26.8	100
Solidarity	1.2	98.8	100	15.2	84.8	100
Complaint	0	100	100	42.9	57.1	100
Educational	27.8	72.2	100	33	67	100
Opinion	33.3	66.7	100	66.7	33.3	100

News stories whose themes are "opinion", "educational" and "risk factors" have the highest proportion of references in prevention. In relation to early detection, this characteristic is

observed in stories regarding “new technology”, “opinion” and “complaint”. On the other hand, the vast majority of stories about “treatment” (99.4%), “real-life story” (99.3%), “New technology” (98.8%), “solidarity” (98.8%) and “complaint (100.0%) do not mention prevention; the same can be said when observing “risk factors” (94.4%) and “solidarity” (84.8%) in relation to early detection.

There was no statistical connection observed between prevention versus credibility and between early detection versus credibility (**Tables 9 and 10**).

Table 9. Number of news stories that address breast cancer prevention, separated according to the credibility of the content.

Credibility	Mentions prevention?		Total
	No	Yes	
n/a	1098	13	1111
Rumour	185	23	208
Verified	230	45	275
Total	1513	81	1594

Table 10. Number of news stories that mention how to detect early-stage breast cancer and/or address screening exams, separated according to the credibility of the content.

Credibility	Mentions early detection/screening?		Total
	No	Yes	
n/a	920	191	1111
Rumour	152	56	208
Verified	208	67	275
Total	1280	314	1594

Of the 30.3% of the news stories that could be classified according to credibility (n=483), a total of 45 (9.3%) are scientifically verified and mention breast cancer prevention measures. However, the vast majority of verified stories (n=230 or 47.61%) do not address this topic. Stories classified as rumours showed a similar pattern, as 23 (4.76%) mention prevention and 185 (38.3%) do not.

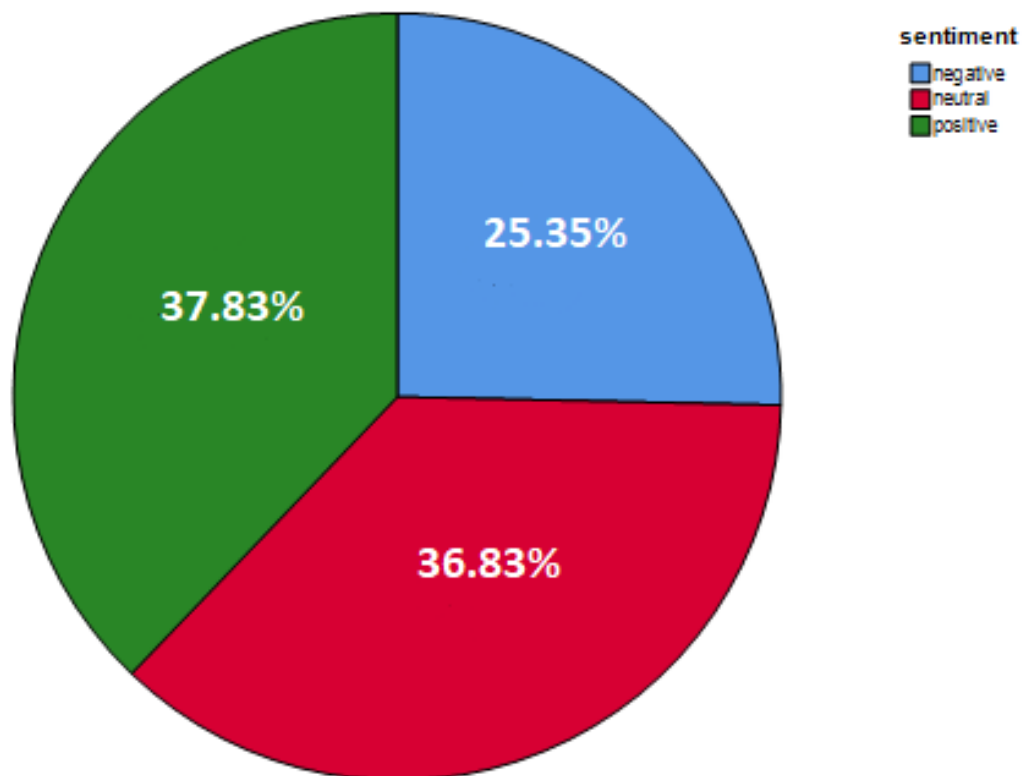
When analysing the news stories according to mentions to breast cancer early detection and screening exams, it is possible to note that 67 of the 483 (13.87%) are scientifically verified and at the same time comment on those issues. On the other hand, 208 (43%) of the stories do

not mention such topics. Again, a similar pattern is observed in stories labelled as rumours: 56 (11.5%) mention early detection/screening and 152 (31.4%) do not.

3.1.6. Sentiment analysis

A balance was observed in relation to sentiments in the sample (**fig. 4**).

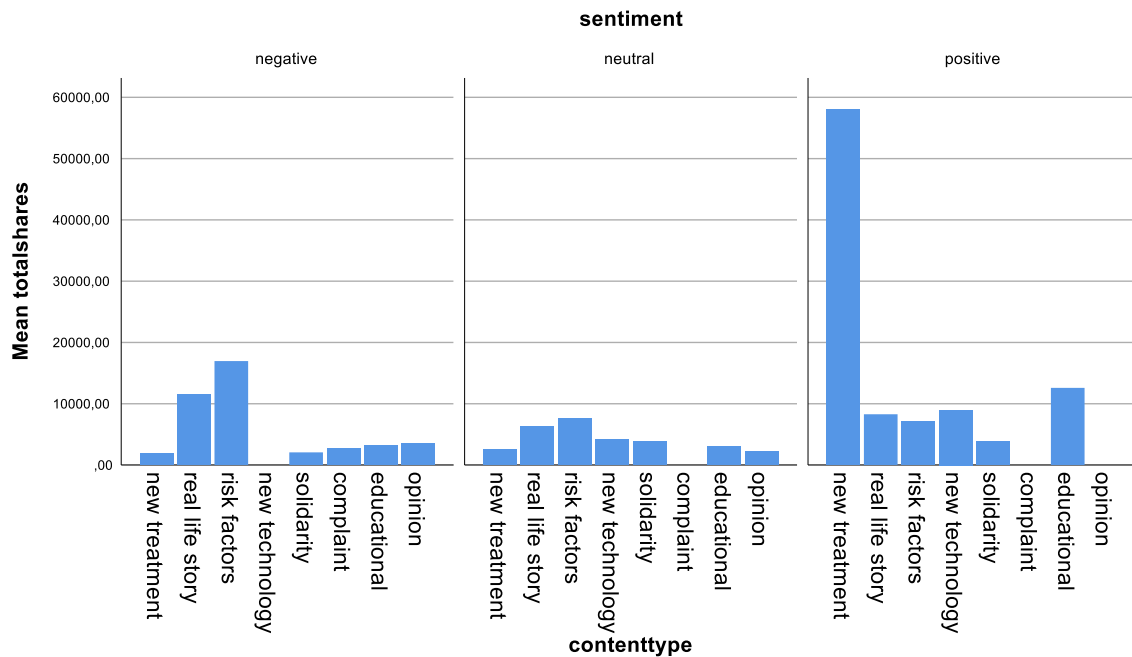
Figure 4. Proportion of sentiments in the analysed sample (n=1,594).



When crossing the different dimensions of the content analysis (**fig. 5**), one aspect stands out, and that is the high number of total shares of positive news stories whose content type is “treatment”. Second to total shares, there are stories with negative content about "risk factors" and thirdly, with a similar number of total shares, are positive stories about "educational" topics and negative stories about "real-life stories".

It is worth noting that the story with the highest number of total shares in the sample (n=1,822,993), titled “Trial vaccine wipes out breast cancer in Florida patient” fits the pattern that tends to have a high number of shares. It's a positive story about a new treatment. However, it was classified as a rumor (false connection/context) as it has not yet been scientifically proven that this vaccine is in fact capable of curing breast cancer, as the text suggests.

Figure 5. Mean of total shares of all types of content in the studied sample, in relation to sentiment.



3.1.7. Mentions of symptoms

In the studied sample, 1354 of the news stories (84.94%) do not mention any type of breast cancer symptoms, whereas 240 (15.05%) do. There is a very strong connection between content type and mentions of symptoms (Chi-square test: $p < 0.001$; Cramer's value=0.281) (Table 11). Nevertheless, no significant connection between source of news and mentions of symptoms was found (Chi-square test: $p = 1.000$).

Table 11. Relationship between content type and mentions of breast cancer symptoms in the studied sample.

Content type	Mentions symptoms?		Total
	No	Yes	
Complaint	13	1	14
Educational	74	23	97
New technology	78	4	82
Opinion	4	2	6
Real life story	642	194	836
Risk factors	161	1	162
Solidarity	239	4	243
Treatment	143	11	154
Total	1354	240	1594

It is possible to observe a significant difference between mention of symptoms in news stories classified as “real life story”. The majority (75.7%) do not mention symptoms. However, this difference is even more discrepant if we analyze other content categories (complaint, new technology, risk factors, solidarity and treatment). Only 1 news story (0.61%) on risk factors mention symptoms, and only 4 in solidarity do so (1.64%).

3.1.8. Mentions of risk factors

Regarding risk factors for breast cancer, 228 news stories mention it (14.30%), whereas 1366 (85.7%) do not refer to this topic. There is a very strong statistical connection between content type and mentions to risk factors (Chi-square test: $p < 0.001$; Cramer’s value=0.820). We did not observe a statistical connection between source of news and mentions to risk factors (Chi-square test: $p = 0.204$).

Table 12. Relationship between content type and mentions of breast cancer risk factors in the studied sample.

Content type	Mentions risk factors?		Total	
	No	Yes		
Complaint		13	1	14
Educational		71	26	97
New technology		81	1	82
Opinion		3	3	6
Real life story		809	27	836
Risk factors		4	158	162
Solidarity		239	4	243
Treatment		146	8	154
Total		1366	228	1594

Similarly to mentions of symptoms, it is noticeable from this table that there are major differences between the content type and mentions to risk factors. Here there is a need to clarify that not all stories classified as "risk factors" actually mention it. That's because a story is classified as mentioning risk factors only when a real and scientifically proven fact is said. In the studied sample, in 4 situations, this news story (with some variations) was shared: "Breast cancer linked to permanent hair dye, chemical hair straighteners", which is not yet a scientific consensus while this study is being written (Das, 2021).

High disparities between ‘yes’ and ‘no’ were observed in those categories: complaint (7.14% ‘yes’, 92.86% ‘no’), new technology (1.21% ‘yes’, 98.79% ‘no’), solidarity (1.64% ‘yes’, 98.36% ‘no’) and treatment (5.19% ‘yes’, 94.81% ‘no’).

3.1.9. Mentions of scientific papers or specialist quotes

Most of the news stories in the sample do not mention a scientific paper or quote a specialist (n=1095, 68.69%). There is a very strong statistical connection between content type and mentions to scientific paper/specialist quote (Chi-square test: $p < 0.001$; Cramer's value=0.774) (Table 13). Again, statistically significant differences between source of news and this variable were not observed.

Table 13. Relationship between content type and mentions of scientific paper/specialist quote in the sample.

Content type	Links sci paper or quotes specialist?		Total	Total
	No	Yes		
Complaint		6	8	14
Educational		30	67	97
New technology		9	73	82
Opinion		2	4	6
Real life story		766	70	836
Risk factors		11	151	162
Solidarity		239	4	243
Treatment		32	122	154
Total		1095	499	1594

Table 14. Relationship between content credibility and mentions of scientific paper/specialist quote in the sample.

Credibility	Links sci paper or quotes a specialist?		Total	Total
	No	Yes		
n/a		1019	92	1111
Rumour		45	163	208
Verified		31	244	275
Total		1095	499	1594

Regarding scientifically verified content, 88.72% link a scientific paper or quote a specialist. With content deemed rumours, 78.36% do so. Of the 499 news stories which link a scientific paper or quote a specialist, 32.66% are rumours, 48.89% are verified and 18.43% cannot be assessed according to credibility.

3.1.10. Celebrity presence

In the Top 20 of the sample (Table 7) a highlight in news that addresses celebrities with breast cancer was noticed (n=4), including the North-American actress Shannen Doherty, the British-

Australian singer Olivia Newton-John, and the North-American television broadcaster Robin Roberts. In total (Figure 3), 262 news stories mention a celebrity (16.44%), whereas 1332 stories do not (83.56%).

There is a very strong connection (Chi-square test: $p < 0.001$; Cramer's value=0.293) between content type and celebrity presence (Table 15). However, the connection between source of news and celebrity presence (Table 16) is weak (Chi-square test: $p = 0.017$; Cramer's value=0.060).

Table 15. Celebrity presence in the sample according to content type

Content type	Celebrity presence		Total
	No	Yes	
Complaint	14	0	14
Educational	94	3	97
New technology	82	0	82
Opinion	6	0	6
Real life story	627	209	836
Risk factors	161	1	162
Solidarity	195	48	243
Treatment	153	1	154
Total	1332	262	1594

Table 16. Celebrity presence in the sample according to the source of news

Source of news	Celebrity presence		Total
	No	Yes	
Digital media	1033	185	1218
Traditional media	299	77	376
Total	1332	262	1594

It is also noteworthy the relationship between celebrity presence, sentiment and credibility (Table 17). Most of the news stories in the sample are neutral and have no celebrity presence. In relation to credibility, most stories cannot be classified according to it, as they do not mention aspects that can be assessed for scientific accuracy. There is a very strong statistical connection (Chi-square test: $p < 0.001$; Cramer's value=0.300) between celebrity presence and sentiment. It is possible to observe a considerable higher proportion of negative news stories with celebrity presence (53.82% *versus* 19.74%), in comparison with stories without celebrities. Analysing the stories without celebrities, 19.7% have "negative sentiment", 41.1 % are neutral and 39.2% are positive. On the other hand, the stories with celebrities are 53.8% of "negative sentiment",

15.3 % neutral and 30.9% positive. Therefore, there are 2.7 times more stories with celebrities that have a negative sentiment than stories with no celebrities.

Moreover, only six from a total of 262 of celebrity stories could be classified according to credibility (2.29%), whereas 477 out of 1332 stories with no celebrities could be classified so (35.81%).

Table 17. Celebrity presence in the sample according to type of rumour and sentiment

	Celebrity presence		Total
	No	Yes	
Negative	263	141	404
n/a	248	141	389
Rumour	5	0	5
Verified	10	0	10
Neutral	547	40	587
n/a	243	37	280
Rumour	112	2	114
Verified	192	1	193
Positive	522	81	603
n/a	364	78	442
Rumour	87	2	89
Verified	71	1	72
Total	1332	262	1594

There is a moderate statistical connection (Chi-square test: $p < 0.001$; Cramer's value=0.138) between celebrity presence and the mention of risk factors for breast cancer (table 18). There are 4.8 more stories which mention risk factors without celebrities than with celebrities. Only 3.4% of the news stories mention both celebrities and risk factors.

Table 18. Relationship between celebrity presence and mention of risk factors for breast cancer in the sample of news stories.

Risk factors	No	Count	Celebrity		Total
			No	Yes	
		Count	1113	253	1366
		Expected Count	1141.5	224.5	1366.0
		% within celebrity	83.6%	96.6%	85.7%
	Yes	Count	219	9	228
		Expected Count	190.5	37.5	228.0
		% within celebrity	16.4%	3.4%	14.3%
	Total	Count	1332	262	1594

Expected Count	1332.0	262.0	1594.0
% within celebrity	100.0%	100.0%	100.0%

When comparing the mention of a celebrity and stories about early detection/screening exams of breast cancer (**table 19**), it is possible to identify a moderate statistical connection (Chi-square test: $p < 0.001$; Cramer's value=0.105). There are two times more stories about early detection without celebrities than with.

Table 19. Relationship between stories that mention celebrity and early detection/screening of breast cancer.

		Celebrity			
		No	Yes	Total	
Early detection	No	Count	1045	235	1280
		Expected Count	1069.6	210.4	1280.0
		% within celebrity	78.5%	89.7%	80.3%
	Yes	Count	287	27	314
		Expected Count	262.4	51.6	314.0
		% within celebrity	21.5%	10.3%	19.7%
Total	Count	1332	262	1594	
	Expected Count	1332.0	262.0	1594.0	
	% within celebrity	100.0%	100.0%	100.0%	

3.1.11. Breast Cancer Awareness Month

To answer RQ2, a comparison of the content of the news published in October (known as the “Breast Cancer Awareness Month” or “Pink October” in a number of countries worldwide) (Glynn et al., 2011) with the other months was created. There are several variations in relation to the topics covered (**Table 20**) (Chi-square test: $p < 0.001$; Cramer's value = 0.300, extraordinarily strong connection)

Table 20. Comparison between October (BCAM) and other months in relation to content type.

		month2			
		Other months	October	Total	
Content type	Treatment	Count	103	51	154
		Expected Count	106	48	154
		% within month2	9.4%	10.30%	9.7%
	Real-life story	Count	598	238	836

	Expected Count	575.3	260.7	836
	% within month2	54.50%	47.9%	52.40%
Risk factors	Count	144	18	162
	Expected Count	111.5	50.5	162
	% within month2	13.10%	3.60%	10.20%
New technology	Count	77	5	82
	Expected Count	56.4	25.6	82
	% within month2	7.00%	1.00%	5.1%
Solidarity	Count	102	141	243
	Expected Count	167.2	75.8	243
	% within month2	9.30%	28.4%	15.20%
Complaint	Count	11	3	14
	Expected Count	9.6	4.4	14
	% within month2	1.00%	0.60%	0.90%
Educational	Count	58	39	97
	Expected Count	66.8	30.2	97
	% within month2	5.30%	7.80%	6.10%
Opinion	Count	4	2	6
	Expected Count	4.1	1.9	6
	% within month2	0.40%	0.40%	0.40%
Total	Count	1097	497	1594
	Expected Count	1097	497	1594
	% within month2	100.00%	100.00%	100.00%

There is a substantial upsurge in news stories classified as "solidarity" in October (28.4% versus 9.3% in other months). In contrast, there was a decline in content that addresses "risk factors" (3.6% versus 13.1% in other months), "real-life stories" (47.9% versus 54.5% in other months) and "technology" (1.0% versus 7.0% in other months). A slight increase in educational content is observed (7.8% versus 5.3%).

By comparing the reliability of the news stories shared in October with the other months of the year (**Table 21**), there is a statistically significant difference in the distribution of the types of rumours (Fisher's exact test: $p = 0.030$; Cramer's value = 0.172, strong connection). There is an upsurge in rumours classified as "false connection/context" (81.3% in October versus 59.3% in other months), whereas it is possible to note a decrease in "misleading content" (15.6% in October versus 38.4% in other months). There is no remarkable difference in relation to "fabricated content" (3.1% in October versus 2.3% in other months).

Table 21. Comparison between October (BCAM) and other months in relation to the type of rumour.

Type of rumour		month2		
		Other months	October	Total
Misleading content	Count	68	5	73
	Expected Count	61.8	11.2	73
	% within month2	38.4%	15.60%	34.9%
False connection/context	Count	105	26	131
	Expected Count	110.9	20.1	131
	% within month2	59.3%	81.3%	62.7%
Fabricated content	Count	4	1	5
	Expected Count	4.2	0.8	5
	% within month2	2.30%	3.1%	2.40%
Total	Count	177	32	209
	Expected Count	177	32	209
	% within month2	100.0%	100.0%	100.00%

When analysing the amount of evidence-based content (verified) with rumours, between October and the other months (**Table 22**), there is a moderate statistical connection (Chi-square test: $p=0.003$; Cramer's value=0.138)

Table 22. Comparison between October (Breast Cancer Awareness Month) and other months in relation to content credibility.

Credibility	Rumours		month2		
			Other months	October	Total
		Count	176	32	208
		Expected Count	162.4	45.6	208
		% within month2	46.70%	30.20%	43.10%
	Verified	Count	201	74	275
		Expected Count	214.6	60.4	275
		% within month2	53.30%	69.80%	56.90%
Total		Count	377	106	483
		Expected Count	377	106	483
		% within month2	100.00%	100.00%	100.00%

Overall, in October there is an increase in news stories classified as “verified” (69.8% in October versus 53.3% in other months).

3.2. Questionnaire results

The online questionnaire was answered by 39 doctors and health professionals who work in Hungary.

3.2.1. Basic demographics

The major socio-demographic characteristics of the study population are presented in **Table 23**. Regarding age, most of respondents (33.3%) are between 31-40 years old and 51-60 (28.2%). The majority of respondents are Hungarian (74.4%), female (53.8%), married (66.7%) and work in Budapest or Pest county (56.4%). About the highest degree, most (59.0%) have a completed PhD degree. Regarding the length of professional experience in the medical field, most reported having between 6-10 years (30.8%) or between 21-30 years (25.6%).

Table 23. Socio-demographic characteristics of the questionnaire respondents (n=39)

		N	%	p-value
Age	18-30	2	5.1%	0.002
	31-40	13	33.3%	Ref.
	41-50	8	20.5%	0.202
	51-60	11	28.2%	0.624
	61-70	4	10.3%	0.014
	above 71	1	2.6%	<0.001
Nationality	Hungarian	29	74.4%	<0.001
	Other	10	25.6%	
Gender	Female	21	53.8%	0.497
	Male	18	46.2%	
Highest degree	DSc	4	10.3%	<0.01
	Habil.	1	2.6%	<0.001
	Masters	9	23.1%	0.001
	MD	2	5.1%	<0.001
	PhD	23	59.0%	Ref.
Marital status	Married	26	66.7%	Ref.
	Single	9	23.1%	<0.001
	Divorced	4	10.3%	<0.001
Place of work	Budapest or Pest	22	56.4%	Ref.
	Baranya	6	15.4%	<0.001
	Hajdú-Bihar	5	12.8%	<0.001
	Bács-Kiskun	2	5.1%	<0.001

Answers to the question “What is the latest news you read about breast cancer?” were grouped into codes which best represented the topic (Table 24).

Table 24. What health professionals remember reading most recently on social media about breast cancer, organized according to themes.

Themes mentioned	N	%	p-value
Treatment	15	51.7%	Ref.
Real life story	7	24.1%	0.030
Educational	3	10.3%	<0.001
Solidarity	3	10.3%	<0.001
New technology	1	3.4%	<0.001
Risk factors	1	3.4%	<0.001

When asked “Where did you read them?”, again the most mentioned website was Medscape (30.8%), followed by PubMed (15.4%). The other websites, mentioned only once each, are: 24.hu (7.7%), ESMO (7.7%), Facebook (7.7%), Medline (7.7%), NEJM (7.7%), Twitter (7.7%) and WHO (7.7%). To answer RQ4, respondents were asked if they knew any science communicators who address the topic breast cancer on social media, for that 69.2% answered “yes” and 20.8% answered “no”. Among those who answered yes, they were asked to mention which platforms are used by these science communicators, and how they evaluate the work of these professionals. Table 25 shows the result of this cross-analysis.

Table 25. How respondents rate the work of breast cancer health communicators on social media (from 0 to 10), according to the social media.

	Average	Median	SD	N	CI	P-value
Facebook	8.0	8	2.1	5	1.9	
LinkedIn	6.2	5	1.6	5	1.4	
Other	6.3	6	0.5	4	0.5	0.271
Research Gate or Academia	7.4	7	1.7	5	1.5	
YouTube	7.8	8	1.5	6	1.2	

Academia and Research Gate are social networks aimed at academics, where it is possible to share, search and read academic journal articles, and there is also the possibility of contacting other academics and educational institutions. Although the p-value was not statistically significant ($p=0.271$), it is observable that the highest score was on Facebook with 8.0 and the lowest was on LinkedIn with 6.2.

3.2.3. Do health professionals who work in Hungary disseminate science on social media?

The questionnaire contained the following question: "Have you ever done any work to communicate science to the general public on social networks/blogs/newspapers?". It is important to note that, here, the question is not necessarily about breast cancer, but science in general. To that, 53.8% answered "yes" and 46.2% answered "no" ($p=0.497$). Table 26 shows which platforms were used by health professionals who answered "yes".

Table 26. Communication platforms mentioned by respondents who declared that they had already worked with science dissemination.

Communication platforms	N	%	p-value
Facebook	7	38.9%	Ref.
YouTube	3	16.7%	0.137
Academia	2	11.1%	0.054
Research Gate	2	11.1%	0.054
LEGO-project	1	5.6%	0.016
Live event	1	5.6%	0.016
Publications of the "Leukémiás Gyermekekért" Foundation	1	5.6%	0.016
Researcher's Night	1	5.6%	0.016
(Online) seminars at the ELTE University in Budapest	1	5.6%	0.016
Tumblr	1	5.6%	0.016
TV channels	1	5.6%	0.016
University's website	1	5.6%	0.016
WhatsApp	1	5.6%	0.016
Wordpress	1	5.6%	0.016

Here, "Leukémiás Gyerekekért" means "For children with leukemia". Tumblr is a social microblogging network that allows users to post and share photos with short captions. Wordpress is a content management system that allows users to build personalized blogs and websites without the need of programming knowledge.

When asked what subjects they covered, the answers were varied. Three health professionals mentioned "anticancer treatments" (21.4%) and two responded "early detection" [of cancer] (14.3%). The other answers were mentioned only once each (7.7%), and these are: bleeding disorders, cancer genetics, cancer prevention, epidemiology of cancer, gastrointestinal oncology, genitourinary oncology, HIV, HPV prevention, irradiation, medical sociology, molecular biology, nutrition, paediatric cancers, radiotherapy, radiotherapy physics, screening, tumour angiogenesis, tumour appropriation of pre-existing vessels.

It is important to mention that there was no statistically significant relationship between the answers to the question "Have you done any work to communicate science to the general public on social networks/blogs/newspapers?" and socio-demographic responses.

3.2.4. Doctor-patient communication: How to deal with misinformation brought by breast cancer patients

Regarding RQ5, among the respondents, 35.9% deal directly with breast cancer patients in their work routine, and 64.1% do not ($p=0.013$). Moreover, 23.1% work directly with people who undergo preventive breast cancer screening exams, and 76.9% do not ($p<0.001$). Seven respondents mentioned what type of misinformation they have already heard from patients, for example: Mammography causes breast cancer, surgery disseminates the breast cancer, cytostatic kills the patient, radiotherapy accelerates the growth of the cancer, cancer is not curable.

When asked "How do you deal with patients who believe false information regarding breast cancer", 86.9% mentioned they tell the patient the scientific truth; 21.7% show patients reliable sources on the Internet; 17.4% show patients reliable sources out of the Internet; 8.7% ask for the help of a family member or friend to clarify the truth; 4.3% don't argue, because it is no use.

Professionals were also asked (**Table 27**) to give a grade from 0 to 10 to the health literacy of their patients regarding breast cancer.

Table 27. Full description of the answers to the question “How do you assess patients' health literacy in relation to breast cancer?”

Average	Median	SD	CV	Q1	Q3	Min	Max	N	CI
4.68	4	1.81	39%	4	6	1	9	22	0.76

After that, respondents had to justify the grade, through an open question. The answers were categorized and analysed (**Table 28**) according to the theme that best fit them.

Table 28. Justifications for the grade given to the health literacy of patients in relation to breast cancer, grouped by theme.

Themes	N	%	P-value
No knowledge on prevention	7	50.0%	Ref.
No knowledge on symptoms	6	42.9%	0.705
No knowledge on screening	3	21.4%	0.115
Knowledge on screening	2	14.3%	0.043
Ignore screening	1	7.1%	0.012
Knowledge level can vary	1	7.1%	0.012
Knowledge on genetic patterns	1	7.1%	0.012
Knowledge on symptoms	1	7.1%	0.012

Half of those who answered this question reported that their patients lack knowledge regarding cancer prevention, and 42.9% are unaware of the symptoms of breast cancer. In addition, 21.4% do not know when or how screening tests are performed, especially mammography. This majority of negative responses in relation to patients' health literacy is a justification for the relatively low average score given to patients on the topic (4.68). The positive response regarding patients' health literacy, which is "knowledge on screening", was mentioned twice by health professionals, or 14.3%. The other positive remarks regarding patients' knowledge about breast cancer were mentioned once each (“knowledge on genetic patterns” and “knowledge on symptoms”).

The last question of the survey was open-ended: "In your opinion, what can be done to increase people's awareness of the importance of prevention + early detection of breast cancer?".

Answers were also grouped into themes (table 29) that reflect the main ideas regarding each part of the response.

Table 29. Responses given to the answer „In your opinion, what can be done to increase people's awareness of the importance of prevention + early detection of breast cancer?“ grouped into themes.

Themes	N	%	p-value
Education	21	58.3%	Ref.
Dissemination in the media	15	41.7%	0.157
Awareness campaigns	8	22.2%	0.002
Access to healthcare	4	11.1%	<0.001
Transformation in healthcare	2	5.6%	<0.001
Better doctor-patient communication	1	2.8%	<0.001
Better work conditions for doctors	1	2.8%	<0.001

More than half of the responses (58.3%) mentioned the importance of education as a way to increase the population's health literacy in relation to breast cancer. To illustrate, some of the answers categorized as “education” are:

“More additional information and screening information programs on metastatic patients and from patients receiving therapy can help.”

“Basic, practical information should be implemented in the school education, started early at the elementary school. Clear recommendations should be made and communicated well in connection with cancer risk, appropriate covered and out-of-pocket screening options.”

“Education, education, education”.

The second most mentioned topic is dissemination in the media (41.7%). Some of the written answers about this topic are:

“I think doctors should be more on social media, and more available to talk to journalists as well.”

“We should be more present on social media, not only in the iron tower of scientific institutions. Communication is the key.”

“More publications in the media which could present current situation and pathway of development.”

Together, these two themes represent the overwhelming majority of responses. In addition to educating both patients and school-age children and adolescents, health professionals recognize the importance of publicity in the media as a way of promoting knowledge about breast cancer.

The other topics mentioned are: "awareness campaigns", for example organizing events on the importance of screening exams, in schools or on the streets; “access to healthcare”, for instance by an “individual invitation for screening” or by making early detection tests more available; “transformation in healthcare”, which means, as mentioned by the professionals “patient-friendly screening options” or “GP system should be more qualified and active in the general screening”; “better doctor-patient communication” and “better work conditions for doctors” were mentioned once each.

4. Discussion

4.1. *Credibility analysis, type of rumour and source of news stories*

Most (69.7%) of the sample could not be categorized as to credibility, as they do not address subjects related to science, technology and treatments. Similar results were found in another study that examined content about cancer on Facebook, regardless of the type (Biancovilli & Jurberg, 2018). Another study focusing only on breast cancer content on Instagram (a social media platform that emphasizes photo and video sharing via its mobile app) shows that the most common characteristics of the content was highlighting individual stories and discussing support for those with breast cancer (Basch & MacLean, 2019). This is something that needs to be changed if we want society to be better informed about what the breast cancer symptoms are, how to prevent and detect the disease as early as possible.

Nevertheless, it is important to note that the news classified as "rumours" (13.05%) had a total number of shares 3.29 times greater than the "verified" ones (17.25%). This trend has previously been observed. In a study that evaluated the accuracy of the most popular articles on social media relating to genitourinary malignancies (Alsyof et al., 2019), there was a significantly higher average number of shares for inaccurate and misleading articles, compared to accurate ones. The same tendency was observed in a study dedicated to examining the spread of information related to Zika virus on the Internet (Sommariva et al., 2018). A study on false news about the COVID-19 pandemic shows us similar results (Pulido Rodríguez et al., 2020).

They compared the amount of evidence-based news with false news shared both on Twitter and Sina Weibo, this last one is a Chinese microblogging application and China's second largest social media platform, with more than 516 million monthly active users as of 2019 (Hu, 2020). Results shows that science-based evidence is more shared on Twitter than in Sina Weibo but is a smaller number than false news. In both social media, misinformation circulates more. In general, not only in health-related matters, misinformation is spread faster and more broadly than verified news. A study that analysed more than 126,000 stories on Twitter (Vosoughi et al., 2018) concluded that falsehood was much more spread in all categories of information, especially false political news.

Most "rumours" in the news stories from the studied sample did not display completely fabricated information, but instead presented "false connection/context" (62.7%) or "misleading content" (34.9%). Being aware of this nuance regarding misinformation about breast cancer on social media is important. Valid information taken out of context can have

even greater potential damage, as it may seem far more convincing to the lay reader—hence the higher number of total shares. This trend has also been observed in other studies. One study about medical misinformation in social media reveals that 40% of the most frequently shared links contained false information, and these were shared more than 450,000 times in a period of five years (Waszak et al., 2018). Another investigation on Twitter content reported that “false news reached more people than the truth; the top 1% of false news cascades diffused to between 1,000 and 100,000 people, whereas the truth rarely diffused to more than 1,000 people” (Vosoughi et al., 2018).

To cite an example, it is possible to mention the most shared news story in the sample, entitled “Trial vaccine wipes out breast cancer in Florida patient” (1,822,993 total shares). It was classified as ‘false connection/context’ because the title implies the vaccine is a reality, since a patient has been cured of cancer. However, the text of the article shows the story is more complex than it may seem at first: the vaccine is still a trial, and this patient was the first one to be tested. The text states, “The drug still has a long way to go, but Knutson said it’s promising and is helping show shades of a future that doctors have been working toward.” Is it recognizable that the title is sensationalist, since it leads readers to conclude something that is not yet realistic. This same story, with the same or similar titles, was reproduced 32 times in the studied sample.

When referring to ‘misleading content’, one example is the news story entitled “Black women are over 6 times more likely to get breast cancer from hair dye and relaxers- New study finds” (145,238 shares). Nevertheless, this study has a serious limitation, as explained by an epidemiologist: “The Sisters Study is a good prospective cohort study—but women were recruited to the study because they had a sister with breast cancer, so the conclusions wouldn’t necessarily hold true for women in the wider population, hence the need for further confirmation” (Jones, 2019). This type of misinformation can cause the spread of unnecessary fear among the lay audience (L. Chen et al., 2018).

Another example of ‘misleading content’ is the story entitled “New blood test could detect breast cancer five years before symptoms arise, research finds” (32,159 shares). This story is not entirely false, since it is true that scientists are investing in this research. However, results are still preliminary, and scientists still need to develop and further validate this test (Preidt, 2019). The early disclosure of preliminary results as if they were advanced can generate unnecessary, false expectations in patients or family members.

The 'verified' story with the highest number of shares in the sample has the title "Mayo Breast Cancer Vaccine Could Be Available In Less Than A Decade" (141,629 shares, 12x less than the most shared news, which is classified 'false connection/context'). This news was considered verified because, in addition to citing an expert, which increases the credibility of the text, the author was careful to be realistic about the time needed for the vaccine to become a reality, including in the title of the article. The text says: "Knutson said the research is in its early phases, and it will be at least three years before a phase 3 trial of Mayo Clinic's cancer vaccine would be available to large numbers of patients." This is considered by us an ideal way to address this topic.

The news with the most shares classified by us as 'fabricated content' is entitled "4 Reasons Your Bra May Be Causing Breast Cancer" (12,230 shares) from a website called "The Truth About Breast Cancer". The article has fully fabricated information, such as "Your Bra May Be Harming Your Lymphatic System", "You May Be Wearing Your Bra Too Many Hours Each Day", "You May Be Wearing a Tight Bra or an Underwire" and "You May be Using Your Bra to Carry Your Cell Phone". To date, there is no scientific evidence to prove these statements and scientists have even contradicted some of these claims (American Cancer Society, 2021b; L. Chen et al., 2014; Schwarcz, 2017). It is important to highlight that the number of shares of the most popular 'fabricated content' is more than 12 times smaller than the most shared news in the sample, which is considered as 'false connection/context'.

Regarding the source of the news stories, most of the stories in the sample were published in digital media (76.73%), whereas 23.27% originated from traditional media. However, traditional media had a total of 9,113,951 shares, whereas digital media had a total of 7,075,117. The considerably higher number of shares in the content conveyed by traditional media is not in line with the literature on the subject (Sommariva et al., 2018), which is still limited.

It is believed that this may have to do with the fact that the information transmitted by traditional media, in the sample, is repeated many times identically or with little change. For example, FOX News has different websites for each region of the United States, and these often propagate the same news stories. In addition, there is also the possibility that users of social networks feel more comfortable in sharing content from traditional media, since these are better known and undergo an editorial process before being published.

4.2. Content type

The most shared “content types” in the sample of this study were “real-life stories” and “solidarity” (67.69%). This seems to indicate a public preference in relation to these themes. Another study which examined Brazilian Facebook pages about cancer shows similar findings; on most pages, content related to “Solidarity”, “Anniversaries” and “Testimonies or real-life stories” was among those with the most engagement on this social media (Biancovilli & Jurberg, 2018).

To illustrate, the most shared articles classified as “real-life story” in the sample include the following: “Loyal boyfriend who stuck with girlfriend during breast cancer proposes on her last day of chemo” (734,482 total shares), “Albuquerque Police Department paints a patrol car pink for Breast Cancer Awareness Month” (635,438 shares) and “Dad with breast cancer 'rejected from support groups because he's a man” (640,106 total shares). The most shared “solidarity” stories are “DeAngelo Williams Pays for 500 Mammograms after Mom Dies of Breast Cancer” (62,836 total shares), “North Charleston Police Department goes pink to help fight breast cancer” (61,769 total shares) and “Cape Town surgeon offers free surgery to breast cancer patients | Good News Daily” (60,829 shares). These stories focus on the routine, or intimate narratives of cancer patients, their family members, or friends. There is no informative or awareness objective regarding risk factors and prevention of breast cancer. One of the stories mentions mammography, but the text does not provide more details about who should undergo the exam, or when it should be scheduled.

It is worth mentioning the fact that, in this sample, the types of content that generated greater public engagement in the form of "total shares" (sum of shares in all social networks analysed) do not correspond to the most frequent content. That is, the seemingly most attractive content is produced on a considerably smaller scale than other content. In this sample, more than half of the content is classified as "real life story" (52.5%). However, the theme that generates the greatest engagement, in much larger numbers, is "treatment", which corresponds to only 9.7% of the total sample. In an analysis produced with Brazilian Portuguese cancer pages on Facebook (Biancovilli & Jurberg, 2018), the same trend was observed. This study investigated 16 Facebook pages, and separated them into four different groups, according to the type of profile to which they belonged (hospitals or foundations, informative, nongovernmental organizations, and personal pages). The categories that generated greater engagement were not those with the highest percentage of content. For example, in the “NGO” group of pages, the

category that generated the greatest engagement was “Anniversaries”. Nevertheless, only 5.1% of the posts fell into this category. The most frequent content in this group of pages was “Solidarity” (48% of the posts), but this category had an engagement rate 2.8 lower than “Anniversaries”.

In addition to the pertinent concern regarding the credibility of what is published on social networks, content producers about breast cancer (and health issues in general) need to be aware of the topics that generate more attention from the public. Therefore, content producers should pay attention to these standards, for example mixing "treatment" content with topics related to risk factors, prevention and early detection of breast cancer.

4.3. Mentions of breast cancer prevention and early detection/screening exams

No more than 5.08% of the articles in the sample focus on prevention, and 19.7% mention early detection. Broad literature emphasizes the importance of adopting habits that help prevent breast cancer, such as not smoking, limiting alcohol consumption, avoiding a sedentary lifestyle and maintaining a healthy weight (Britt et al., 2020; Mayo Clinic, 2021; Sauter, 2018).

It is also particularly crucial that the population is well informed about the importance of early diagnosis, including the symptoms of the disease, as screening is proven to be the most efficient way to diagnose breast cancer at an early stage, decreasing mortality rates (Cancer Research UK, 2015b). Furthermore, a study conducted in Hungary revealed most respondents were unaware of the fact that breast cancer self-examination should be initiated two decades earlier than mammography, when women turn twenty years old (Reményi Kissné et al., 2021). In this same study, it was also shown that both laywomen and screening attendees had insufficient knowledge of the signs and symptoms of breast cancer; lumps are a well-known symptom among surveyed Hungarian respondents, but only 50% of them knew that mamillar discharge can also be a warning sign.

The lack of knowledge and awareness on breast cancer is also an identified concern in a number of highly populated countries, such as Ethiopia (Getachew et al., 2020), Nigeria (Idowu et al., 2019), and Brazil (Vasconcellos-Silva et al., 2018). In Ethiopia, for instance, one of the mentioned barriers to early diagnosis of breast cancer is belief in alternative medicine and religious practices as a way of treatment. On the other hand, in Brazil there is a lack of a prevention culture for breast cancer, and low confidence in health system.

A systematic review of breast cancer screening materials on social media (Döbrössy et al., 2020) suggests there is a considerable presence of unscientific arguments shared about the topic, such as “breast cancer can be prevented by organic food” or “mammography causes breast cancer”. A study which investigated Facebook data from the United States shows that 6% of all the top links shared by users aged 35-54 are false information from a website that advocates against breast cancer screening (Huesch et al., 2017). This sort of misinformation is hazardous, as it can dissuade women from booking the screening exam.

4.4. Sentiment analysis

Regarding the sentiment analysis, the most shared news stories in the studied sample are those related to "treatment" with a positive content. Second among the most shared positive content stories is the category "educational". On the other hand, the stories with a preponderant negative sentiment that were shared the most are the “risk factors”, and in second place we can see “real-life stories”. As shown in Figure 5, the median number of shares of positive news about treatments is considerably higher than the second place, which serves as an indication of what type of content should be used as a basis for addressing topics such as early detection, symptoms, or prevention. A similar trend has been observed in previous investigations (Carrion et al., 2017; Picanço et al., 2018).

However, the present analysis partially diverges from another study that investigated what makes content go viral on the Internet. According to the results of this analysis, positive content is more viral than negative content, but virality is to some extent motivated by physiological arousal – that is, content that evokes high-arousal feelings, be them positive or negative, tend to be more viral (Berger & Milkman, 2012). Another study on video ad sharing in social media platforms revealed that “positive emotions of amusement, excitement, inspiration, and warmth positively affect sharing” (Tellis et al., 2019).

It is encouraging that the most shared news is positive, as this is the opposite sentiment that people in different countries have in relation to cancer diagnosis and treatment. A research that was conducted to identify the public perception of cancer in six countries reveals that “only 31% of general public responders were very or extremely confident in the cancer care provided by their respective health care systems” (Ramers-Verhoeven et al., 2013). Moreover, only 36% of the public respondents in Japan disagreed that a cancer diagnosis is a death sentence; but people are more optimistic in the United States, where 65% of the respondents disagree with this. Nevertheless, a study conducted in a university in London, UK, revealed that almost all

respondents relate cancer to pain, death and fear (Robb et al., 2014); the same trend was observed in a study organized in Brazil (INCA, 2007). In the UK, however, participants mentioned that advances in cancer treatment in recent years have considerably improved the quality of life of patients, who can even live normal lives.

4.5. Mentions of prevention, early detection, symptoms, risk factors, scientific paper or specialist quotes

In the sample, 94.92% of the news stories do not address prevention, 80.3% do not mention early detection, 84.94% do not mention symptoms, 85.7% do not refer to risk factors and 68.69% do not quote a specialist or link a scientific paper. As if that were not enough, part of the content that mentions these themes is not backed by science, which can give rise to risky behaviour or refusal to conventional medicine. Literature on health misinformation in social media identifies a considerable amount of vaccine and cancer-related false information, including unproven natural cures for cancer and other diseases (Poulose, 2021). An investigation conducted in 2019 reveals that cancer was the most popular topic of health misinformation online that year, with many articles citing marijuana as a natural way of curing cancer (which is unproven by science); moreover, an article that was engaged more than 800 thousand times is entitled “Ginger is 10,000x more effective at killing cancer than chemo”, another unscientific claim (Zadrozny, 2019).

A study dedicated to analyse breast cancer screening content on Twitter reveals that publications frequently contain claims that are false, “not explicitly backed by scientific evidence, and in favour of alternative “natural” breast cancer prevention and treatment” (Nastasi et al., 2018).

In the studied sample, one example of misleading content with a specialist quote is the story entitled: “‘It’s Empowering’: Surgeon Kristi Funk on Diet and Reducing Breast Cancer Risk”. The following quote was found: “Far and away, No. 1 is cruciferous vegetables and leafy greens. Cruciferous vegetables are really highly effective in killing breast cancer.” Although it is known that a diet rich in vegetables and leafy greens is healthy, saying that a particular food group directly kills breast cancer is wrong, sensationalist and may open room for misinterpretation. That is, some people may believe that chemotherapy or other therapies are not necessary to cure the disease.

The same type of misinformation was found in the news story entitled “Eating Mushrooms Is A Delicious And Healthy Way Of Fighting Breast Cancer”. This story is not entirely false as

there are studies indicating that dietary mushrooms intake decreased breast cancer risk in pre- and postmenopausal women (Hong et al., 2008; Zhang et al., 2009). However, this title again leaves room for misinterpretation, as it may imply that conventional therapies for the treatment of breast cancer are not necessary.

The most shared (n=71,739) verified story which mentions a risk factor and quotes a specialist is “One cup of milk per day associated with up to 50 per cent increase in breast cancer risk: study”. This story links an observational study published at the International Journal of Epidemiology in February 2020 (Fraser et al., 2020), which concludes that “higher intakes of dairy milk were associated with greater risk of breast cancer, when adjusted for soy intake”.

Another good example with a considerable amount of shares (n=24,441) is the story “Breast Cancer Mortality Rate Continues to Drop”. It mentions a report from the American Cancer Society which reveals that the death rate for breast cancer has continued to decline in the United States in 2019 (DeSantis et al., 2019). The story quotes Carol DeSantis, lead author of the report, which explains and summarizes the main findings.

In efforts to combat misinformation, it is essential that there is a greater participation of health professionals and communicators committed to the dissemination of real science on social networks. On March 11, 2020, the World Health Organization declared the novel coronavirus (COVID-19) outbreak a global pandemic (Cucinotta & Vanelli, 2020). Since then, another challenge that emerged is the *infodemic risk*, which means a huge amount of information about the topic, including evidence-based, misleading and completely false information (Biancovilli, Makszin, & Jurberg, 2021). With this enormous amount of information circulating daily in all the media, it can be difficult for the non-health-specialized population to distinguish which information is backed by science and which should be discarded. One of the main consequences of this *infodemic* in 2021 is COVID-19 vaccine hesitancy, and this problem seriously affect highly populated countries, such as the United States (Pierri et al., 2021) and India (Wagner et al., 2021). This is why it is of fundamental importance to join efforts to tackle misinformation, and some initiatives used against the anti-vaccine discourse in the COVID-19 pandemic can be applied in other areas. A study from Poland (Rzymyski et al., 2021) suggest a series of actions, such as continuously communicate science to the general public, tracking and combating misinformation, and equipping celebrities and politicians with accurate, evidence-based information about the vaccine, so that they can be allies of science.

Other studies on false information show that this is a problem that should be in the sights of public health policies. An investigation done on Pinterest analysed 797 posts and found that 11.4% of the total sample contains some type of misinformation about breast cancer prevention or treatment (Wilner & Holton, 2020). Another study on HPV vaccination in the United States reveals that social media messages have a crucial ability to influence HPV vaccination rates, positively or negatively (Teoh, 2019). Finally, an observational study dedicated to analyse content related to dermatology in social media shows us that 44.7% of the shared content was rated as imprecise, 20% as confusing, and 35.3% as precise (Iglesias-Puzas et al., 2021). Misinformation is an overarching issue that exists across different social media, the Internet and broadcasting media.

4.6. Celebrity presence

It is worth mentioning the fact that, in the studied sample, most stories involving a celebrity have negative sentiment (53%). In contrast, in stories that do not mention celebrities, this number is much lower (19.7%). As mentioned earlier, the most shared theme in the sample is related to treatment, with a positive sentiment. Messages and posts that generate positive feelings in the audience tend to be more popular on social media. Therefore, an improvement in this regard could include the more frequent use of celebrities to address topics considered optimistic, such as treatments, latest developments in science, or real stories of hope and motivation, just to name a few examples.

A good example found in the sample is the article titled “Angelina Jolie’s Doctor Launches Pro-Vegan Breast Cancer Awareness Campaign”. It mentions a worldwide famous celebrity, the North-American actress Angelina Jolie, quotes a specialist, which is her breast cancer doctor, has a positive sentiment by mentioning good, evidence-based ways to prevent breast cancer: “Healthful foods from plants (vegetables, fruits, whole grains, and beans) lower breast cancer risk in several ways. They help with weight loss, because they are typically low in calories and high in appetite-taming fiber. In addition, high-fiber, low-fat diets can help you gently reduce estrogen levels. In turn, lower estrogen levels can lower your risk of cancer. Plant-based foods are packed with nutrition, and plant-based diets can reduce the risk of multiple diseases. Even so, you’ll want to ensure you get complete nutrition. To do that, include a variety of vegetables, fruits, whole grains and beans in your routine. And be sure to have a reliable source of vitamin B12 daily, such as a simple B12 supplement.”

Recent large-scale studies have verified the effectiveness of a number of strategies to prevent breast cancer, such as low-energy density diets, highly nutritious plant-based regimes, physical activity, and body/abdominal adiposity management (Chang et al., 2017; Penniecook-Sawyers et al., 2016; Shapira, 2017).

Angelina Jolie received media attention in 2013 when she underwent a preventive double mastectomy when she discovered she had the BRCA1 gene, which increases her risk of breast and ovarian cancer. This has triggered all over the world the so-called “Angeline Jolie effect”, which means that by that time the demand for BRCA 1/2 testing increased exponentially, and more women opted for the same type of preventive surgery to reduce the risk of developing breast cancer (Schnipper, 2021). This is just one example of the power that world-renowned celebrities have in influencing health decisions. It is not to imply that the case of Angelina Jolie is absolutely positive, after all it is not a common practice to take a family history of cancer in primary care (Evans et al., 2014), and there is no medical consensus on the usefulness of this surgery (Annadurai et al., 2017).

Nevertheless, numerous studies have shown that the diagnosis of a celebrity with cancer greatly increases public interest in the topic. For instance, in 2011 the Brazilian actor Reynaldo Gianecchini was diagnosed with lymphoma. When his diagnosis was made public, there was a sudden and massive rise in searches for the terms ‘Gianecchini’ and ‘linfoma’ (lymphoma in Portuguese) in Google Brazil, as mentioned in a study about the case (Biancovilli et al., 2015). However, this same study shows that the media gave more attention to the celebrity itself, and did not alert the population sufficiently about the symptoms, risk factors and the development of the disease. It is believed that these cases of celebrities diagnosed with cancer can be used as a hook to raise awareness about prevention, symptoms, types of treatment, risk factors and early detection.

Another example that was investigated by science communicators was the breast cancer diagnosis of the Australian singer Kylie Minogue in 2005. At the time, the singer was at the height of her fame and was only 36 years old, which generated even more commotion; her diagnosis generated the so-called "Kylie effect" in Australia, which is a 40% increase in appointment bookings for mammograms in the two weeks after the diagnosis, plus a 101% increase in mammograms for previously unscreened women in the eligible age group of 40–69 years (S. Chapman et al., 2005). A similar effect was also observed in the United Kingdom (Twine et al., 2006). In Australia, the media made a point of emphasizing the importance of

early detection of breast cancer to save lives, which was the case of the artist — journalists emphasized explicitly that vigilance and mammograms were relevant for all women (S. Chapman et al., 2005).

Unlike the case study in question, this news story sample barely addresses early detection/screening exams at the same time as mentioning celebrities. Only 27 (1.69%) out of 1595 news stories do so. One example is the story “Journalist diagnosed with breast cancer while getting mammogram on Facebook Live” (3736 total shares), which tells the case of the North-American journalist Ali Meyer. The article tells her story and is also informative. Some of its excerpts: “Ali's official diagnosis was non-invasive ductal breast cancer. Luckily, it is one of the most survivable forms of breast cancer,” and “Ali reiterates, ‘My surgical options, my recovery, and my outcome were all better because my mammogram found the cancer before I even knew it was there.’ That is the importance of getting your routine mammogram.” We consider this a good example that should be replicated more often.

Another good example is the story “Former NFL star DeAngelo Williams sponsors over 500 mammograms, honors mom who died of breast cancer” (1849 shares). One excerpt says: “Former NFL Pittsburgh Steelers running back DeAngelo Williams’ foundation has sponsored more than 500 mammograms since 2015 to honor his mother who died of breast cancer. The football star began covering the mammogram screenings for women in 2015 through The DeAngelo Williams Foundation, which has sponsored “well over 500 mammograms and have no plans of stopping!” the foundation said in a Facebook post Wednesday.” Although the text does not explain exactly how a mammogram is performed and who should undergo this examination, the mere fact that a celebrity cites the breast cancer screening exam can instigate curiosity in the public to seek more information. However, the ideal would be for the text to already contain more detailed information about it.

4.7. Pink October – Breast Cancer Awareness Month

Some important changes in the content released in October were noted, when compared to other months of the year. As mentioned in the results section, there is a considerable increase in news stories whose focus is solidarity (28.4% in October and 9.3% in other months). There is also an increase in stories whose credibility is considered "verified" (69.8% in October x 53.3% in other months).

On the other hand, there is a significant decrease in stories that are more likely to generate some kind of awareness about the importance of prevention and early detection of breast

cancer. For example, the frequency of news stories about risk factors considerably decreased in October (3.6% x 13.1% in other months). There was also a slight decrease in educational topics, although the opposite was expected to happen. A study conducted in Brazil (Vasconcellos-Silva et al., 2017) observed that there is a significant increment in searches on Google for the terms “breast cancer” and “mammography” (more than 100%) during Pink October awareness month. In Malaysia, the same trend was detected (Mohamad & Kok, 2019).

A study of Twitter usage during awareness month in the United States showed that posts from celebrities were more prominent (in the form of impressions) than posts from anonymous users, and the majority of tweets did not promote any specific preventive behavior (Thackeray et al., 2013). Another investigation conducted in the United States observed that, from January 2004 to December 2009, there was a consistent increase of online activity related to breast cancer, and the October campaign stimulates online activity more effectively than equivalent campaigns for other types of cancer, such as prostate or lung (Glynn et al., 2011).

Social media have an important impact as an education and awareness tool. Moreover, the number of active users on social networks around the world does not stop growing. According to Statista (2020), there were 2.86 billion social network users worldwide in 2017; in 2021, this number raised to 3.78 billion and it will likely reach 4.41 billion in 2025.

This is why it is of great importance to improve the quality of content related to breast cancer during the Pink October. It is necessary to produce more content on preventive behavior and also on topics with a positive sentiment that tend to generate a greater number of shares, according to the sample (table 5): treatment, educational, technology and real-life story.

4.8. Questionnaire discussion

The main objective of this questionnaire is to understand if health professionals working in Hungary with cancer research use social media to consume or produce information about breast cancer, and what they think about the quality of the material found. In addition, their opinions on how to deal with patient misinformation wanted to be heard, and how to improve the health literacy of the lay population about breast cancer.

In the analysed sample, the vast majority of respondents use the Internet to search for news about breast cancer, mainly scientific journals and health databases. The breast cancer topics that researchers recall reading most recently revolve around “treatments” and “real-life stories”. In the sample of news stories, more than half were categorized as "real-life stories"

(52.5%) and stories about "treatments" represent 9.7% of the total. However, when analysing the stories with the highest number of shares (Table 2), a different phenomenon is perceived. Eight of the 20 most shared stories are about "treatments" and 10 are about "real-life stories". Such a result indicates two possibilities: stories that narrate real lives tend to attract more attention and remain in memory longer, or the fact that most news stories produced by the media deal with real lives can also make people naturally remember these themes. The same phenomenon, in a slightly smaller proportion, happens in relation to news stories that address treatments.

When it comes to knowing online science communicators who address the topic of breast cancer, the results differ. Most respondents (69.2%) cannot recall any of them. Among those who know people or institutions that carry out this work, the highest rating was given to those who use Facebook (average=8), followed by YouTube (average=7.8). These ratings coincide exactly with the social media with the highest number of active users in the world. First is Facebook (2.895 billion users) and second is YouTube (2.291 billion users) (Statista, 2021g). This is positive, as it may indicate that the most popular social media are also those chosen by the most efficient health communicators.

Furthermore, in the sample, just under half of the respondents (46.2%) have already used social media to develop science dissemination work. Among those, most used Facebook (38.9%) and YouTube (16.7%) as platforms. Two respondents mentioned they have already used social media to communicate about early detection of breast cancer, and one mentioned cancer prevention. In the sample of news stories, 5.08% of the stories comment on prevention and 19.7% mention early detection. That is, the same trend of low frequency of this type of content was observed in both investigations.

These results may help to justify the main complaint of health professionals who responded to the survey regarding the health literacy of their patients ("no knowledge on prevention", 50%; "No knowledge on symptoms", 42.9%; and "No knowledge on screening", 21.4%). A stronger presence of health professionals on the Internet and social media is of fundamental importance to counter the spread of health misinformation and, at the same time, increase the quality of the content that circulates among users.

A study on the social media use by physicians (Campbell et al., 2016) shows that a considerable number of professionals claim they do not have time to use social networks and produce content regularly, as this would affect their work with patient care. Moreover, others expressed

uncertainty about their potential impact and repercussions, and are not sure whether it is a duty of all physicians to provide health information online. “While some participants were insistent that more physicians should be involved, most were equivocal, stating that physicians should only participate if they feel they would enjoy it and are equipped to do so.” (Campbell et al., 2016, results section).

The respondents of the survey seem to agree on the importance of a wider use of media (including social media) to communicate with the lay population and cancer patients (as 41.7% of the answers to the question “In your opinion, what can be done to increase people’s awareness of the importance of prevention + early detection of breast cancer” mention “dissemination in media” as a suggested solution. The topics “education” and “awareness campaigns”, which were mentioned 58.3% and 22.2% respectively are also partially related to the use of social media, as it is one of the possible ways to make educational or awareness campaigns reach more people.

A survey conducted with breast cancer patients showed that more than 50% of respondents have unmet information needs (Schmidt et al., 2016), even though they are in continuous contact with doctors, social service workers, gynaecologists and other healthcare professionals. Most of the unanswered questions are about coping with long-term side effects, follow-up care after acute treatment, and heredity of breast cancer. The reasons for this gap in doctor-patient communication are not entirely clear, but this may motivate patients to seek information about their diagnosis and queries on the Internet and social media. Another study, also with breast cancer patients (Kugbey et al., 2019), showed that access to health information improve quality of life of breast cancer patients, by reducing anxiety and depression levels. The presence of false and misleading information online, therefore, must be considered a problem with a high level of importance.

In the survey, the health literacy score of breast cancer patients was relatively low (average=4,68; median=4), which converges with the scientific literature in the area. “Poor knowledge about breast cancer is known as a main issue for breast cancer screening barriers, delayed treatment, and thus contributes to the high morbidity and mortality rates.” (Rakhshkhorshid et al., 2018).

In a study carried out in the context of the COVID-19 pandemic, which measured and crossed levels of health literacy, mental health and compliance with COVID-19 preventive measures, it was observed that people with higher levels of health literacy suffered less from anxiety,

problems of sleep and depression (Hermans et al., 2021). This relationship has already been observed in other investigations (H. C. Nguyen et al., 2020; H. T. Nguyen et al., 2020).

5. Conclusions

The content analysis of news stories on social networks revealed that, although the volume of verified, evidence-based content is moderately greater in the sample than misinformation, unscientific articles are shared 3.29 times more, on average. No more than 31.31% of the news stories mention scientific papers or quote a specialist. Moreover, 69.7% of the sample have not been classified according to credibility. This is because these news items do not address science, risk factors, prevention, treatment or other aspects, which can be assessed for scientific accuracy.

A greater presence of these themes in online narratives about breast cancer is needed, whether inside or outside social media, to inform the population about treatments, symptoms and early detection in an adequate and consistent way. For this objective to be achieved, it is of fundamental importance that health professionals and science journalists with knowledge in the health area produce scientifically correct and reliable content on social media, dialoguing not only with cancer patients and their families but also with the general population.

Most of the sample is made up of news stories within the themes 'real-life story' (52.5%) and 'solidarity' (15.2%). Furthermore, stories about 'treatment' generated more engagement in the form of shares than any other topics, despite being only 9.7% of the sample. As the cut is composed of the stories with the most shares in a one-year period, it is implied that these are the topics that attract more attention from the general public. It would be interesting, for example, to include information on prevention and early diagnosis in stories of these types. After all, only 5.08% of the stories in the sample comment on prevention and 19.7% mention early detection, including mammography. The same should be done during the Breast Cancer Awareness Month, when there is an increase in internet searches on the topic.

Regarding the questionnaire aimed at health professionals working with cancer in Hungary, it was observed that most of them use the Internet to search for content about science and breast cancer. On the other hand, less than half have already produced any scientific content on social media. Respondents seemed to agree on the importance of a wider use of media (including social media) to communicate with the lay population and cancer patients, and a need for further education on the subject was mentioned repeatedly.

During the COVID-19 pandemic, several studies that address the health literacy of the population and what are the advantages of greater medical knowledge were published. They reveal that higher health literacy is related with lower rates of anxiety and depression. Most

likely, the same relationship can be extended to breast cancer patients as well. Knowing better the biology of the disease, treatments, side effects, among other topics, would help people to better deal with the diagnosis. This type of information is also important for the general population, as if they or a friend/family member are diagnosed with the disease in the future, access to reliable information will help them deal with the treatment in the best possible way.

6. Limitations

This study has some limitations that must be addressed. Firstly, in the content analysis, the limited number of investigated news stories should be noted, as there were not enough resources to analyse qualitatively thousands of articles whilst keeping the quality of the process. Because of this, there is no way of knowing whether the result of the content analysis of the entire corpus will be the same as the analysis of the sample selected for this study. Secondly, is the fact that the sample is limited to news stories in English. If other languages were analysed, variations in the topics covered and in the credibility of the news might have been encountered. Consequently, most likely it is not possible to generalize the results observed in this article to all languages and cultural settings. In addition, we did not analyse social media content in Hungarian, due to the lack of proficiency in the language of the author of this thesis. This fact makes the comparison between the analyses of news stories in English and the responses of health professionals working in Hungary slightly less accurate.

Regarding the questionnaire, an important limitation is the low number of respondents and the fact that it is a convenience sample, which makes the sample non-representative. One factor that affected the outcome of this part of the research was the outbreak of the COVID-19 pandemic, as access to hospitals for direct communication with healthcare professionals became impossible for many months. Another factor is the difficulty, already reported in the literature (Gruppen, 2007), in obtaining sample sizes in the medical field that are generalizable and have statistical power. In the case of this research, the fact that the questionnaire was produced in English was another possible limiting factor for obtaining more answers. A potential solution would be to expand the data collection time, so that it is possible to include the largest possible number of participants and increase the representativeness of the sample.

Nevertheless, the findings of this study may be beneficial to assist in the development of online health communication strategies in breast cancer. Doctors, scientists, and health journalists can develop the dialogue with the lay audience on the topic, countering online misinformation.

7. Further perspectives

Future directions for the development of this investigation may include:

- Production of content for social media on breast cancer according to the results measured in this investigation. This includes but is not limited to a greater presence of content on prevention and early detection, created by experts from reliable sources, in news stories that narrate "real-life stories" and "solidarity"; production of content that addresses the same themes, using celebrities in positive contexts.
- Another path involves the analysis of breast cancer news stories, using the same methodology, in a different time frame. In this way, it will be possible to compare the two periods and measure similarities and differences.
- It is interesting to analyse online content about breast cancer in other languages and cultural settings, so that the results and consequent communication interventions in social media are tailored according to each environment.
- The continuity of research with health professionals in Hungary is of paramount importance, so that the sample becomes more representative. One possible way is to conduct interviews with these experts, followed by a qualitative analysis of their responses.
- A possible path also includes the elaboration of comparative studies with online materials from different medical fields or different areas of science.

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List of Publications

Article related to the thesis

Biancovilli, P., Makszin, L., Amer, F., & Csongor, A. (2022). Celebrities and Breast Cancer: A Multidimensional Quali-Quantitative Analysis of News Stories Shared on Social Media. *International journal of environmental research and public health*, 19(15), 9676. <https://doi.org/10.3390/ijerph19159676>

Biancovilli, P., Makszin, L., & Csongor, A. (2021). Breast cancer on social media: A qualitative study on the credibility and content type of the most shared news stories. *BMC Women's Health*, 21(1), 202. <https://doi.org/10.1186/s12905-021-01352-y>

Additional articles

Biancovilli, P., de Oliveira, E. M., Thomer, L., & Jurberg, C. (2022). Social support and positivity: Analyzing user-generated comments on the Instagram pages of two Brazilian cancer hospitals. *Journal of Media and Communication Studies*, 14(2), 44-52. <https://doi.org/10.5897/JMCS2022.0769>

Biancovilli, P., Makszin, L., & Jurberg, C. (2021). Misinformation on social networks during the novel coronavirus pandemic: A qualitative case study of Brazil. *BMC Public Health*, 21(1), 1200. <https://doi.org/10.1186/s12889-021-11165-1>

Biancovilli, P., & Jurberg, C. (2020). *When governments spread lies, the fight is against two viruses: A study on the novel coronavirus pandemic in Brazil* [Preprint]. Public and Global Health. <https://doi.org/10.1101/2020.10.20.20215962>

Biancovilli, P., & Jurberg, C. (2018). How to Optimize Health Messages About Cancer on Facebook: Mixed-Methods Study. *JMIR Cancer*, 4(2), e11073. <https://doi.org/10.2196/11073>

Conference presentations

Biancovilli, P., Csongor, A. (2021, November). Hungarian doctors, health professionals and cancer researchers' attitudes towards online health communication on breast cancer. Poster presentation at the Magyar Onkológusok Társasága (MOT) XXXIV. Kongresszusa, Szeged, Hungary.

Biancovilli, P., Csongor, A. (2020, October). Breast cancer and social networks: analysis of the credibility of the most shared content on Facebook and Twitter. Oral presentation at XXIII. Tavaszi Szél Konferencia 2020, Budapest, Hungary.

Biancovilli, P.; Csongor, A. (2019, November). Breast cancer cure and fake news: an analysis of content shared on social network sites. Poster session presented at MEDPécs (Medical Conference for PhD Students and Experts of Clinical Sciences), Pécs, Hungary.

Biancovilli, P. Csongor, A. (2019, September). Spreading reliable information on social networks: how can health educators counteract fake news about breast cancer. Oral presentation at Arguing Health Communication in the Digital Era #healthsci19, Brescia, Italy.

Biancovilli, P.; Jurberg, C. (2019, May). How to optimize health messages about cancer on Facebook. Poster session presented at 8th Interdisciplinary Doctoral Conference (IDK 2019), Pécs, Hungary.

Appendix

List of tables

Table 1. Ten most incident cancers and number of deaths worldwide in 2020 (the percentage refers to all 36 measured cancer sites)	7
Table 2. List of the five countries with the highest cancer incidence and highest mortality rates in 2020 (number of cases per 100,000 people)	8
Table 3. Social media with the largest number of active users worldwide in October 2021... 15	
Table 4. Facebook fan pages with the largest number of followers as of June 2021	16
Table 5. Instagram accounts with the highest number of followers as of July 2021	17
Table 6. Coding manual, comprising the coding schedule (the column headings indicate the dimensions to be coded) and its categories	27
Table 7. Top 20 most popular news stories related to breast cancer (measured by total shares in social networking sites), its credibility and content type, between June 2019 and June 2020	35
Table 8. Percentage of news stories that mention prevention and early detection, according to the content type	39
Table 9. Number of news stories that address breast cancer prevention, separated according to the credibility of the content.	40
Table 10. Number of news stories that mention how to detect early-stage breast cancer and/or address screening exams, separated according to the credibility of the content.....	40
Table 11. Relationship between content type and mentions of breast cancer symptoms in the studied sample.....	42
Table 12. Relationship between content type and mentions of breast cancer risk factors in the studied sample.....	43
Table 13. Relationship between content type and mentions of scientific paper/specialist quote in the sample.	44
Table 14. Relationship between content credibility and mentions of scientific paper/specialist quote in the sample.	44
Table 15. Celebrity presence in the sample according to content type.....	45

Table 16. Celebrity presence in the sample according to the source of news	45
Table 17. Celebrity presence in the sample according to type of rumour and sentiment	46
Table 18. Relationship between celebrity presence and mention of risk factors for breast cancer in the sample of news stories.	46
Table 19. Relationship between stories that mention celebrity and early detection/screening of breast cancer.....	47
Table 20. Comparison between October (BCAM) and other months in relation to content type.	47
Table 21. Comparison between October (BCAM) and other months in relation to the type of rumour.....	49
Table 22. Comparison between October (Breast Cancer Awareness Month) and other months in relation to content credibility.....	49
Table 23. Socio-demographic characteristics of the questionnaire respondents (n=39)	50
Table 24. What health professionals remember reading most recently on social media about breast cancer, organized according to themes.....	52
Table 25. How respondents rate the work of breast cancer health communicators on social media (from 0 to 10), according to the social media.	52
Table 26. Communication platforms mentioned by respondents who declared that they had already worked with science dissemination.....	53
Table 27. Full description of the answers to the question “How do you assess patients' health literacy in relation to breast cancer?”.....	55
Table 28. Justifications for the grade given to the health literacy of patients in relation to breast cancer, grouped by theme.	55
Table 29. Responses given to the answer „In your opinion, what can be done to increase people's awareness of the importance of prevention + early detection of breast cancer?” grouped into themes.....	56

List of figures

Figure 1. Mean of total shares of content classified as ‘verified’ and ‘rumours’ both in traditional and digital media.37

Figure 2. Percentage of news stories per content type.....38

Figure 3. Average shares according to content type in the sample.....39

Figure 4. Proportion of sentiments in the analysed sample (n=1,594).41

Figure 5. Mean of total shares of all types of content in the studied sample, in relation to sentiment.42

Figure 6. Word cloud that shows all the answers given to the question "Which online news pages do you use to get information related to breast cancer?". The larger the font size of the response, the more frequently that response was cited.51

Ethical approval



1

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HATÁROZAT

A(z) Pécsi Tudományegyetem Egészségtudományi Doktori Iskola, mint megbízó (7621 Pécs Vörösmarty M. u 4.) képviseletében Priscila Biancovilli, Szántóné Dr. Csongor Alexandra (7621 Pécs Vörösmarty M. u 4.) (továbbiakban: Kérelmezők) "Megbízható információk a közösségi oldalakon: az egészségnevelés szerepe az emlőrákkal kapcsolatos téves információk kezelésében" című, beavatkozással nem járó vizsgálat engedélyezése iránt kérelmet nyújtottak be az Egészségügyi Tudományos Tanács Tudományos és Kutatásetikai Bizottságához (az ETT TUKEB-hez).

Az ETT TUKEB, mint **elsőfokú** hatóság, a vizsgálat engedélyezése iránti kérelmet megvizsgálta és a következő, testületi véleményen alapuló döntést hozta:

Az ETT TUKEB a benyújtott kérelem szerinti, beavatkozással nem járó vizsgálatra

a szakmai-etikai engedélyt megadja.

Az eljárás során eljárási költség nem merült fel tekintettel arra, hogy a kérelmezett vizsgálat nem kereskedelmi vizsgálat.

A Bizottság döntése ellen a közlést követő 15 napon belül van helye fellebbezésnek az ETT Elnökségéhez. A fellebbezést az ETT TUKEB-hez kell benyújtani.

A fellebbezési eljárás illeték- és díjmentes.

INDOKOLÁS

A Kérelmezők "Megbízható információk a közösségi oldalakon: az egészségnevelés szerepe az emlőrákkal kapcsolatos téves információk kezelésében" című, beavatkozással nem járó vizsgálat engedélyezése iránt kérelmet nyújtottak be ETT TUKEB-hez, ami 2020. október 15-én érkezett meg a Bizottsághoz.

Az eljárás megindult és az ETT TUKEB az általános közigazgatási rendtartásról szóló 2016. évi CL. törvény (továbbiakban: *Ákr.*) 43.§ (1) bekezdésében foglalt intézkedéseket mellőzte, és tekintettel arra, hogy a teljes eljárás feltételei fennállnak, a Bizottság a kérelmet az *ÁKR* 43 §-a alapján teljes

Ügyiratszám: IV/9147-1/2020/EKU

eljárásban bírálta el. Az ETT TUKEB az ÁKR 43 § (2) bekezdése alapján 2020. október 23-án erről és az ÁKR 43 § (2) bekezdésében meghatározott egyéb tényekről tájékoztatta a Kérelmezőket.

Az eljárás során az ETT TUKEB megvizsgálta és megtárgyalta a kérelmet és a csatolt dokumentumokat.

A tervezett, beavatkozással nem járó vizsgálat azonosító adatai:

A vizsgálat címe:

"Megbízható információk a közösségi oldalakon: az egészségnevelés szerepe az emlőrákkal kapcsolatos téves információk kezelésében"

Kutatásvezető, aki az egész vizsgálatot vezeti: Priscila Biancovilli, Szántóné Dr. Csongor Alexandra
Kutatásvezetők munkahelye: Pécsi Tudományegyetem Egészségtudományi Doktori Iskola

Megbízó neve és címe:

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7621 Pécs, Vörösmarty M. u 4.

A vizsgálat tervezett időtartama: 2020.11.01 - 2021.07.31

A vizsgálatban részt vevő vizsgálóhelyek felsorolása, valamint az adott vizsgálóhelyen a vizsgálat vezetője: -

Az ETT TUKEB a kutatási engedély iránti kérelemről *az emberen végzett orvostudományi kutatások, az emberi felhasználásra kerülő vizsgálati készítmények klinikai vizsgálata, valamint az emberen történő alkalmazásra szolgáló, klinikai vizsgálatra szánt orvostechnikai eszközök klinikai vizsgálata engedélyezési eljárásának szabályairól szóló 235/2009. (X. 20.) Korm. rendelet (a továbbiakban: 235/2009. Korm. rendelet) 18. § (2) bekezdése alapján a következőket állapította meg:*

a) A beadott kérelem tárgyául szolgáló vizsgálat valóban beavatkozással nem járó vizsgálat-e?
Igen

b1) A tervezett vizsgálat érdemi, szakmai tudományos kérdésfelvetéseket tartalmaz-e?
Igen

b2) A tervezett vizsgálat módszerei alkalmasak-e az érdemi, szakmai tudományos kérdésfelvetések megválaszolására?
Igen

c1) A betegtájékoztató és a belegyező nyilatkozat tervezett szövege megfelel-e az emberen végzett orvostudományi kutatásokról szóló miniszteri rendeletben foglaltaknak?
Igen

c2) A toborzás tervezett szövege megfelel-e az emberen végzett orvostudományi kutatásokról szóló miniszteri rendeletben foglaltaknak?
Igen

Mindezek alapján az ETT TUKEB a rendelkező résznek megfelelően határozott, és engedélyezte a kutatási engedély iránti kérelemben megjelölt beavatkozással nem járó vizsgálatot.

Felhívjuk a Kérelmezők figyelmét arra a jogszabályi kötelezettségére, mely szerint a beavatkozással nem járó vizsgálat befejezését követő kilencven napon belül értesíteniük kell az ETT TUKEB-et a vizsgálat befejezéséről, a bevont betegek számáról, illetve köréről, továbbá a vizsgálat befejezését

Ügyiratszám: IV/9147-2/2020/EKU

követő százyolcvan napon belül értesíteniük kell az ETT TUKEB-et a vizsgálat célkitűzésére adott válasziról. (Ezt az előírást az *emeren végzett orvostudományi kutatásokról szóló 23/2002. (V. 9.) EüM rendelet* (továbbiakban: *23/2002. (V. 9.) EüM rendelet*) 20/O. § tartalmazza.)

Kérjük, amennyiben a beavatkozással nem járó vizsgálat nem kezdődik el, vagy idő előtt lezárásra kerül, akkor erről - az indokok felsorolásával - e-mailen és levélben is tájékoztassák az ETT TUKEB-et. (Ezt a *235/2009. Korm. rendelet* 21. § (3) bekezdése írja elő.)

Az ETT TUKEB eljárása és határozata elsősorban az *egészségügyről szóló 1997. évi CLIV. törvény* (továbbiakban: *Eütv.*) 164/A. § (1) és (2).bekezdésein, a *235/2009. (X. 20.) Korm. rendelet* 17/A. § (1) - (4), a 18. § (1) és (2) bekezdésein, valamint a a 80. § (1) bekezdésén és az *Ákr.* 81. § (1) és (4) bekezdésein alapul.

A kutatás engedélyezési eljárásokban az *Eütv.* 164/B. § kimondja "Az orvostudományi kutatás, valamint a 164/A. § szerinti beavatkozással nem járó vizsgálat engedélyezési eljárásáért - az egészségügyért felelős miniszternek az adópolitikáért felelős miniszterrel egyetértésben kiadott rendeletében meghatározott - igazgatási szolgáltatási díjat kell fizetni."

A kérelemben foglaltak alapján az ETT TUKEB megállapította, hogy a tervezett kutatás nem kereskedelmi vizsgálat a *23/2002. EüM. rend.* 20/B. § f) pontja alapján, ezért a Kérelmezőknek eljárási költsége, és így igazgatási szolgáltatási díj fizetési kötelezettsége sem keletkezett a *23/2002. EüM. rend.* 15. §-a és 20/R. § (1) bekezdése szerint.

A Bizottság hatásköre és illetékessége az *Eütv.* 164/A. § (2) bekezdésén, valamint *235/2009. Korm. rend.* 16. § a) pontján, a 17. § (1) bek. a) pontja ab) alpontján alapul.

A fellebbezés lehetőségét az *Ákr.* 116. § (1) bekezdésének megfelelően az *Eütv.* 164/A. § (2) bekezdése mondja ki, mely szerint "A (3) és (5) bekezdésben nem említett beavatkozással nem járó vizsgálat esetében a szakmai-etikai engedélyről az emeren végzett orvostudományi kutatásokról szóló kormányrendelet szerinti kutatás-etikai bizottság a kérelem megérkezését követő naptól számított negyvenöt napon belül dönt. A döntés ellen fellebbezésnek van helye, a másodfokú eljárást az ETT elnöksége folytatja le."

A fellebbezési eljárás illetékmentességét az *illetékekről szóló 1990. évi XCIII. Törvény* 67. § (3)-(5) bekezdései alapján a *23/2002. EüM. rend.* 15. §-a és 20/R. § (1) bekezdése mondja ki, tekintettel arra, hogy a kérelmezett kutatás nem kereskedelmi vizsgálat a *23/2002. EüM. rend.* 20/B. § f) pontja alapján.

A fellebbezés előterjesztésére az *Ákr.* 118. § (3) bekezdése vonatkozik.

Budapest, 2020. november 3.

P.H.

Dr. Schaff Zsuzsa
akadémikus, egyetemi tanár,
az ETT TUKEB elnöke



Kapják:

- 1./ Kutatásvezető
- 2./ Intézetvezető
- 3./ Intézményvezető
- 4./ Irattár

Ügyiratszám: IV/9147-1/2020/EKU

Questionnaire - Hungarian doctors, health professionals and cancer researchers' attitudes towards online health communication on breast cancer

You are invited to participate in a research study titled "Hungarian doctors and cancer researchers' attitudes towards online health communication". This study is being conducted by Dr. Alexandra Csongor and Priscila Biancovilli, from the Doctoral School of Health Sciences, University of Pécs, Hungary. The purpose of this study is to identify how Hungarian doctors, health professionals and researchers on cancer use social networks to consume and produce information on health and breast cancer. If you agree to take part in this study, please complete the online survey that follows. It will take you approximately 10 minutes to complete. The results of this investigation will help researchers understand how to use social networks as a more efficient and engaging health communication tool among scientists, journalists, doctors and the lay population. There are no specific risks identified with this research. The researchers will take all necessary steps to ensure that personally identifiable information is kept confidential. The results of this study may be used in reports, presentations, and publications; however, participants will remain anonymous and the research will not identify them in any situation. Participation in this project is voluntary, and refusal to participate or withdraw from participation at any time during the project will involve no penalty or loss of benefits to which the subject may be otherwise entitled. If you have any questions about this project, you can contact Priscila Biancovilli at biancovilli.priscila@etk.pte.hu or Dr. Alexandra Csongor at alexandra.csongor@aok.pte.hu.

I accept to undertake the survey.

I don't accept it.

(Questions marked with * are required)

Socio-demographic information

1. What is your age? *

18-30

31-40

41-50

51-60

61-70

above 71

I prefer not to answer

2. Nationality*

Hungarian

Other

I prefer not to answer

3. Gender*

Female

Male

I prefer not to answer

4. Highest degree*

Bachelors

Masters
PhD
I prefer not to answer
Other:

5. Specialty (if applicable)

Open answer

6. Marital status*

Single
Married
Divorced
I prefer not to answer
Other:

7. Where do you work (county)?*

Budapest or Pest
Baranya
Csongrád-Csanád
Hajdú-Bihar
Borsod-Abaúj-Zemplén
Heves
Nógrád
Jász-Nagykun-Szolnok
Szabolcs-Szatmár-Bereg
Bács-Kiskun
Békés
Komárom-Esztergom
Fejér
Veszprém
Győr-Moson-Sopron
Vas
Zala
Somogy
Tolna
Other:

8. Years of experience in the medical field.

1-5
6-10
11-15
16-20
21-30
More than 30

Breast cancer information on the internet

9. Do you use the internet to read news related to breast cancer (both news on media outlets aimed at the general public, or latest research results in academic journals)?*

Yes
No

10. Which online news pages (scientific journals AND media outlets aimed at the general public) do you use to get information related to breast cancer?*

Open answer

11. What is the latest breast cancer related news you remember reading on the internet? Where did you read it? What did you think of this news? (it does not have to be science related news, it could be news about a charity event, the report of a person with cancer, the announcement of someone's death from cancer, etc).*

Open answer

12. Do you know science communicators online who address the topic breast cancer? (do not consider scientific journals aimed at peers, but scientists / journalists / doctors who speak to the general public. Not only in Hungary, they can be in other countries as well).*

Yes

No

13. If YES, who are they?

Open answer

14. Which social platforms do they use?

Facebook

Instagram

Tik Tok

Twitter

YouTube

Pinterest

Quora

Blogging service (for example Wordpress, Tumblr, etc.)

LinkedIn

Research Gate or Academia

Discord

WhatsApp

Telegram

Other

15. How do you evaluate the work of these science communicators?

Terrible

1

2

3

4

5

6

7

8

9

10

Outstanding

16. Please explain your evaluation.

Open answer

Doctors and researcher's science outreach activities on social media

17. Have you done any work to communicate science to the general public on social networks/blogs/newspapers? Please DO NOT consider academic journals.*

Yes

No

18. If YES, which platform did you use?

Facebook

Instagram

Tik Tok

Twitter

YouTube

Pinterest

Quora

Blogging service (for example Wordpress, Tumblr, etc.)

LinkedIn

Research Gate or Academia

Discord

WhatsApp

Telegram

None

Other:

19. If YES, what subjects were covered by you? If you disclosed something about breast cancer, what topics were covered?

Open answer

Patients literacy on breast cancer

20. Do you work directly with breast cancer patients?*

Yes

No

21. Do you work directly with people who undergo preventive breast cancer screening exams?*

Yes

No

22. If you answered YES to questions 20 OR 21, please follow this section. If you answered NO to the two previous questions, skip to question 26. Have your patients ever reported believing in any misinformation related to breast cancer? If yes, which one(s)?

Open answer

23. How do you deal with patients who believe false information regarding breast cancer (check all the appropriate alternatives).

I tell the patient the scientific truth.

I don't argue, because it's no use.

I ask for help from a family member / friend of the patient to clarify the truth.

I show patients reliable sources on the Internet.
I show patients reliable sources out of the Internet.
Other

24. How do you assess patients' health literacy in relation to breast cancer? Eg., do they know what to do to prevent cancers? Do they know what the symptoms of breast cancer are? Do they know when they should start to do screening exams?

Terrible

1

2

3

4

5

6

7

8

9

10

Outstanding

25. Please explain your evaluation.

Open answer

26. In your opinion, what can be done to increase people's awareness of the importance of prevention + early detection of breast cancer?*

Open answer

27. Please feel free to share any thoughts or comments regarding the research subject.

Open answer

Submission of the doctoral dissertation and declaration of the originality of the dissertation

The undersigned,

Name: Priscila Biancovilli

Maiden name: Priscila Biancovilli

Mother's maiden name: Elineide Ludovino de Souza

Place and time of birth: Rio de Janeiro, Brazil, 14 October 1985

on this day submitted my doctoral dissertation entitled:

Breast cancer on social media: a quali-quantitative analysis of the content that generates more public engagement and how to improve its reliability

to the

PR-1. Frontiers of Health Sciences Programme

of the Doctoral School of Health Sciences, Faculty of Health Sciences, University of Pécs.

Names of the supervisor(s): Alexandra Csongor

At the same time, I declare that

- I have not submitted my doctoral dissertation to any other Doctoral School (neither in this country nor abroad),
- my application for degree earning has not been rejected in the past two years,
- in the past two years I have not had unsuccessful doctoral procedures,
- my doctoral degree has not been withdrawn in the past five years,
- my dissertation is independent work, I have not presented others' intellectual work as mine, the references are definite and full, on preparation of the dissertation I have not used false or falsified data.

Dated: 1st September 2022

Candidate

Supervisor

Co-supervisor

Data availability statement

The datasets used in this research are available from the author upon reasonable request.

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